

# NEONATOLOGY TODAY

Peer Reviewed Research, News and Information in Neonatal and Perinatal Medicine



Volume 18 / Issue 5 May 2023

**NeoHeart 2023: Cardiovascular Disease in the Neonate: A Special Issue from Neonatology Today in Collaboration with the Neonatal Heart Society and the 8th World Congress of Pediatric Cardiology and Cardiac Surgery**  
 Gil Wernovsky MD, Amir Ashrafi, MD, John Cleary, MD\*, Mitchell I. Cohen MD, David Cooper MD MPH, Kathryn M. Dodds, MSN, CRNP, Cristen Hemingway BA, Victor Levy, MD, Victoria Servin Meskin, MSN, RNC-NIC, Mitchell Goldstein MD, Jeffrey P. Jacobs MD  
 .....Page 3

**In Memory of John Patrick Cleary, MD**  
 Christine Bixby, MD, Meghan Cleary Robins, JD-MPP  
 .....Page 41

**Letter to Editor: Comment on "National Perinatal Association: The Hidden Side of Maternal Mental Health"**  
 Nicole Poladian OMS3, Viktoriya Rembelinska OMS3, Saba Saleem, DO, MPH  
 .....Page 52

**Letter to the Editor: "Response to HRO: Engagement Matters" How to Employ Full Spectrum Analysis to Improve the Quality of the Response**  
 Adian Wolfberg, PhD, Daved Van Stralen, MD, Sean McKay, Thomas A. Mercer, Mitchell Goldstein, MD, BMA, CML  
 .....Page 54

**Impaired Engagement in High-Reliability Organizing (HRO): 3. Reasoning Impairs Engagement**  
 Daved van Stralen, MD, FAAP, Sean D. McKay, Errol van Stralen, Thomas A. Mercer, RAdm, USN (Retired)  
 .....Page 63

**Briefly Legal: The "Half-hour Rule" in Obstetrics**  
 Barry S. Schiffrin, MD; Wayne R. Cohen, MD, Maureen Sims, MD;  
 .....Page 79

**Bits & Bites**  
 Rob Graham, R.R.T./N.R.C.P.  
 .....Page 85

**Summit Highlights Scope of Research and Activities to Cut Sudden Unexplained Infant Death**  
 Alison Jacobson  
 .....Page 93

**8th World Congress of Pediatric Cardiology and Cardiac Surgery. August 27-September 1, 2023, Washington, DC Program Guide**  
 Gil Wernovsky MD  
 .....Page 101

**Gravens By Design: Six Weeks that Changed the Preterm Infant Brain: Insights from the Family Nurture Intervention (FNI) Randomized Controlled Trials**  
 Martha G Welch, MD, Robert J Ludwig, BA, Amie A. Hane, PhD, Michael M Myers. PhD  
 .....Page 217

**Fragile Infant Forums for Implementation of IFCDC Standards: Key Cornerstone of the IFCDC Standards: Infant Mental Health**  
 Joy V. Browne, Ph.D., PCNS, IMH-E  
 .....Page 230

**NPA 2023 Conference Reflection**  
 Chavis A. Patterson, Ph.D  
 .....Page 237

**Loresstry: Parent-Led Child Development Monitoring Every Child Has A Story**  
 Linda Craib, RN, MBA; Catherine J. Everett, MD, MBA; David Kovel, MSIS, CPHIMS; Bridget Gulotta, RN, MSN, MBA; Ashleigh Coltman, Harvard Class of 2024; and Alexa Garvin, MSc.  
 .....Page 241

**FCC Taskforce Newsletter**  
 Malathi Balasundaram, MD  
 .....Page 253

**Latest Data Show Maternal Mortality Continues to Spike**  
 Josie Cooper  
 .....Page 267

**"Empowering Pediatric Patients Worldwide"**  
 Sabina Schmidt Goldstein-Becerra  
 .....Page 272

**Medical News, Products & Information**  
 Compiled and Reviewed by Saba Saleem, BS, OMS 4  
 .....Page 284

**Genetics Corner: Noonan Syndrome and Central Conducting Lymphatic Anomaly: Trametinib Treatment for Chronic Chylothorax Following Cardiovascular Surgery**  
 Robin Dawn Clark, MD  
 .....Page 296

**American Medical Association Survey Finds Nearly One in Three Physicians Have Been Sued During Their Careers**  
 Jonathan M. Fanaroff, MD, JD  
 .....Page 303

**Safety in the NICU**  
 Susan Hepworth, Mitchell Goldstein, MD, MBA, CML  
 .....Page 307

**Clinical Pearl: The Effects of Prenatal Exposure to Marijuana: Is Legalization in 21 States a Good Idea for the Fetus?**  
 Joseph R Hageman, MD, Lolita Alkureishi, MD, Mitchell Goldstein, MD  
 .....Page 316

**Upcoming Meetings,**  
 .....Page 322

**Subscriptions and Contact Information**  
 .....Page 322

**Editorial Board**  
 .....Page 327

**Animal and Human Research**  
 .....Page 329

**Manuscript Submission**  
 .....Page 329

**Neonatology & the Arts**  
 Mita Shah, MD  
 .....Page 329

**Sichuan Takin**  
 Paula Whiteman, MD  
 .....Page 331

**Lark**  
 Paula Whiteman, MD  
 .....Page 332



**NEONATOLOGY TODAY**  
 © 2006-2023 by Neonatology Today  
 Published monthly. All rights reserved.  
 ISSN: 1932-7137 (Online), 1932-7129 (Print)  
 All editions of the Journal and associated manuscripts are available on-line:  
[www.NeonatologyToday.net](http://www.NeonatologyToday.net)  
[www.Twitter.com/NeoToday](http://www.Twitter.com/NeoToday)



Loma Linda Publishing Company  
 A Delaware "not for profit" 501(c) 3 Corporation.  
 c/o Mitchell Goldstein, MD  
 11175 Campus Street, Suite #11121  
 Loma Linda, CA 92354  
 Tel: +1 (302) 313-9984  
[LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)

Sheraton Sand Key Resort in  
Clearwater Beach, FL

# The Gravens Conference

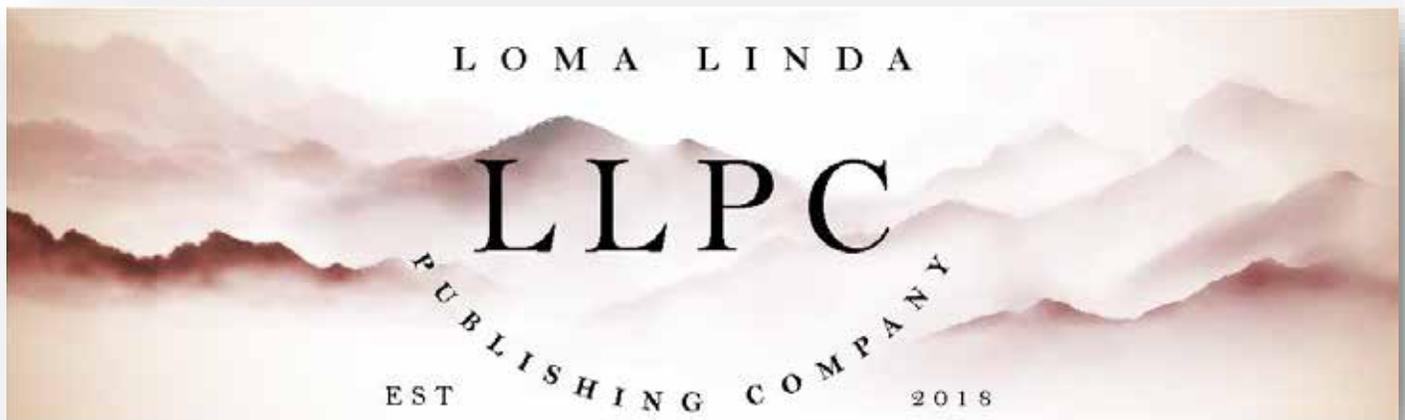
March 6-9, 2024

**2024 THEME:  
THE POWER OF VOICE:  
USING YOUR VOICE FOR BABIES,  
FAMILY, STAFF AND BEYOND.**

# Connect & Learn



<https://www.neonatologytoday.net/>



# NeoHeart 2023: Cardiovascular Disease in the Neonate: A Special Issue from Neonatology Today in Collaboration with the Neonatal Heart Society and the 8<sup>th</sup> World Congress of Pediatric Cardiology and Cardiac Surgery

Gil Wernovsky MD, Amir Ashrafi, MD, John Cleary, MD\*, Mitchell I. Cohen MD, David Cooper MD MPH, Kathryn M. Dodds, MSN, CRNP, Cristen Hemingway BA, Victor Levy, MD, Victoria Servin Meskin, MSN, RNC-NIC, Mitchell Goldstein MD, Jeffrey P. Jacobs MD

*\* In Memoriam. We will always remember and dedicate this Neonatology Today issue to our dear friend, mentor, and colleague John Patrick Cleary, MD. Dr. Cleary was an internationally renowned cardiac neonatologist and a passionate defender of childhood. He devoted his career to advancing the care of neonates with physiologic and structural heart disease.*



Figure 1. Term newborn following complex reconstructive surgery with massive technological support

## Special Issue: NeoHeart 2023: Cardiovascular Disease in the Neonate

Figure 1 was taken in early 2023; a neonate in a cardiac intensive care unit in Washington DC (but it could be a neonate with heart disease seemingly anywhere - in a resource-rich economy), surrounded by monitors and infusion pumps, with a continuous EEG, nitric oxide, a ventilator, cerebral and somatic NIRS monitoring, and if you look closely, two Pedimag™ ventricular assist devices. How in the world did we get here???

### Disruptive Events in the Treatment of Neonates with Cardiovascular Disease: A Historical Perspective

This special first-time track at the 8<sup>th</sup> World Congress of Pediatric Cardiology and Cardiac Surgery (WCPCCS; see below) demonstrates the “**Convergent Evolution**” of current neonatal and congenital cardiac care.

Convergent Evolution in Neonatology and Pediatric Cardiology/ Cardiac Surgery. As we approach the NeoHeart 2023 and the Historic 8<sup>th</sup> WCPCCS, with the featured scientific track on “**Cardiovascular Disease in the Neonate**” (more on that below), it is imperative to recognize the seminal roles of two medications

### Convergent Evolution:

- When organisms independently find their way to the same evolutionary solution for the same environmental problem
- When species occupy similar ecological niches and adapt in similar ways in response to similar selective pressures

- Prostaglandin (PGE<sub>1</sub>) and surfactant - in the care of critically ill neonates. The “younger generation” may not remember, or may be not know, how recently it was that babies with critical congenital heart disease (cCHD) such as hypoplastic left heart syndrome (HLHS), transposition of the great arteries (TGA), and other “duct-dependent” cCHDs were considered untreatable. Typically, these neonates were diagnosed postnatally, as prenatal cardiac diagnosis had not been perfected and was not the standard of care. They typically presented to medical care with profound hypoxemia, or in cardiovascular shock, in duress with profound acidosis, and then required high-risk invasive catheterization to make a diagnosis - echo was in its infancy. Following diagnostic catheterization, the family’s life was forever altered, as they were told about the lethal cardiac condition, may have been placed in the corner of a NICU, as the baby passed away from progressive heart failure and/or profound hypoxemia. Additionally, and equally distressing, not in a family-centered, quiet isolation room as in most NICUs of today, but in an open bay, surrounded by other ill neonates with grieving and frightened parents.

*“Following diagnostic catheterization, the family’s life was forever altered, as they were told about the lethal cardiac condition, may have been placed in the corner of a NICU, as the baby passed away from progressive heart failure and/or profound hypoxemia.”*

This unimaginably sad story occurred over 1000 times annually in the USA alone. However, in 1981, everything changed. PGE<sub>1</sub> was approved to maintain the patency of the ductus arteriosus. It’s hard to believe, but this was only 1-2 generations ago after many of the readers of this article were born! (Of interest, at the time, the recommendation for the infusion of PGE<sub>1</sub> was to infuse the drug in an umbilical arterial catheter “at the level of the ductus” – to “bathe” the ductus in PGE<sub>1</sub>!!). How did we get from the era of high mortality and little hope for these babies to our current optimistic outcomes, as well as how did we get to the “normalcy” of the technology in the figure? What has changed in neonatology and pediatric cardiology?

---

***“On August 8, 1938, the era of pediatric cardiac surgery began with the first successful ligation of a patent ductus arteriosus by Dr. Robert E. Gross in a 7-year-old patient at the Children’s Hospital in Boston”***

---

### **Congenital and Acquired Heart Disease in the Neonate**

On August 8, 1938, the era of pediatric cardiac surgery began with the first successful ligation of a patent ductus arteriosus by Dr. Robert E. Gross in a 7-year-old patient at the Children’s Hospital in Boston. On November 29, 1944, a little girl (“Eileen”) with tetralogy of Fallot underwent the first “creation of a ductus” by Alfred Blalock and Vivien Thomas at the urging of cardiologist Helen Taussig. In 1954 (date unknown), C. Walton Lillehei’s disruptive innovation was controlled cross-circulation in an 11-year-old boy with a ventricular septal defect. The boy’s anesthetized father served as the oxygenator! Blood flow was routed from the patient’s caval system to the father’s femoral vein and lungs, where it was oxygenated and then returned to the patient’s carotid artery. This technique was not adopted due to the risk it posed to the donor. On May 6, 1953, the first successful open-heart operation with cardiopulmonary bypass was performed by Dr. John H. Gibbon, Jr, when he closed an atrial septal defect on an 18-year-old college student with repeated episodes of right heart failure. While groundbreaking, these techniques were initially limited to children and young adults. No babies with critical CHD survived long enough even to consider surgical intervention – until Prostaglandin changed the entire landscape.

---

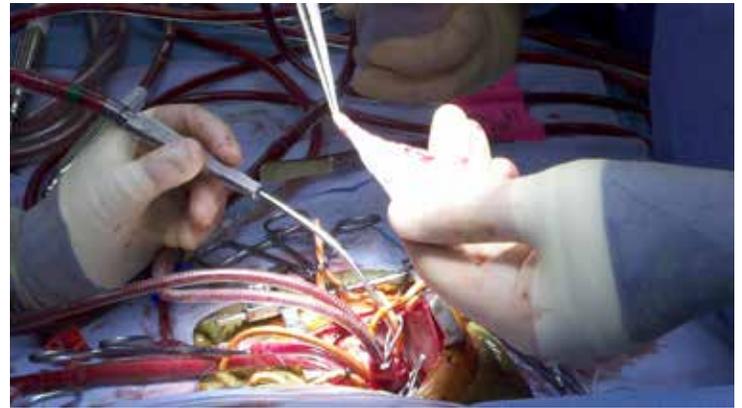
***“While groundbreaking, these techniques were initially limited to children and young adults. No babies with critical CHD survived long enough even to consider surgical intervention – until Prostaglandin changed the entire landscape.”***

---

The art and science of pediatric cardiac care have undergone tremendous evolution. Of note, the field of neonatal cardiac surgery has rapidly expanded secondary to multiple critical advances, including:

- the shift from palliative cardiac surgery to complete repair in the young
- the development of smaller cannulas for cardiopulmonary bypass, as well as smaller cardiopulmonary bypass machines
- improved surgical instrumentation
- improved cardioplegia
- enhanced diagnostic imaging with improved echocardiography, computerized axial tomography, and magnetic resonance imaging
- the development and evolution of pediatric critical care and neonatal critical care

- the overall dramatic improvement in the outcomes experienced by neonates undergoing cardiac surgery



*Figure 2. The operative field during cardiopulmonary bypass in the neonate. In this small space are two venous cannula and one arterial cannula for cardiopulmonary bypass, various catheters and suction devices, equipment to aid in hemostasis, and the hands of the operating surgeon, assistant(s) and much more.*

Neonates with bradyarrhythmias and tachyarrhythmias continue to be a particularly troubling group of patients to care for. While many arrhythmias in the neonatal population are relatively short-lived and self-resolving, others may result in significant hemodynamic perturbations and impact other organ functions. There are now many more safe and efficacious anti-arrhythmic strategies; invasive trans-catheter electrophysiologic interventions are now being performed in selected neonates with arrhythmias unresponsive to drug therapy. One of the most challenging groups of neonates to care for are those with significant bradyarrhythmias and complete heart block – either postoperatively or congenital: a result of some forms of cCHD or, more commonly, from maternal autoimmune disease. There are currently micro or miniature pacemakers in clinical practice and evolution.



*Figure 3. The continued miniaturization of internal pacemakers, including early prototypes of tiny pacemakers with wireless technology (right) for neonates, infants and children.*

As technology and treatments for critically ill neonates evolved, so did clinician training. Just as the above advances paved the way for increasing care for the neonate with critical CHD, in the mid-1980s – 1990s, the field of pediatric cardiac intensive care developed, with it dedicated cardiac intensive care units (CICU) and advanced specialized training. These dedicated CICUs care for premature neonates to adults with congenital heart disease. In caring for the critically ill neonate, congenital cardiac teams must collaborate with neonatology to ensure optimal care, especially in

low birth weight and/or premature neonates and those with complex extra-cardiac pathologies and genetic syndromes. Likewise, the training of the cardiac intensivist has evolved with dedicated sub-sub-specialty fellowship training. Currently, to practice cardiac intensive care, a physician most commonly has had training in cardiology or critical care followed by an additional year of dedicated cardiac intensive care fellowship. Alternatively, physicians have obtained dual training in cardiology and critical care. Lastly, some have obtained dual training in cardiology and neonatology, or neonatology, followed by an additional year of dedicated cardiac intensive care fellowship. In these early years after PGE, other simultaneous developments were bedside echocardiography, color Doppler, cross-sectional imaging with CT scans and MRI, and more.

---

***“Likewise, the training of the cardiac intensivist has evolved with dedicated sub-sub-specialty fellowship training. Currently, to practice cardiac intensive care, a physician most commonly has had training in cardiology or critical care followed by an additional year of dedicated cardiac intensive care fellowship.”***

---

Because of these tremendous advances, many previously untreatable congenital cardiac malformations are now successfully treated in neonates.

#### **The Neonate Born Prematurely**

While care of the newborn with congenital heart disease was rapidly evolving, care for the premature neonate with surfactant deficiency was lagging. Many in the neonatal care team recall the gut-wrenching inevitability of watching fragile newborns gasping for air. The only techniques available were invasive rudimentary mechanical ventilation, escalating supplemental oxygen, and ventilator pressures. The severity of lung injury and the need for frequent chest tubes could only be treated with steroids and sedation. It is hard to believe the son of President John F Kennedy died of severe respiratory distress syndrome (RDS) at 35 weeks gestational age.

---

***“Many in the neonatal care team recall the gut-wrenching inevitability of watching fragile newborns gasping for air. The only techniques available were invasive rudimentary mechanical ventilation, escalating supplemental oxygen, and ventilator pressures.”***

---

Then in 1991 (10 years after PGE), everything changed again. Surfactant was approved for use in neonates with suspected respiratory distress syndrome due to surfactant insufficiency. The

ability to administer surfactant directly into the lungs of premature infants revolutionized the treatment of RDS. It improved lung compliance, reduced the need for mechanical ventilation, and significantly lowered the mortality rate. We can now provide more targeted and effective care with fewer complications and better long-term outcomes.

---

***“With just the two previous breakthroughs, as a community, we were now able to maintain infants alive on prostaglandin, and we were able to optimize care for our preterm infants. The convergence of the two is exemplified by the advancement of treating and growing preterm infants with heart disease to the point that they are “big enough” to perform surgery.”***

---

With just the two previous breakthroughs, as a community, we were now able to maintain infants alive on prostaglandin, and we were able to optimize care for our preterm infants. The convergence of the two is exemplified by the advancement of treating and growing preterm infants with heart disease to the point that they are “big enough” to perform surgery. Over time, we have made breakthroughs to further “miniaturize” our techniques to address cardiac disease in neonates.

Also during this time frame was the simultaneous development and improvement of Extracorporeal Membrane Oxygenation (ECMO) for hypoxemic/hypercarbic respiratory failure in the neonate with a structurally normal heart, as well as for profound hypoxemia in certain forms of critical CHD at presentation, low cardiac output after cardiac surgery, and as a salvage procedure during cardiopulmonary resuscitation (eCPR). Lessons learned from cardiopulmonary bypass (CPB) were applied to ECMO, including miniaturization and improvement of the oxygenator, tubing, type of pump (roller versus centrifugal), and much more. (In the simplest terms, ECMO is nothing more than modified CPB applied outside of the cardiac operating room and for a significantly longer duration.)

Finally, around the same time (the early 1990s), nitric oxide revolutionized the care of hypoxemic respiratory failure and treating pulmonary hypertension in all forms of critical disease in the neonate, including but not limited to cCHD.

---

***“Finally, around the same time (the early 1990s), nitric oxide revolutionized the care of hypoxemic respiratory failure and treating pulmonary hypertension in all forms of critical disease in the neonate, including but not limited to cCHD.”***

---

These four medical and technological advances in the 80s and 90s (table) paved the way for cardiac surgeons to mend the hearts of neonates, neonatologists to save the lives of increasingly premature infants, sub-specialties to be formed in nursing, cardiac imaging, interventional catheterization, respiratory therapy, pediatric perfusion, electrophysiology, improvements in mechanical ventilation, our consultants (renal, general surgery, neurology, etc.) and many more to become familiar with the unique properties of the term and preterm neonate.



*Figure 4. Although technology for cCHD has become increasingly small in order to care for neonates with cCHD, most technology has not kept pace with the current size of premature neonates. Echo imaging can still be quite challenging, and can cause significant respiratory or cardiac compromise, as well as hypothermia. Although “non-invasive” is the term most frequently applied to echocardiography, echocardiography should be considered an “invasive procedure” in the very small premature baby, with appropriate monitoring and human surveillance.*

A quick look at the chronologically arranged “selected references” at the end of this article shows the disruptive events and synergistic advances in the management of these critically ill neonates, specifically (1) PGE<sub>1</sub>, (2) Surfactant, (3) Nitric Oxide and (4) Extracorporeal Membrane Oxygenation (ECMO). Many of these advances were applied even before some of our current staff were born! In response to the survival of babies with increasingly complex illnesses, there has been a growing need for improvement and miniaturization in monitoring, cardiopulmonary bypass and ECMO, invasive and non-invasive technology, cardiac and non-cardiac surgery in the neonate, the evolution of specialized nursing care, including expanded roles of advanced practice providers, in both the Neonatal and Cardiac intensive care units, and finally, the recognition of the surprisingly similar neurodevelopmental clinical phenotypes in the survivors of all forms of critical disease in the neonate.

#### **Convergent Evolution: The Four Key Factors Contributing to the Dramatic Improvement in Survival of Critically Ill Neonates in the Last Four Decades**

Extracorporeal Membrane Oxygenation (1977)	
Cardiac	Non-Cardiac
Prostaglandin E <sub>1</sub> (approved 1981)	Surfactant (approved 1991)
Inhaled Nitric Oxide (approved 1999)	

**In 1986, Scientific American published an essay penned by the iconic Dr. Bernard Lown entitled “Intensive Heart Care” (Vol 219). He stated, decades before our current care model, “Neither monitors nor the most complicated electronic gear makes a coronary care unit. The fundamental ingredient is a properly indoctrinated nursing staff. The reason for this is obvious. The nurse is usually the only trained medical professional at the bedside during important clinical events..... In fact, many well-functioning units have been successful because of the elite spirit and competence of the nursing staff.”**

#### **The Essential Role of Nursing in the Care of the Critically Ill Neonate**

The field of intensive care nursing has been revolutionized and specialized for neonates born prematurely, as well as for term babies with critical medical or surgical diseases. Similar nursing specialization and advanced practice models have evolved in parallel in the neonatal and pediatric/cardiac intensive care units. As opposed to the previous models of task-oriented nursing, current models now include collaborative front-line bedside staff, nurse specialists, education specialists, advanced practice nurse practitioners, and more.

Collaboration, continuing education (see below), and concentrated skill development have become increasingly imperative to the outcomes of patients. In addition, team-work and cohesive workflows in algorithms, standardized protocols, and streamlined communication have proven beneficial to all healthcare patients – particularly critically ill neonates – as well as for their families and us, the providers!

**“Collaboration, continuing education (see below), and concentrated skill development have become increasingly imperative to the outcomes of patients. In addition, team-work and cohesive workflows in algorithms, standardized protocols, and streamlined communication have proven beneficial to all healthcare patients – particularly critically ill neonates – as well as for their families and us, the providers!”**

The Neonatal Heart Society and [NeoHeart](#)

Back in 2013, an idea was born as we discussed improving the care of newborns with physiologic and anatomic heart disease through multispecialty and multidisciplinary collaboration. From this vision, the international meeting [NeoHeart](#) was created. [NeoHeart](#) is dedicated to bridging the gap between subspecialties by bringing together neonatologists, cardiologists, intensivists, anesthesiologists, and surgeons caring for neonates with heart disease. Everyone can learn from one another in this milieu, and the clinical silos slowly disappear.

However, cardiovascular disease goes beyond the heart, and we realized the importance of including neurologists, gastroenterologists, pulmonologists, geneticists, and others in these important conversations. With that, we expanded the care of the neonate with heart disease. Despite our best efforts, we had created our own imaginary “silos” by not including nursing and advanced practitioners in the mix. In 2018, we incorporated nursing into our education and training efforts. Moreover, that same year, the Neonatal Heart Society (NHS, [www.neoheart.org](http://www.neoheart.org)) was born out of necessity and collaboration. The society enhances collaborative research, quality improvement, advocacy, and program development to improve neonatal outcomes in patients with acquired and congenital heart disease.

If there ever was an individual who understood the importance of collaboration of care and the continuum of care needed, **John Patrick Cleary, MD**, defined it with his career. In a year where the neonatal and cardiac worlds lost many pioneers, our dear friend, mentor, and colleague John Patrick Cleary, MD, has left an unending influence. He devoted his career to the idea that we could always do better for our neonates with physiologic and structural heart disease. One cannot mention **NeoHeart** or the Neonatal Heart Society without thinking about Dr. Cleary, as he was one of the founding members and co-creators of the international conference NeoHeart. After nearly three decades of service, Dr. Cleary leaves an inspiring legacy for each of us and the thousands of patients and families whose lives he impacted.



*Figure 5. Founders of the Neonatal Heart Society and NeoHeart, from left to right: John Cleary MD, Amir Ashrafi MD and Victor Levy MD, who also served as the Track Chairs for the “Cardiovascular Disease in the Neonate” track at the 8th World Congress of Pediatric Cardiology and Cardiac Surgery.*

Caregivers for critically ill neonates with structurally normal and congenitally malformed hearts have a good deal to learn from and teach others. In recognition of the observations noted above, for the first time, there will be a collaborative track for “Cardiovascular Disease in the Neonate” at the 8<sup>th</sup> World Congress of Pediatric Cardiology and Cardiac Surgery.

The NHS and **NeoHeart** are excited to be part of the WCPCCS – now just three months away!!! This will be the first neonatology and neonatal-cardiac intensive care to have a dedicated track at this prestigious event. We are seeing our society grow by leaps and bounds, and we are now ready to delve into other areas that will continue to develop programs to support the care of neonates with cardiac and pulmonary disease.

**The 8<sup>th</sup> World Congress of Pediatric Cardiology and Cardiac**

## Surgery.

**August 27th – September 1st, 2023 Washington DC USA**

For complete information, see [www.wcpccs2023.org](http://www.wcpccs2023.org)

For just a bit of history, separate Pediatric Cardiology (est. 1980) and Cardiac Surgery (est. 1989) World Congresses were combined to form the current collaborative structure in 1993. Previous meetings have been held in Paris, Bangkok, Toronto, Buenos Aires, Cairns, Cape Town, and Barcelona. We (Dr. Jeff Jacobs, a cardiovascular surgeon in Florida, and Dr. Gil Wernovsky, a Pediatric Cardiologist and Cardiac Intensivist in Washington DC) first envisioned bringing this historic meeting to the USA in 2009.

In 2015, after six years of extensive research and planning and competing against seven other countries, the International Steering Committee (with appropriate pomp and circumstance and in response to the WCPCCS swag; see **Figures 6 and 7**) awarded the bid to host the 8<sup>th</sup> WCPCCS to the USA. An executive committee was formed to include Mitchell Cohen MD as the scientific chair, Katie Dodds MSN, CPNP, as the interdisciplinary chair, and David Cooper MD MPH as the Societal and Industry Liaison and Financial Chair. (**Figure 8**)



*Figure 6. Prague 2015. The USA Bid Committee after learning that the International Steering Committee awarded the 8th World Congress to the USA.*

*Figure 7. Co-Chairs Dr. Jeffrey P. Jacobs (left) and Dr. Gil Wernovsky (right)*



Figure 8. Executive Committee of the 8th World Congress of Pediatric Cardiology and Cardiac Surgery during a 2020 planning meeting in St. Petersburg, Florida, USA. From left to right: Jeff Jacobs MD, Mitchell Cohen MD, Gil Wernovsky MD, Katie Dodds MSN and David Cooper MD

The group has collaborated for over two decades with meeting organizers Christina Mannices and Melodye Farrar, who comprise the Organizing Committee of the WCPCCS. This historic meeting, held every four years and considered the “Olympics of Our Profession,” will occur in our nation’s capital, Washington DC, August 27 – September 1, 2023, and represents our team’s hard work and planning for over 14 years. (Figure 9)



Figure 9: Barcelona 2017. Executive Committee members (from left to right) Dr. Gil Wernovsky, Dr. Mitchell Cohen and Dr. David Cooper receiving the “World Congress Flag” during the official transition ceremony of the 7th World Congress from Barcelona, Spain to the 8th World Congress in Washington DC, USA

---

**“Mission: To organize the most comprehensive scientific forum ever convened for this patient population and their caregivers to improve the duration and quality of life for neonates, infants, children, and adults with pediatric and congenital cardiovascular disease.”**

---

**Vision:** To improve the global standard for pediatric and congenital cardiac care.

**Mission:** To organize the most comprehensive scientific forum ever convened for this patient population and their caregivers to improve the duration and quality of life for neonates, infants, children, and adults with pediatric and congenital cardiovascular disease.

**Core Values:**

- Economic, Ethnic, Gender and Geographic Diversity
- Advocacy for Patients and Families Across the Globe at the Educational, Institutional, Governmental, and Economic Levels
- Training the Next Generation of Health Care Providers
- Seamless Sharing of Best Practices
- Interdisciplinary Collaboration
- Inter-Institutional Collaboration

**Goals:**

- To create the most technologically advanced, state-of-the-art World Congress to date, featuring a Scientific Program that is unique and unparalleled.
- To bring together non-governmental organizations and patient/family advocacy groups in a “Global Village” to share best practices and develop strategies for improved and sustainable access to patient care in low- and middle-income countries.
- To use the scientific presentations to create “Enduring Materials,” providing up-to-date online education for caregivers in low- and middle-income countries.

Every aspect of the WCPCCS has been planned with the following philosophy in mind:

1. *To Educate and Disseminate Information*
  - Our primary mission is to improve the duration and quality of life for millions of children and young adults worldwide with heart and cardiovascular diseases.
2. *To Foster Collaborative Innovation*
3. *To Develop Sustainability of Care in Low- and Middle-Income Nations*
4. *To “Pay-It-Forward”*
  - We will create open-access enduring materials of cardiac research and share best clinical practices, utilizing interdisciplinary collaboration, new internet technologies, innovation, and partnership with industry.

Worldwide, over 1000 scientific society and other organizational meetings annually provide education, research, and advocacy regarding general heart disease. These meetings are typically selective in scope and goal, are regional, country, or pathology specific, and, if on an international platform, solely focused on a very limited agenda of pathologies discussed. The WCCPCS, on the other hand, is the only global meeting that encompasses the broadest clinical format, with top experts from around the world and thought leaders from individual national and international societies who come together only every four years to share the newest and most groundbreaking techniques, technologies, and advanced medical innovations.

---

*“The WCCPCS, on the other hand, is the only global meeting that encompasses the broadest clinical format, with top experts from around the world and thought leaders from individual national and international societies who come together only every four years to share the newest and most groundbreaking techniques, technologies, and advanced medical innovations.”*

---

Specifically, the WCPCCS is the major international scientific event for the global pediatric cardiac community, providing an opportunity for specialists from around the globe to gather and highlight and review the previous four years of research and technological developments in surgical techniques, basic sciences, translational and clinical research, and advanced therapeutic interventions. This critical meeting provides an ideal gathering place for a global coalition of physicians, nurses, allied health professionals, and scientists worldwide who use research and technological development to provide better care for babies, children, and adults with congenital and acquired cardiac disease. The international faculty includes over **800 members** and will share new science and years-acquired wisdom across the different cardiac disciplines - from research, invasive interventions, imaging, and non-invasive procedures to critical care and surgical procedures.

---

*“The WCPCCS supports the notion that all children with cardiac disease should not be denied the benefits of medical science, and our vision is to use this Congress as a platform to spread cardiac care ideas and techniques to caregivers of those children in regions without access.”*

---

The WCPCCS supports the notion that all children with cardiac disease should not be denied the benefits of medical science, and our vision is to use this Congress as a platform to spread cardiac care ideas and techniques to caregivers of those children in regions without access. It is an occasion to emphasize the glar-

ing inadequacies in delivering neonatal and cardiac care in many countries and to use this global forum to find creative humanitarian solutions to develop new services in resource-poor environments.

Of course, while the limitations to developing cardiac care in the presence of financial, managerial, and human resource constraints are problems shared with colleagues from all nations, poorer nations carry a heavier burden. The WCPCCS offers health policy planners, health system managers, and health economists a unique forum to find health systems solutions necessary to initiate, develop, and improve cardiac care for children in less robust medical environments.

---

*“The WCPCCS offers health policy planners, health system managers, and health economists a unique forum to find health systems solutions necessary to initiate, develop, and improve cardiac care for children in less robust medical environments.”*

---

Numerous international societies and institutions have shared the vision that the WCPCCS is the defining international event in the lives of those committed to helping neonates, infants, children, and adolescents with cardiac disease and adults with congenital cardiac disease. The World Congresses have successfully brought together delegates from dozens of countries across varying healthcare environments for stimulating educational meetings where individuals can network and learn from one another.

The World Congress has effectively fostered a collegial spirit between the many specialties involved in children's heart health, providing a range of opportunities for trainees and established practitioners to upgrade skills, cooperate, and collaborate for the good of all children with cardiac diseases worldwide.

The WCPCCS will bring together over 4,500 physicians, nurses, scientists, the medical industry, administrative stakeholders, and technology leaders from around the globe to collaborate and develop innovative and sustainable models of care for children and young adults with congenital and acquired heart disease. (**Figure 10 a,b**)

- ~2300 Talks in ~250 Individual Sessions, with ~800 Faculty Across 22 tracks
- Emphasis on diversity in faculty – geographic, gender, age, and race.
- ~1500 Abstracts of New Science will be projected to be submitted
- “Trainee and Early Career Track” Throughout the Meeting
- Global Health and Advocacy Village (see below)
  - A collection of over 125 NGOs and Patient/Parent Advocacy will share their Visions and Missions from around the world.
- Creation of Enduring Materials, White Papers, and Scientific Statements
- The WCPCCS has garnered International support from the Association of European Cardiologists, the Cardiac Society of Australia and New Zealand, the Pediatric Cardiology Soci-

Figures 10 a,b: The large plenary session hall at the most recent (7th) World Congress of Pediatric Cardiology and Cardiac Surgery in Barcelona, Spain, 2017





Figures 11 a,b,c:  
The Display Booth  
of the 8th World  
Congress in  
Barcelona. Note  
the 2021 dates  
pre-pandemic



ety of India, and Global Arch – Global Alliance for Rheumatic and Congenital Heart Disease, and many more (see below).

### Featured Track: Cardiovascular Disease in the Neonate

As we continue to develop as a medical community, we realize that the complexities associated with neonates with cardiovascular disease require a collaborative and cohesive strategy. There continues to be a significant amount of divergence in care throughout all neonatal and pediatric cardiac centers. Despite many well-meaning attempts at a multidisciplinary approach for this population, there is a lack of equipoise in standardizing neonatal cardiac care among multiple subspecialties.

*“We believe having a written or generally agreed-upon strategy for a multidisciplinary approach to these patients is not enough. Instead, standards need to be developed so that any patient with a neonatal cardiovascular condition, no matter their location, will receive more uniform and optimal care.”*

We believe having a written or generally agreed-upon strategy for a multidisciplinary approach to these patients is not enough. Instead, standards need to be developed so that any patient with a neonatal cardiovascular condition, no matter their location, will receive more uniform and optimal care. As previously stated, the overarching goal of the WCPCCS is to bring individuals and centers together by establishing and improving communication and co-management across clinical disciplines by identifying promising approaches to strengthen the interface between multiple disciplines in caring for neonates (and others) with cardiac disease.

*“ These children frequently have multiple chronic conditions that often require the participation of community- and hospital-based providers. The current fragmentation of existing health systems for this population frequently makes it difficult to get the continuum of cardiac care that they need.”*

Children with medical complexities (CMC), including neonates with cardiac disease, require care from multiple services and providers, and the many benefits of care coordination on health and patient experience outcomes have been well documented. These children frequently have multiple chronic conditions that often require the participation of community- and hospital-based providers. The current fragmentation of existing health systems for this population frequently makes it difficult to get the continuum of cardiac care that they need.

The 8<sup>th</sup> WCPCCS, in collaboration with the Neonatal Heart Society (NHS), has established the first neonatal tract within the 8<sup>th</sup> WCPCCS

with the above in mind, aiming to streamline communication and break down silos of care. Indeed, the NHS was established for that very purpose. To that end, the NHS most recently established the Neonatal Cardiac Care Collaborative with the help of several subspecialty societies, such as the American Heart Association, the American College of Cardiology and the American Academy of Pediatrics (*NeoC3*). The NeoC3's mission is to improve medical care for neonates with congenital and acquired heart disease and enhance outcomes. Much of the scientific program of the “Cardiovascular Disease in the Neonate” track at the WCPCCS was informed by this effort.

*“ These children frequently have multiple chronic conditions that often require the participation of community- and hospital-based providers. The current fragmentation of existing health systems for this population frequently makes it difficult to get the continuum of cardiac care that they need.”*

### Selected Sessions in NeoHeart 2023 “Cardiovascular Disease in the Neonate” Track

- Hemodynamics of the Extremely Premature Infant
- Cardiovascular Implications in Patients with Congenital Diaphragmatic Hernia
- Echocardiography by the Neonatal ICU Practitioner
- Hemodynamics of Septic Shock
- The Fetal and Neonatal Brain in Congenital Heart Disease
- Management Of the PDA in Very Tiny Babies: Does it Need Closure? If So, How?
- Oral Abstracts in Neonatal Cardiology
- The Effects of Pain, Analgesia, and Sedation on the Neonatal Brain
- Pulmonary Hypertension: Basics & Beyond in 2023
- Surgery and Cath in Tiny Babies - Why?, When?, How?
- Featured Plenary Sessions on
  - Hypoplastic Left Heart Syndrome
  - Transposition of the Great Arteries
  - Tetralogy of Fallot
  - Heterotaxy/Isomerism
- Ethical Issues in Intensive Care
- Roundtable Lunch: How to Best Optimize Neurodevelopmental Care?
- Quality Improvement in the NICU
- Hands-On ECMO
- Acute Persistent Pulmonary Hypertension of the Newborn: State-of-the-Art Management
- Arrhythmias in the NICU



Figure 12: QR code for registration and full details regarding the 8th World Congress of Pediatric Cardiology and Cardiac Surgery.



Figure 13: Over 1500 poster presentations are expected at the 8th WCPCCS. Accepted posters will be on display Monday August 28th – Wednesday 30th, 2023

The 8<sup>th</sup> World Congress of Pediatric Cardiology and Cardiac Surgery (WCPCCS) will occur August 27 – September 1, 2023, in Washington, DC, USA. Over 4,500 clinicians, scientists, administrators, and allied health professionals will gather for this once-in-a-lifetime event – held in the USA for the first time since 1985.

Attendees are encouraged to submit research as abstracts for presentation at the 8th World Congress of Pediatric Cardiology and Cardiac Surgery (WCPCCS).

#### Important Dates

- Notification of abstract acceptance will be on a rolling basis
- All abstracts received before May 31, 2023, will be considered for oral and poster presentations.
- Abstracts received after May 31, 2023, will only be considered for poster presentation
- Notification of presentation format: June 16<sup>th</sup>, 2023 by 5:00pm EST
- Final abstracts submission deadline June 30, 2023
  - those received and accepted between May 15 and June 30 will be presented as posters

Seventeen of the scientific tracks will have dedicated abstract sessions. Delegates will have the opportunity to submit their presentations to one of these 17 sessions. Most of the accepted abstracts will be presented as posters, with the “top nine” in each session given the opportunity for oral presentation (8-minute presentation, 5-minute discussion). The audience will vote in real-time for the “Best Abstract” in each session utilizing a live audience-response system.

#### Sub-Specialty Oral Abstract Sessions

- 1 Adult Congenital Heart Disease
- 2 Basic and Translational Science
- 3 Cardiac Anesthesia

**Note: Work that has been previously presented at other conferences, but *not yet published in manuscript form*, may be submitted to the 8<sup>th</sup> WCPCCS. After all, this is a different audience—present your work to the world!**

**Abstracts will be published in a special issue of *Cardiology in the Young* (unless your work has already been published as an abstract, in part or in whole, in another publication)**

**“Seventeen of the scientific tracks will have dedicated abstract sessions. Delegates will have the opportunity to submit their presentations to one of these 17 sessions.”**

**Call for Abstracts!!**

**NEONATOLOGY TODAY** is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)

- 4 Cardiac Catheterization
- 5 Cardiac, Neonatal, and Pediatric Intensive Care/ECMO\*
- 6 Cardiac Surgery and Cardiopulmonary Bypass
- 7 Cardiac Nursing Clinical Inquiry
- 8 Nursing Clinical Inquiry - Quality Improvement, Evidence-Based Practice
- 9 Nursing Science - IRB Approved Nursing Science/Research
- 10 Echocardiography
- 11 Electrophysiology
- 12 Fetal Cardiology
- 13 General Pediatric Cardiology
- 14 Global Cardiac Health
- 15 Heart Failure, Transplant, and Mechanical Circulatory Support
- 16 Neurodevelopment
- 17 Rheumatic Heart Disease

### **Best Abstract of the World Congress**

No other World Congress has offered this opportunity to young trainees, faculty, and other investigators. A comprehensive afternoon plenary session on August 31 will be held where each of the 17 “Best Subspecialty Abstracts” will be represented to the entire Congress (8-minute presentation, no discussion) for recognition of excellence and ‘cross-talk’ between disciplines. Using state-of-the-art audience response systems, the large, multidisciplinary audience will select the Best Abstract of the 8th World Congress of Pediatric Cardiology and Cardiac Surgery in real time!

\*Abstracts may be submitted specifically for the Neonatal Track

***“No other World Congress has offered this opportunity to young trainees, faculty, and other investigators. A comprehensive afternoon plenary session on August 31 will be held where each of the 17 “Best Subspecialty Abstracts” will be represented to the entire Congress (8-minute presentation, no discussion) for recognition of excellence and ‘cross-talk’ between disciplines.”***

(combined with the ECMO and Cardiac ICU tracks), and accepted abstracts will be presented as oral or poster presentations. The “Best NICU/CICU/ECMO track” winner will also compete with the top abstracts of 16 other tracks for the Best Abstract of the 8th World Congress Award. See [www.wcpccs2023.org](http://www.wcpccs2023.org) for details.

### **Other New Features of the 8<sup>th</sup> World Congress of Pediatric Cardiology and Cardiac Surgery**

**The Multi-Dimensional Anatomy Lab** (first of its kind) integrates historical pathologic heart specimens, traditional angiography, echo, and cross-sectional imaging, newer approaches to 3D print-

ing, surgery and/or catheter intervention planning, and state-of-the-art virtual and augmented reality.

### **Digital Futures and Technology** (first of its kind) features hands-



Figure 14: Left: 3D reconstructed heart of a 7 year old with transposition of the great arteries (TGA) after the arterial switch operation. Right: 3D reconstructed heart of the same patient at 3 days of age with TGA prior to surgery

***“Digital Futures and Technology (first of its kind) features hands-on sessions with academic centers and tech industry partners. There will be scheduled demonstrations and presentations from global experts in artificial intelligence, machine learning, augmented, virtual, extended reality, applied visual effects, and gamification/simulation.”***

on sessions with academic centers and tech industry partners. There will be scheduled demonstrations and presentations from global experts in artificial intelligence, machine learning, augmented, virtual, extended reality, applied visual effects, and gamification/simulation.

**Global and Advocacy Village** At the 2023 WCPCCS, we will host Global Health and Advocacy Village in the Exhibit Hall. “The Village,” Olympic in its scope with nearly 100 participants, is composed of the following two hamlets: (1) Global Health Hamlet for Non-governmental agencies that support charitable heart surgery [NGO’s], and (2) Advocacy Hamlet for patient and parent advocacy groups.

The goals of the Global Health and Advocacy Village include:

- Create a platform for collaboration and exchange of ideas amongst organizations dedicated to global health and advocacy related to pediatric and congenital cardiac care.
- Provide educational opportunities for organizations dedicated to global health and pediatric and congenital cardiac care advocacy.
- Develop strategies that allow this collaboration, exchange of

ideas, and education to lead to saving the lives of those in need of pediatric and congenital cardiac care.

- Empowering constituents by
  - Bulk purchasing of equipment (e.g., cardiopulmonary bypass machines, ventilators)
  - Bulk purchasing of disposables (e.g., oxygenators, sutures, cardiopulmonary bypass tubing, endotracheal tubes, etc.)
  - Bulk purchasing of medications
- Generate a position paper regarding the global needs of patients who require pediatric and congenital cardiac care.

#### **International Seminars at World Congress At the 2023**

***“Global and Advocacy Village At the 2023 WCPCCS, we will host Global Health and Advocacy Village in the Exhibit Hall. “The Village,” Olympic in its scope with nearly 100 participants, is composed of the following two hamlets: (1) Global Health Hamlet for Non-governmental agencies that support charitable heart surgery [NGO’s], and (2) Advocacy Hamlet for patient and parent advocacy groups. ”***

WCPCCS, we will host International Seminars on Wednesday, August 30, 2023, from 4:30 PM to 6:00 PM. The following continental and regional organizations will all host and direct 90-minute Seminars:

- Adult Congenital and Pediatric Cardiology Section (ACPC) of The American College of Cardiology (ACC)
- African Society for Pediatric and Congenital Heart Surgery (ASPCHS) and Pan African Society of Cardiology (PASCAR)
- Asia-Pacific Pediatric Cardiac Society (APPCS)
- Association for European Paediatric and Congenital Cardiology (AEPC)
- Cardiac Society of Australia and New Zealand (CSANZ)
- Gulf Heart Group – Fetal Cardiology
- Pan-Arab Congenital Heart Disease Association (PACHDA)
- Pediatric Cardiac Society of India (PCSI)
- Sociedad Latina de Cardiología y Cirugía Cardiovascular Pediátrica



#### **Two Once-In-A-Lifetime Opportunities for Nurses!**

##### **#1 – Nursing CHD Academy**

This special and comprehensive two-day academy – immediately before the 8<sup>th</sup> WCPCCS - focuses on the spectrum of congenital heart disease, from simple to complex, from presentation in the neonate to those presenting at older ages, from the operating room and ICU to home.

***“The course content is particularly interesting to nurses and advanced practice providers who care for neonates, infants, children, and adolescents in the intensive care unit (neonatal, pediatric and/or cardiac), other inpatient units, the operating room, cath lab, outpatient clinic, and elsewhere.”***

The course content is particularly interesting to nurses and advanced practice providers who care for neonates, infants, children, and adolescents in the intensive care unit (neonatal, pediatric and/or cardiac), other inpatient units, the operating room, cath lab, outpatient clinic, and elsewhere. There is something for providers from all levels of training and experience in this comprehensive academy.

A primer on cardiac nomenclature, and the “building blocks” of congenital heart disease management will be followed by in-depth reviews on defects that will include patent ductus, coarctation, septal defects, abnormal connections of the pulmonary veins, interruption of the aortic arch, tetralogy of Fallot, transposition, and the single ventricle/functionally univentricular heart. The course will also discuss important longer-term outcomes, including neurodevelopmental outcomes, nutrition, post-intensive care syndrome, and transition to adult care.

***“A primer on cardiac nomenclature, and the “building blocks” of congenital heart disease management will be followed by in-depth reviews on defects that will include patent ductus, coarctation, septal defects, abnormal connections of the pulmonary veins, interruption of the aortic arch, tetralogy of Fallot, transposition, and the single ventricle/functionally univentricular heart. ”***

This once-in-a-lifetime opportunity will draw from the internationally renowned faculty from the largest and most experienced programs worldwide, who are invited faculty for the 8<sup>th</sup> World Congress of Pediatric Cardiology and Cardiac Surgery following the Nursing CHD Academy. Please take advantage of this opportunity. You

will not be disappointed!

**Saturday August 26<sup>th</sup>, 2023**

**10:30 AM – 12:30 PM**

**Nursing CHD Academy: The Building Blocks of Congenital Heart Disease**

- What Is Normal?
- Presentation, Diagnosis, Initial Management
- What Happens in the OR?
- Impact of Cardiopulmonary Bypass: What is LCOS?
- The 1st 24 Hours: Hemodynamic Monitoring/Vasoactive Medications
- Post Operative Arrhythmias
- Temporary Pacing
- Pain, Sedation, Delirium
- Cardiopulmonary Interactions

**1:30 PM – 3:30 PM**

**Nursing CHD Academy: Congenital Heart Defects: Part 1**

- Patent Ductus Arteriosus
- Coarctation of the Aorta
- Atrial Septal Defects
- Total Anomalous Pulmonary Venous Return
- Ventricular Septal Defects
- Atrioventricular Septal Defects/Atrioventricular Canal Defects

**4:00 PM – 6:00 PM**

**Nursing CHD Academy: Congenital Heart Defects: Part 2**

- Interruption of the Aortic Arch
- Tetralogy of Fallot
- Tetralogy of Fallot with Major Aortopulmonary Collaterals
- Truncus Arteriosus
- Transposition of the Great Arteries and the Arterial Switch
- Congenitally Corrected Transposition of the Great Arteries (cc-TGA) and Surgical Options (Double Switch, Rastelli, Fontan)

**Sunday August 27<sup>th</sup>, 2023**

**8:00 AM – 10:00 AM**

**Nursing CHD Academy: Congenital Heart Defects Part 3: Single Ventricle**

- Tricuspid Atresia
- Pulmonary Atresia/Intact Ventricular Septum
- HLHS and Variants
- Stage I Norwood

- Interstage Management
- Bidirectional Glenn
- Fontan Operation
- Nutrition, Feeding, and Growth Issues

**8:30 AM – 12:30 PM**

**Nursing CHD Academy-Neurodevelopmental Concerns**

- Neurodevelopmental Issues
- Modifiable and Non-Modifiable Factors Impacting Outcomes
- Palliative Care and CHD: The Scope
- Post Intensive Care Syndrome
- Emotional Health Issues
- Transition and ACHD Care
- A Patient Perspective

**1:30 PM – 3:30 PM**

**Option 1: Nursing CHD Academy: Multidimensional Anatomy Lab**

- Content TBD

**Option 2: Stabilization of the Newborn with Complex CHD**

- Strategies in the Delivery Room for Newborns with Prenatally Diagnosed Complex CHD
- Stabilization of the Neonate with Left-Sided Heart Disease: Those With and Without a Prenatal Diagnosis
- Stabilization of the Neonate with d-TGA
- When is ECMO the Treatment of Choice in the Critically Ill Preoperative Neonate?
- Monitoring in the Preoperative Neonate
- Timing of Surgery 1: New Insights Into the Transitional Circulation in Neonates with Single Ventricle
- Timing of Surgery 2: Cerebral Oxygen Delivery in the Preoperative Neonate
- Evaluation of Other Organ Systems
- Surgeons Perspective: What do I Need? What Don't I Need?
- The Best Way To Stabilize is the Operate Within Hours of Birth: Update on Umbilical Cord Blood for CPB Priming

---

***“The Nursing Track is specifically designed for inpatient and outpatient nurses, neonatal, pediatric, and cardiac intensive care nurses, advanced practice and bedside nurses, administration nurses, research nurses, and more.”***

---



8th World Congress of  
Pediatric Cardiology  
and Cardiac Surgery  
AUGUST 27 - SEPTEMBER 1, 2023  
WASHINGTON D.C.

For more information visit  
[WCPCS2023.org](http://WCPCS2023.org)







Figure 15: "Surface cooling" prior to cardiopulmonary bypass with deep hypothermic circulatory arrest circa 1978. The anesthetized and wrapped neonate is covered with ice, and placed on cardiopulmonary bypass when temperature reached approximately 34°C. Currently, surface cooling is achieved with cooling blankets in an operating room air conditioned to 18-20°C.

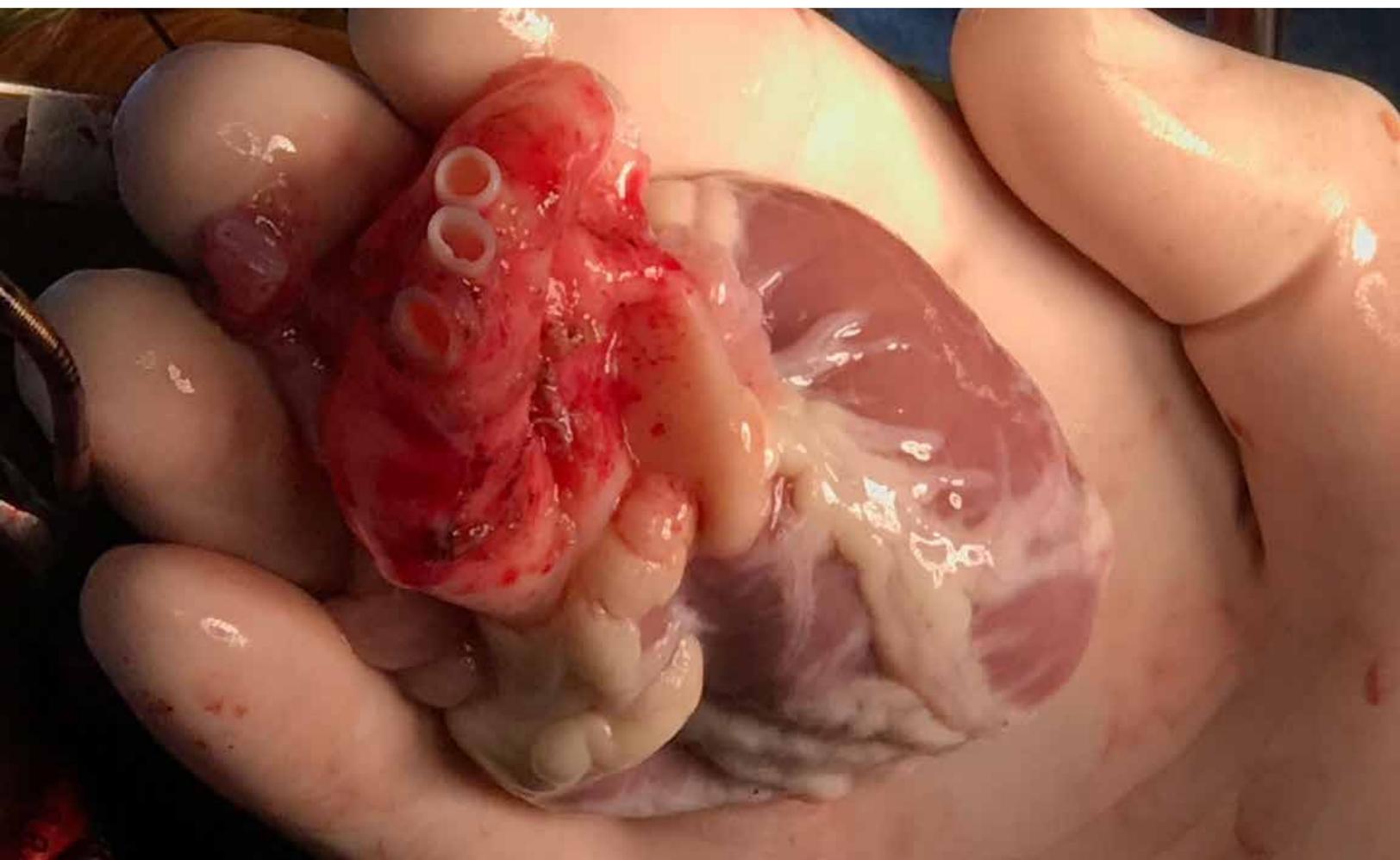


Figure 16 a,b: The remarkable size of donated neonatal hearts, prior to orthotopic heart transplantation.

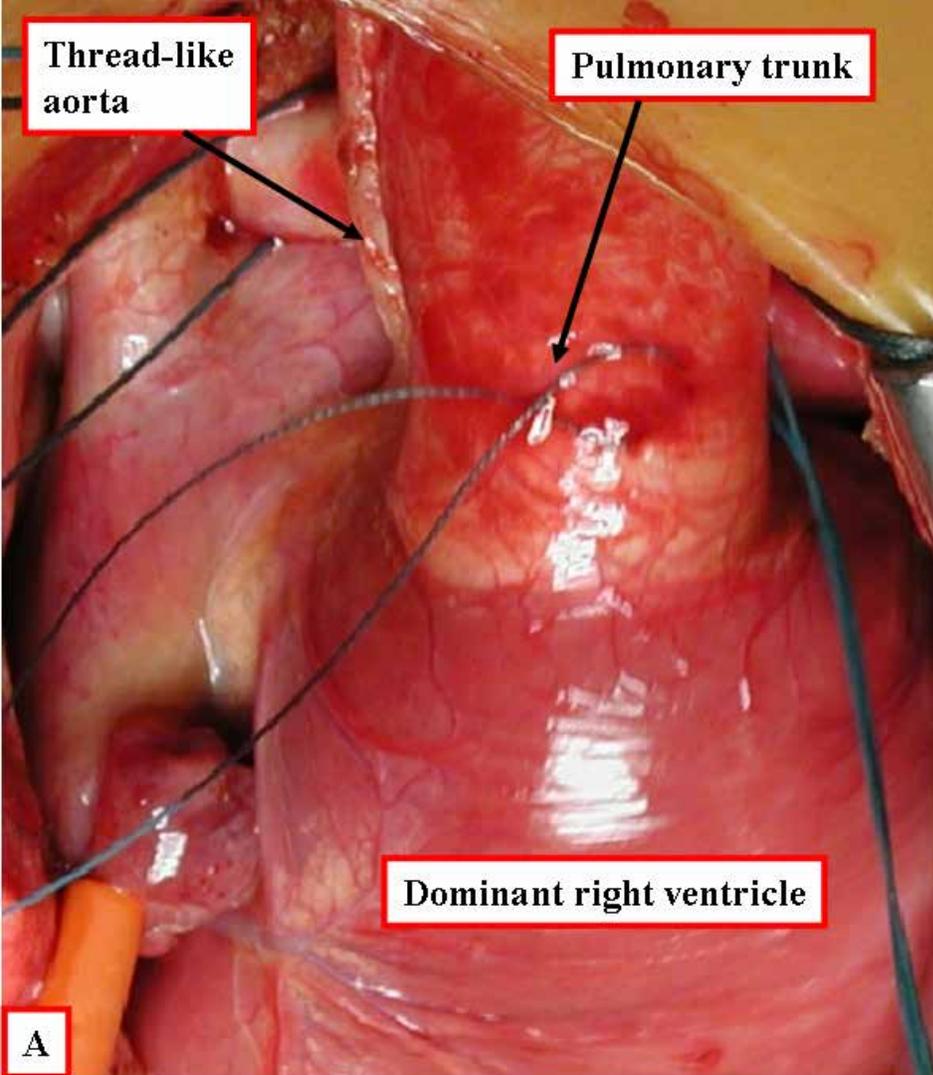


Figure 17: Intraoperative image of a heart with hypoplastic left heart syndrome. Note the 2 mm ascending aorta, particularly compared to the size of the pulmonary artery. These two vessels must be surgically connected to create a 'neo-aorta' as part of the Norwood procedure.

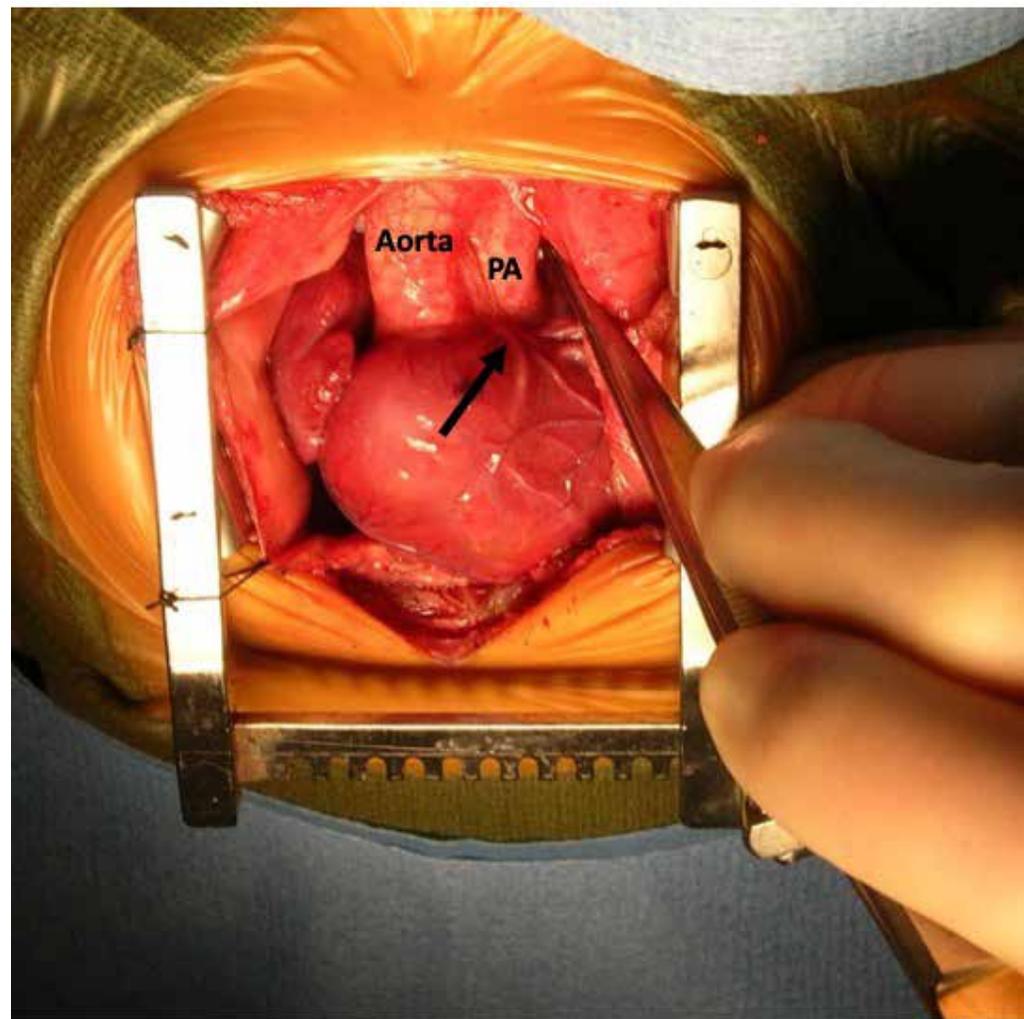
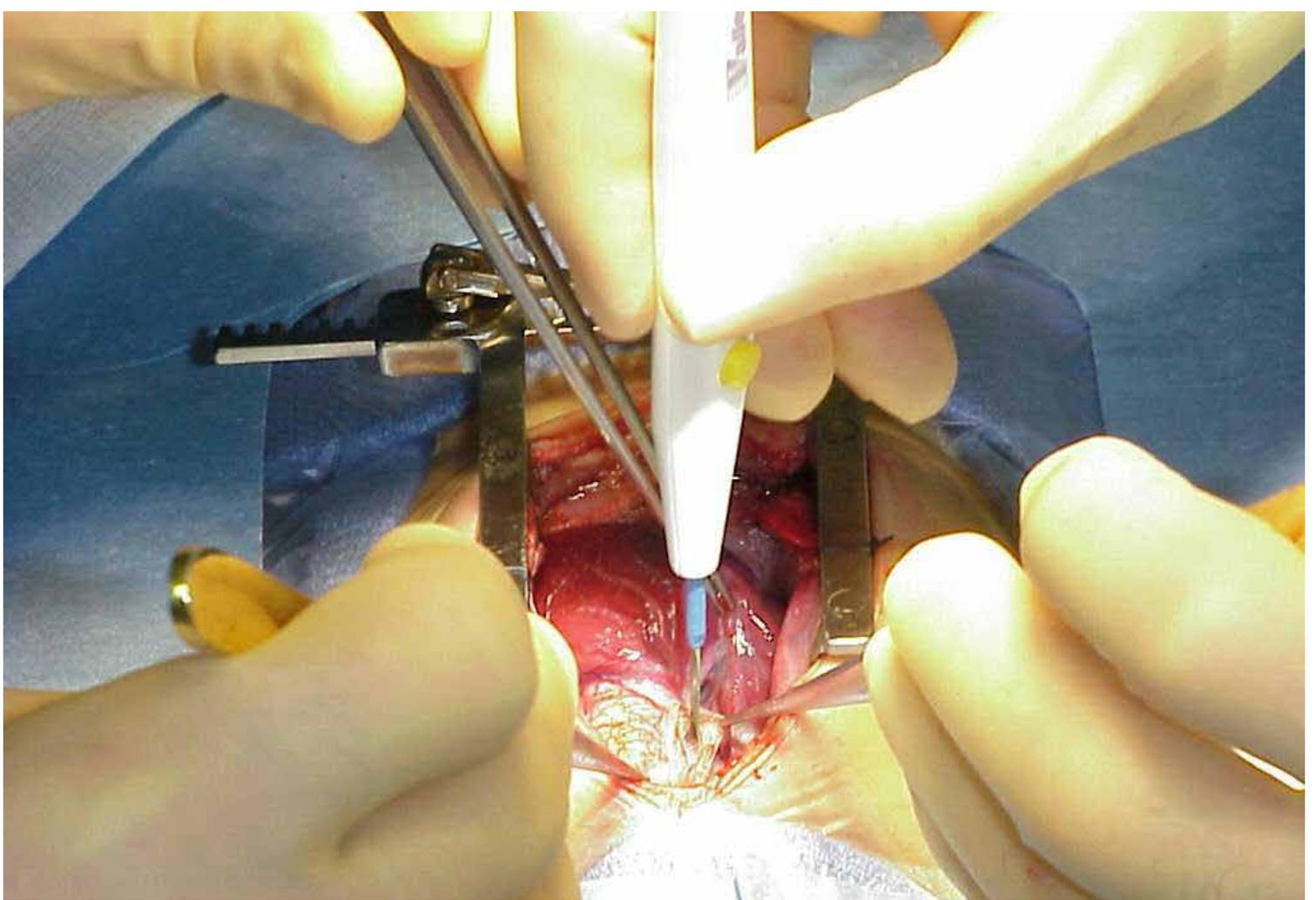


Figure 18: Intraoperative image of a heart with transposition of the great arteries, with the aorta anterior and to the right (connected to the right ventricle) of the pulmonary artery (connected to the left ventricle). Note the size (~2mm) of the left coronary artery which must be translocated posteriorly to the pulmonary artery (which will become the 'neo-aorta')



*Figure 19: The small operative field, along with cardiopulmonary bypass tubing and instruments, during neonatal cardiac surgery*



*Figure 20: Delayed sternal closure has become nearly routine following cardiac surgery with cardiopulmonary bypass in the neonate.*





*Figure 23: Continuous EEG has become standard of care monitoring of the central nervous system following cardiopulmonary bypass in the neonate. Increasingly, critical care neurologists are involved in the care of neonates in both the neonatal and pediatric/cardiac intensive care units. The findings and challenges are very similar in both patient populations, including brain immaturity, seizures, and white matter injury. Long term follow-up reveals similar types and frequencies of developmental challenges*

*Figure 21: (left upper) Bedside diagnostic echocardiography. Although currently standard practice, prior to about 1985-1988, cardiac catheterization was performed for diagnostic purposes in neonates, infants, and children with CHD.*

*Figure 22: (left lower) ECMO with central cannulation is required following 5-8% of neonatal cardiac surgery with cardiopulmonary bypass.*

# NeoHeart 2023



Neonatal Heart Society



Figure 24: Dr. John Cleary moderating the Keynote Lecture at NeoHeart 2022 in Anaheim, California, USA



Figure 25: From left to right: Dr. John Cleary, Dr. Richard van Praagh (Keynote Speaker Neoheart 2019), Dr. Victor Levy and Dr. Amir Ashrafi



Figure 26: From left to right: Dr. Victor Levy, Dr. Abraham Rudolph (Keynote Speaker, NeoHeart 2018), Dr. John Cleary and Dr. Amir Ashrafi



Figure 27: Dr. John Cleary (left) and Dr. Gil Wernovsky (right) at Neoheart 2018



Figure 28: Left to right: Dr. Mitchell Cohen, Dr. Victor Levy and Dr. Gil Wernovsky at Neoheart 2018

#### INSTITUTIONAL PARTNERS

1. Advent Health for Children
2. Advocate Children's Hospital
3. Alfred I DuPont Hospital for Children
4. American Family Children's Hospital
5. Ann & Robert H. Lurie Children's Hospital of Chicago
6. Arkansas Children's Hospital
7. Arnold Palmer Hospital for Children
8. Batson Children's Hospital
9. Boston Children's Hospital
10. C.S. Mott Children's Hospital
11. Children's Hospital at Montefiore
12. Children's Hospital of Philadelphia
13. Children's Medical Center - Dallas
14. Children's Mercy Hospital
15. Children's Minnesota
16. Children's Hospital of Alabama
17. Children's Healthcare of Atlanta
18. Children's Hospital & Medical Center
19. Children's Hospital Colorado
20. Children's Hospital Los Angeles
21. Children's Hospital of Michigan
22. Children's Hospital of Wisconsin
23. Children's Memorial Hermann Hospital
24. Children's National Hospital
25. Cincinnati Children's Hospital Medical Center
26. Cleveland Clinic
27. Cohen Children's Medical Center
28. Connecticut Children's Medical Center
29. Cook Children's Medical Center
30. Dell Children's Medical Center
31. Duke University Medical Center
32. Golisano Children's Hospital at Strong
33. Harley Street Clinic Children's Hospital (United Kingdom)
34. Hospital for SickKids (Canada)
35. INOVA LJ Murphy Children's Hospital
36. Joe DiMaggio Children's Hospital
37. Johns Hopkins All Children's Hospital
38. Johns Hopkins Children's Center
39. Le Bonheur Children's Hospital
40. Levine Children's Hospital
41. Lucile Packard Children's Hospital at Stanford

42. Masonic Children's Hospital
43. Mayo Clinic Children's Center
44. Medical City Children's Hospital
45. Methodist Children's Hospital
46. Monroe Carrell Jr. Children's Hospital at Vanderbilt
47. MUSC Shawn Jenkins Children's Hospital
48. Nationwide Children's Hospital
49. New York-Presbyterian/Columbia/Cornell
50. Nicklaus Children's Hospital
51. Norton Children's Hospital
52. Phoenix Children's Hospital
53. Presbyterian St. Luke's Rocky Mountain Hospital for Children
54. Primary Children's Hospital
55. Riley Hospital for Children
56. Seattle Children's Hospital
57. Stollery Children's Hospital (Canada)
58. Sunrise Children's Hospital
59. Texas Children's Hospital
60. The Barbara Bush Children's Hospital
61. UC Davis Children's Hospital
62. UCSF Benioff Children's Hospital
63. University of Florida Shands Children's Hospital
64. University of Virginia Children's Hospital
65. UPMC Children's Hospital of Pittsburgh
66. Yale-New Haven Children's Hospital

### Endorsing Societies

- Adult Congenital Heart Association
- Advanced Cardiac Therapies Improving Outcomes Network
- American Academy of Pediatrics
- American Association for Thoracic Surgery
- American Association of Critical Care Nursing
- American College of Cardiology
- American Heart Association
- American Society of Extracorporeal Technology
- Cardiac Networks United
- Cardiac Neurodevelopmental Outcome Collaborative
- Cardiac Society of Australia and New Zealand
- Centers for Disease Control
- Children's Heart Foundation
- Congenital Cardiac Anesthesia Society
- Congenital Cardiac Nurses Association
- Congenital Heart Surgeons' Society

- European Society of Paediatric and Neonatal Intensive Care
- Extracorporeal Life Support Organization
- Fetal Heart Society
- Global Arch
- International Society for Adult Congenital Heart Disease
- International Society for Heart and Lung Transplantation
- International Society for Nomenclature of Paediatric and Congenital Heart Disease
- International Society for Pediatric Mechanical Cardiopulmonary Support
- Joint Council on Congenital Heart Disease
- Mended Little Hearts
- Midwest Pediatric Cardiology Society
- Mobassaleh Symposium on Sudden Cardiac Death in the Young
- National Association of Pediatric Nurse Practitioners
- National Pediatric Cardiology Quality Improvement Collaborative
- Neonatal Heart Society
- New England Congenital Cardiology Association
- Northeast Pediatric Cardiology Nurses Association
- Pediatric Acute Care Cardiology Collaborative
- Pediatric and Adult Interventional Catheterization Symposium
- Pediatric and Congenital Electrophysiology Society
- Pediatric Cardiac Critical Care Consortium
- Pediatric Cardiac Intensive Care Society
- Pediatric Congenital Heart Association (Conquering CHD)
- Pediatric Heart Transplant Society
- Sisters-By-Heart/Brothers-By-Heart
- Society for Cardiovascular Magnetic Resonance
- Society of Pediatric Cardiovascular Nurses
- Society of Thoracic Surgeons
- Southeast Pediatric Cardiology Society
- Western Society of Pediatric Cardiology
- World Congress of Pediatric and Congenital Rhythm Disorders (PediRhythm)
- World Federation of Pediatric Intensive and Critical Care Societies
- World Heart Federation
- World Society for Pediatric and Congenital Heart Surgery

### Embedded Societies and Postgraduate Courses:

**19 Meetings In One!**



Two new postgraduate two-day academies\* have been added before the World Congress. In addition to the Neonatal Heart Society and featured topics on Cardiovascular Disease in the neonate, 18 additional societies and postgraduate courses have canceled their annual stand-alone meetings and have embedded scientific content in the World Congress

1. Cardiac Neurodevelopmental Outcome Collaborative
2. Congenital Cardiac Anesthesia Society
3. Fetal Heart Society
4. Global Alliance for Rheumatic and Congenital Hearts
5. Grown-Up Childhood Heart Disease for the Internist and Adult Cardiology Practitioner\*
6. International Society for Adult Congenital Heart Disease
7. International Society for Nomenclature of Pediatric and Congenital Heart Disease
8. International Society for Pediatric Mechanical Circulatory Support
9. Mobassaleh Symposium on Sudden Cardiac Death in the Young
10. Neonatal Heart Society
11. Nursing Congenital Heart Disease Academy
12. Northeast Pediatric Cardiology Nursing Association
13. Pediatric and Congenital Interventional Cardiovascular Society
14. Pediatric Cardiac Intensive Care Society
15. Pediatric Cardiology for the Primary Care Practitioner\*
16. Pediatric Heart Transplant Society
17. PediRhythm<sup>x</sup>
18. Society of Pediatric Cardiac Nursing

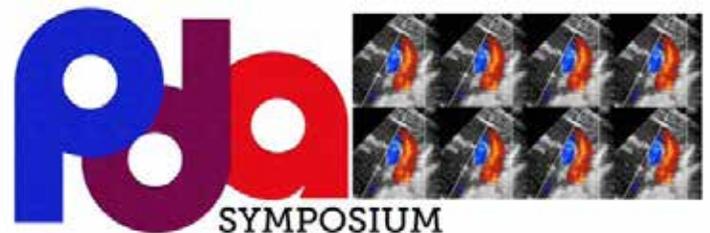
19. World Society for Pediatric and Congenital Heart Surgery

\* Pediatric Cardiology for the Primary Care Provider and Grown-up Pediatric Heart Disease for the Adult Cardiologist

Two additional meetings “In Conjunction With” the World Congress!!!

### PDA Symposium 2023

A Multispecialty Symposium on Advanced Management of the Patent Ductus Arteriosus (PDA) in Newborns. This course brings experts worldwide to have a robust discussion on the current management of the PDA in premature infants. This multispecialty symposium encompasses state-of-the-art practices on keeping the PDA open and closing the PDA in newborn infants. The special focus will be transcatheter PDA Closure in infants with extremely low birth weight.



### PICS LIVE!

The Pediatric and Congenital Interventional Cardiovascular Society (PICS) is excited to host the 26th Annual Scientific Sessions alongside and within the 8th World Congress of Pediatric Cardiology and Cardiac Surgery (WCPCCS) in Washington DC, from Sunday, August 27 through Friday, September 1, 2023.

Our Scientific Committee has worked closely with the WCPCCS team to produce our most comprehensive scientific sessions ever, including, for the first-time, extensive collaboration with many other societies, such as the Congenital Cardiac Anesthesia Society, the World Society for Pediatric and Congenital Heart Surgery, the

Neonatal Heart Society, the Pediatric Cardiac Intensive Care Society, the International Society for Adult Congenital Heart Disease and more. Each morning, "PICS LIVE" will feature Live Cases from ten international sites across four continents with real-time discussion by experts in the field (add-on registration required). Taped cases from four international sites will also be presented.



Following lunch, the PICS track will be fully embedded within the WCPCCS, including the ever-popular "Nightmare Cases in the Cath Lab."

### Thanks to All of Our Educational Partners

Neonatology Today

Cardiology in the Young

Congenital Cardiology Today

Congenital Heart Academy

Heart University

Pediheart: Pediatric Cardiology Today Podcast

The World University of Pediatric and Congenital Heart Surgery  
Selected Frequently Cited References

Pertaining To Cardiovascular Disease in the neonate (in chronological order):

*Note: Many of the earliest manuscripts on cardiovascular disease in the neonate and cardiovascular physiology, in general, were written primarily by neonatologists or by neonatologists as well as pediatric cardiologists in collaboration*

The Pioneers of Neonatal Cardiology: Setting the Stage

#### 1938 - 1975

- Blalock A, Cunningham RS, Robinson CS.
  - Experimental production of chylothorax by occlusion of the superior vena cava. *Ann Surg.* **1936**;104:359-64
- Gross RE.
  - Surgical management of the patent ductus arteriosus: with summary of four surgically treated cases. *Ann Surg.* **1939** Sep;110:321-56
- Blalock A, Taussig HB.
  - The surgical treatment of malformations of the heart in which there is pulmonary stenosis or pulmonary atresia. *JAMA.* **1945**;128:189-202
- Hart EW, Philipp EE.
  - Congenital complete heart block in a newborn infant. *Middx Hosp J.* **1946**;46:85-8.
- Gross RE, Longina LA
  - The patent ductus arteriosus; observations from 412 surgically treated cases. *Circulation* **1951**;3:125-37
- Schnabel TG Jr, Fitzpatrick HF, Peterson LH, Rashkind WJ, Talley DI, Raphael RL
  - A technic of vascular catheterization with small

plastic catheters; its utilization to measure the arterial pulse wave velocity in man. *Circulation.* **1952**;5:257-62.

- Lillehei CW, Cohen M, Warden HE, Read RC, Aust JB, Dewall RA, Varco RL.
  - Direct vision intracardiac surgical correction of the tetralogy of Fallot, pentalogy of Fallot, and pulmonary atresia defects; report of first ten cases. *Ann Surg.* **1955**;142:418-42
- Rudolph AM, Paul MH.
  - Chronic catheterization of pulmonary and systemic circulations: a technique for repeated measurement of cardiac output and pulmonary and systemic pressures in the unanesthetized dog. *J Appl Physiol.* **1957**;10:327-8.
- Rowe RD.
  - Cardiac catheterization in the newborn infant. *Heart Bull.* **1960**;9:61-3.
- Weiss M, Piwnica A, Lenfant C, Sprovieri L, Laurent D, Blondeau P, Dubost C.
  - Deep hypothermia with total circulatory arrest. *Trans Am Soc Artif Intern Organs.* **1960**;6:227-39
- Auld PA, Rudolph AJ, Avery ME, Cherry RB, Drorbaugh JE, Kay JL, Smith CA.
  - Responsiveness and resuscitation of the newborn. The use of the Apgar score. *Am J Dis Child.* **1961** Jun;101:713-24.
- Rudolph AM, Drorbaugh JE, Auld PA, Rudolph AJ, Nadas AS, Smith CA, Hubbell JP.
  - Studies on the circulation in the neonatal period. The circulation in the respiratory distress syndrome. *Pediatrics.* **1961**;27:551-66.
- Avery ME
  - Cardiopulmonary changes in respiratory distress. Clinical observation and physiological exploration. *Pediatrics* **1962**;30:859-61.
- Auld PA, Johnson AL, Gibbons JE, McGregor M.
  - Changes in pulmonary vascular resistance in infants and children with left-to-right intracardiac shunts *Circulation* **1963** Feb;25:7-60.
- Avery ME, Chernick V, Dutton Re, Permutt S.
  - Ventilatory response to inspired carbon dioxide in infants and adults. *J Appl Physiol.* **1963**;18:895-903.
- Boesen I.
  - Complete transposition of the great vessels: importance of septal defects and patent ductus arteriosus. Analysis of 132 patients dying before age 4. *Circulation.* **1963**;28:885-7
- Emmanouilides GC, Moss AJ, Duffie ER Jr, Adams FH
  - Pulmonary arterial pressure changes in human newborn infants from birth to 3 days of age. *J Pediatr.* **1964**;65:327-33
- Rudolph AM

- Diagnostic methods for congenital heart disease. *Am J Surg*. **1964**;107:463-8
  - Moss AJ, Emmanouilides GC, Adams FH, Chuang K.
    - Response of the ductus arteriosus and pulmonary and systemic arterial pressure to changes in the oxygen environment in newborn infants. *Pediatrics*. **1964**;33:937-44
  - Rashkind WJ, Miller WW.
    - Creation of an atrial septal defect without thoracotomy. A palliative approach to complete transposition of the great arteries. *JAMA*. **1966**;196:991-2
  - Avery ME, Gatewood OB, Brumley G.
    - Transient tachypnea of newborn. Possible delayed resorption of fluid at birth. *Am J Dis Child*. **1966**;111:380-5.
  - Gruenwald P.
    - Pulmonary surfactant and stability of aeration in young human fetuses. *Pediatrics*. **1966**;38:912-3.
  - Rudolph AM, Heymann MA.
    - The circulation of the fetus in utero. Methods for studying distribution of blood flow, cardiac output and organ blood flow. *Circ Res*. **1967**;21:163-84.
  - Shafer RM, Kidd L.
    - Acid-base balance in complete transposition of the great vessels. *Br Heart J*. **1967**;29:207-11
  - Rudolph AM, Heymann MA.
    - The fetal circulation. *Annu Rev Med*. **1968**;19:195-206.
  - Hitchcock JF, Beck W, O'Donovan TG, Piller LW.
    - Artificial pacing for congenital complete heart block. *S Afr Med J*. **1969**;43:477-9.
  - Cayler GG, Smeloff EA, Miller GE Jr.
    - Surgical palliation of hypoplastic left side of the heart. *N Engl J Med*. **1970**;282:780-3
  - Michaëlsson M, Engle MA.
    - Congenital complete heart block: an international study of the natural history. *Cardiovasc Clin*. **1972**;4:85-101
  - Krovetz LJ, Rowe RD.
    - Patent ductus, prematurity and pulmonary disease. *N Engl J Med*. **1972**;287:513-4
  - Gay JH, Daily WJ, Meyer BH, Trump DS, Cloud DT, Molthan ME.
    - Ligation of the patent ductus arteriosus in premature infants: report of 45 cases. *J Pediatr Surg* **1973**;8:677-83
  - Barnard MS, Voss TJ, Barnard CN.
    - The treatment of congenital heart disease in infants. Surface cooling, deep hypothermia, limited cardiopulmonary bypass and circulatory arrest. *S Afr Med J*. **1973**;47:469-71.
  - Freed MD, Keane JF, Rosenthal A.
    - The use of heparinization to prevent arterial thrombosis after percutaneous cardiac catheterization in children. *Circulation*. **1974**;50:565-9
  - Todres ID, Rogers MC.
    - Methods of external cardiac massage in the newborn infant. *J Pediatr*. **1975**;86:781-2
  - Krauss AN, Auld PA.
    - Metabolic rate of neonates with congenital heart disease. *Arch Dis Child*. **1975**;50:539-41.
  - Henschel WG, Urban AE, Keck EW, Stark J.
    - Erfolgreiche Korrektur der Fehleinmündung aller Lungenvenen in die Pfortader bei einem 10 Tage alten Säugling [Successful surgical correction of total anomalous pulmonary venous drainage into the portal vein in a ten days old infant (author's transl)]. *Thoraxchir Vask Chir*. **1975**;23:142-51
  - Levin DL, Stanger P, Kitterman JA, Heymann MA.
    - Congenital heart disease in low birth weight infants. *Circulation*. **1975**;52:500-3
  - Sahn DJ, Allen HD, Goldberg SJ, Soling R, Meyer RA.
    - Pediatric echocardiography: a review of its clinical utility. *J Pediatr*. **1975**;87:335-52.
  - Bowles L, Diehl AM.
    - Pediatric nurse associate. A new dimension in pediatric cardiology. *J Kans Med Soc*. **1975**;76:11-12
- The Current Era of Neonatal Cardiac Care and Next Steps (highly selected and frequently cited references): Innovative procedures, technologies, shift from mortality to morbidity, quality improvement, and long-term outcomes
- 1976 - onward**
- Cooley DA.
    - Technical considerations in cardiovascular surgery for neonates. *J Thorac Cardiovasc Surg*. **1976**;71:551-3.
  - Bartlett RH, Gazzaniga AB, Fong SW, Jeffries MR, Roohk HV, Haiduc N.
    - Extracorporeal membrane oxygenator support for cardiopulmonary failure: experience in 28 cases. *J Thorac Cardiovasc Surg* **1977**;73:375-376.
  - Duff DF, Nihill MR, McNamara DG.
    - Infradiaphragmatic total anomalous pulmonary venous return. Review of clinical and pathological findings and results of operation in 28 cases. *Heart*. **1977**;39:619-26.
  - Freed MD, Keane JF.
    - Cardiac output measured by thermodilution in infants and children. *J Pediatr*. **1978**;92:39-42
  - Westenskow DR, Wong KC, Johnson CC, Wilde CS.
    - Physiologic effects of deep hypothermia and microwave rewarming: possible application for neonatal cardiac surgery. *Anesth Analg*.

- Browdie DA, Norberg W, Agnew R, Altenburg B, Ignacio R, Hamilton C.
  - The use of Prostaglandin E<sub>1</sub> and Blalock-Taussig shunts in neonates with cyanotic congenital heart disease. *Ann Thorac Surg* **1979**;27:508-513.
- Clyman RI, Sniderman SH, Ballard RA, Roth RS.
  - What pediatricians say to mothers of sick newborns: an indirect evaluation of the counseling process. *Pediatrics*. **1979**;63:719-23.
- Lang P, Freed MD, Bierman FZ, Norwood WI Jr, Nadas AS.
  - Use of prostaglandin E1 in infants with d-transposition of the great arteries and intact ventricular septum. *Am J Cardiol*. **1979**;44:76-81
- Norwood WI, Kirklin JK, Sanders SP.
  - Hypoplastic left heart syndrome: experience with palliative surgery. *Am J Cardiol*. **1980**;45:87-91
- Lang P, Williams RG, Norwood WI, Castaneda AR.
  - The hemodynamic effects of dopamine in infants after corrective cardiac surgery. *J Pediatr*. **1980**;96:630-4
- Freed MD, Heymann MA, Lewis AB, Roehl SL, Kensey RC.
  - Prostaglandin E1 in infants with ductus arteriosus-dependent congenital heart disease. *Circulation* **1981**;64 899-905.
- Hardesty RL, Griffith BP, Debski RF, Jeffries MR, Borovetz HS.
  - Extracorporeal membrane oxygenation: Successful treatment of persistent fetal circulation following repair of congenital diaphragmatic hernia. *J Thorac Cardiovasc Surg* **1981**;81:556-563.
- Bailey LL, Jacobson JG, Merritt WH, Doroshow RW, Petry EL.
  - Mustard operation in the 1<sup>st</sup> month of life. *Am J Cardiol*. **1982**;49:766-70
- Piccuch RE, Roth RS, Clyman RI, Sniderman SH, Riedel PA, Ballard RA.
  - Videophone use improves maternal interest in transported infants. *Crit Care Med*. **1983**;11:655-6
- Norwood Wi, Lang P, Hansen DD.
  - Physiologic repair of aortic atresia-hypoplastic left heart syndrome. *N Engl J Med*. **1983**;308:23-26
- Castaneda AR, Norwood WI, Jonas RA, Colon SD, Sanders SP, Lang P.
  - Transposition of the great arteries and intact ventricular septum: anatomical repair in the neonate. *Ann Thorac Surg* **1984**;38:438-43.
- Wladimiroff JW, Stewart PA, Tonge HM.
  - fetal cardiac abnormalities. *Ultrasound Med Biol*. **1984**;10:457-63
- Danford DA, Stancombe BB, McNamara DG.
  - Heart disease presenting in the first week of life: implications of advances in diagnosis and management since 1973. *Tex Heart Inst J*. **1984**;11:290-5
- Bailey LL, Nehlsen-Cannarella SL, Concepcion W, Jolley WB.
  - Baboon-to-human cardiac xenotransplantation in a neonate. *JAMA*. **1985**;254:3321-9
- Enhorning G, Shennan A, Possmayer F, Dunn M, Chen CP, Milligan J.
  - Prevention of neonatal respiratory distress syndrome by tracheal instillation of surfactant: A randomized clinical trial *Pediatrics* **1985**;76:145-153.
- Bailey LL, Nehlsen-Cannarella SL, Doroshow RW, Jacobson JG, Martin RD, Allard MW, Hyde MR, Dang Bui RH, Petry EL.
  - Cardiac allotransplantation in newborns as therapy for hypoplastic left heart syndrome. *N Engl J Med*. **1986**;315:949-51
- Samánek M, Goetzová J, Benesová D.
  - Causes of death in neonates born with a heart malformation. *Int J Cardiol* **1986**;11:63-74.
- Kanter KR, Pennington DG, Webere, TR, Zambie MA, Braun P, Martychenko V.
  - Extracorporeal membrane oxygenation for post-operative cardiac support in children. *J Thorac Cardiovasc Surg* **1987**;93:27-35.
- Castañeda AR, Mayer Jr, JE, Jonas RA, Lock JE, Wessel DL, Hickey PR.
  - The neonate with critical congenital heart disease: Repair – a surgical challenge. *J Thorac Cardiovasc Surg* **1989**;98:869-75.
- Costakos DT, Blackwell CE, Krauss AN, Eisen C, Violaris K, Wiercinski AE Jr, Auld PA.
  - Aortic root blood flow increases after pancuronium in neonates with hyaline membrane disease. *Crit Care Med*. 1991;19:187-90
- Kinsella JP, Neish SR, Shaffer E, Abman SH.
  - Low-dose inhalational nitric oxide in persistent pulmonary hypertension of the newborn. *Lancet* **1992**;34:818-819.
- Roberts Jr JD, Polaner DM, Zapol WM, Lang P.
  - Inhaled nitric oxide in persistent pulmonary hypertension of the newborn. *Lancet* **1992**;34:818-819.
- Numa A, Butt W, Mee RB.
  - Outcome of infants with birthweight 2000 g or less who undergo major cardiac surgery. *J Paediatr Child Health*. **1992**;28:318-20.
- Newburger JW, Jonas RA, Wernovsky G, Wypij D, Hickey PR, Kuban K, Farrell DM, Holmes GL, Helmers SL,

- Constantinou J, Carrazana E, Barlow JK, Walsh Z, Lucius KC, Share JC, Wessel DL, Hanley FL, Mayer, Jr, JE, Castañeda AR, Ware JH.
- A comparison of the perioperative neurologic effects of hypothermic circulatory arrest versus low-flow cardiopulmonary bypass in infant heart surgery. *N Engl J Med* **1993**;329:1057-1064.
  - Robertson CMT, Finer NN.
    - Long-Term follow-up of term neonates with perinatal asphyxia. *Clinics in Perinatology* **1993**;20:483-499.
  - Brooks-Gunn K, Klebanov PK, Liaw F, Spiker D.
    - Enhancing the development of low-birthweight, premature Infants: Changes in cognition and behavior over the first three years. *Child Development* **1993**;64:736-753.
  - Brooks-Gunn J, Klebanov PK, Liaw F, Spiker D.
    - Enhancing the development of low-birthweight, premature infants: changes in cognition and behavior over the first three years. *Child Dev* **1993**;64:736-53.
  - Wessel DL, Adatia I, Giglia TM, Thompson JE, Kulik TJ, David L.
    - Use of inhaled nitric oxide and acetylcholine in the evaluation of pulmonary hypertension and endothelial function after cardiopulmonary bypass. *Circulation*. **1993**;88:2128-2138.
  - Miller O, Celermajer DS, Deanfield JE, Macrae DJ.
    - Very-low-dose inhaled nitric oxide: A selective pulmonary vasodilator after operations for congenital heart disease *J Thorac Cardiovasc Surg* **1994**;108:487-94.
  - Wernovsky G, Wypij D, Jonas RA, Mayer JE Jr, Hanley FL, Hickey PR, Walsh AZ, Chang AC, Castañeda AR, Newburger JW, Wessel DL.
    - Postoperative course and hemodynamic profile after the arterial switch operation in neonates and infants. A comparison of low-flow cardiopulmonary bypass and circulatory arrest. *Circulation*. **1995**;92:2226-35
  - Borowski A, Schickendantz S, Mennicken U, Korb H.
    - Open heart interventions in premature low- and very-low-birth-weight neonates: risk profile and ethical considerations. *Thorac Cardiovasc Surg*. **1997**;45:238-41.
  - Cohen MI, Wieand TS, Rhodes LA, Vetter VL.
    - Electrophysiologic properties of the atrioventricular node in pediatric patients. *J Am Coll Cardiol*. **1997**;29:403-7.
  - Dittrich S, Dähnert I, Vogel M, Stiller B, Haas NA, Alexi-Meskishvili V, Lange PE.
    - Peritoneal dialysis after infant open heart surgery: observations in 27 patients. *Ann Thorac Surg*. **1999**;68:160-3
  - Limperopoulos, C, Majnemer A, Shevell MI, Rosenblatt B, Rohlicek C, Tchervenkov C.
    - Neurodevelopmental status of newborns and infants with congenital heart defects before and after open heart surgery. *J Pediatr* **2000**;137:638-645.
  - Wernovsky G, Stiles KM, Gauvreau K, Gentles TL, duPlessis AJ, Bellinger DC, Walsh AZ, Burnett J, Jonas RA, Mayer Jr, JE, Newburger JW.
    - Cognitive development after the Fontan. *Circulation* **2000**;102: 883-88.
  - Jacobs JP, Ojito JW, McConaghey TW, Boden BD, Chang AC, Aldousany A, Zahn EM, Burke RP.
    - Rapid cardiopulmonary support for children with complex congenital heart disease. *Ann Thorac Surg*. **2000**;70:742-9
  - Hoffman TM, Wernovsky G, Atz AM, Bailey JM, Akbary A, Kocsis JF, Nelson DP, Chang AC, Kulik TJ, Spray TL, Wessel DL.
    - Prophylactic intravenous use of milrinone after cardiac operation in pediatrics (PRIMACORP) study. Prophylactic Intravenous Use of Milrinone After Cardiac Operation in Pediatrics. *Am Heart J*. **2002**;143:15-21
  - Hoffman TM, Bush DM, Wernovsky G, Cohen MI, Wieand TS, Gaynor JW, Spray TL, Rhodes LA.
    - Postoperative junctional ectopic tachycardia in children: incidence, risk factors, and treatment. *Ann Thorac Surg*. **2002**;74:1607-11.
  - Hoffman TM, Wernovsky G, Wieand TS, Cohen MI, Jennings AC, Vetter VL, Godinez RI, Gaynor JW, Spray TL, Rhodes LA.
    - The incidence of arrhythmias in a pediatric cardiac intensive care unit. *Pediatr Cardiol*. **2002**;23:598-604
  - Dodds KM, Merle C.
    - Discharging neonates with congenital heart disease after cardiac surgery: a practical approach. *Clin Perinatol* **2005**;32:1031-42
  - Zuppa AF, Nicolson SC, Adamson PC, Wernovsky G, Mondick JT, Burnham N, Hoffman TM, Gaynor JW, Davis LA, Greeley WJ, Spray TL, Barrett JS.
    - Population pharmacokinetics of milrinone in neonates with hypoplastic left heart syndrome undergoing stage I reconstruction. *Anesth Analg*. **2006**;102:1062-9.
  - Alkan T, Akçevin A, Türkoglu H, Paker T, Sasmazel A, Bayer V, Ersoy C, Askn D, Aytaç A.
    - Postoperative prophylactic peritoneal dialysis in neonates and infants after complex congenital cardiac surgery. *ASAIO J*. **2006**;52:693-7.
  - Wernovsky G.
    - Current insights regarding neurological and developmental abnormalities in children and young adults with complex congenital cardiac disease. **2006**;16:92-104.
  - Wernovsky G, Kuijpers M, Van Rossem MC, Marino BS, Ravishankar C, Dominguez T, Godinez RI, Dodds KM, Ittenbach RF, Nicolson SC, Bird GL, Gaynor JW, Spray

- TL, Tabbutt S.
- Postoperative course in the cardiac intensive care unit following the first stage of Norwood reconstruction. *Cardiol Young* **2007**;17:652-65
  - Curzon CL, Milford-Beland S, Li JS, O'Brien SM, Jacobs JP, Jacobs ML, Welke KF, Lodge AJ, Peterson ED, Jaggers J.
    - Cardiac surgery in infants with low birth weight is associated with increased mortality: analysis of the Society of Thoracic Surgeons Congenital Heart Database. *J Thorac Cardiovasc Surg*. **2008**;135:546-51.
  - Dorfman AT, Marino BS, Wernovsky G, Tabbutt S, Ravishankar C, Godinez RI, Priestley M, Dodds KM, Rychik J, Gruber PJ, Gaynor JW, Levy RJ, Nicolson SC, Montenegro LM, Spray TL, Dominguez TE.
    - Critical heart disease in the neonate: presentation and outcome at a tertiary care center. *Pediatr Crit Care Med* **2008**;9:193-202
  - James H. Moller, Sara J. Shumway, Vincent L. Gott,
    - The First Open-Heart Repairs Using Extracorporeal Circulation by Cross-Circulation: A 53-Year Follow-Up. **2009** *Ann Thorac Surg* 88;3:1044-1046,
  - Chrysostomou C, Sanchez De Toledo J, Avolio T, Motoa MV, Berry D, Morell VO, Orr R, Munoz R.
    - Dexmedetomidine use in a pediatric cardiac intensive care unit: can we use it in infants after cardiac surgery? *Pediatr Crit Care Med* **2009**;10:654-60.
  - Nevvazhay T, Chernogrivov A, Biryukov E, Biktasheva L, Karchevskaya K, Sulejmanov S, Kalinicheva J and Artemiev N
    - Arterial switch in the first hours of life: no need for Rashkind septostomy?. *European journal of cardiothoracic surgery* **2012**;42:520-523.
  - Costello JM, Pasquali SK, Jacobs JP, He X, Hill KD, Cooper DS, Backer CL, Jacobs ML.
    - Gestational age at birth and outcomes after neonatal cardiac surgery: an analysis of the Society of Thoracic Surgeons Congenital Heart Surgery Database. *Circulation* **2014** 17;129:2511-7.
  - Ford MA, Gauvreau K, McMullan DM, Almodovar MC, Cooper DS, Rycus PT, Thiagarajan R.
    - Factors associated with mortality in neonates requiring extracorporeal membrane oxygenation for cardiac indications: Analysis of the extracorporeal life support organization registry data. *Pediatr Crit Care Med*. **2016**;17:860-70
  - Hickey PA, Pasquali SK, Gaynor JW, Hi X, Hill KD, Connor JA, Gauvreau K, Jacobs ML, Jacobs JP, Hirsch-Romano JC.
    - Critical care nursing's impact on pediatric patient's outcomes. *Ann Thorac Surg* **2016**;102:1375-1380.
  - Su F, Gastonguay MR, Nicolson SC, DiLiberto M, Ocampo-Pelland A, Zuppa AF.
    - Dexmedetomidine pharmacology in neonates and infants after open heart surgery. *Anesth Analg*. **2016**;122:1556-66
  - Oster ME, Chen S, Dagingcourt N, Bar-Cohen Y, Brothers M, Cain N, Colan SD, Czosek RJ, Decker JA, Gamboa DG, Idriss SF, Kirsh JA, LaPage MJ, Ohye RG, Radojewski E, Shah M, Silver ES, Singh AK, Temple JD, Triedman J, Kaltman JR; Pediatric Heart Network Investigators.
    - Development and impact of arrhythmias after the Norwood procedure: A report from the Pediatric Heart Network. *J Thorac Cardiovasc Surg*. **2017**;153:638-645
  - Wildbolz M, Dave H, Weber R, Gass M, Balmer C.
    - Pacemaker implantation in neonates and infants: Favorable outcomes with epicardial pacing systems. *Pediatr Cardiol*. **2020**;41:910-917.
  - Sethi N, Klugman D, Said M, Hom L, Bowers S, Berger JT, Wernovsky G, Donofrio MT.
    - Standardized delivery room management for neonates with a prenatal diagnosis of congenital heart disease: A model for improving interdisciplinary delivery room care. *J Neonatal Perinatal Med*. **2021**;14:317-329.
  - Puia-Dumitrescu M, Sullivan LN, Tanaka D, Fisher K, Pittman R, Kumar KR, Malcolm WF, Gustafson KE, Lodge AJ, Goldberg RN, Hornik CP.
    - Survival, morbidities, and developmental outcomes among low birth weight infants with congenital heart defects. *Am J Perinatol*. **2021**;38:1366-1372.
  - Levy VY, Bhombal S, Villafane J, McBride ME, Chung S, Figueroa M, Hopper A, Johnson JN, Costello JM
    - Neonatal Cardiac Care Collaborative (NeoC3). Status of multidisciplinary collaboration in neonatal cardiac care in the United States. *Pediatric Cardiology*. **2021**;42:1088-101.
  - Levy VY, Bhombal S, Villafane J, McBride ME, Thiagarajan R, Figueroa M, Hopper A, Johnson JN, Costello JM.
    - Introduction to the **Neonatal Cardiac Care Collaborative Supplement**. *Pediatrics*. **2022**;150(Supplement 2).
  - Cooper DS, Hill KD, Krishnamurthy G, Sen S, Costello JM, Lehenbauer D, Twite M, James L, Mah KE, Taylor C, McBride ME.
    - Acute cardiac care for neonatal heart disease. *Pediatrics* **2022**;150
  - Archer JM, Nixon CS, Sura L, Neal D, Jacobs JP.
    - Lessons learned from linking two complementary databases: The Society of Thoracic Surgeons Congenital Heart Surgery Database and The Vermont Oxford Network Expanded Database. *Cardiol Young*. **2022**:1-7.
  - Henmi S, Essa Y, Öztürk M, Tongut A, Desai M, Yerebakan C, d'Udekem Y.
    - Cardiovascular surgery in very low birth weight ( $\leq 1500$ g) neonates. *Eur J Cardiothorac Surg*. **2022**;63:ezac552

- Reddy RK, McVadon DH, Zyblewski SC, Rajab TK, Diago E, Southgate WM, Fogg KL, Costello JM.
  - Prematurity and congenital heart disease: A contemporary review. *Neoreviews*. **2022**;23:e472-e485
- Ruffatti A, Cerutti A, Tonello M, Favaro M, Del Ross T, Calligaro A, Grava C, Zen M, Hoxha A, Di Salvo G.
  - Short and long-term outcomes of children with autoimmune congenital heart block treated with a combined maternal-neonatal therapy. A comparison study. *J Perinatol*. **2022**;42:1161-1168.
- Bleiweis MS, Philip J, Peek GJ, Stukov Y, Janelle GM, Pitkin AD, Sullivan KJ, Nixon CS, Sharaf OM, Neal D, Jacobs JP.
  - A single-institutional experience with 36 children smaller than 5 kilograms supported with the Berlin heart ventricular assist device (VAD) over 12 Years: Comparison of patients with bi-ventricular versus functionally univentricular circulation. *World J Pediatr Congenit Heart Surg*. **2023**;14:117-124.
- Christensen R, Chau V, Synnes A, Guo t, Grunau RE, Miller SP.
  - Preterm neurodevelopmental trajectories from 18 months to 4.5 years. *J Pediatr* **2023** doi: 10.1016/j.jpeds.2023.113401. Epub ahead of print.
- Sanz JH, Cox S, Donofrio MT, Ishibashi N, McQuillen P, Peyvandi S, Schlatterer S.
  - Trajectories of neurodevelopment and opportunities for intervention across the lifespan in congenital heart disease. *Child Neuropsychol* **2023** doi: 10.1080/09297049.2023.2173162. Epub ahead of print.
- Wolfe KR, Caprarola SD, Clark C, Davidson J, Everitt MD, Faul L, Hageman C, Kelly SL, Maloney E, Patteson H, Scott S, Talbot A, Tong S, DiMaria KL.
  - Implementation of the Cardiac Inpatient Neurodevelopmental Care Optimization (CINCO) program: an interdisciplinary, generalizable approach to inpatient neurodevelopmental care. *Cardiol Young*. 2023 Apr 12:1-8. doi: 10.1017/S1047951123000562. Epub ahead of print.
- Coles J, McCrindle B, Adatia I, Kirsh J, Lee J, Williams G, Webb G, Somerville J, Trusler G, Williams B, Freedom B.
  - The 3rd World Congress of Pediatric Cardiology and Cardiac Surgery **2001**
- Nuri HA, & Giamberti IA
  - 5TH WORLD CONGRESS of Paediatric Cardiology and Cardiac Surgery. **2010** *Cardiology*;20:1-422.
- Somerville J.
  - The World Congress of Paediatric Cardiology and Cardiac Surgery: a short factual history by Jane Somerville. *Cardiol Young*. **2012**;22:633-8.
- Hugo-Hamman C and Jacobs JP.
  - The World Congress of Paediatric Cardiology and Cardiac Surgery: "The Olympics of our Profession" *Cardiol Young* **2012**;22:630-632
- Hayes N, Chubb H, Narayan S, Qureshi S.
  - Highlights of the 6th World Congress in Paediatric Cardiology and Cardiac Surgery. *Future Medicine* **2013**;9:309-312
- Zuhke L.
  - Zuhlke L. Successes, failures, challenges and groundbreaking research: messages from the 6th World Congress of Paediatric Cardiology and Cardiac Surgery *Cardio News*. **2013**;93-95
- Hugo-Hamman C.
  - The 6th World Congress of Paediatric Cardiology and Cardiac Surgery, Cape Town **2013**. *Cardiol Young* 23;80:8-812
- Karl TR
  - The 2017 Seventh World Congress of Pediatric Cardiology & Cardiac Surgery: week in review – cardiac surgery. *Cardiol Young* **2017**;27:2023-2024
- Selamet-Tierney E.
  - The 2017 Seventh World Congress of Pediatric Cardiology & Cardiac Surgery: Week in review: Imaging. *Cardiol Young* **2017**;27:1991-1996.
- Karl TR, Martin GR, Jacobs JP, Wernovsky G.
  - Key events in the history of cardiac surgery and paediatric cardiology. *Cardiol Young* **2017**: 2029-2062.
- Cohen MI, Jacobs JP, Cicek S.
  - The 2017 Seventh World Congress of Paediatric Cardiology and Cardiac Surgery: "The Olympics of our Profession". *Cardiol Young*. **2017**;27:1865-1869.
- Rounding GO
  - 7th World Congress of Pediatric Cardiology & Cardiac Surgery *Abstracts*. **2017** *Cardiology*;27:S1-S653.

#### Historical Details of Previous World Congresses

- Morgan, Beverly C.
  - "Paediatric Cardiology—Volume 4: Proceedings of the World Congress of Paediatric Cardiology held in London in 1980." **1982** *Western Journal of Medicine* 137: 472.
- Doyle EF, Engle MA, Gersony WM, Rashkind, WJ, & Talner NS (Eds.).
  - *Pediatric Cardiology: Proceedings of the Second World Congress*. **1986**. Springer Science & Business Media.
- Imai Y & Momma K (Eds.).
  - *Proceedings of the Second World Congress of Pediatric Cardiology and Cardiac Surgery*. **1998** Wiley-Blackwell.



We look forward to a truly historic scientific meeting and are particularly excited about the roles that the Neonatal Heart Society and Neonatology Today are playing in encouraging attendance from Neonatology and Neonatal nursing fields. Breaking down these silos is long overdue. We can promise that the first ever global “Cardiovascular Disease in the Neonate” track at the 8<sup>th</sup> World Congress of Pediatric Cardiology and Cardiac Surgery will be unparalleled in its scope. Hope to see you in Washington, DC, August 27 – September 1, 2023!

“Invest a week in your career. The results will last a lifetime!”

**And Finally....**

This is a tribute to one of the most important and creative pediatric cardiologists you’ve never heard of. He focused on the neonate with heart disease long before “Cardiovascular Disease in the Neonate” was a concept or developing subspecialty.

***“This is a tribute to one of the most important and creative pediatric cardiologists you’ve never heard of. He focused on the neonate with heart disease long before “Cardiovascular Disease in the Neonate” was a concept or developing subspecialty.”***

In 1965, the very first year the specialty of Pediatric Cardiology was recognized by the American Board of Pediatrics, the following well-known figures in pediatric cardiology received certification: Forrest H Adams, George C. Emmanouilides, Don Fyler, Arthur Moss, Norm Talner, Milton Paul, Jacquie Noonan, Dick Rowe, Helen Taussig, Alexander Nadas, Paul Adams, Ron Laurer, Dick Golinko, Peter Vlad, Genie Doyle, Mary Allen Engle, Abe Rudolph, Sam Kaplan, Jerry Liebman, Rachel Ash, Sidney Friedman, Dan McNamara, Richard van Praagh, Stella van Praagh and many more.

***“While these are well regarded, frequently referenced, and have textbooks, hospital floors, and even cardiac centers named for them, the most unknown is Glen G. Cayler, MD (May 11, 1926 – October 19, 2000). Other than his dates of birth and death, he is virtually a ghost on the internet.”***

While these are well regarded, frequently referenced, and have textbooks, hospital floors, and even cardiac centers named for them, the most unknown is **Glen G. Cayler, MD** (May 11, 1926 – October 19, 2000). Other than his dates of birth and death, he is virtually a ghost on the internet. He has no Wikipedia page, no procedures named for him (although he does deserve credit for describing the precursor of what would become the “hybrid procedure” for hypoplastic left heart syndrome in the New England Journal of Medicine in 1970), no lectureships, no hospital wings. There is an unsubstantiated statement that he was on the list of physicians disciplined by the California Medical Board in 2021, although given his date of death in 2000, this is undoubtedly in error. He was outspokenly critical regarding heart transplantation and the early attempts at liver transplantation by Dr. Thomas Starzl (see reference #50 below). He is probably the first to describe craniofacial syndrome (later cardiofacial syndrome) before Spritzen and DiGeorge. Nevertheless, he lives in anonymity.

***“ He is probably the first to describe craniofacial syndrome (later cardiofacial syndrome) before Spritzen and DiGeorge. Nevertheless, he lives in anonymity.”***

We thought it would be of interest to our readers to list his bibliography, publishing over a 20-year career, and most certainly ahead of his time re: health screening, cardiovascular physiology in congenital heart disease, cor pulmonale from obstructive adenoids and tonsils, the aforementioned description of surgical palliation of hypoplastic left heart syndrome, to a (somewhat crusty) editorial toward the end of his career.

For unclear reasons, Dr. Cayler may have been one of the first neonatal cardiologists, but very few of us have known him until now. Enjoy his career path through his bibliography.

1. Infantile cortical hyperostosis; report of seventeen cases. *AMA J Dis Child*. 1956 Feb;91(2):119-25.
2. Bacterial meningitis in infants and children. *Hawaii Med J*. 1957 Jan-Feb;16(3):267-72.
3. Water intoxication; report of a fatality following a barium enema. *Am J Roentgenol Radium Ther Nucl Med*. 1957 Jan;77(1):69-70.
4. Water intoxication; report of a fatality following a barium enema. *Am J Roentgenol Radium Ther Nucl Med*. 1957 Jan;77(1):69-70.
5. Cardiac catheterization in infants and children. *Pediatr Clin North Am*. 1958 Nov;5(4):907-43.
6. Relation of systolic pressure in the right ventricle to the electrocardiogram; a study of patients with pulmonary stenosis and intact ventricular septum. *N Engl J Med*. 1958 May 15;258(20):979-82.
7. Correction of congenital cardiac defects utilizing the pump oxygenator. *J Okla State Med Assoc*. 1959 Apr;52(4):221-7.
8. Selection of pediatric patients for cardiac diagnostic and surgical procedures. *J Okla State Med Assoc*. 1959 Jul;52(7):446-50.
9. Extracorporeal circulation in consecutive open-heart surgery patients. Successful use without repriming. *Arch Surg*. 1960 Dec;81:969-70.
10. Neonatal pediatrics. Part I. Cardiovascular evaluation. *Am Pract Dig Treat*. 1960 Feb;11:98-100.
11. Cardiorespiratory syndrome of obesity (Pickwickian syndrome) in children. *Pediatrics*. 1961 Feb;27:237-45.
12. The successful use of cardiac bypass in the correction of congenital heart lesions in infants and small children. *J Okla State Med Assoc*. 1961 Apr;54:148-52.
13. In complete transposition of the great vessels (Taussig-Bing complex): Physiological evaluation of six cases and the results of palliative surgery. *Am J Cardiol*. 1962 Aug;10:166-82.
14. The postpericardiotomy syndrome and other major complications of open-heart surgery. *J Okla State Med Assoc*. 1962 Jul;55:272-5.
15. Cystic fibrosis of the pancreas. *J Okla State Med Assoc*. 1962 May;55:191-201.
16. New type of catheter tip for retrograde catheterization of the left ventricle in congenital aortic stenosis. *N Engl J Med*. 1962 May 24;266:1101-3.
17. Ventricular fibrillation during cardiac catheterization successfully treated with external defibrillation and closed chest cardiac massage. *Am J Cardiol*. 1962 Jul;10:120-3
18. Management of congenital heart disease in infants. *J Okla State Med Assoc*. 1962 Jul;55:276.
19. The "new" approach to the management of congenital heart disease in infants. *Am Pract Dig Treat*. 1962 Jul;13:442-9.
20. Preoperative diagnosis and surgical correction of supra-ventricular mitral stenosis and ventricular septal defect. *Circulation*. 1962 May;25:854-61.
21. Oxygen cost of breathing in children. *J Lab Clin Med*. 1963 Feb;61:292-301.
22. Pulmonary artery banding in infants with congenital heart defects other than ventricular septal defect. *Am Surg*. 1963 Mar;29:160-5.
23. Total anomalous pulmonary venous drainage. Results of openheart correction in four infants. *Am J Dis Child*. 1963 Jan;105:42-52.
24. Systemic blood flow in infants and children with and without heart disease. *Pediatrics*. 1963 Aug;32:186-201.
25. Pericarditis with effusion in infants and children. *J Pediatr*. 1963 Aug;63:265-72
26. An approach to the diagnosis of congenital heart disease in infants and children; for the "non cardiologist" physician. *Med Times*. 1963 May;91:423-38.
27. An unusual case of bacterial endocarditis in an infant with congenital heart Ebstein's anomaly in the neonate. a clinical study of three cases observed from birth through infancy. *Am J Dis Child*. 1964 Feb;107:165-72.
28. Ebstein's anomaly in the neonate. A clinical study of three cases observed from birth through infancy. *Am J Dis Child*. 1964 Feb;107:165-72
29. Total correction of Ebstein's anomaly by means of tricuspid replacement. *J Thorac Cardiovasc Surg*. 1964 Jun;47:755-61.
30. The effect of total body perfusion on digitalis tolerance. *Dis Chest*. 1964 Aug;46:130-7.
31. Severe valvar pulmonary stenosis. Successful surgical treatment with hypothermia and inflow occlusion in the first week of life. *Calif Med*. 1964 Jul;101(1):44-7.
32. The clinical diagnosis of congenital heart disease in children without recourse to expert auscultation. *Med Times*. 1965 Jan;93:74-6.
33. Pulmonary artery banding in infants with cardiac anomalies other than ventricular septal defects: including an evaluation of a new technique for determining a critical degree of banding. *Dis Chest*. 1965 Jan;47:88-97.
34. Signs and symptoms of serious heart disease in the pediatric patient. *Med Times*. 1966 Jan;94(1):42-7.
35. The use of valve prostheses in childhood. *J Thorac Cardiovasc Surg*. 1966 Jun;51(6):839-43.
36. Spontaneous functional closure of symptomatic atrial septal defects. *N Engl J Med*. 1967 Jan 12;276(2):65-73.
37. Preoperative objective assessment of venous hemodynamics in patients with varicose veins. *Med Times*. 1968 Dec;96(12):1183-9.
38. Neonatal cardiac distress. A practical approach to recognition, diagnosis, and management. *Calif Med*. 1968 Mar;108(3):188-200.

**Abstract:**

The death rate among neonates with cardiovascular disease is 50 percent during the first six months, with the majority dying during the first month. With early diagnosis most of these babies could be saved. In approaching the diagnosis of cardiac distress in the newborn, it is important to remember that the types of cardiovascular disease which causes symptoms and death early in life are quite different from those in older children. Lesions such as hypoplasia of the left heart, transposition of the great arteries, endocardial fibroelastosis, pulmonary atresia, mitral atresia, tricuspid atresia and truncus arteriosus are common, not rare, causes of cardiac distress in the newborn. A classification of neonatal cardiovascular diseases into seven pathophysiological groups is presented as a basis for an effective, practical approach to the differential diagnosis of the potentially lethal lesions. This approach is simplified further since over 90 percent of babies with cardiac distress have one of three lesions: (1) Large left-to-right shunt (characterized by the presence of massive plethora on the chest roentgenogram), (2) Large right-to-left shunt (association with intense cyanosis) or (3) Severe obstruction (including hypoplasia of the left heart, which is the most common cause of death due to cardiac distress during the first week of life).

39. Heart failure due to enlarged tonsils and adenoids. The cardiorespiratory syndrome of increased airway resistance. *Am J Dis Child.* 1969 Nov;118(5):708-17.
40. Cardiofacial syndrome. Congenital heart disease and facial weakness, a hitherto unrecognized association. *Arch Dis Child.* 1969 Feb;44(233):69-75.
41. Mass screening of school children for heart disease. *Public Health Rep (1896).* 1969 Jun;84(6):479-82.

42. A new clinical sign of anomalous coronary artery. *Dis Chest.* 1969 Feb;55(2):163-6.
43. Congenital complete heart block in newborns, infants, children, and adults: recognition and treatment. *J Natl Med Assoc.* 1969 Jul;61(4):295-302.
44. Congenital complete heart block in newborns, infants, children, and adults. *Med Times.* 1969 Oct;97(10):113-23.
45. Congenital aortic stenosis. Correlation of clinical and hemodynamic findings with the severity of the lesion. *Dis Chest.* 1969 May;55(5):368-71.
46. Surgical palliation of hypoplastic left side of the heart. *N Engl J Med.* 1970 Apr 2;282(14):780-3.
47. Relevance in medical education. *Calif Med.* 1970 May;112(5):82.
48. A new approach to the delivery of pediatric cardiology services. *Chest.* 1970 Oct;58(4):316-7.
49. Benefits from mass evaluation of school children for heart disease (experience with 6,625 children). *Chest.* 1970 Oct;58(4):349-51.
50. Heart transplantation—the American way of preserving misery. *J Natl Med Assoc.* 1970 May;62(3):247-8
51. Further studies of patients with the cardiofacial syndrome. *Chest.* 1971 Aug;60(2):161-5.
52. Effect of cardiac 'nondisease' on intellectual and perceptual motor development. *Br Heart J.* 1973 May;35(5):543-7.
53. An innocent thrill. A common finding with an innocent mur-



## 8th World Congress of Pediatric Cardiology and Cardiac Surgery

WASHINGTON D.C.

In 2023, for the first time ever, the World Congress of Pediatric Cardiology and Cardiac Surgery will be held in the continental United States of America. The 2023 WPCCSS promises to be the most comprehensive, up-to-date and technologically advanced meeting ever designed for Pediatric and Congenital Heart Disease.



AUGUST 27 – SEPTEMBER 1, 2023

### SUBSPECIALTY TRACKS

- Cardiac Surgery • Ambulatory Cardiology •
- Cardiac Catheterization • Multimodal Imaging •
- Cardiovascular Nursing • Rheumatic Heart Disease •
- Fetal Cardiology • Adult Congenital Heart Disease •
- Cardiovascular Disease in the Neonate •
- Basic and Translational Science • Neurodevelopment •
- Heart Failure and Transplantation • Echocardiography •
- Administration & Leadership • Cardiac Anesthesia •
- Pulmonary Hypertension • Global Cardiac Health •
- Electrophysiology • Quality Improvement •
- Special Sessions for Trainees and Junior Faculty •
- Big Data, New Technology & Artificial Intelligence •
- Cardiac Intensive Care Advocacy • Cardiopulmonary Bypass, ECMO & Mechanical Circulatory Support •

Please subscribe to our mailing list and visit the website for the latest information on abstract submission, registration, lodging and more details to help you prepare for #WPCCSS2023

Join our mailing list at  
[WPCCSS2023.org](https://www.WPCCSS2023.org)

Connect and learn  
#WPCCSS2023



Abstract Submission is Now Open

mur. JAMA. 1976 May 31;235(22):2417.

54. Physician, can you justify your job description? J Natl Med Assoc. 1976 May;68(3):253-4, 252.

If any readers have additional information, photos, or published articles by Dr. Cayler, please share!

Gil Wernovsky MD

Children's National Hospital

Washington DC, USA

[gwernovsky@childrensnational.org](mailto:gwernovsky@childrensnational.org)

**Disclosures:** There are no stated conflicts of interest.

**NT**



*John Cleary, MD\**  
*Former Regional Director of Neonatology*  
*CHOC PSF*  
*Orange, CA*

*Corresponding Author*



*Gil Wernovsky MD, FAAP, FACC*  
*Senior Consultant in Cardiac Critical Care and Pediatric Cardiology*  
*Children's National Hospital*  
*Professor of Pediatrics*  
*George Washington University School of Medicine and Health Sciences*  
*Washington, DC*  
<https://childrensnational.org/visit/find-a-provider/gil-wernovsky>  
<https://linkedin.com/in/gil-wernovsky-md-1096a0>  
*Email:* [gwernovsky@childrensnational.org](mailto:gwernovsky@childrensnational.org)



*Mitchell I. Cohen MD*  
*Co-Director of the Pediatric Heart Program*  
*Chief of Pediatric Cardiology at Inova L.J. Murphy Children's*  
*Hospital.*  
*Alexandria, VA*



*Amir Ashrafi, MD*  
*Neonatologist*  
*Children's Hospital of Orange County*  
*Orange, CA*



*David S. Cooper, MD, MPH*  
*Medical Director, Heart Institute*  
*Medical Director, Cardiac Intensive Care Unit*  
*Medical Director, Cardiac Anesthesia Recovery Unit*  
*Professor, UC Department of Pediatrics*  
*Cincinnati Children's Hospital Medical Center*  
*Cincinnati, OH*



*Kathryn M. Dodds, RN, MSN, CRNP,  
Clinical Program Manager  
Fontan FORWARD Program  
Children's Hospital of Philadelphia.  
Philadelphia, PA*



*Victoria Servin Meskin, MSN, RNC-NIC  
NICU & Pediatric Critical Care trained nurse  
Los Angeles and Orange County, CA*



*Cristen Hemmingway BA  
Manager,  
CME Programs & Events @ CHOC  
Orange, CA*



*Mitchell Goldstein, MD, MBA, CML  
Professor of Pediatrics  
Loma Linda University School of Medicine  
Division of Neonatology  
Department of Pediatrics  
Email: [mgoldstein@llu.edu](mailto:mgoldstein@llu.edu)*



*Victor Levy, MD  
NICU Medical Director and Neonatal Cardiac Intensivist;  
Fort Worth, TX*



*Jeffrey P Jacobs, MD, FACS, FACC, FCCP  
Professor Of Surgery And Pediatrics  
UF Health Congenital Heart Center and UF Health  
Shands Children's Hospital  
University of Florida  
Gainesville, FL 32611*



sanofi

**RSV:**

The leading cause of  
infant hospitalization.

**All infants  
need protection.**

**Reference:** Suh M, et al. *J Infect Dis.* 2022;226(Suppl 2):S154-S163.

MAT-US-2300724 V1.0 January 2023

Respiratory Syncytial Virus is a

# Really Serious Virus

Here's what you need to watch for this RSV season

Coughing that gets worse and worse



Breathing that causes their ribcage to "cave-in"

Rapid breathing and wheezing



Bluish skin, lips, or fingertips

RSV can be deadly. If your baby has these symptoms, don't wait.

Call your doctor and meet them at the hospital.

If your baby isn't breathing call 911.



Thick yellow, green, or grey mucus



that clogs their nose and lungs, making it hard to breathe

Fever that is higher than 101° Fahrenheit



which is especially dangerous for babies younger than 3 months



[www.nationalperinatal.org/rsv](http://www.nationalperinatal.org/rsv)

## Which Infants are More Vulnerable to Respiratory Syncytial Virus?

RSV is a respiratory virus with cold-like symptoms that causes 90,000 hospitalizations and 4,500 deaths per year in children 5 and younger. It's 10 times more deadly than the flu. For premature babies with fragile immune systems and underdeveloped lungs, RSV proves especially dangerous.

But risk factors associated with RSV don't touch all infants equally.\*

\*Source: Respirator Syncytial Virus and African Americans

Caucasian Babies	Risk Factor	African American Babies
11.6%	 Prematurity	18.3%
58.1%	 Breastfeeding	50.2%
7.3%	 Low Birth Weight	11.8%
60.1%	 Siblings	71.6%
1%	 Crowded Living Conditions	3%

**!** AFRICAN AMERICAN BABIES bear the brunt of RSV. Yet the American Academy of Pediatrics' restrictive new guidelines limit their access to RSV preventative treatment, increasing these babies' risk.



Readers can also follow  
**NEONATOLOGY TODAY**  
 via our Twitter Feed  
**@NEOTODAY**

## In Memory of John Patrick Cleary, MD

Christine Bixby, MD, Meghan Cleary Robins, JD-MPP



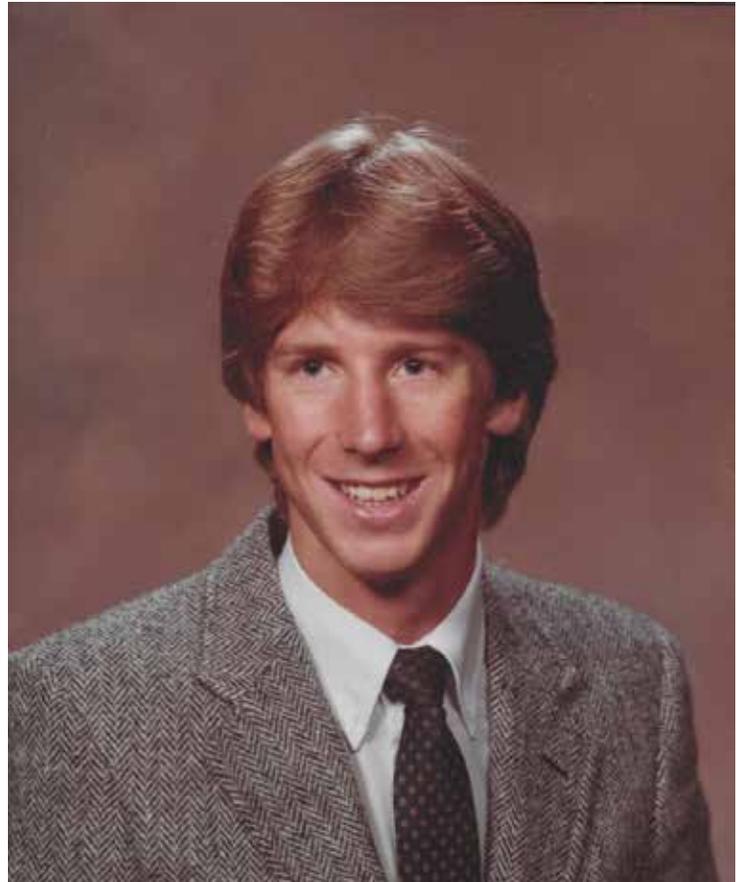
Dr. John Patrick Cleary, MD, peacefully left this world surrounded by his family on Wednesday, October 26, 2022, after a heroic battle with colorectal cancer. He was an extraordinary neonatologist, husband, father, brother, son, uncle, physician leader, coach, mentor, and friend to so many in the Orange County, San Diego, and Boston communities throughout his 60 years of life. He leaves behind his devoted wife of 35 years, Joyce Teitz Cleary; his four children, Patrick and wife Libby, Meghan Robins and wife Elizabeth, Shannon and Finn; nephew Michael Teitz and grandchildren, Olivia and John Leo.

John was born in Boston, Massachusetts, and raised in Milton, MA, the son of Maureen and the late Paul Cleary. He was raised in a large and loving family as the fourth of six brothers and one sister- Paul, Michael, Steven, Timothy, Patrick, and Maura. As a child, he was credited with saving all of his siblings from having to attend catholic school because he had a lisp that required speech therapy through the public school, a story he would tell

*“Dr. John Patrick Cleary, MD, peacefully left this world surrounded by his family on Wednesday, October 26, 2022, after a heroic battle with colorectal cancer.”*

**NEONATOLOGY TODAY** is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)





proudly for years to come. A graduate of Milton High School, he ran cross country and track and field and was also president of his class. John initially hoped to join his brother Michael at Tulane University in New Orleans before making a late switch to Boston University, where he was awarded an excellent scholarship.

---

***“A graduate of Milton High School, he ran cross country and track and field and was also president of his class. John initially hoped to join his brother Michael at Tulane University in New Orleans before making a late switch to Boston University, where he was awarded an excellent scholarship.”***

---

His many accomplishments at BU included graduating Phi Beta Kappa with a degree in Biology, serving as President of the Bay State Student Government, witnessing a legendary (or perhaps infamous) concert-turned-riot of a favorite band, The Stompers, and meeting lifelong friends, who surrounded him right up to his death. Most importantly, at BU, he met his beloved wife, Joyce

Teitz, on a fateful night at a basement bar near Fenway Park, “The Dugout Cafe.”



After graduation, John was accepted to medical school at the University of Massachusetts. His father opened the acceptance letter while John and Joyce attended a Maine wedding. When they returned to the Cleary home in Milton, they were greeted by champagne and celebrations as John’s parents were thrilled he would be staying close to home! John attended medical school in Worcester while Joyce worked as a nurse in Boston, and in



---

*“In San Diego, the family made more dear friends and fell in love with the west coast. After a year-long stint in Shrewsbury, MA, the family returned to Southern California permanently in 1994.”*

---



1987 they were married in Dorchester, MA, followed by a dinner cruise around Boston Harbour. Not long after their wedding, they became a family of three when their first son, John Patrick Cleary, Jr, or "Pat," was born. Three years later, their daughter Meghan arrived shortly before John completed his residency in Pediatrics, also at the University of Massachusetts. The family then moved to sunny San Diego, CA, where John completed a neonatal and perinatal medicine fellowship at the University of California, San Diego, and served on a helicopter transport team. In San Diego, the family made more dear friends and fell in love with the west coast. After a year-long stint in Shrewsbury, MA, the family returned to Southern California permanently in 1994.



### A Tribute to John Cleary

John Patrick Cleary, MD, New England family man, ace clinician, and mensch, was an exemplary neonatologist and a truly great, liberal and progressive man.

John and I moved to La Jolla and Del Mar, CA from Worcester, MA, and Lexington, KY, respectively, mid 1991 to pursue NPM fellowship training at UCSD, in our late 20s. In the following 3 decades, we lived and practiced, almost exclusively in California: friends, clinical investigation/RCT collaborators, truth-seekers and mutual admirers.

His dedication to speak for the unspoken, challenge the status quo, devoid fear of establishment, while comically reminiscent of revolutionary zeal, was so well-intended and ever-oriented to improve the lives of his patients, families, generations of trainees, and "all his peeps" in general. Fourth of 7 children, he loved and cherished the great love of his life, his wife Joyce; and was proudest of his 5 children and 2 grandchildren, all of whom were with him, at and until the very end.

Nominated by Jaqueline Anne Noonan to the Irish American Pediatric Society, he was an active member, leader and multiple award winner, in many of our professional societies. He was devoted to the future of children with congenital heart disease, founding the collaborative enterprise of NeoHeart. He was instrumental in the recruitment of (the late) Joyce Denson-Lino and (the late) Ira Adams-Chapman into NPM fellowship at UCSD in 1994.

He is fondly remembered for his many St. Patrick's day parties and his passion for live bands, music, golf and fine wine.

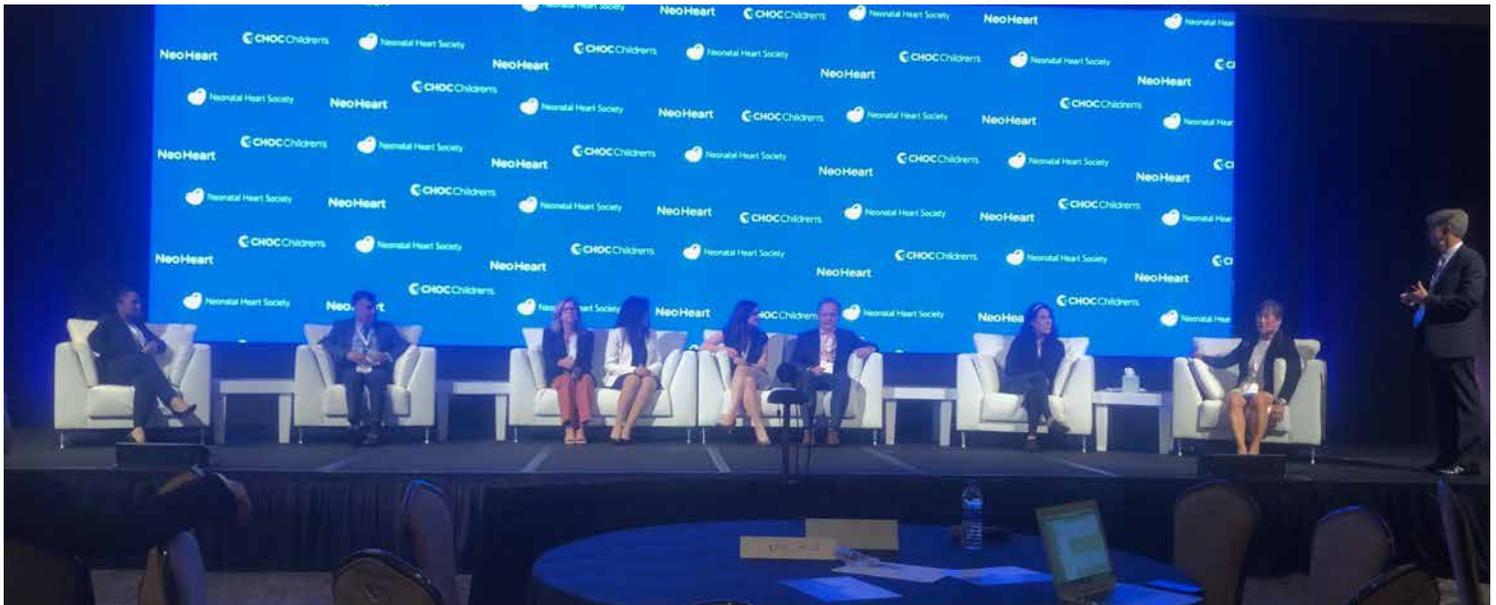
As spake Charles Dickens to his oldest friend, John Forster, upon completion of both, A Tale of Two Cities, and Great Expectations, "I am quite confident I should rust, break and die, if I spared myself. Much better to die, doing." This seemingly, is John Cleary's loving legacy to us, his peers in Neonatal-Perinatal Medicine.

Balaji Govindaswami, May 19, 2023

Settling in North Tustin, CA, John was a dedicated member of the Orange County community as a physician at CHOC and a parent and coach. The family welcomed two more children- Shannon and Finn, with Shannon's birth being captured by Discovery Health while a film crew was following John for a show about premature babies. First on the little league field and later on the lacrosse field, Coach Cleary, who was also affectionately referred to simply as "Doc," touched the lives of athletes at Hewes Middle School and Foothill High School as he fell in love with the sport of lacrosse. He enjoyed coaching the 7th Graders at Hewes so much that he continued to do so long after his children had moved on from the sport. When his daughters were less athletically inclined and found a love of theater, John built wooden trees that would be set pieces on stage for dozens of shows for years to come.

However, more importantly, John's children loved going on "adventures" with him, which often involved rides in the convertible with the top down to an unknown location, usually breakfast near the beach. John was the life of every party, particularly when hosting his annual "Irish Party," which began as a small family gathering and eventually grew to include neighbors, friends, nurses, doctors, and more, all enjoying Irish music and lively toasts.

***"Settling in North Tustin, CA, John was a dedicated member of the Orange County community as a physician at CHOC and a parent and coach."***



### A Tribute to John Cleary

I first met John Cleary at a Western Perinatal Meeting while I was still a fellow. Over the years, I had gotten to know him through the California Association of Neonatology, the various meetings that we had in common in Southern California and our "in parallel" positions at CHOC and Loma Linda as director of the Neonatal ECMO programs. John was very helpful when I started in as editor of Neonatology Today both as a contributor and my liaison to CAN for the publication of their abstracts. He was one of the primary organizers of 8<sup>th</sup> World Congress of Pediatric Cardiology and Cardiac Surgery and I had hoped to see him there.

Mitchell Goldstein, MD

Professor of Pediatrics

Loma Linda University Children's Hospital

*“At CHOC since 1995, Dr. Cleary has cared for thousands of patients, served on multiple committees, and held several leadership roles, including medical director of the NICU Extracorporeal Life Support Program (ECLS) for over 20 years.”*





### A Tribute to John Cleary

"John was one of my first NICU friends at CHOC. While I was still a PICU Fellow, John always treated me like a colleague and a physician partner. He never looked down at me or treated me as inferior to him. We became close friends as did our wives and our children, We were family. One of the many things that I loved about John was his absolute inability to tolerate the "status quo" and his well-honed skill of how to best "stir the pot" with anyone at the Hospital or in our physician group, in an effort to make us push the envelope, think outside the box and be the best version of ourselves at every turn. He often made such comments with a sly smirk on his face that said "Watch where this goes."

John Cleary was an excellent physician, my golfing buddy, a mentor, and most importantly, my great friend. I am a better physician, husband, father and man for having known him. I miss him dearly."

Jason Knight, MD

Division Chief – Critical Care

Medical Director – PICU

Associate Clinical Professor of Pediatrics – UCI

John loved to spend his free time golfing with good friends and colleagues, particularly Nick Anas and Jason Knight. Always glad to take the opportunity to get away to Pebble Beach, where he once made a hole-in-one! The Cleary family spent their Januaries in Newport Beach, savoring sunsets together between the hustle and bustle of work and school. John brought both meaning and humor to every situation he encountered. His children will think of him at every sunset and with every glass of chardonnay. They will always remember not to "ruin a great story with the truth."

Professionally, Dr. Cleary thrived in the Newborn Intensive Care Unit. At CHOC since 1995, Dr. Cleary has cared for thousands of patients, served on multiple committees, and held several leadership roles, including medical director of the NICU Extracorpor-

### A Tribute to John Cleary

John was brilliant. John was passionate. John was innovative. These are traits that have been ascribed to many physicians however, what sets John apart was his added reputation as the compass for right versus wrong. He was regarded as the North Star by many within his own division and beyond. He was also a dedicated mentor. Personally, he taught me the nuances of establishing a professional career while balancing the needs of a young family. I am better in all facets of my life because I knew John. He was a friend, mentor, and big brother. John will always be loved.

Amir Ashrafi, MD

Children's Hospital of Orange County

real Life Support Program (ECLS) for over 20 years. He had a particular skill with complex clinical care decision-making and served on the CHOC ethics committee for many years. His colleagues regularly sought his counsel on medically and ethically complex cases. He had an uncanny ability to evaluate complex situations and develop possible options. Family-centered care, a hallmark of the care at CHOC, was greatly supported and modeled by Dr. Cleary. His passion for teaching was well known, and many eagerly sought him out to have the opportunity to learn from him, knowing that they would be challenged to think beyond the textbook. With more than 60 publications to his name, Dr. Cleary was prolific in research, with interests including synchronized mechanical and high-frequency ventilation, pulmonary hypertension, and non-invasive monitoring. John was also a mentor to physicians in all disciplines. John was known for his ability to speak honestly and advocate passionately. Many frequently quote him, "Do what's right, not what's easy."

Equally impressive was Dr. Cleary's work outside of CHOC, all anchored by a devotion to the health and well-being of children. He served as president of the California Association of Neonatologists (CAN), bringing a research symposium to the start of the annual conference. John also served on the executive committee

### A Tribute to John Cleary

"John and I joined the CHOC Division of Neonatology the same day in July of 1995. John was driven by clinical excellence, defined by quality and was passionate about teaching and research. He was a great mentor and a strong advocate for trainees and faculty. He contributed hugely to where we are today as the CHOC Neonatal Network in the service of patients and families in Southern California. You are missed every day, my friend."

Vijay Dhar, MD

Division Chief, Neonatology,

CHOC Children's/UC Irvine

In-patient Network Director

CHOC Children's Specialists

Professor of Pediatrics

University of California, Irvine School of Medicine

of the Children's Specialty Care Coalition of California. He was incredibly proud of his work in Sacramento. He would often text his daughter and daughter-in-law, who work in public policy and public health, to share about his "policing," as he called it, and to call upon their expertise. He was a founding and board member of the Neonatal Heart Society and co-creator of the international NeoHeart conference.

***"He would often text his daughter and daughter-in-law, who work in public policy and public health, to share about his "policing," as he called it, and to call upon their expertise. He was a founding and board member of the Neonatal Heart Society and co-creator of the international NeoHeart conference."***

John's life was abruptly interrupted when the otherwise strong and healthy physician was diagnosed with Stage 4 colorectal cancer in the late summer of 2022. Despite a valiant battle involving chemotherapy, radiation, and immunotherapy from excellent doctors at both UC Irvine and MD Anderson at Scripps La Jolla, within a year, it became apparent that, unfortunately, his life would be cut short. His last days were spent surrounded by his family, beloved children, closest colleagues, dearest friends, and most impor-

tantly, his heroic wife Joyce, who cared for him in his final days. One of the last highlights of his life, John was thrilled to meet his grandson and namesake John Leo, who was born shortly before his death in Washington, DC but made it to California to see his "Doc" before he left us.

### A Tribute to John Cleary

"Some of the people who impress me the most in our field are not those that know the answers, but those that ask the questions. The questions that can seem from out of left field, and then you think "What an Incredible way to think about that". John was one of those people.

And as good as is was as a teacher, a mentor, a clinician, it was apparent as we got to know each other than family and friends came first and foremost. I admired him in every way possible. He was a true friend."

Gil Wernovsky MD, FAAP, FACC

Senior Consultant in Cardiac Critical Care and Pediatric Cardiology

Children's National Hospital

Professor of Pediatrics

George Washington University School of Medicine and Health Sciences

***"Do what's right, not what's easy." AND  
"Don't ruin a great story with the truth."  
John Patrick Cleary***





As a tribute to Dr. Cleary, the keynote address at NeoHeart will now be named the John Patrick Cleary Keynote Address. In addition, as Dr. Cleary was an avid golfer, the winning team at the annual CHOC Golf Classic will receive the John Patrick Cleary Award.

**NT**

*Corresponding Author:*



*Christine Bixby, MD, FAAP, IBCLC  
Division of Neonatology,  
CHOC Children's Specialists  
Medical Director, CHOC Lactation  
Orange, CA  
Email: [CBixby@choc.org](mailto:CBixby@choc.org)*



*Meghan Cleary Robins, JD-MPP  
Daughter of John Patrick Cleary*

Readers can also follow  
**NEONATOLOGY TODAY**  
via our Twitter Feed  
**@NEOTODAY**

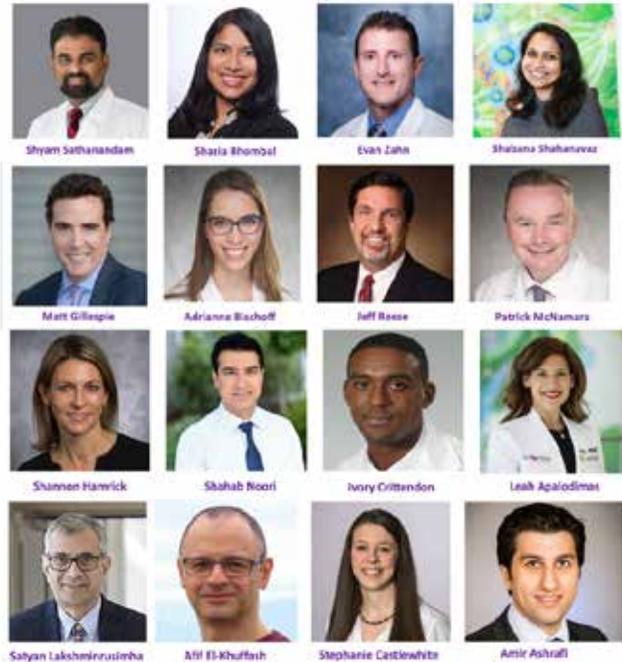
## The 5<sup>th</sup> International PDA Symposium in Partnership with the 8<sup>th</sup> World Congress of Pediatric Cardiology and Cardiac

### Program highlights

Joint statement on management recommendations for PDA in the extremely premature infants from the International PDA symposium, World Congress of Pediatric Cardiology and Cardiology Surgery and the NeoHeart Society.

- In depth discussion of PDA treatment options in the extremely premature infants, indications, patient selection, follow-up, and outcomes.
- Examination of current evidence and clinical trials.
- Updates on ongoing clinical trials.
- Hands-on workshop on performing echocardiography to image the PDA in the newborn.
- Hands-on workshop on transcatheter device closure of the PDA in the newborn.
- Debates on whether PDA needs to be closed or not, timing of PDA closure, techniques of PDA closure and interventions to keep the PDA patent in the newborn period.
- Case discussions including taped cases of transcatheter PDA closures.
- Meet the experts session.
- Abstract presentations.
- Updates in interventional techniques to treat PDA in the extremely low birth weight infants.
- Discussion of long-term outcomes of extremely low birth weight infants with PDAs.
- Global trends in PDA management in the extremely premature

### Featured Speakers



*8th World Congress of  
 Pediatric Cardiology  
 and Cardiac Surgery*

AUGUST 27 – SEPTEMBER 1, 2023  
 WASHINGTON D.C.



## Letters to the Editor

### Letter to Editor: Comment on “National Perinatal Association: The Hidden Side of Maternal Mental Health”

Dear Editor,

I read your publication of “National Perinatal Association: The Hidden Side of Maternal Mental Health” with great interest. The topic was particularly interesting as it was presented from the perspective of a female author who shared her experiences with childbirth and motherhood [1]. Given the long-standing stigmas against mental health and seeking care for psychiatric illness, the article highlights the importance of such topics and their relevance and prevalence by incorporating current research and personal experience (2). I commend the author for highlighting this critical issue, which has far-reaching implications for the well-being of mothers, their infants, and their families.

***“Given the long-standing stigmas against mental health and seeking care for psychiatric illness, the article highlights the importance of such topics and their relevance and prevalence by incorporating current research and personal experience (2). I commend the author for highlighting this critical issue, which has far-reaching implications for the well-being of mothers, their infants, and their families.”***

I believe this discussion can be further strengthened by more explicit consideration of the impact of maternal mental health on infant outcomes. As psychiatric struggles are influenced by biopsychosocial factors, prematurity, including other complications rendering a newborn to NICU, and family mental health difficulties serve as potential risk factors for developing psychiatric illness in childhood (3,4). By delving into how maternal mental health affects infant development, attachment, and long-term outcomes, the article provides a more compelling argument for prioritizing perinatal mental health care.

Additionally, normalizing these struggles and providing appropriate tools for parents to manage their health can significantly impact parents’ and infants’ long-term generational care. This includes access to screening and assessment services and effective treatments and support programs addressing the complex

interplay of biological, psychological, and social factors contributing to perinatal mental health disorders. The author provides several examples of issues that can be addressed to increase mental health access and resources for mothers seeking support (1). These efforts demonstrate the value of a collaborative and multidisciplinary approach to perinatal care and provide a blueprint for others to follow.

***“ The author provides several examples of issues that can be addressed to increase mental health access and resources for mothers seeking support (1). These efforts demonstrate the value of a collaborative and multidisciplinary approach to perinatal care and provide a blueprint for others to follow.”***

In conclusion, I would like to express my gratitude to Neonatology Today and the author for bringing attention to this critical issue and for their efforts to improve maternal mental health outcomes. The next steps are to encourage further discussion, research, and publication regarding the effects of psychiatric struggles within neonatology. By working collectively, we can make a difference in the lives of countless women and their families.

***“In conclusion, I would like to express my gratitude to Neonatology Today and the author for bringing attention to this critical issue and for their efforts to improve maternal mental health outcomes. The next steps are to encourage further discussion, research, and publication regarding the effects of psychiatric struggles within neonatology. By working collectively, we can make a difference in the lives of countless women and their families.”***

#### References:

1. Grogan, C. (2023). National Perinatal Association: The Hidden Side of Maternal Mental Health. *Neonatology*, (18)4, 103-104.
2. Gaebel, W., Zäske, H., Cleveland, H. R., Zielasek, J., Stuart, H., Arboleda-Florez, J., Akiyama, T., Gureje, O., Jorge, M. R., Kastrup, M., Suzuki, Y., Tasman, A., & Sartorius, N. (2011). Measuring the stigma of psychiatry and psychiatrists: devel-

opment of a questionnaire. *European archives of psychiatry and clinical neuroscience*, 261 Suppl 2, S119–S123.

- Blount, A. J., Adams, C. R., Anderson-Berry, A. L., Hanson, C., Schneider, K., & Pendyala, G. (2021). Biopsychosocial Factors during the Perinatal Period: Risks, Preventative Factors, and Implications for Healthcare Professionals. *International journal of environmental research and public health*, 18(15), 8206.
- Papadimitriou G. (2017). The “Biopsychosocial Model”: 40 years of application in Psychiatry. *Psychiatriki*, 28(2), 107–110.

Sincerely,

Nicole Poladian OMS 3, Viktoriya Rembelinska OMS 3

Dear Nicole Poladian and Viktoriya Rembelinska,

Thank you for contributing to the ongoing discussion about maternal mental health and its impact on infant outcomes. I agree that more studies are required on prematurity as a risk factor for developing a mental health condition later in life. However, instead of only focusing on maternal mental health and its role in infant development, it may be more beneficial to analyze the mental health of both caregivers when applicable.

**“However, instead of only focusing on maternal mental health and its role in infant development, it may be more beneficial to analyze the mental health of both caregivers when applicable.”**

The current research shows that mothers are initially more depressed than fathers when preterm infants are hospitalized in the NICU. However, maternal scores on the Edinburgh Postpartum Depression (PPD) Scale decrease 30 days after discharge compared to paternal scores (1). This emphasizes the importance of also recognizing, screening, diagnosing, and treating paternal postpartum depression, better referred to as paternal perinatal affective disorder (PPAD). The data suggest that PPAD, like PPD, adversely affects mothers, their children, and the parental relationship (1). However, unlike PPD, it is underscreened, underdiagnosed, and undertreated. Some studies suggest that “toxic masculinity” is a factor as these fathers are less likely to report sadness and more likely to discourage breastfeeding and demonstrate externalizing symptoms such as anger, substance abuse, and domestic violence (1).

**“The referenced study provides four specific interventions for treating fathers with PPAD, and these overlap with the treatment for mothers seeking support for PPD.”**

The referenced study provides four specific interventions for treating fathers with PPAD, and these overlap with the treatment for mothers seeking support for PPD. The interventions mentioned are: 1) Identify mothers and fathers with depression risk factors and provide close follow-up after NICU discharge. 2) Screen fathers at a 4-month well visit for PPAD when mothers are already screened for PPD. 3) Advocate to include fathers in current proposals for paid postpartum family leave. 4) Advocate for developing a workforce with expertise in parental mental health that treats men with PPD (1).

**“The interventions mentioned are:  
1) Identify mothers and fathers with depression risk factors and provide close follow-up after NICU discharge. 2) Screen fathers at a 4-month well visit for PPAD when mothers are already screened for PPD. 3) Advocate to include fathers in current proposals for paid postpartum family leave. 4) Advocate for developing a workforce with expertise in parental mental health that treats men with PPD (1).”**

We know that preterm infants are more likely than term infants to struggle with anxiety and depression later in life (2). As the topic of improving mental health continues to gain significance and we begin to close the gap for maternal PPD, it is important to treat the whole family unit if we want to make a more meaningful difference in the long-term health outcomes of premature babies. Thank you again for helping advance this discussion.

References:

- Michael W. Yogman; Parental Depression After Preterm Birth: An Opportunity for Prevention. *Pediatrics* August 2021; 148 (2): e2021051136. 10.1542/peds.2021-051136
- “Long-Term Health Effects of Premature Birth.” *March of Dimes*, Oct. 2019, [www.marchofdimes.org/find-support/topics/birth/long-term-health-effects-premature-birth#:~:text=Premature%20babies%20may%20be%20more%20likely%20to%20have%20anxiety%20or,needs%20treatment%20to%20get%20better](http://www.marchofdimes.org/find-support/topics/birth/long-term-health-effects-premature-birth#:~:text=Premature%20babies%20may%20be%20more%20likely%20to%20have%20anxiety%20or,needs%20treatment%20to%20get%20better)

Sincerely,



Saba Saleem, DO, MPH

Associate Fellowship Editor

Neonatology Today

Psychiatry PG-1

NT

## Letters to the Editor

### Letter to the Editor: "Response to HRO: Engagement Matters" How to Employ Full Spectrum Analysis to Improve the Quality of the Response

Hi Dave,

I just read your "HRO: Engagement Matters...." piece in *Neonatology Today*. It was fascinating because you connected physiological behavior and responses to macro-level behavior at the dyad and organizational levels.

***"I just read your "HRO: Engagement Matters...." piece in Neonatology Today. It was fascinating because you connected physiological behavior and responses to macro-level behavior at the dyad and organizational levels. "***

From a personal perspective, I have been inquiring into my own historical experiences regarding the sources of fear and how these sources occur at an individual level, much like the example of the attending who had a bad experience when in the military with a commanding officer who would not authorize helicopter operations, and the venue for the communication was by phone, not in person.

***"From a personal perspective, I have been inquiring into my own historical experiences regarding the sources of fear and how these sources occur at an individual level, much like the example of the attending who had a bad experience when in the military with a commanding officer who would not authorize helicopter operations, and the venue for the communication was by phone, not in person."***

I see every day, just in my own life, how distant sources of communication -- like phones, texting, email, etc. -- are so limiting when it comes to effectively engaging with others to understand and move forward through the midst of fear and stress.

There are so many key insights in your article. Well done!

Just a small admin observation based on the PDF posted on ResearchGate, somehow, the reference to my FSA article, endnote #77, is not included in the Reference section, as the last reference is #76.

All the best

Adrian Wolfberg, Ph.D.

Senior Program Officer at the National Academy of Sciences

National Academy of Sciences

Washington, DC

Dr. Wolfberg,

I apologize for missing your paper's citation, *Full-spectrum analysis: A new way of thinking for a new world* (1). Dennis Kowal, a neuropsychologist with the Institute for Defense Analysis, was working with us regarding the psychology of HRO. He introduced us to your paper shortly after it was published, advising us that "Full Spectrum Analysis" (FSA) had a major influence on military tactics and strategy during the Global War on Terrorism.

***" Dennis Kowal, a neuropsychologist with the Institute for Defense Analysis, was working with us regarding the psychology of HRO. He introduced us to your paper shortly after it was published, advising us that "Full Spectrum Analysis" (FSA) had a major influence on military tactics and strategy during the Global War on Terrorism."***

Your presentation of mystery-solving versus problem-solving and searching the full spectrum of domains enabled our public safety and healthcare group to become more effective while operating in crises. We had learned by doing, precepted by experienced veterans in public safety and military operations. Your paper gave substance to our experience and improved our capabilities. The benefit of mystery solving not only advanced our effectiveness but also became our means of introducing novices to decision-making in ambiguous situations.

***"When pediatric critical care was starting, there were no books. Later I moved to complex and chronic care and found the same problem. Full Spectrum Analysis and mystery solving explained our work in the PICU and helped expand the same approach into pediatric chronic care. "***

When pediatric critical care was starting, there were no books. Later I moved to complex and chronic care and found the same problem. Full Spectrum Analysis and mystery solving explained our work in the PICU and helped expand the same approach into pediatric chronic care. We now infuse FSA into our HRO articles for *Neonatology Today*. We are preparing an article showing the similarity of pediatric complex chronic care and neonatal care with missions conducted by a SOCOM team.

---

***“We became perceptive of failure trajectories in others, particularly leaders. When we view decision-making as a mystery to solve using full spectrum analysis, we find that healthcare is far behind. From critical care to multiple chronic conditions, everyone suffers, and sadly, so do our patients.”***

---

We became perceptive of failure trajectories in others, particularly leaders. When we view decision-making as a mystery to solve using full spectrum analysis, we find that healthcare is far behind. From critical care to multiple chronic conditions, everyone suffers, and sadly, so do our patients.

Reference:

1. Wolfberg A. Full-spectrum analysis: A new way of thinking for a new world. *Military Review*. 2006;86(4):35-42.

Thank you,

Daved van Stralen, MD, FAAP

Associate Professor, Pediatrics

Department of Pediatrics

Loma Linda University School of Medicine

Sean McKay

Executive Partner / Director, Disruptive Rescue & Austere Medicine

Element Rescue - Response Solutions within Nonlinear Complex Environments

Greenville, South Carolina, United States

Thomas A. Mercer

Rear Admiral

United States Navy (Retired)



**Readers can also follow**  
**NEONATOLOGY TODAY**  
**via our Twitter Feed**  
**@NEOTODAY**

---

Dear All,

The concept of full spectrum analysis is brilliant and interacts well with the intricacies of neonatal and pediatric intensive care. Although know-how may be lacking, strategies to approach and conceptualize are practical ways to find solutions to problems we never knew we had or were too distracted to notice.

---

***“Although this is unclear to the unindoctrinated, this iterative process defines mature AI and provides a path beyond chatbots with random inputs. We need to channel our response to these adaptive technologies and, at the same time, identify a path forward.”***

---

The series by Dr. Van Stralen and his colleagues present a pragmatic way of using a concept to organize a response at a much higher level than the knowledge base. Although this is unclear to the unindoctrinated, this iterative process defines mature AI and provides a path beyond chatbots with random inputs. We need to channel our response to these adaptive technologies and, at the same time, identify a path forward.

Sincerely,

Mitchell Goldstein, MD, MBA, CML



Editor in Chief

**NT** **NEONATOLOGY TODAY**

Loma Linda Publishing Company

A Delaware “not for profit” 501(c) 3 Corporation.

c/o Mitchell Goldstein, MD

11175 Campus Street, Suite #11121

Loma Linda, CA 92354

Tel: +1 (302) 313-9984

[LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)

© 2006-2023 by Neonatology Today ISSN: 1932-7137 (online)

Published monthly.

All rights reserved.

[www.NeonatologyToday.net](http://www.NeonatologyToday.net)

Twitter: [www.Twitter.com/NeoToday](https://www.Twitter.com/NeoToday)

**NT**



## Experience True Practice Quality



Envision neonatologists serve as **vital members of their hospitals**, often participating on quality and medical executive committees or taking on mentoring roles and leadership positions.

Envision is committed to providing **an exceptional quality of practice** and **empowering you to excel professionally**.

### Featured Neonatologist Opportunities Across the Nation



#### Flowers Hospital

Dothan, AL

[APPLY NOW](#)



#### St. Francis Medical Center

Colorado Springs, CO

[APPLY NOW](#)



#### Baptist Medical Center

Montgomery, AL

[APPLY NOW](#)

Ready to elevate your neonatology career?

**844.387.6019**

**GET STARTED**

 **Envision**  
PHYSICIAN SERVICES

**Erratum (Neonatology Today April, 2023)**

Neonatology Today is not aware of the erratum affecting the April, 2023 edition.

Corrections can be sent directly to [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com). The most recent edition of Neonatology Today including any previously identified erratum may be downloaded from [www.neonatologytoday.net](http://www.neonatologytoday.net).

NT

# Should Infants Be Separated from Mothers with COVID-19?

## FIRST DO NO HARM

**SEPARATION**  
may not prevent  
**INFECTION.**



**SKIN to SKIN CARE**  
supports newborns' physiology.



**SEPARATION**  
stresses parents and babies.



**SEPARATION**  
weakens immune protections.



**SEPARATION**  
disrupts breastfeeding putting babies' health at risk.

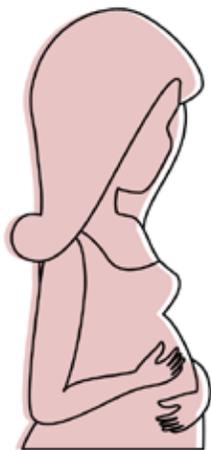


**SEPARATING the DYAD**  
doubles providers' workload, burdening systems.



### NATIONAL PERINATAL ASSOCIATION

#### Update: **CORONAVIRUS** COVID-19



According to data published in The Lancet

**Pregnancy and the risk of VERTICAL TRANSMISSION**

**LOW**



[www.nationalperinatal.org](http://www.nationalperinatal.org)

BASED ON THE ARTICLE:

Should Infants Be Separated from Mothers with COVID-19?  
First, Do No Harm

© Alison Stuebe, 2020. Published by Mary Ann Liebert, Inc.

# Fellow's Column: Identification and Management of Neonatal Rashes in Skin of Color

Kundan Malik OMS-4, MS, MHS; Saba Saleem, DO, MPH

## Introduction:

Neonatal rashes vary in the presentation in "skin of color," which increases the risk of misdiagnosis and improper treatment since management differs slightly for infants with lighter skin. Erythema toxicum neonatorum (ETN) is a common rash that affects up to 50% of term infants within the first few weeks of life (1, 2). It is less common in premature babies, but when it does occur, it happens several weeks after birth (6). A rash similar to this is acne neonatorum, also known as neonatal acne. This rash affects up to 20% of newborns, with a slightly higher prevalence in male infants (11, 12). Both conditions are usually benign and self-limiting but can cause significant distress for parents and caregivers, especially in infants with "skin of color" (13). This situation can necessitate testing and treatment (1, 3). This manuscript will discuss the differentiating etiology, clinical features, and management between ETN and acne neonatorum in infants with "skin of color."

***"Both conditions are usually benign and self-limiting but can cause significant distress for parents and caregivers, especially in infants with "skin of color" (13)."***

## Etiology:

The exact causes of ETN and acne neonatorum are unknown, but both are considered physiologic responses to the newborn's environment (1, 4). ETN is presumed to be related to colonizing the infant's skin by various bacteria, fungi, and viruses acquired during birthing (4, 5). Specifically, ETN is associated with the presence of *Staphylococcus epidermidis* and *Corynebacterium* species on the skin of affected infants. However, the prevalence and diversity of these microorganisms on the skin of infants with skin of color are not well studied (5, 6).

***"The exact causes of ETN and acne neonatorum are unknown, but both are considered physiologic responses to the newborn's environment (1, 4)."***

Acne neonatorum is believed to be related to hormonal fluctuations during fetal and neonatal life (14, 15). Specifically, acne neonatorum is related to the activation of sebaceous glands in

response to maternal androgens. This process can increase sebum production and follicular hyperkeratosis (14, 15). Additionally, colonization of the skin by *Propionibacterium acnes* and other bacteria may contribute to the development of acne neonatorum (15, 16).



**Figure 1:** Comparison of ETN in infants with light and dark skin (7,8).

## Clinical Features:

ETN typically presents as small, erythematous, yellow-white papules or pustules surrounded by a halo of erythema (1, 3). The lesions can appear on any part of the body but are most commonly found on the face, trunk, and extremities (1, 4). In infants with "skin of color," the rash may appear as dark red or brown papules, making it difficult to distinguish from other conditions such as miliaria or neonatal acne (see Figure 1). Additionally, the lesions may be more extensive and involve a larger body area in infants with "skin of color" (1, 5).

***"In infants with "skin of color," the rash may appear as dark red or brown papules, making it difficult to distinguish from other conditions such as miliaria or neonatal acne (see Figure 1)."***

Acne neonatorum typically presents as erythematous papules, pustules, or comedones on the face, scalp, and upper trunk, with a predilection for the cheeks and forehead (11, 13). A halo of erythema may surround the lesions and range in size from 1 to 3 mm (11, 13). In infants with "skin of color," acne neonatorum may be

more challenging to diagnose than ETN (see Figure 2). This variation is because the lesions may be less conspicuous and blend in with the background pigmentation (13).



**Figure 2:** Comparison of Acne Neonatorum in infants with light and medium complexion (9,10).

### Diagnosis:

The diagnosis of ETN is primarily clinical and based on the characteristic appearance of the rash. A thorough clinical examination is essential in infants with "skin of color" to differentiate ETN from other skin conditions such as miliaria or neonatal acne. The biopsy is not typically necessary for diagnosis, but if performed, it will show an infiltrate of eosinophils and neutrophils in the upper dermis (1, 3).

The diagnosis of acne neonatorum is also primarily clinical, based on the characteristic appearance of the lesions (11, 13). However, in rare cases, a skin biopsy may be necessary to rule out other diagnoses, such as miliaria or impetigo (11). In infants with "skin of color," a Wood's lamp examination may also help visualize the lesions (13).

---

***“A thorough clinical examination is essential in infants with "skin of color" to differentiate ETN from other skin conditions such as miliaria or neonatal acne.”***

---

### Management:

Treatment of ETN and acne neonatorum is not typically necessary, as the rashes are self-limited and resolve independently within 1-2 weeks or a few weeks to months, respectively (1, 2, 11, 13). However, reassurance and education for parents and caregivers are essential to prevent unnecessary concern and healthcare utilization (3). In infants with "skin of color," it is essential to provide additional education on the expected clinical course of ETN, as the rash may appear differently and may take longer to resolve compared to infants with lighter skin. If pruritus is present, topical emollients or mild topical corticosteroids can be used (1, 2). For acne neonatorum, it is crucial to avoid topical acne medications or harsh cleansers, as they can irritate the skin and exacerbate the condition (11, 16). If the lesions are extensive or associated with significant inflammation or scarring, referral to a dermatolo-

gist may be considered (11, 14).

### Conclusion:

ETN and acne neonatorum are common, self-limiting, and usually benign rashes with different clinical features and management in infants with "skin of color." The diagnosis may be more challenging due to the less conspicuous appearance of the lesions. However, it is important to provide additional education and reassurance to parents and caregivers for both conditions to prevent unnecessary interventions.

### References:

1. Gupta AK, Skinner AR. Erythema toxicum neonatorum. eMedicine. Updated June 18, 2021. Accessed March 30, 2023. <https://emedicine.medscape.com/article/911535-overview#a6>
2. James WD, Berger TG, Elston DM. Erythema toxicum neonatorum. In: Andrews' Diseases of the Skin: Clinical Dermatology. 13th ed. Elsevier; 2020:88-89.
3. Krzysztofciak A, Strobel K, Specht K, Metze D, Böer-Auer A. Erythema toxicum neonatorum: clinical characteristics and microbiology in neonates born in a German hospital. Arch Dermatol Res. 2015;307(7):591-597.
4. Marcano-Bonilla L, Obeid G. Skin of color in newborns. Dermatol Clin. 2014;32(2):197-208.
5. Mancini AJ. Skin. In: Kliegman RM, St Geme JW, Blum NJ, Shah SS, Tasker RC, Wilson KM, eds. Nelson Textbook of Pediatrics. 21st ed. Elsevier; 2020:3094-3096.
6. Cranwell, William. Erythema toxicum. Australian Parenting Website. Updated August 27, 2021. Accessed May 24, 2023. <https://raisingchildren.net.au/guides/a-z-health-reference/erythema-toxicum>
7. Creative Commons CC0 License. (2019, October 28). Erythema Toxicum Neonatorum. Wikimedia Commons. [https://commons.wikimedia.org/wiki/Category:Erythema\\_toxicum\\_neonatorum](https://commons.wikimedia.org/wiki/Category:Erythema_toxicum_neonatorum)
8. Creative Commons Attribution ShareAlike 4.0 International License. (2014, August 26). Erythema Neonatorum Toxicum [Photograph]. WikiDoc. [https://s3.amazonaws.com/static.wd7.us/4/42/Erythema\\_neonatorum\\_toxicum01.jpg](https://s3.amazonaws.com/static.wd7.us/4/42/Erythema_neonatorum_toxicum01.jpg)
9. Creative Commons Attribution ShareAlike 4.0 International License. (2014, July 9). Acne neonatorum [Photograph]. WikiDoc. [https://www.wikidoc.org/index.php/File:Acne\\_neonatorum\\_02.jpeg](https://www.wikidoc.org/index.php/File:Acne_neonatorum_02.jpeg)
10. Creative Commons Attribution ShareAlike 4.0 International License. (2016, April 23). Acné de nourrisson [Photograph]. Wikimedia Commons. [https://commons.wikimedia.org/wiki/File:Acn%C3%A9\\_de\\_nourrisson.JPG](https://commons.wikimedia.org/wiki/File:Acn%C3%A9_de_nourrisson.JPG)
11. Eichenfield LF, Friedlander SF, Zaenglein AL, et al. Guidelines of care for the management of acne vulgaris. J Am Acad Dermatol. 2013;68(5):1-41.
12. Lee WJ, Choi YH, Sohn MY, et al. Clinical characteristics of

acne neonatorum in Korea: a retrospective analysis. *Pediatr Dermatol.* 2013;30(3):345-348.

13. Alexis AF, Lamb A, Williams M, et al. Acne in patients with skin of color: practical management. *Am J Clin Dermatol.* 2014;15(1):7-16.
14. Darmstadt GL. Acne neonatorum. *eMedicine.* Available at: <http://emedicine.medscape.com/article/1198022-overview>. Accessed April 11, 2023.
15. Balighi K, Taheri AR, Jafari M, et al. Neonatal acne vulgaris: a review. *Acta Dermatovenerol Croat.* 2012;20(3):182-187.
16. Suh DH, Kwon HH. What's new in the physiopathology of acne? *Br J Dermatol.* 2015;172 Suppl 1:13-19.

**Disclosures:** Authors have no competing interests to declare.

**NT**

**Corresponding Author**



Kundan Malik, MS, MSH  
DO Candidate 2024  
Touro University California  
College of Osteopathic Medicine  
University of California, San Francisco, Graduate Division  
Email: [kmalik@student.touro.edu](mailto:kmalik@student.touro.edu)  
Phone: (916) 335-4559



Saba Saleem, BS  
DO, MPH Candidate 2023  
Western University of Health Sciences  
College of Osteopathic Medicine of the Pacific  
Johns Hopkins Bloomberg School of Public Health  
Email: [saba.saleem@westernu.edu](mailto:saba.saleem@westernu.edu)

**Fellow's Column is published monthly.**

- Submission guidelines for "Fellow's Column":
- 2000 word limit not including references or title page. Exceptions will be made on a case by case basis
- QI/QA work, case studies, or a poster from a scientific meeting may be submitted..
- Submission should be from a medical student, resident, fellow, or NNP in training.
- Topics may include Perinatology, Neonatology, and Younger Pediatric patients.
- No more than 20 references.
- Please send your submissions to:

Elba Fayard, MD, Interim Fellowship Column Editor  
or Saba Saleem, OMS IV Fellowship Column Assistant Editor  
[LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)



**Readers can also follow**

**NEONATOLOGY TODAY**

**via our Twitter Feed**

**@NEOTODAY**

**READ**

NPA's statement: **BLACK LIVES MATTER**



# Neonatology Grand Round Series

Earn accredited CE while learning about pressing neonatology topics!



The only worldwide monthly publication exclusively serving Pediatric and Adult Cardiologists that focus on Congenital/Structural Heart Disease (CHD), and Cardiothoracic Surgeons.



**Subscribe Electronically**  
Free on the Home Page

[www.CongenitalCardiologyToday.com](http://www.CongenitalCardiologyToday.com)



National Network  
of **NICU**  
Psychologists

[www.nationalperinatal.org/psychologists](http://www.nationalperinatal.org/psychologists)

COVID-19

## FREE RESOURCES for your NICU

- Helping Children and Families Cope
- Bonding with Your Baby
- Caregivers Need Care Too

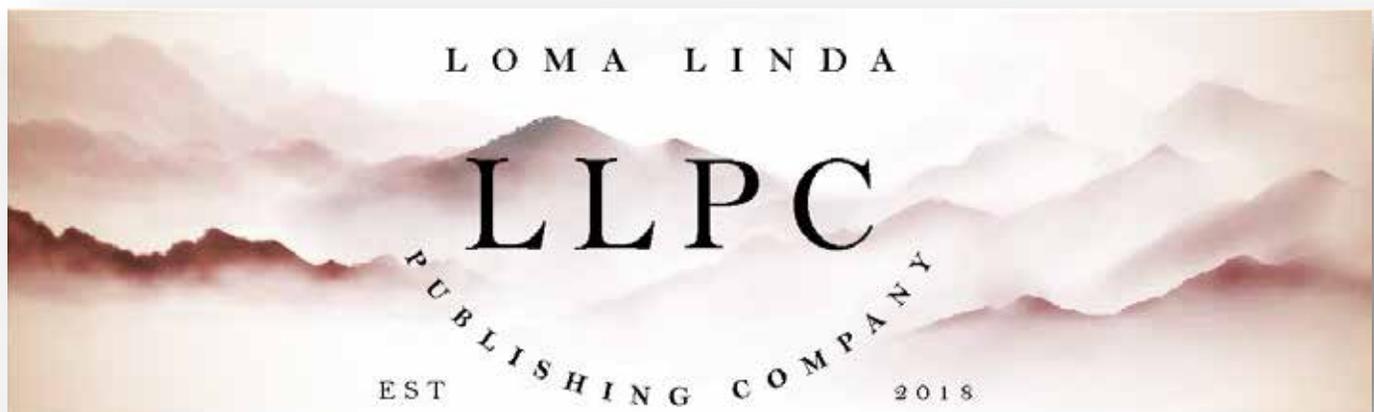
# 99nicu

Sign up for free membership at 99nicu, the Internet community for professionals in neonatal medicine. Discussion Forums, Image Library, Virtual NICU, and more..."

[www.99nicu.org](http://www.99nicu.org)

**NEONATOLOGY TODAY** is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)



# SAVE THE DATE: Upcoming Webinars

## Neonatology Grand Rounds Series



View future topics  
and reserve  
your spot!

Join us the **first Wednesday of every month at 4 p.m. Eastern Time** for our hour-long, complimentary Neonatology Grand Rounds webinars. Learn about the latest advances in neonatal-perinatal medicine while earning accredited CEs. Upcoming topics include:

- **June 7** — Articles that should change NICU care in 2023
- **July 5** — Latest innovations in fetal surgery
- **August 2** — Antibiotic stewardship in pregnancy: maternal and neonatal implications



## SAVE THE DATE: 2024 Conferences

Our annual 2024 NEO: The Conference for Neonatology and Specialty Review in Neonatology will be held Feb. 19-24 at Caesars Palace in Las Vegas. Join us!



Learn more  
and register!

### NEO: The Conference for Neonatology

[neoconference.com](http://neoconference.com)

Feb. 21-23, 2024

Las Vegas, NV

(Caesars Palace)

**NEO** THE CONFERENCE  
FOR NEONATOLOGY

 **pediatrix**



Learn more  
and register!

### Specialty Review in Neonatology

[specialtyreview.com](http://specialtyreview.com)

Feb. 19-24, 2024

Las Vegas, NV

(Caesars Palace)

**SPECIALTY  
REVIEW**  
IN NEONATOLOGY.

 **pediatrix**

# Impaired Engagement in High-Reliability Organizing (HRO): 3. Reasoning Impairs Engagement

Daved van Stralen, MD, FAAP, Sean D. McKay, Errol van Stralen, Thomas A. Mercer, RAdm, USN (Retired)

## Abstract

*We engage contingencies to make them more orderly. Removing context supports objective approaches that are also more orderly. 'Subjective' becomes a derisive term. Preparation for abrupt change includes well-developed plans and people who follow those plans. The event itself is not a part of the planning. This resulting normative stance is transportable and favored by leaders and scholars. An organization or industry institutionalizes competency because generalizable principles can be taught to a high-turnover, novice workforce. Abrupt change makes visible the fundamental gap between reason and action. Cause-and-effect relationships are less visible because nonlinearity allows multiple causes to generate multiple effects. The color of environmental noise, the flow of events, and one's position inside or outside the event benefit from different levels of analysis. Arguing across these different levels creates false debate. The dominant account, relying on classical logic and deductive reasoning, becomes a mistranslation of the environment. Modal logics support inference in situations of incomplete information and can drive action. Paraconsistent logics support contradictions and treat inconsistencies as informative. Paracomplete logics allow continuous change; there is no need to assume "A" or "not-A." The ability to work under uncertainty must not be sacrificed for the tractability of objectivity.*

***“An organization or industry institutionalizes competency because generalizable principles can be taught to a high-turnover, novice workforce. Abrupt change makes visible the fundamental gap between reason and action.”***

## Introduction

The actual world is messy. From far away, the mess seems in need of organizing. We engage a flux of contingencies to make them more orderly. Coincidentally, distance makes that organizing appear tractable. Engineering models, classical logic, and deductive reasoning support the belief that we can manage a crisis as a technological system from a distance.

Removing context and using objective approaches, independent of context, operates from the image of scientific principles such as thermodynamics and gravity. Principles are true and applicable regardless of the person or situation. The same occurs with the value we place on information or objects; we consider the value we place as objective. (In practice, we also consider the value others place on the information or object as subjective.) Part of the acculturation process into a domain and organization is learning what value to place on information and objects. The acculturation process gives legitimacy to value placement; hence the sense of

objectivity and 'objective' becomes a privileged frame.

'Subjective,' then, too quickly becomes a derisive term for what value an individual places on an object or judgment – the value we place is prudent or comes from good judgment, the value they place is 'subjective.' We disregard the immediate environment, natural nonlinear interactions, human perception, and necessary affective judgment. Nevertheless, the adaptive, subjective judgment of many individuals working in concert controls a disruption.

***“We disregard the immediate environment, natural nonlinear interactions, human perception, and necessary affective judgment. Nevertheless, the adaptive, subjective judgment of many individuals working in concert controls a disruption.”***

The authors routinely compare disciplines, domains, and organizations to identify objective approaches that are more likely subjective. Congruity implies an objective basis, while discrepant approaches support subjectivity.

Preparation for an abrupt change includes identifying plausible events, plans created for such events, and how people respond. Though some administrators prefer well-developed plans and people who follow them, the event is not a part of the planning or human response. We cannot know how a person will perceive the event as it emerges, nor what value they will place on that information.

***“The principles of engineering, deductive reasoning, and classical logic are timeless. However, reason, independent of context and long-evolved human survival drives and adaptive behaviors, will not help.”***

The principles of engineering, deductive reasoning, and classical logic are timeless. However, reason, independent of context and long-evolved human survival drives and adaptive behaviors, will not help.

The human mind developed to think effectively and naturally under stress and fear. However, sometimes even prepared individuals falter at the moment while unprepared individuals rise to the occasion. The authors state this as a shared observation over thousands of incidents, not because the authors wish to undermine knowledge and planning. These are almost micro-local interactions visible only in the immediate vicinity.

Through study, reasoning, and design, we gain a sense of mastery over the causes of and responses to abrupt change. Neverthe-

less, we sacrifice trust and adaptability while creating gratuitous stress and the ecology of fear – "Did I do the right thing?" followed by "What is the right thing?" This program will focus on the situation: identification, specific response, and how did it happen? Unfortunately, "How did it happen?" is more likely to be asked early in the event.

The strength and finality of engineering principles, deductive reasoning, and classical logic give reassurance that success is achievable when we comply with the program and the plans developed from the program. Abrupt events force the formation of gaps between what was planned to work and what will work. Confounding preparation is the misinterpretation of stability and misrepresentations of how HRO can help. It is the individual who engages in these challenges. HRO describes the coherence of individuals engaging across multiple levels of analysis that more effectively brings resolution.

When observing a wide view of the field, we can fit engineering principles, deductive reasoning, and classical logic into our understanding of the situation. Nevertheless, it is in the intimacy of the situation that we experience movement and pressure. What worked before no longer does. What failed before will now ensure success. We cannot change a hypothesis once proven by the rules of logic. The value and meaning of acts change during the flux of events; we can no longer guarantee a hypothesis. In the to-and-fro of action, subjective judgment and the ability to change course ensure effective engagement rapidly.

---

***We cannot change a hypothesis once proven by the rules of logic. The value and meaning of acts change during the flux of events; we can no longer guarantee a hypothesis. In the to-and-fro of action, subjective judgment and the ability to change course ensure effective engagement rapidly.***

---

#### **Creation of a PICU:**

Creating a new PICU in 1989, staff RNs and Respiratory Care Practitioners (RCPs) came from the children's hospital wards, though a few had experience in NICUs or adult ICUs. Responding to a sudden deterioration, one of the authors (DvS) entered the room where a staff member immediately confessed, "I did it!" and quickly recounted their actions leading to the emergency. The author responded, "Great! Now, I know who did it. I know what they did. But I don't know what happened." New PICU staff had brought with them a cultural legacy of blame that developed from the pattern of knowing the situation, doing the right response, and knowing there was a singular cause that could have prevented the event (commonly, this "cause" would be blamed on a human error made by the lowest ranking member in the hierarchy).

The senior intensivist (Ronald M. Perkin) gave these two guiding principles: support the bedside caregiver and do not criticize—these two principles derived from his experience as a US Naval Aviator during the Vietnam War. One of the authors (DvS) brought two action-oriented principles from his experience as a fire rescue ambulance medic: increase the capabilities of staff and the early engagement of any discrepancy or disruption.

The new PICU and its pediatric critical care transport service grew over three years to become the second largest in California while sustaining low rates of mortality and complications. The Institute of Medicine (IOM), conducting a study of patient safety in the nursing environment, invited one of the authors (DvS) for a presentation. They were specifically interested in his experience bringing HRO to the PICU and the similar results in a nearby pediatric subacute care facility.

---

***“She used the OODA Loop, developed for aerial combat decision-making and described elsewhere, to outmaneuver rapidly changing physiology during resuscitation. She described the integration of decision-making into a program that increases the capabilities of the individual and team as High-Reliability Organizing, or "HRO".”***

---

Karlene Roberts, one of the founders of the field of HRO, had heard how one of the authors (DvS) taught emergency medical decision-making. She used the OODA Loop, developed for aerial combat decision-making and described elsewhere (1, 2), to outmaneuver rapidly changing physiology during resuscitation. She described the integration of decision-making into a program that increases the capabilities of the individual and team as High-Reliability Organizing, or "HRO" (3).

The greatest difficulty in achieving these accomplishments came from the decontextualization of the consequential incident:

- Situations and problems are like puzzles (Search for the pieces, and you find the answer) (4).
- Criticism and complaints by decontextualizing decisions and actions of PICU staff and residents
- Reliance on engineering models that create and follow plans while conforming to a rigid hierarchy
- The use of classical, linear logic to diagnose and prescribe treatment specific to that diagnosis
- Deductive reasoning is that by gathering facts, we will guarantee our hypothesis.

---

***“The two intensivists contributed their expertise in supporting people who engage in abrupt change; logics we can now identify as modal, paraconsistent, and paracomplete; inductive reasoning; and decision-making with incomplete information during flux.”***

---

This illustrates the fundamental gap created by the abrupt change described above. Administrators, legal counsel, and spectators brought to the PICU and emergency management their mastery of technological systems, 'scientific logic,' and deductive reasoning. The two intensivists contributed their expertise in supporting people who engage in abrupt change; logics we can now identify as modal, paraconsistent, and paracomplete; inductive reasoning; and decision-making with incomplete information during flux.

---

***“Focusing on stress-impaired cognition and fear-circuit behaviors was critical to success. Not only for the care of a child and family but stress and fear originating from colleagues, legal counsel, and administrators – the ecology of fear where a threat causes more harm by its absence than its presence.”***

---

Focusing on stress-impaired cognition and fear-circuit behaviors was critical to success. Not only for the care of a child and family but stress and fear originating from colleagues, legal counsel, and administrators – the ecology of fear where a threat causes more harm by its absence than its presence (5).

Vital to the whole enterprise were the efforts of John Mace, chairman of the Department of Pediatrics, and himself, a US Navy Medical Corps veteran. Though a pediatric endocrinologist and well ensconced in clinical practice and administration, Dr. Mace provided much necessary indirect support, deflected opponents, and addressed the friction natural to any novel, rapidly growing program. His interventions continued long after his retirement as department chair and are worthy of a separate review. Except that, because of his diplomatic skills, those in opposition were rarely aware of his support. Diplomacy started early with Dr. Mace. Pursuing a program might terminate as he learns about strategic plans, someone's firmly held beliefs, or another program's overriding interest.

---

***“Bedside staff resisted in one facility, and hospital administration resisted in another. Similar to the efforts of Dr. Mace, a respiratory care supervisor mediated efforts with bedside caregivers, and a nursing supervisor did the same for administrators. These are three examples of the necessity for an outside leader to assist in bridging the theory and practice gap.”***

---

This is not a trite digression. One of the authors (DvS) identified a similar problem introducing HRO into two pediatric subacute care facilities. Bedside staff resisted in one facility, and hospital administration resisted in another. Similar to the efforts of Dr. Mace, a

respiratory care supervisor mediated efforts with bedside caregivers (6), and a nursing supervisor did the same for administrators. These are three examples of the necessity for an outside leader to assist in bridging the theory and practice gap.

### **The Color of the Environment:**

The messiness an outsider observes is deceiving. Noise is an intrinsic property of an open system. This is compatible with the concept that noise is a signal that carries no information that has meaning to the receiver. The flow of energy (dissipation) is the thermodynamic principle of entropy. Noise energy entering a system generates nonlinear feedback. The response within the system is autocorrelation – past events impact current events to produce long-period frequencies ("red" after the longer wavelengths of red light). Longer frequencies carry more energy, the power of red noise as a forcing function on the environment, "forcing" a response (7).

---

***“The messiness an outsider observes is deceiving. Noise is an intrinsic property of an open system. This is compatible with the concept that noise is a signal that carries no information that has meaning to the receiver.”***

---

Energy, having frequencies, flows into and out of an open system. When all the frequencies are equally represented, we are in a white noise environment (similar to sound canceling "white noise"). In the actual world, not all frequencies are equally represented due to entropy. Longer wavelengths, or frequencies in the red spectrum, have more power. Note that shorter wavelengths from the blue spectrum carry higher energy. Infrequent events carry more power and can force people and the environment to respond – the forcing function of red noise.

- White noise is the "noise" of everyday activity.
- Red noise is the noise of sudden unanticipated events.

When energy enters the system, white noise can cancel the intruding energies like noise-canceling earphones, giving stability. These environments are sufficiently stable that data distribution forms a Gaussian distribution. We can make statistical calculations and probability predictions.

In white noise, a convergent, deductive, analytic approach makes sense. We search for facts and information because that guarantees our hypothesis—the structures we create and our actions reinforce the normative frame and the security they offer. The linearity and stability, however, impede generating stochastic resonance for stability (8). Rigid structure and linearity narrow and increasingly confine our responses.

Abrupt change creates a gap between the event and how people respond. People imagine and plan for a serious event. Engineering design and materials science is embedded for structural stability. We have sacrificed adaptability from subjective judgment for the security of objective structures.

Nuclear power plants on the northeast coast of Japan have seawalls constructed for protection from post-earthquake tsunamis. Engineers determine the seawall's height from the tsunami's predicted height. Yanosuke Hirai, an engineer for one of the nuclear

power plants, used his subjective interpretation of the data to insist on a higher seawall than predicted and the use of specific cooling pumps should a tsunami reach the power plant (9).

On March 11, 2011, tsunamis from Great East Japan (Tōhoku) Earthquake reached the Fukushima Daiichi and Onagawa nuclear power plants. The failure of the Daiichi power plant, 150 km from the epicenter, was the world's third most severe nuclear power plant failure. With relatively little damage, the two fully operating reactors at the Onagawa plant reached a cold shutdown the next morning (10). The Onagawa plant was 80 km from the epicenter of the earthquake. The Onagawa plant had a higher seawall due to Yanosuke Hirai's insistence (personal communication, Najmedin Meshkati, Professor of Civil Engineering, University of Southern California).

How people respond is on both sides of the gap and can be the same – which is adaptive or maladaptive depending on the source of the behavior. Modeling behaviors from the white noise environment prepares the organization for unrecognized, confusing failure from disruptions of any magnitude. Modeling behaviors from red noise or pink noise environments embeds the capabilities for adaptive change into the organization. HRO supports the sensitive detection of discrepancies and disruptions for early intervention.

---

***“How people respond is on both sides of the gap and can be the same – which is adaptive or maladaptive depending on the source of the behavior. Modeling behaviors from the white noise environment prepares the organization for unrecognized, confusing failure from disruptions of any magnitude.”***

---

#### **Gaps from Structure and Behavior:**

Abrupt change makes the gap between reason and action visible, but circumstances supported reasoning as the preferred approach long before the abrupt event. Long periods give the impression of stability and linearity. As discussed above, long-period red noise has the behavior of white noise, producing the belief that the organization is fully prepared for abrupt change – plans are in place.

At the level of individual experience, we may identify short-time segments that appear linear because of minimal change. We "linearize the curve," consciously or unconsciously converting red noise to white noise to gain tractability. For example, residents in the PICU report urine output for a time segment of 24 hours. Changing to an eight-hour time segment revealed new meaning for a report of 1 mL/hour for 24 hours: 0.5 mL/hour, 1 mL/hour, 1.5 mL/hour or 1.5 mL/hour, 1 mL/hour, 0.5 mL/hour. The former could represent increasing blood volume and the latter decreasing blood volume. Each set has 1 mL/hour for a 24-hour time segment. Changing time segments identified an otherwise occult information gap for blood volume or kidney function.

Linearization of the curve can support the belief that the actual world is stable or that the planners' program has maintained stability. We lose the sense of anticipation, a necessary attribute while working in dangerous contexts. Unconscious conversion from red to white noise risks the loss of subtle or nuanced signals. Similar-

ly, we forgo tractability when we mislabel the meaning of changes, overemphasizing their significance. Conscious linearization of the curve reduces gaps, facilitates the use of classical logic, and enables deductive reasoning. In high-risk circumstances, linearization can be deadly.

---

***“Conscious linearization of the curve reduces gaps, facilitates the use of classical logic, and enables deductive reasoning. In high-risk circumstances, linearization can be deadly.”***

---

This produces what we describe as *the normative stance* that an 'outside' leader has a complete view of the actual world. Objective and decontextualized, the normative stance aligns with theory and *scientific rationality* (11, 12). The normative frame is orderly, measurable, amenable to experimental study, and can be mastered. Abrupt events allow rapid application of response processes while leaders demonstrate mastery of command and problem-solving skills.

---

***“The normative frame is orderly, measurable, amenable to experimental study, and can be mastered. Abrupt events allow rapid application of response processes while leaders demonstrate mastery of command and problem-solving skills.”***

---

The appearance of mastery in leadership and problem-solving creates an identity for the individual. But it is an identity derived from scholastic achievement, years in the field, and/or the person's position in the hierarchy. Social order develops as the leader organizes responses with commands from *outside* the event. Subordinates *within* the event, carrying out these commands, gain a sense of security. The leader's sense of mastery increases as subordinates more closely follow commands. The subordinate's sense of security increases as they "do the right thing."

These leaders act with the certitude of Tetlock's hedgehog, moving employees to submit to the leader. A Confucian social order develops as the leader becomes the guarantor of employee welfare, sometimes misconstrued as the "servant leader." Employees carry out the leader's plan without disagreement or question. The leader becomes stronger. Information flow becomes impeded by suppression of disconfirming information and "shooting the messenger." These subtle changes create what Ron Westrum (13) describes as the "pathological organization."

Philip E. Tetlock (14) found the worst success rate for forecasters from those with the greatest certitude and higher rates from those who entertained the most doubt. He turned to Isaiah Berlin's essay *The Hedgehog and the Fox* for an explanation.

*Hedgehogs* will extend their one theory to many domains with great confidence. When they are wrong, they focus on

justifying their decision.

*Foxes, the 'superforecasters,' know many things but to a far lesser degree. They use a point-counterpoint thinking style to sustain doubt and understand how opposing and contradictory forces yield stability, a feature that confounds prediction. Superforecasters pursue and update information, revising conclusions as information becomes available.*

Cause-and-effect relationships are less visible; their nonlinearity allows multiple causes to generate multiple possible effects. From the inside, reactions generate a meaningful trajectory described using qualitative continuous measures of position and pressure. Individuals moving within the trajectory can influence the system's movement without knowing causation. Oscillations from nonlinear feedback generate stochastic resonance. Weak or relatively small noise can create and sustain significant oscillations (15).

---

***“Oscillations from nonlinear feedback generate stochastic resonance. Weak or relatively small noise can create and sustain significant oscillations.”***

---

As the situation becomes contextualized, subjective interpretations and affective judgment increase error. In practice, decisions exist as processes of incremental self-correcting interactions giving the appearance of instability to those outside the event. This is the *practical rationality* of the *pragmatic stance*, the stance of HRO (11, 16).

---

***“In practice, decisions exist as processes of incremental self-correcting interactions giving the appearance of instability to those outside the event. This is the practical rationality of the pragmatic stance, the stance of HRO.”***

---

The normative stance is transportable, making it favored by leaders and scholars who will more likely move to areas with different circumstances and different people. From the normative stance, we identify the situation or diagnosis which allows a specific response or treatment, respectively. "First, do no harm," the treatment will have greater effectiveness with minimal complications.

The pragmatic stance is local, vigilant for consequences, and ready for early intervention. The pragmatic stance effectively prevents failure by not allowing a disruption to cascade toward irreversible failure. This stance, however, creates the circumstances for its failure – the dramatic drop in consequential failure leads people to question the reason for the intervention. It would seem obvious that people will remember the reasons for the program. The baseline for knowledge is the experience that is reset to the time the member joins the system (17). Knowledge and experience are lost.

#### **Stability:**

A pragmatic frame with stochastic resonance enhances our capability to solve problems emerging from deeper, unidentifiable

structures (18). The stabilizing benefits of stochastic resonance come from greater degrees of freedom and complex interactions between nonlinearities. This stochastic randomness, rather than a particular frequency, ensures stability (19).

Besides stochastic resonance, we can organize and sustain stability by commands from the outside, a technological system we describe above. Or a system becomes structured from internal processes with order emerging from local nonlinear processes in a self-organizing system. As described in an earlier *Neonatology Today* article (11), when fire rescue ambulance medics went 'on scene,' they become part of the problem: they may need to rescue themselves; their presence alone changes the scene, and you can only solve these problems from within the problem. This is the gap between those who offer commands outside the system and those operating within the event.

---

***“The use of a rigid, linear response to a nonlinear forcing function is driven by the certitude of deductive reasoning (the facts guarantee the hypothesis), the explanatory power of statistical analysis, the predictive power of probability calculations, the linearity of cause-and-effect, and the finality of a hypothesis derived using classical logic.”***

---

The use of a rigid, *linear response* to a *nonlinear forcing function* is driven by the certitude of deductive reasoning (the facts guarantee the hypothesis), the explanatory power of statistical analysis, the predictive power of probability calculations, the linearity of cause-and-effect, and the finality of a hypothesis derived using classical logic. We can then form a codifying framework of guiding principles. However, the emphasis gets misplaced when those principles are seen as the core to producing reliability (11).

The difficulty lies in translating the knowledge and experience gained in new or dangerous contexts to those routine operations with only the potential for serious harm. An engineering approach with the cognitive domain aligns well with classical logic and deductive reasoning. With a well-circumscribed body of knowledge, the individual has the proficiency to engage in commonly encountered situations. We can engineer solutions, but we cannot engineer judgment.

---

***“The difficulty lies in translating the knowledge and experience gained in new or dangerous contexts to those routine operations with only the potential for serious harm.”***

---

An organization or industry may institutionalize competency rather than proficiency because generalizable principles can be taught to a high-turnover, novice workforce (20). Moving to proficiency requires using specifics, the particular, and case reports. It demands more time, training, shared insight, and modeling of senior, more

experienced people. Competency-based programs form the rule-based system of Jens Rasmussen's skills, rules, and knowledge (SRK) framework in his ecological interface design system (21). James Reason (22) adapted this framework for his model of error management now used in healthcare. This is almost institutionalization to impair institutional extension.

---

***“In dangerous contexts, skill acquisition occurs as semi-autonomous engagement under the watchful supervision of veterans, all of whom share the duty to ensure that the novice learns appropriately.”***

---

Unrecognized in this training and education approach is the neglect of judgment as a means to gain stability. Patricia Benner (20) described the discontinuity between the competent level of performance obtained in preparatory education and the proficiency necessary for more independent professional functioning. The student moves from what can be taught by precept to what can only be learned through experience. In dangerous contexts, skill acquisition occurs as semi-autonomous engagement under the watchful supervision of veterans, all of whom share the duty to ensure that the novice learns appropriately (23).

---

***“The demonstrated reciprocal feedback used to improvise solutions was vital to such engagement – a clear demonstration of HRO as natural human actions when freed from convention and central authority.”***

---

The demonstrated reciprocal feedback used to improvise solutions was vital to such engagement – a clear demonstration of HRO as natural human actions when freed from convention and central authority. Visible in the commentary of those who maintained engagement despite repeated failures was the development and reward of moral agency. Patricia Benner (20) described the moral agency as a result of the individual acting independently, then observing that the actions made someone's life better. Benner placed the development of moral agency at the crossing of the gap between simple competence and the richness of expertise. The *moral agency* gives meaning to one's actions, either internalized by the individual or interpreted for the individual by a leader. *Meaning giving* can reduce the effects of stress that may develop into post-traumatic stress (24).

The risk lies in mistranslation by those inexperienced in dangerous contexts or by those who lack a vocabulary that is familiar or readily accessible to spectators (11, 23). The salience and meaning spectators could use to expand their cognitive, affective, and behavioral repertoires are missing or not recognized (25). Knowledge and experience reduce the bravado that comes from the influence of movies and television (5), the substitution of the abstract for the contextual (26, 27), or understanding of what lies beyond the grasp of outsiders (11). The authors have organized a series of articles in *Neonatology Today* that combines the primary

sciences, primary experience, and practical ways to overcome mistranslations while bridging this gap.

---

***“Knowledge and experience reduce the bravado that comes from the influence of movies and television, the substitution of the abstract for the contextual, or understanding of what lies beyond the grasp of outsiders.”***

---

#### **Levels of Analysis:**

There are differences in analysis for the color of the environment, the flow of events, and one's position inside or outside the event. Arguing across levels of analysis creates false debate. We do not argue against engineering models, deductive reasoning, or classical logic (28). We argue that people and organizations choose their approach because they *want* to, not because they *must*.

Constrained, decontextualized approaches generally come from an authority group and limit one's perspective. When they become the dominant approach, they limit meaning and interpretation. Once a dominant account develops, voices become hidden, and knowledge is lost. With the dominant account, we lose the effect of the liminal experience (29) and the liminal space (30). The dominant account reduces problems within the liminal space to science versus practice, which creates inaccurate models – models that can kill (31).

---

***“Deduction and classical logic quickly become dominant when those in authority repeatedly discuss failures of individual judgment or threats such as liability.”***

---

Deduction and classical logic quickly become dominant when those in authority repeatedly discuss failures of individual judgment or threats such as liability. Described out of context and in the abstract, they become real and conform to behavior without the authority group. Individuals become hesitant, if not afraid, to decide and act.

In using classical logic and deductive reasoning, the dominant account becomes a mistranslation of the environment. Not recognizing the salience or meaning of signals, with the distance converting crisp details into ambiguous signals and the loss of contextualization, the disengaged observer readily simplifies the situation. Ambiguity is shed, evidence becomes fact, facts fit into the spectator's understanding, and knowledge becomes certitude. This emerging certitude, developed from mistranslated signals, supports the incorporation of mistranslations into the continuing use of classical logic and deductive reasoning. This creates demand for discrete data and the information necessary for the facts that will guarantee the hypothesis.

The clean separation of objects supports the laws of classical logic, a two-value logic: Truth and falsity are incompatible. Every proposition is true or false (*law of the excluded middle*); there is no gradation. The same proposition cannot be true and false simultaneously (*law of noncontradiction*). We can produce a truth table

with a two-value logic, but the proposition cannot have a value between truth and falsity, nor can it have both simultaneously. The patient *has* or *does* not have hypoxemia or fever, which will be determined by the number recorded from the measuring instrument. We have fallen into a cycle of forcing ambiguity into facts that will guarantee our hypotheses.

The mistranslation of the environment reduces complexity, which allows further use of classical logic and deductive reasoning. The drive for facts to support classical logic and deductive reasoning creates more mistranslations. This simplifying process supports the further use of classical logic and deductive reasoning. We have collected data, filed out forms, and classified the disease into the ICD-10 – we have reached our endpoint. The spectator can move on.

Framed from the fixed point of a non-engaged spectator, we can more easily explain our actions using nonoverlapping objects, classical logic, and deductive reasoning. We reduce and simplify our reasoning to fit the normative view of an unconnected spectator. However, context and meaning, critical for engagement, are lost. The dominant group sets the discourse, defines categories and classifications, limits what can be spoken about and what cannot, and who can speak with legitimacy. The dominant account is the privilege of being listened to (32). Lost are the hidden voices in the moving, turbulent, small-field view.

This is the context where reasoning impairs engagement.

---

***“Engagement happens because an individual acts locally to reduce negative consequences (12). The organization and leaders can support the individual in public safety and military operations. In civilian organizations, for various reasons, such support is less reliable.”***

---

#### **Engagement:**

Engagement happens because an individual acts locally to reduce negative consequences (12). The organization and leaders can support the individual in public safety and military operations. In civilian organizations, for various reasons, such support is less reliable. Nevertheless, the individual will engage in a way that makes sense to that individual at that place at that time.

The individual can use the situation to extend understanding through engagement, like a Los Angeles Fire Department firefighter approaching an emergency told one of the authors (DvS), "I don't know what is happening, but I know what to do." Engagement bridges gaps between objective knowledge and subjective experience as the situation moves toward disorder. Engagement creates structure as it generates information. But this is information in flux, meaning that engagement constantly updates our information as we continually revise our understanding.

Operators in the field will develop their logic of practice built upon contextual relations entwined with people and work (16). The engagement of practice moves theory into the practical world, closing the gap between theory and practice and creating *the practical domain of engagement* (33).

Or the individual can fit the situation into their understanding –

through deductive reasoning and classical logic. Though neither *create* information nor knowledge, they can be used to *apply* information and knowledge. However, a situation of changing information and emerging properties cannot fit into the certitude of deductive reasoning and classical logic. Reliability is more assured when practical engagement dominates, allowing the practice to adjust to the flux of circumstances.

---

***“Reliability is more assured when practical engagement dominates, allowing the practice to adjust to the flux of circumstances.”***

---

#### **Functional Descriptions**

An event has flux within the environment. How the observer or participant experiences that flux influences information and communication. A functional description of a forcing function focuses on the disruption produced rather than *how* the event was caused. An event flows through time as energy dissipates and transforms into other types of energy.

The Eulerian specification is decontextualized, using a fixed point of reference *outside* the flow of events (34). The Eulerian specification describes the organization's motion without reference to the forces which cause the motion. This 'top-down' perspective lies at a fixed point outside the flux of events. The benefit is qualitative and more precise information to generate state variables and demands independent of causation. Leaders and authorities use this external reference frame to create models for the reddened environment. However, the reddening of the environment increases variance, dissolving Gaussian distributions used for these models (35).

---

***“Leaders and authorities use this external reference frame to create models for the reddened environment. However, the reddening of the environment increases variance, dissolving Gaussian distributions used for these models.”***

---

The Lagrangian flow specification describes the velocity and gradients of events *within* the flow of events. This produces descriptions of demands on individual elements at specific points.

Within the flux of events, a 'bottom-up' perspective with the Lagrangian view, the operator is personally at risk, and changing contexts necessitates updating less reliable information. Rather than algorithms that fit a specific situation, accuracy becomes the platform for decision-making.

We sacrifice accuracy for conceptual tractability when we separate the organization from the environment.

#### ***The Local Field View – Experiencing Movement***

The Lagrangian flow specification generates qualitative measures from the view *within* the flow of events. This is not only contextual at the moment but also measures the changing context in

real-time, more closely revealing the operator's experience. It is a continuous measure of the changing position and the pressure experienced by the individual, small groupings, or teams.

### *The Whole Field View – Observing the Action*

The Eulerian flow specification provides quantitative measures from a fixed point of reference *outside* the flow of events. The decontextualized focus is on a specific location, though multiple, fixed positions can provide these measurements. The benefit is producing an objective measure of the rate of change in the system. Because of the de-contextual characteristic of the whole field view, the most productive use is when the observation points are operationally relevant. Staffing these points with observers having intimate knowledge, that is, knowledge by acquaintance, of the particular operations, is vital for the meaning and interpretation of information.

---

***“The engaged whole field observer seeks out hidden voices for the local specific information they can access. The experienced engaged observer can calibrate information for accuracy and support the free flow of information in a generative organization.”***

---

The *engaged* observer in the whole field view is indispensable during the engagement. The whole field view reveals distant or approaching threats, identifies useful resources, and contributes thought processes uncontaminated by stress or fear. The engaged whole field observer seeks out hidden voices for the local specific information they can access. The experienced engaged observer can calibrate information for accuracy and support the free flow of information in a generative organization (13, 36). Mistranslation remains possible, but connected involvement can calibrate information in real time.

The farther from the situation the observer is, whether by experience, physical distance, or distance in the hierarchy, the less effective or reliable the judgment will be necessary for these operations. At the worst, the observer becomes a spectator.

---

***“The objective, dispassionate, decontextualized frame becomes privileged because objective knowledge can readily be inserted. The danger is the 'logical' acceptance of these insertions.”***

---

The objective, dispassionate, decontextualized frame becomes privileged because objective knowledge can readily be inserted. The danger is the 'logical' acceptance of these insertions. For example, one of the authors (DvS) has had multiple discussions with intensivists, emergency physicians, respiratory care practitioners (RCPs), and paramedics about the cause of the sense of suffocation in patients. Generally, the belief that low oxygen saturation or high carbon dioxide levels cause the sensation of suffocation is inserted as objective science. Special Operations Force (SOF)

operators experienced in HALO (High-Altitude Low-Opening) parachute jumps and military aviators trained in high-altitude pressure chambers have found this belief hard to understand. A rudimentary internet search will produce US Air Force training videos that demonstrate the giddiness or euphoria caused by hypoxemia.

One of the authors (DvS) had personal experience with hypoxemia during an episode of high-altitude pulmonary edema at 20,000 feet in the Himalayas. During the solo descent to high camp, the author observed a glacier covered with what appeared to be fresh snow or, in his confusion from hypoxemia, white vegetable shortening. Discerning the difference between snow and shortening was even more challenging when his vision went from tunnel to binocular vision with the loss of depth perception. The author considered a side trip to examine the glacier's covering, especially since it appeared to be a few steps away. Though breathing rapidly, the author never experienced suffocation. The experts continue to insist otherwise. (The elevation of the glacier was 13,000 feet. The author did not step over to the glacier.)

The farther one is from the engagement experience, the easier these insertions are.

---

***“The privilege of the whole field view comes from the distance central authority has from evolving events. Viewing from a distance reduces the details while decontextualizing the view.”***

---

The privilege of the whole field view comes from the distance central authority has from evolving events. Viewing from a distance reduces the details while decontextualizing the view. With muddled details and lessened environmental interference, "it's not complicated." From a fixed position outside the event, elements of the problem appear discrete, and solutions flow in a linear, "dose-dependent" manner. The rate of change and flow of events are *quantitative* measures preferred by spectators for their discrete character and tractability. On the other hand, *qualitative* descriptions tell you about the thing, such as traits and texture, allowing overlapping characteristics and contributing to ambiguity (37). It is in ambiguity and complexity that we identify effective interactions.

The clarity of distance allows the mastery of research articles, concepts, and rules (there is a singular "right way") to be masked as clinical expertise. Deductive reasoning (facts guarantee the hypothesis) gives protection by its daunting, impenetrable certitude. The finality of classical logic (logically derived hypotheses cannot be changed) stops discussion. Too quickly, this becomes a leader's identity, if not a description of the ideal leader.

### **Classical Logic:**

*The classical predicate or first-order logic* is a formal language expressing propositions regarding predicates, variables, and quantifiers. Predicates express propositions as statements involving the arguments. The simplest predicates express properties of things. A statement makes an assertion that may be true or false contingent on the values of the variables.

Classical logic and scientific rationality are founded on deductive reasoning (facts guarantee the conclusion), statements that are either true or false (bivalence), and discrete entities having distinct properties (law of the excluded middle). Environmental stochastic noise separates the world of practice from scientific theory. It sep-

arates the formal knowledge produced by management scholars from the applied knowledge needed by practitioners.

The rigidity of classical logic can artificially create tension, corrupt communication, and impair the extension of medical care to benefit patients.

---

***“The rigidity of classical logic can artificially create tension, corrupt communication, and impair the extension of medical care to benefit patients.”***

---

An agitated patient with mechanical ventilation can disconnect from the ventilator. Cardiac arrest can come quickly. Rapid administration of sedative medication brings quick resolution. Sedation is not available in the subacute nursing facility. One of the authors (DvS) taught the subacute RCPs to hand ventilate for patient calm (38). Over time, the property of mechanical ventilation shifted from *enabling life* to *enhancing life* as children began smiling, talking, and interacting with their parents.

Further extension occurred for infants with weak abdominal musculature who developed acute respiratory distress during a bowel movement. The RCPs learned mild backpressure, a PEEP of 8 cm H<sub>2</sub>O, would prevent ventilator-related agitation. More significant was the experience of hand ventilation for agitation in children with neurological deficits. After a few breaths, they awaken, and older children may begin talking. Discussion with a neuropsychiatrist revealed that these children were likely in hypoactive delirium (an ICD-10 diagnosis) secondary to hypoventilation.

The scientific method uses classical logic closely related to the study of *correct reasoning*, making this the presumptive correct logic for science (39). However, as noted in the vignettes above, our experience belies classical logic as correct reasoning. Classical logic can impair the extension of a discipline.

At the beginning of one of the author's (DvS) experiences with long-term ventilation, he followed the goal of weaning the child from the ventilator following blood gas evaluation for O<sub>2</sub> and CO<sub>2</sub>. One day a child's grandmother beseeched an LVN to ask if the doctor could leave her grandson on the ventilator. She liked that he smiled, and he had never smiled before. The difference in ventilator management by blood gas versus smile created logical inconsistency with staff from various PICUs. The child's affective response contradicted scientific rationality and logic, along with standard respiratory care references that mechanical ventilation was difficult for a patient to tolerate. After several such experiences, the author began teaching that because we can wean the child from the ventilator, it does not mean we should. Many objective intensivists do not share this subjective view.

#### **Other Logics:**

Reddened noise environments give us partial (incomplete) and excessive (contradictory) information. "A logic is called paraconsistent if it 'tolerates contradictions' and paracomplete if it does not 'enforce completeness/exhaustiveness'" (40). Paraconsistent and paracomplete logic systems allow us to work with partial truths, meeting the needs for rapidly changing, conflicting information and adjusting solutions. This is the operator, working contextually "bottom-up" from within the trajectory, inside events, feeling the

pressure of elements. Nonmonotonic logics allows us to change our solutions as events evolve.

*Modal logics* conform to changing events and support flexible thinking, allowing qualifications such as "necessarily" and "possibly."

*Paraconsistent logics* allow contradictions. Therefore, there is no "principle of explosion." In classical logic, accepting a contradiction means everything and anything can follow – the "explosion." Paraconsistent logics allow us to make logical inferences using contradictions.

*Paracomplete logics* do not have the "law of excluded middle" (either the proposition is true or false). This allows the use of gradations and shared qualities.

---

***“We can use these logics to infer reliable information from imperfect information, understand our changing beliefs in a dynamic world, manipulate uncertain information, appreciate how time changes the truths and information with which we work, and comprehend how situations create different but logical duties and obligations. ”***

---

We can use these logics to infer reliable information from imperfect information, understand our changing beliefs in a dynamic world, manipulate uncertain information, appreciate how time changes the truths and information with which we work, and comprehend how situations create different but logical duties and obligations.

#### *Modal Logics*

Classical logic evaluates a premise by its appearance or form. The modal logics evaluate a premise through different ways or modes that things are true. In this way, modal logics address the limits of scientific logic. This is the logic of "modalities," *modes* (means) of truth, by using a variety of operators dependent on the domain of the logic (41).

These partial operators limit the operator's action, classifying propositions as *contingently* true or false and allowing claims about what is necessary, possible, contingent, essential, and accidental. In the 20<sup>th</sup> Century, modal logics developed to work with time, knowledge, belief, belief revision, and moral obligation (42). Modal logics conform to changing events and support flexible thinking.

#### *Paraconsistent Logics*

*Inconsistency* is the acceptance of contradictions; the rigid restraints of classical logic impair usage for uncertainty and inconsistency, particularly the law of the excluded middle. Paraconsistent logics were developed to handle conflicting information and allow contradictory yet non-trivial theories (43).

Paraconsistent logics permit inference from conflicting information in a non-trivial fashion, accommodate inconsistency in a controlled way, and treat inconsistent information as potentially

informative (44, 45). Paraconsistency is also an essential feature of common-sense reasoning which can use exceptions and counterfactuals (46-48)

---

***“For example, using the same information and relying on the same logic system, medical specialists will develop their findings from their knowledge and experience. They may reach different, inconsistent diagnoses.”***

---

For example, using the same information and relying on the same logic system, medical specialists will develop their findings from their knowledge and experience. They may reach different, inconsistent diagnoses.

Three-valued, paraconsistent logics have an additional third value, "both true and false." This process allows reasoning with variables not embedded directly in a contradiction (48, 49).

#### *Paracomplete Logics*

Every property or statement (true or false) can be derived from within the system in complete logic systems. Systems, however, cannot be complete, the subject of Kurt Gödel's Second Incompleteness Theorem (50). Paracomplete logics allow us to work with entities undergoing continuous change. There is no need to assume "A" or "not-A." Noncontradiction, however, does apply to these logics.

#### **Reasoning:**

We strengthen our knowledge with *deduction* and the analysis of new information. We create knowledge through *induction* for synthesis when we encounter new information.

---

***“We strengthen our knowledge with deduction and the analysis of new information. We create knowledge through induction for synthesis when we encounter new information.”***

---

#### *Deductive Reasoning*

No deduction can take the argument from true premises to a false conclusion. Thus, deductions *preserve truth*, claiming that everything derivable in the system is accurate. Deductive reasoning seems a better approach as the conclusion is guaranteed to be true. However, this is only if the premises are true. We miss the falsity as the safety margin is only putative. The premises for deductive reasoning *must* be correct. For this reason, deductive processes and classical logic do not permit changing a solution or deduction once it is reached.

#### *Inductive Reasoning*

At first contact, all we have for learning is observation. *Induction* is to learn through action. The observation begins the inductive process, how we gain knowledge, and how we extend our under-

standing.

---

***“Key to this is the acceptance that knowledge is not truth in inductivism. Conclusions from inductive reasoning are plausible rather than having the certainty of the truth we see with deductive reasoning.”***

---

Key to this is the acceptance that knowledge is not truth in inductivism. Conclusions from inductive reasoning are plausible rather than having the certainty of the truth we see with deductive reasoning. The strength of inductive reasoning comes from the relentless pressure to confirm the plausible conclusion, described by Leonhard Euler (51) in George Pólya (52):

"[Observations] will lead us continually to new properties which we shall endeavor to prove afterwards. The kind of knowledge which is supported only by observations and is not yet proved must be carefully distinguished from the truth; it is gained by induction, as we usually say...Indeed, we should use such a discovery as an opportunity to investigate more than exactly the properties discovered and to prove or disprove them; in both cases, we may learn something useful."

Euler believed knowledge could be inductively "assured of its truth" by the number of examples: "Anybody can satisfy himself of its truth by as many examples as he may wish to develop. And since I must admit that I am not in a position to give it a rigorous demonstration, I will justify it by a sufficiently large number of examples" (51, 52).

"When pains are taken to make each aspect of the movement as accurate as possible, the movement toward building up the idea is known as inductive discovery (induction, for short); the movement toward developing, applying, and testing, as deductive proof (deduction, for short). While induction moves from fragmentary details (or particulars) to a connected view of a situation (universal), deduction begins with the latter and works back again to particulars, connecting them and binding them together. The inductive movement is toward discovery of a binding principle; the deductive toward its testing confirming, refuting, modifying it on the basis of its capacity to interpret isolated details into a unified experience. So far as we conduct each of these processes in the light of the other, we get valid discovery or verified critical thinking," John Dewey (53).

#### **Avoidance of the Actual World:**

A Respiratory Care Practitioner (RCP) called the Pulmonologist about a newly admitted infant dependent on mechanical ventilation. The infant became agitated and struggled in the prescribed ventilator settings. She hand-ventilated the infant and found a pattern that calmed the infant. The Pulmonologist insisted on the prescribed settings. She repeatedly advised the Pulmonologist that the prescribed settings caused severe agitation, even though previous blood gas analyses in the PICU objectively supported them. She continued to describe how she could calm the child with what she learned by hand ventilation. A physician at the facility intervened in support of the RCP.

One of the authors (DvS) discussed the predicament with the

RCP. Early in his career, a cardiothoracic surgeon requested the author to manage a patient after extensive surgery. The surgeon advised the author on how to treat an expected problem that might arise overnight. In the morning, the surgeon was angry that the treatment was not used. The author described the incident and that the treatment did not work. The surgeon insisted the author should have tried again. The author had. The surgeon insisted there should have been a third trial. There were four trials, and the treatment never worked. The surgeon continued his anger.

When events do not follow the expected course, events move outside of one's understanding, creating fear and protective responses. Crises create abrupt gaps between what we thought we could do with what we must do. Perhaps there can be too much truth.

---

***“When events do not follow the expected course, events move outside of one's understanding, creating fear and protective responses. Crises create abrupt gaps between what we thought we could do with what we must do. Perhaps there can be too much truth.”***

---

These are not isolated incidents. This situation is the gap and the consequences between the decontextualized dominant account and the hidden, silent voice experiencing movement and pressure in the actual world. We then disregard the silent voice of the individual at the cusp of decision, driven to indecision, then into inaction.

The laboratory, controlled studies, and the distant administrator or leader become the dominant view through decontextualization. This example is more than a physical context. Individuals carry their contexts of experience and family of origin. Styles of leadership, management, and teamwork inform context. This context also encompasses culture, experience, physiology, and the Orient function in John Boyd's OODA Loop. Boyd was a US Air Force officer and strategist who created the OODA (Observe, Orient, Decide, and Act) Loop.

For Boyd (54), Orient "Shapes the way we interact with the environment...The way we *observe*, the way we *decide*, the way we *act*." "Seen as a result, represents images, views, or impressions of the world shaped by *genetic heritage, cultural tradition, previous experiences, and unfolding circumstances*." To give up context is to lose the Orient function of the OODA Loop: how we update information, analyze and synthesize from feedback, synthesize new information, and build support for our decisions.

The dominant account fails to appreciate how actors work in their natural spaces. We lose the "heterogeneity of population and practice, diverse afterlives, how spaces of science construct individual and group expertise" (55). This excludes the silent voices of other members of the organization, which are ignored or expressed by others (56).

Faced with too much truth, the individual is at risk of decontextualizing the situation for self-protection. Knowing one thing well and keeping it out of context allows the individual to extend their theory to many domains (14) confidently. The individual can suppress voices, making them hidden, creating a subculture that may undercut the program.

The individual who decontextualizes events can entertain and obfuscate (56). How actors work in their natural spaces is disregarded (56). We can distract people from the damage of poor leadership, management, and administration and silence the voices of those lower in the hierarchy or who are considered outliers (56).

---

***“The individual who decontextualizes events can entertain and obfuscate (56). How actors work in their natural spaces is disregarded (56). We can distract people from the damage of poor leadership, management, and administration and silence the voices of those lower in the hierarchy or who are considered outliers.”***

---

"Any lesson in leadership, we believe, that ignores context, or that fails to pay attention to other, less powerful voices, is a hollow lesson that likely serves other purposes and interests," Michael Elmes and Bob Frame (56).

#### **Conclusion:**

Engineering models fail to account for individual preferences and variances in capabilities. Classical logic blocks the flexibility necessary to incorporate new and emerging information. Unavailable to operators are logics that allow qualifications, contradictions, and the use of gradations and shared qualities. Deductive reasoning guarantees conclusions that are, at best, transient in the flux of reddened noise-forcing functions.

HRO methods emerged from environments formed by forcing functions. The ability to work under uncertainty and extend understanding must not be sacrificed for the tractability of objectivity.

#### **References:**

1. McConnell M, van Stralen D. Emergency medical decision-making in the tactical environment. *The Tactical Edge* (National Tactical Officers Association). 1997;15(3):32-9.
2. van Stralen D, Mercer TA. High-Reliability Organizing (HRO), Decision Making, the OODA Loop, and COVID-19. *Neonatology Today*. 2021;16(8):86-96.
3. van Stralen DW, Calderon RM, Lewis JF, Roberts KH. Changing a pediatric sub-acute facility to increase safety and reliability. *Patient Safety and Health Care Management*. 7: Emerald Group Publishing Limited; 2008. p. 259-82.
4. Wolfberg A. Full-spectrum analysis: A new way of thinking for a new world. *Military Review*. 2006;86(4):35-42.
5. van Stralen D, Mercer TA. Pandemic COVID-19, the High-Reliability Organization (HRO), and the Ecology of Fear. *Neonatology Today*. 2020;15(12):129-38. doi: 10.51362/neonatology.today/2020121512129138.
6. van Stralen D. High-reliability organizations: Changing the culture of care in two medical units. *Design Issues*. 2008;24(1):78-90.

7. van Stralen D, McKay SD, Mercer TA. Disaster Series: High Reliability Organizing for (HRO) Disasters—Disaster Ecology and the Color of Noise. *Neonatology Today*. 2021;16(12):96-109. doi: <https://doi.org/10.51362/neonatology.today/2021161296108>.
8. Ivanov PC, Amaral LN, Goldberger AL, Stanley HE. Stochastic feedback and the regulation of biological rhythms. *EPL (Europhysics Letters)*. 1998;43(4):363.
9. Synolakis C, Kánoğlu U. The Fukushima accident was preventable. *Philosophical Transactions of the Royal Society A: Mathematical, Physical and Engineering Sciences*. 2015;375:20140379. doi: <https://doi.org/10.1098/rsta.2014.0379>.
10. Plants CoLLftFNAfISaSoUSN. Lessons learned from the Fukushima nuclear accident for improving safety of US nuclear plants. Washington, DC: The National Academies Press; 2014. 366 p.
11. van Stralen D. Pragmatic High-Reliability Organization (HRO) During Pandemic COVID-19. *Neonatology Today*. 2020;15(4):3-9.
12. van stralen D, McKay SD, Stralen Ev, Mercer TA. Disaster Series: The Function of Engagement for High Reliability Organizing (HRO). *Neonatology Today*. 2022;17(12):16-28.
13. Westrum R. A typology of organisational cultures. *Quality and Safety in Health Care*. 2004;13(suppl\_2):ii22-ii7. doi: 10.1136/qshc.2003.009522.
14. Tetlock PE. *Expert Political Judgment*. Princeton, NJ: Princeton University Press; 2009.
15. van Stralen D, McKay SD, Mercer TA. Disaster Series: High Reliability Organizing (HRO) as Self-Organization. 2022;17(2):14-27.
16. Sandberg J, Tsoukas H. Grasping the logic of practice: Theorizing through practical rationality. *Academy of management review*. 2011;36(2):338-60.
17. Pauly D. Anecdotes and the shifting baseline syndrome of fisheries. *Trends in Ecology & Evolution*. 1995;10(10):430.
18. van Stralen D, McKay SD, Hart CA, Mercer TA. High Reliability Organizing (HRO) for the Color of Noise: Forcing Functions, Collaboration, and Safety. 17. 2022;4:19-30.
19. McDonnell MD, Abbott D. What is stochastic resonance? Definitions, misconceptions, debates, and its relevance to biology. *PLoS Comput Biol*. 2009;5(5):e1000348. Epub 2009/06/30. doi: 10.1371/journal.pcbi.1000348. PubMed PMID: 19562010; PubMed Central PMCID: PMC2660436.
20. Benner P. *From Novice to Expert: Excellence and Power in Clinical Nursing Practice*. Menlo Park, CA: Addison-Wesley; 1984.
21. Rasmussen J, Vicente KJ. Coping with human errors through system design: implications for ecological interface design. *International Journal of Man-Machine Studies*. 1989;31(5):517-34. doi: 10.1016/0020-7373(89)90014-x.
22. Reason J. *Human Error*. New York, NY: Cambridge University Press; 1990.
23. van Stralen D, Mercer TA. High-Reliability Organizing (HRO) in the COVID-19 Liminal Zone: Characteristics of Workers and Local Leaders. *Neonatology Today*. 2021;16(4):90-101. doi: 10.51362/neonatology.today/2021416490101.
24. Dixon DP, Weeks M, Boland R, Perelli S. Making Sense When It Matters Most: An Exploratory Study of Leadership In Extremis. *Journal of Leadership & Organizational Studies*. 2016;24(3):294-317. doi: 10.1177/1548051816679356.
25. van Stralen D, Mercer TA. During Pandemic COVID-19, the High-Reliability Organization (HRO) Identifies Maladaptive Stress Behaviors: The Stress-Fear-Threat Cascade. *Neonatology Today*. 2020;15(11):113-24. doi: 10.51362/neonatology.today/202011511113124.
26. Weick KE. *Arrested Sensemaking: Typified Suppositions Sink the El Faro*. in press. 2022.
27. van Stralen D, Mercer TA. The Nature of Neonatal Experience during Pandemic COVID-19. *Neonatology Today*. 2021;16(3):87-97. doi: 10.51362/neonatology.today/202131638797.
28. MacDougall-Shackleton SA. The levels of analysis revisited. *Philos Trans R Soc Lond B Biol Sci*. 2011;366(1574):2076-85. Epub 2011/06/22. doi: 10.1098/rstb.2010.0363. PubMed PMID: 21690126; PubMed Central PMCID: PMC3130367.
29. Morris DJ. *The Evil Hours: A biography of post-traumatic stress disorder*. Boston, MA: Houghton Mifflin Harcourt; 2015.
30. Tempest S, Starkey K, Ennew C. In the Death Zone: A study of limits in the 1996 Mount Everest disaster. *Human Relations*. 2007;60(7):1039-64.
31. Heggie V. Experimental physiology, Everest and oxygen: from the ghastly kitchens to the gasping lung. *The British Journal for the History of Science*. 2013;46(1):123-47. doi: 10.1017/s0007087412000775.
32. Elmes M, Frame B. Into hot air: A critical perspective on Everest. *Human Relations* 2008;61(2):213-41.
33. Zundel M, Kokkalis P. Theorizing as engaged practice. *Organization Studies*. 2010;31(9-10):1209-27.
34. van Stralen D, Mercer TA. Inductive Processes, Heuristics, and Biases Modulated by High-Reliability Organizing (HRO) for COVID-19 and Disasters. *Neonatology Today*. 2021;16(9):104-12. doi: 10.51362/neonatology.today/20219169104112.
35. Halley JM. Ecology, evolution and 1f-noise. *Trends in ecology & evolution*. 1996;11(1):33-7.
36. Weick KE. Organizing for Transient Reliability: The Production of Dynamic Non-Events. *Journal of Contingencies and Crisis Management*. 2011;19(1):21-7. doi: 10.1111/j.1468-5973.2010.00627.x.
37. van Stralen D. Ambiguity. *Journal of Contingencies and Crisis Management*. 2015;23(2):47-53. doi: 10.1111/1468-5973.12082.
38. van Stralen D, Westmoreland T. Management of a Mechanical Ventilator Using Patient Calm as an Endpoint. *Special Operations Medical Association Scientific Assembly (SOM-*

- SA); December 8-11, 2014; Tampa, Florida: Special Operations Medical Association (SOMA); 2014.
39. Shapiro S, Kissel TK. Classical Logic. In: Zalta EN, editor. The Stanford Encyclopedia of Philosophy. Spring 2021 Edition ed: Metaphysics Research Lab, Stanford University; 2021.
  40. Fuenmayor D. Topological semantics for paraconsistent and paracomplete logics in Isabelle/HOL. arXiv preprint arXiv:210404284. 2021.
  41. Garson J. Modal Logic. In: Zalta EN, editor. The Stanford Encyclopedia of Philosophy: Metaphysics Research Lab, Stanford University; 2021.
  42. Ballarín R. Modern Origins of Modal Logic. In: Zalta EN, editor. The Stanford Encyclopedia of Philosophy. Fall 2021 Edition ed: Metaphysics Research Lab, Stanford University; 2012.
  43. Arieli O, Avron A, Zamansky A. Ideal paraconsistent logics. *Studia Logica*. 2011;99(1-3):31.
  44. Priest G. Paraconsistent logic. In: DM G, F. G, editors. Handbook of philosophical logic. 6. Second ed. Dordrech, Germany: Springer; 2002. p. 287-393.
  45. Priest G, Tanaka K, Weber Z. Paraconsistent logic. In: Zalta EN, editor. The Stanford Encyclopedia of Philosophy Summer 2018 Edition ed: Metaphysics Research Lab, Stanford University; 2018.
  46. van Stralen D, Mercer TA. Common Sense High Reliability Organizing (HRO) in the Response to COVID-19. *Neonatology Today*. 2021;16(7):90-102. doi: 10.51362/neonatology.today/2021716790102.
  47. Rudnicki K. The psychological aspects of paraconsistency. *Synthese*. 2021;199(1):4393-414.
  48. Konieczny S, Marquis P, editors. Three-valued logics for inconsistency handling. European Workshop on Logics in Artificial Intelligence; 2002: Springer.
  49. Ciucci D, Dubois D. Three-valued logics, uncertainty management and rough sets. In: Peters JF, Skowron A, editors. Transactions on Rough Sets XVII. Lecture Notes in Computer Science. Berlin, Germany: Springer-Verlag; 2014. p. 1-32.
  50. Raatikainen P. Gödel's Incompleteness Theorems. In: Zalta EN, editor. The Stanford Encyclopedia of Philosophy: Metaphysics Research Lab, Stanford University; 2021.
  51. Euler L. Opera Omnia, ser. 1, vol. 2. In: Pólya G, editor. Mathematics and plausible reasoning: Induction and analogy in mathematics. 1. Princeton, NJ: Princeton University Press; 1761.
  52. Pólya G. Mathematics and plausible reasoning: Induction and analogy in mathematics. Princeton, NJ: Princeton University Press; 1954.
  53. Dewey J. How we think. New York, NY: D. C. Heath & Co.; 1910.
  54. Boyd J. A discourse on winning and losing. Maxwell AFB, Alabama: Air University Press; 2018.
  55. Heggie V. Higher and colder: The success and failure of boundaries in high altitude and Antarctic research stations. *Soc Stud Sci*. 2016;46(6):809-32. Epub 2016/12/28. doi: 10.1177/0306312716636249. PubMed PMID: 28025914; PubMed Central PMCID: PMC5207293.
  56. Elmes M, Frame B. Into hot air: A critical perspective on Everest. *Human Relations*. 2008;61(2):213-41. doi: 10.1177/0018726707087785.

*Disclosures: No author has professional or financial relationships with any companies that are relevant to this study. There are no conflicts of interest or sources of funding to declare.*

**NT**

**Corresponding Author**



*Daved van Stralen, MD, FAAP  
Associate Professor, Pediatrics  
Department of Pediatrics  
Loma Linda University School of Medicine  
11175 Campus Street  
CP-A1121  
Loma Linda, CA 92350  
Email: [DVanStra@llu.edu](mailto:DVanStra@llu.edu)*



*Sean McKay  
Executive Partner / Director, Disruptive Rescue & Austere  
Medicine  
Element Rescue - Response Solutions within Nonlinear Complex  
Environments  
Greenville, South Carolina, United States*



*Errol van Stralen  
Program Director at Ancora Corporate Training  
Tuscumbia, Alabama, United States*

**Acknowledgments**

Karl Weick, Rensis Likert Distinguished University Professor of Organizational Behavior and Psychology, Emeritus, University of Michigan

William J. Corr, Captain II, Los Angeles City Fire Department (retired)

Adrian Wolfberg, National Academy of Sciences, Defense Intelligence Agency Steve

Timothy Watson, MD, FAAP, Mission Pediatrics



*Thomas A. Mercer  
Rear Admiral  
United States Navy (Retired)*

**New subscribers are always welcome!**

**NEONATOLOGY TODAY**

**To sign up for a free monthly subscription,  
just click on this box to go directly to our  
subscription page**

**Readers can also follow**

**NEONATOLOGY TODAY**

**via our Twitter Feed**

**@NEOTODAY**



**NEONATOLOGY TODAY** is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)

# INFANT AND FAMILY-CENTERED DEVELOPMENTAL CARE (IFCDC)

STANDARDS AND SAMPLE RECOMMENDATIONS FOR INFANTS IN THE INTENSIVE CARE UNIT

## SYSTEMS THINKING IN COMPLEX ADAPTIVE SYSTEMS



- Are the baby and family central to the mission, values, environment, practice & care delivery of IFCDC in the unit?
- Are the parents of each baby fully integrated into the team and treated as essential partners in decision-making and care of the infant?
- What are the strategies and measurements used to improve and sustain IFCDC in the unit?

## POSITIONING & TOUCH FOR THE NEWBORN

- Are the positioning plans therapeutic and individualized, given the care needs and development of the baby?
- Are the positioning and touch guidelines continually reviewed by the team, including the parents, and adapted to meet the changing comfort needs of the baby?



## SLEEP AND AROUSAL INTERVENTIONS FOR THE NEWBORN

- Can the team confidently describe the "voice" or behavioral communication of the baby?
- Are the baby's unique patterns of rest, sleep, and activity documented by the team and protected in the plan of care?



## SKIN-TO-SKIN CONTACT WITH INTIMATE FAMILY MEMBERS

- Is the practice of skin-to-skin contact supported and adjusted to the comfort needs of each baby, parent, & family member?
- Are the parents & family members supported to interact with the baby to calm, soothe, & connect?



## REDUCING AND MANAGING PAIN AND STRESS IN NEWBORNS AND FAMILIES

- Are parents supported to be present and interactive during stressful procedures to provide non-pharmacologic comfort measures for the baby?
- Are there sufficient specialty professionals to support the wellbeing of the team, including parents, families, and staff? Examples include mental health, social, cultural, & spiritual specialists.



## MANAGEMENT OF FEEDING, EATING AND NUTRITION DELIVERY

- Are the desires of the m/other central to the feeding plan? Is this consistently reflected in documentation with input of the m/other?
- Does the feeding management plan demonstrate a feeding & nutrition continuum from in-hospital care through the transition to home & home care?



WANT TO KNOW MORE ABOUT THE STANDARDS AND RECOMMENDATIONS? VISIT: [HTTPS://NICUDESIGN.ND.EDU/NICU-CARE-STANDARDS/](https://nicudesign.nd.edu/nicu-care-standards/)

©CONSENSUS PANEL ON INFANT AND FAMILY-CENTERED DEVELOPMENTAL CARE 2022

# Keeping Your Baby Safe

during the COVID-19 pandemic

## How to protect your little one from germs and viruses

Even though there are some things we don't know about COVID-19 yet, there are many more things that we do know. We know that there are proven protective measures that we can take to stay healthy.

### Here's what you can do...

#### Wash Your Hands

- This is the single, most important thing you can do to stop the spread of viruses.
- Use soap.
- Wash for more than 20 seconds.
- Use alcohol-based sanitizers.



#### Limit Contact with Others

- Stay home when you can.
- Stay 6 feet apart when out.
- Wear a face mask when out.
- Change your clothes when you get home.
- Tell others what you're doing to stay safe.



#### Provide Protective Immunity

- Hold baby skin-to-skin.
- Give them your breast milk.
- Stay current with your family's immunizations.



#### Take Care of Yourself

- Stay connected with your family and friends.
- Sleep when you can.
- Drink more water and eat healthy foods.
- Seek mental health support.



**Immunizations** Vaccinations save lives. Protecting your baby from flu and pertussis lowers their risks for complications from coronavirus.

**WARNING**

#### Never Put a Mask on Your Baby

- Because babies have smaller airways, a mask makes it hard for them to breathe.
- Masks pose a risk of strangulation and suffocation.
- A baby can't remove their mask if they're suffocating.



#### If you are positive for COVID-19

- Wash with soap and water and put on fresh clothes before holding or feeding your baby.
- Wear a mask to help stop the virus from spreading.
- Watch out for symptoms like fever, confusion, or trouble breathing.
- Ask for help caring for your baby and yourself while you recover.



We can help protect each other.

[Learn more](#)

[www.nationalperinatal.org/COVID-19](http://www.nationalperinatal.org/COVID-19)



Brilliant! Dr. Bell bridges the journey from grief to growth.  
This is classic wisdom on healing from our heartbreaks  
and ultimately enjoying a fulfilling life.

– CHRISTINE THEARD, M.D.

# Post-Traumatic Thriving

The Art, Science, & Stories of Resilience



Randall Bell, Ph.D.

# Briefly Legal: "Half-hour Rule" in Obstetrics

Barry S. Schifrin, MD; Wayne R. Cohen, MD, Maureen Sims, MD;

*"In anticipation of rapid delivery, he ruptured the membranes artificially, precipitating a prolapse of the umbilical cord. He declared an emergency and called for an immediate cesarean section. In response, all the obstetrical nurses then on duty were recruited to deal with the emergency, leaving the primigravida unattended."*

## Abbreviations

CP – Cerebral Palsy

CTG – Cardiotocograph

D-I - Decision to Incision Interval

EFM – Electronic Fetal Monitor

FHR – Fetal Heart Rate

ROM – Rupture of Membrane

The "30-minute rule" refers to the interval between the decision to effect cesarean delivery and the time the incision is begun. This decision-incision (D-I) interval has been considered the outside limit for initiating a cesarean section once the decision has been made. Failure to meet this "rule" frequently appears in allegations of obstetrical malpractice and hospital quality assurance reviews.

## Case synopsis:

This legal case involves two different obstetrical patients who were cared for by a single attending obstetrician. Both patients were at term with uneventful pregnancies. The first, a primigravida, entered the small community hospital at about 3 am in early labor. The attending obstetrician was notified of her arrival. He ordered routine surveillance and no uterine stimulation and went back to sleep, anticipating that he would see the patient in the morning when he made rounds. He was to be called if her labor became active. At 5 am, the second patient, a multiparous woman in early labor, presented at the hospital. The attending was notified about her and said he would come in to attend to both patients.

On examination of the multipara, he found her cervix to be 4 cm dilated, with the fetal head at -2 station. In anticipation of rapid delivery, he ruptured the membranes artificially, precipitating a pro-

lapse of the umbilical cord. He declared an emergency and called for an immediate cesarean section. In response, all the obstetrical nurses then on duty were recruited to deal with the emergency, leaving the primigravida unattended. The baby was delivered with high Apgar scores and pursued a normal neonatal course. While the cesarean was being carried out, the FHR pattern of the primigravida deteriorated to the point of obvious fetal hypoxemia. However, there was no one available to deal with the problem. Upon completion of the emergency cesarean, an examination of the primigravida revealed the abnormal FHR pattern, and the remobilization of the cesarean section crew began. It required 45 minutes before the procedure could start. At delivery, the newborn was significantly compromised and was found to have hypoxic-ischemic encephalopathy and subsequent cerebral palsy.

*"In 1987, a survey of over 500 hospitals found that almost all hospitals were capable of performing emergency cesarean sections within 30 minutes."*

## Allegations were brought against the hospital and the obstetrician:

- The emergency was created by the negligent rupture of the membranes with the fetus at a high station.
- The emergency required the mobilization of the available nurses and a deflection of the care required by the first patient.
- The attending physician was required to understand not only the potential complications of rupturing membranes at a high station (a prolapsed cord) but that creating such an emergency under the prevailing coverage would compromise the attention to the first patient.
- In his defense, the obstetrician claimed that he had no responsibility for the coverage of the unit or any disparity in care of other patients his actions might create. While he might be the "captain of the ship," he was not the "admiral of the fleet."

## Discussion:

The 5th edition of Standards for Obstetrics and Gynecology (1982), published by The American College of Obstetricians and Gynecologists (ACOG), stated that "An obstetric service that generally cares for high-risk patients should be staffed and equipped to handle emergencies and to be able to begin cesarean delivery within 15 minutes." (1) In 1987, a survey of over 500 hospitals found that almost all hospitals were capable of performing emergency cesarean sections within 30 minutes. (2) As a result, in 1988, in the 6th edition of Standards for Obstetricgynecologic

Services and Guidelines for Perinatal Care, the 15-minute "rule" became a "30-minute rule." (3). This "standard" has prevailed to the current day with considerable discussion over its medical relevance and its use in medico-legal cases.

A recent article on the 30-minute rule offers insight into the divergent views relating to the D-I interval. However, it avoids certain seemingly relevant discussions that surface in this case: (4) there are appropriate reasons for urgent intervention, as in the first patient, but the vast majority of babies delivered emergently are not compromised, leading to the potentially paradoxical notion that these interventions were unnecessary. While the presence of newborn encephalopathy or umbilical acidemia at or shortly after birth are reasonable short-term endpoints to assess the benefits of emergency intervention, the risk of cerebral palsy and other long-term consequences of a hostile uterine environment cannot be established at the time of birth. Nor do all the fetuses that will suffer long-term harm from the events of labor and delivery manifest abnormality immediately after birth or result in NICU admission, or show very low umbilical pH values. (5, 6)

---

***“Not all fetal bradycardias require emergency intervention. The most common cause of reversible bradycardia is uterine tachysystole – a fact that argues for the scrupulous prevention of excessive uterine activity in the first place.”***

---

#### **Neonatal concerns with rapid delivery:**

While fetal acidemia worsens as a function of the duration of the 2 (nd) stage as well as the duration of fetal bradycardia, (7,8,9) Kamoshita examined the effect of the interval between onset of sustained fetal bradycardia and cesarean delivery on long-term neonatal neurologic prognosis. (10) Among 19 pregnancies, fetal bradycardia was attributed to umbilical cord prolapse (n=5), placental abruption (n=4), uterine rupture (n=3), maternal respiratory failure (n=1), and other causes (n=6). The mean onset of fetal bradycardia to delivery interval was 21 minutes. The mean decision-to-cesarean delivery interval was 11 minutes and was negatively correlated with umbilical arterial pH. at delivery. There were 3 postnatal deaths, but neurologic assessment at 2 years revealed that 15 of 16 surviving children were neurologically normal. When the interval from bradycardia to delivery was less than 25 minutes, all term pregnancies survived and had normal neonatal neurologic development.

Not all fetal bradycardias require emergency intervention. The most common cause of reversible bradycardia is uterine tachysystole – a fact that argues for the scrupulous prevention of excessive uterine activity in the first place. In a study by Leung et al., the "retrospective" diagnosis of "potentially reversible" bradycardia involved only 22/235 or less than 10% of the cases of bradycardia. (11) The reversibility of the bradycardia would seem to rest with the context in which it occurs. Those associated with cord prolapse are not reasonably reversible, and there is probably little benefit from attempting to replace the cord. Elevating the present-

ing part and reducing the frequency of contractions while preparations for a cesarean section are potentially helpful. Those bradycardias arising from a previously abnormal tracing are unlikely to recover, demand immediate preparations, and lessen optimism about recovery. (10) In some cases, 30 minutes may be too long a decision-to-incision time, such as the umbilical cord prolapse seen in this case. Conversely, several studies of neonates delivered emergently have shown an inverse relationship between the speed of intervention and lower Apgar scores, umbilical artery pH of <7.10 (12), and a higher rate of delivery room intubation. (13, 14, 15, 16)

---

***“Although prompt action to deliver a compromised infant is admirable, this relies on timely and reliable recognition of irreversible hypoxia and the response to treatment – presumably while preparations for cesarean section are being undertaken.”***

---

The argument that improved outcomes among those delivered with less haste may be attributable to fetal recovery after maternal hypotension. (17) Other studies have shown no difference in neonatal outcomes, including low Apgar scores, umbilical acidemia, NICU admission, seizures, and fetal or neonatal death, in intervals well beyond 30 minutes. (18, 19, 20, 21, 22) The potential for bias in these studies is obvious – if those at greatest jeopardy are delivered sooner, with outcomes likely dependent upon the cause of the fetal bradycardia.

In a review of the available literature in 2013, Leung and Lao (23) concluded that in certain life-threatening situations, the more rapid the delivery, the better for fetal well-being. They emphasized the importance of identifying and addressing potential causes of hypoxia and acknowledged 30 minutes as an achievable standard if not one supported by outcome data.

Despite the broad debate over the 30-minute rule, there is little logic to support any utility to the metric. Of what value is the D-I time when the total duration and severity of hypoxia best correlates with adverse neonatal outcomes (10, 11)? Although prompt action to deliver a compromised infant is admirable, this relies on timely and reliable recognition of irreversible hypoxia and the response to treatment – presumably while preparations for cesarean section are being undertaken.

#### **Maternal concerns with rapid delivery:**

Rapidly performed emergency cesarean sections increase the risk of maternal complications irrespective of the rapidity of intervention. (13, 18, 24) Risks include wound infections, postpartum hemorrhage requiring transfusion, and surgery complications. (25, 26, 27, 28) There is also an increased risk of mental/emotional disturbances, including severe postpartum depression, self-injury, suicidal ideation, and posttraumatic stress disorder (29, 30). While these responses may result from disappointment over the failed attempt at vaginal delivery, in our experience, it is the urgency, uncertainty, and sometimes chaos surrounding emergency

delivery. That most affect maternal (and paternal) mental health.

Similarly, as in the above case, we know cases where the mobilization of resources to deal with an emergency cesarean section removes attention from other laboring patients with the risk of harm. Thus, there are numerous reasons why the time-limited metric may not be met, because the mother is obese, anesthesia or an operating room is unavailable, or as in the case above there was already a cesarean section going on. How do we interpret the 30-minute rule when there is already a cesarean section being undertaken on another patient? Especially for the defense of medico-legal cases, we suggest including in the medical record, the reason for any delay.

#### **Designation of Delivery Urgency:**

Divergent notions of the urgency of delivery mire the specialty. At the extremes, an "emergency" delivery may represent one in which the utmost haste is demanded or a cesarean section that has not been scheduled beforehand. Thus, "stat," "emergency," and "urgent" are frequently used without consistent definitions. In Robson's 10-category classification of cesarean section, indication by urgency is not a metric. (31) Other classifications of urgency, however, have been proposed. (32, 33)

---

***“More important than the discussion of the management of the problem is the importance of preventing its appearance in the first place by avoiding excessive uterine activity and controlling the strategy of pushing in the 2nd stage, thereby avoiding both the need for urgent (conservative) intervention or emergency operative delivery.”***

---

#### **Classifications of urgency have been proposed: (21, 33, 34)**

**Class I**—An urgent delivery related to an immediate threat to the life of the mother or fetus.

Examples:: umbilical cord prolapse, persistent fetal bradycardia, suspected major placental abruption or uterine rupture—cases of maternal cardiac arrest or impending maternal arrest.

**Class II**—An expedited delivery because of a developing concern for the fetus or mother while allowing for the determination of the impact of resuscitative measures or such logistical details as the arrival of additional personnel, cross-matching of blood, or administration of regional anesthetic.

Examples; non-bradycardic category III fetal heart tracing, worsening preeclampsia remote from delivery, and developing concerning maternal or fetal conditions. In situations where the fetus presents with an abnormal tracing from the outset of labor. Many will intervene primarily, but only rarely, requiring an emergency stat cesarean section.

**Class III**—A purposeful delivery without an immediate perceived

threat to the mother or fetus.

Examples: labor arrest disorders with reassuring maternal and fetal status

**Class IV**—An elective delivery scheduled to accommodate the individuals concerned best.

Examples: elective cesarean delivery, malpresentation, non-bleeding placenta previa

In some legal cases, getting the cesarean section done within 30 minutes of the decision provided an insufficient defense for unnecessary delays when the procedure could have been performed sooner.

Pinas and Chandraharan (35) have identified a CTG pattern called "sub-acute fetal hypoxia" developing in the 2nd stage of labor. They recommend immediate "conservative intervention with reduced oxytocin and cessation of pushing. It is reasonable, however, that some practitioners would have intervened on an emergency basis for this pattern. More important than the discussion of the management of the problem is the importance of preventing its appearance in the first place by avoiding excessive uterine activity and controlling the strategy of pushing in the 2nd stage, thereby avoiding both the need for urgent (conservative) intervention or emergency operative delivery. (36)

---

***“By bolstering education and including simulations for responding to FHR and labor patterns and controlling oxytocin may yield better neonatal outcomes than increasing the speed and urgency of delivery.”***

---

#### **Recommendations:**

The "30-minute rule" is not a meaningful measure of the quality of care, the best practice guideline, or most importantly, a standard of care, most often noted in the courtroom. It fails in these areas because of a lack of insight into the quality of care or evidence that it can be meaningfully used to improve outcomes for either mother or the neonate.

All hospitals offering obstetric services must be able to respond to emergencies rapidly To minimize serious maternal, fetal, and neonatal consequences. While important to our minds, developing flowcharts to expedite emergency cesarean deliveries addresses only part of the problem and may, paradoxically, encourage more frequent use of emergent deliveries. (37) By bolstering education and including simulations for responding to FHR and labor patterns and controlling oxytocin may yield better neonatal outcomes than increasing the speed and urgency of delivery. (38)

While enhanced educational efforts and eliminating impediments to performing emergency cesarean sections are important initiatives, the better way to enhance maternal and neonatal outcomes derives from diminishing the need for emergent intervention. This intervention is not an issue where the patient presents in labor with a prolapsed cord. On the other hand, how shall we classify the present case in which rupture of the membranes at a high sta-

tion precipitated a prolapse of the cord? We diminish the need for emergency intervention by observing the fetal responses to contractions, avoiding excessive uterine activity, and controlling the strategy of pushing in the 2nd stage, thereby avoiding emergency operative delivery. We further reduce urgency by recognizing that not all operative vaginal deliveries (vacuum or forceps) succeed and that attempts at operative vaginal delivery for "fetal distress" be accompanied by simultaneous availability of cesarean section should the procedure prove difficult or impossible.

It is important to balance maternal safety with the perceived need for speed of delivery. There must be an understanding of which patients require emergent cesarean section because of iatrogenic activities unrelated to care. The urgency of intervention must be made into a reliable, well-defined metric, and the preventability of that urgency must also be defined. The need for urgent intervention in a patient undergoing a trial of labor with a normal fetus and normal delivery prospects is surely a measure of the quality of care. It is a statistic that should approach 0. Does it not seem reasonable to analyze cesarean section's "preventable" urgency?

In this sense, it is not the 30-minute rule that has failed but the lack of required quality components that must be known before the statistic makes sense. In its present form, it is the wrong question being asked. Thomas Pynchon stated, "If you ask the wrong question, the answers don't matter." Alternatively, channeling the sentiments of Ernest King, Admiral of the Navy during World War II: "The mark of a great shiphandler is never getting into situations that require a great shiphandler."

#### References:

1. ACOG. Standards for Obstetric-Gynecologic Services: The Committee; 1982.
2. Shiono PH, Fielden JG, McNellis D, Rhoads GG, Pearse WH. Recent trends in cesarean birth and trial of labor rates in the United States. *JAMA* 1987;257:494-7.
3. ACOG. Standards for Obstetric Services. 6 ed: The College; 1988.
4. Bank TC, Macones G, Sciscione A. The "30-minute rule" for expedited delivery: fact or fiction? *Am J Obstet Gynecol* 2023.
5. ACOG. Neonatal Encephalopathy and Neurologic Outcome: ACOG; 2014.
6. Kirton A, Deveber G, Pontigon AM, Macgregor D, Shroff M. Presumed perinatal ischemic stroke: vascular classification predicts outcomes. *Ann Neurol* 2008;63:436-43.
7. Katz M, Shani N, Meizner I, Insler V. Is end-stage deceleration of the fetal heart ominous? *Br J Obstet Gynaecol* 1982;89:186-9.
8. Korhonen J, Kariniemi V. Emergency cesarean section: the effect of delay on umbilical arterial gas balance and Apgar scores. *Acta Obstet Gynecol Scand* 1994;73:782-6.
9. Heller G, Bauer E, Schill S, et al. Decision-to-Delivery Time and Perinatal Complications in Emergency Cesarean Section. *Deutsches Arzteblatt international* 2017;114:589-96.
10. Kamoshita E, Amano K, Kanai Y, et al. Effect of the interval between onset of sustained fetal bradycardia and cesarean delivery on long-term neonatal neurologic prognosis. *Int J Gynaecol Obstet* 2010;111:23-7.

11. Leung TY, Chung PW, Rogers MS, Sahota DS, Lao TT, Hung Chung TK. Urgent cesarean delivery for fetal bradycardia. *Obstet Gynecol* 2009;114:1023-8.
12. Tolcher MC, Johnson RL, El-Nashar SA, West CP. Decision-to-Incision Time and Neonatal Outcomes: A Systematic Review and Meta-analysis. *Obstet Gynecol* 2014;123:536-48.
13. Bloom SL, Leveno KJ, Spong CY, et al. Decision-to-incision times and maternal and infant outcomes. *Obstet Gynecol* 2006;108:6-11.
14. Holcroft CJ, Graham EM, Aina-Mumuney A, Rai KK, Henderson JL, Penning DH. Cord gas analysis, decision-to-delivery interval, and the 30-minute rule for emergency cesareans. *J Perinatol* 2005;25:229-35.
15. Sayegh I, Dupuis O, Clement HJ, Rudigoz RC. Evaluating the decision-to-delivery interval in emergency cesarean sections. *Eur J Obstet Gynecol Reprod Biol* 2004;116:28-33.
16. Hillemanns P, Hasbargen U, Strauss A, Schulze A, Genzel-Boroviczeny O, Hepp H. Maternal and neonatal morbidity of emergency caesarean sections with a decision-to-delivery interval under 30 minutes: evidence from 10 years. *Arch Gynecol Obstet* 2003;268:136-41.
17. Schauburger CW, Rooney BL, Beguin EA, Schaper AM, Spindler J. Evaluating the thirty minute interval in emergency cesarean sections. *J Am Coll Surg* 1994;179:151-5.
18. Grobman WA, Bailit J, Sandoval G, et al. The Association of Decision-to-Incision Time for Cesarean Delivery with Maternal and Neonatal Outcomes. *Am J Perinatol* 2018;35:247-53.
19. Lurie S, Sulema V, Kohen-Sacher B, Sadan O, Glezerman M. The decision to delivery interval in emergency and non-urgent cesarean sections. *Eur J Obstet Gynecol Reprod Biol* 2004;113:182-5.
20. Thomas J, Paranjothy S, James D. National cross sectional survey to determine whether the decision to delivery interval is critical in emergency caesarean section. *BMJ* 2004;328:665.
21. MacKenzie IZ, Cooke I. What is a reasonable time from decision-to-delivery by caesarean section? Evidence from 415 deliveries. *Bjog* 2002;109:498-504.
22. Onah HE, Ibeziako N, Umezulike AC, Effetie ER, Ogbuokiri CM. Decision - delivery interval and perinatal outcome in emergency caesarean sections. *J Obstet Gynaecol* 2005;25:342-6.
23. Leung TY, Lao TT. Timing of caesarean section according to urgency. *Best Pract Res Clin Obstet Gynaecol* 2013;27:251-67.
24. Moroz L, DiNapoli M, D'Alton M, Gyamfi-Bannerman C. Surgical speed and risk for maternal operative morbidity in emergent repeat cesarean delivery. *Am J Obstet Gynecol* 2015;213:584 e1-6.
25. Kolås T, Hofoss D, Oian P. Predictions for the decision-to-delivery interval for emergency cesarean sections in Norway. *Acta Obstet Gynecol Scand* 2006;85:561-6.
26. Schneid-Kofman N, Sheiner E, Levy A, Holcberg G. Risk factors for wound infection following cesarean deliveries. *Int J Gynaecol Obstet* 2005;90:10-5.

27. Nasrallah FK, Harirah HM, Vadhera R, Jain V, Franklin LT, Hankins GD. The 30-minute decision-to-incision interval for emergency cesarean delivery: fact or fiction? *Am J Perinatol* 2004;21:63-8.
28. Magann EF, Evans S, Hutchinson M, Collins R, Lanneau G, Morrison JC. Postpartum hemorrhage after cesarean delivery: an analysis of risk factors. *South Med J* 2005;98:681-5.
29. Guglielminotti J, Li G. Exposure to General Anesthesia for Cesarean Delivery and Odds of Severe Postpartum Depression Requiring Hospitalization. *Anesth Analg* 2020;131:1421-9.
30. Andersen LB, Melvaer LB, Videbech P, Lamont RF, Joergensen JS. Risk factors for developing posttraumatic stress disorder following childbirth: a systematic review. *Acta Obstet Gynecol Scand* 2012;91:1261-72.
31. Robson MS. Classification of caesarean sections. *Fetal and Maternal Medicine Review* 2001;12:23-39.
32. Lucas DN. The 30 minute decision to delivery time is unrealistic in morbidly obese women. *Int J Obstet Anesth* 2010;19:431-5.
33. Lucas DN, Yentis SM, Kinsella SM, et al. Urgency of caesarean section: a new classification. *J R Soc Med* 2000;93:346-50.
34. NICE. Caesarean birth. 2021:48.
35. Pinas A, Chandrachan E. Continuous cardiotocography during labour: Analysis, classification and management. *Best Pract Res Clin Obstet Gynaecol* 2016;30:33-47.
36. Eden RD, Evans MI, Britt DW, Evans SM, Schifrin BS. Safely lowering the emergency Cesarean and operative vaginal delivery rates using the Fetal Reserve Index. *J Matern Fetal Neonatal Med* 2018:1-7.
37. Mooney SE, Ogrinc G, Steadman W. Improving emergency caesarean delivery response times at a rural community hospital. *Qual Saf Health Care* 2007;16:60-6.
38. Clark S, Belfort M, Saade G, et al. Implementation of a conservative checklist-based protocol for oxytocin administration: maternal and newborn outcomes. *Am J Obstet Gynecol* 2007;197:480 e1-5.

Disclosures: The authors have no disclosures

**NT**



*Barry Schifrin, M.D.,  
Western University of Health Sciences, Pomona, California  
Formerly, Professor of Obstetrics & Gynecology  
Keck School of Medicine, University of Southern California, Los Angeles*



*Wayne R. Cohen, M.D.  
Professor of Obstetrics and Gynecology  
University of Arizona College of Medicine  
Tucson, Arizona*

*Corresponding Author:*



*Maureen E. Sims, M.D.  
Professor of Pediatrics  
Geffen School of Medicine,  
University of California, Los Angeles  
Los Angeles, California  
email: [mes@g.ucla.edu](mailto:mes@g.ucla.edu)*

**Readers can also follow**  
**NEONATOLOGY TODAY**  
**via our Twitter Feed**  
**@NEOTODAY**

ONCE UPON A PREEMIE ACADEMY

# eLearning Courses

## Health and Racial Equity Continuing Education Courses

- + An Intro to Health and Racial Equity and Implicit Bias
- + Solutions for Addressing Inequities and Implicit Bias In the NICU
- + Black NICU Mother's Mental and Emotional Health
- + Black Premie Parents as Partners in Premie Care

**Register at**  
**OnceUponAPremieAcademy.com**

**\$150**

physicians

**\$175**

equity-focused  
solutions for  
healthcare  
professionals



The first and only virtual training academy focused on delivering health and racial equity educational programs for perinatal and neonatal healthcare professionals. Our purpose is to raise awareness and offer real-time solutions for addressing health and racial equity.

- + Earn Continuing Education Credits
- + Learn from nationally recognized perinatal and neonatal professionals and premie parents
- + Gain actionable tools to drive health and racial equity solutions in your organization!

## Bits & Bites

Rob Graham, R.R.T./N.R.C.P.

*I dedicate this column to the late Dr. Andrew (Andy) Shennan, the founder of the perinatal program at Women's College Hospital (now at Sunnybrook Health Sciences Centre). To my teacher, my mentor and the man I owe my career as it is to, thank you. You have earned your place where there are no hospitals and no NICUs, where all the babies do is laugh and giggle and sleep.*

***“A recent study on transpyloric versus gastric feeding found a significant difference in the number and severity of hypoxemic episodes in those infants receiving transpyloric feeds, but only if non-invasively ventilated.”***

It has been an exciting month between the Pediatric Academic Societies (PAS) annual meeting and posts from various neonatal groups. This month I share several things that have come across my proverbial desk, some of which relate to previous columns in Neonatology Today (NT).

A presentation at PAS showed a discrepancy between set and delivered pressures using the RAM® cannula interface. Delivered pressure was found to be lower than set pressure, the difference increasing with increasing set pressure. This confirms my findings in a bench study I shared in NT in October 2020 (1,2).

In April's edition of NT, I discussed non-invasive ventilation in the micro-premature and its relationship with the gastrointestinal system (3). A recent study on transpyloric versus gastric feeding found a significant difference in the number and severity of hypoxemic episodes in those infants receiving transpyloric feeds, but only if non-invasively ventilated. It is not stated whether this is related to decreased reflux, but it is a reasonable thought. While the study did not involve infants of less than 26 weeks post-menstrual age (PMA), it may hold promise in improving NIV outcomes in the sub-26-week PMA cohort (4).

March's NT column discussed dexmedetomidine use in the NICU. A PAS presentation showed improved respiratory stability in preterm infants receiving the drug, another plus for this relatively new pharmacological intervention (5).

Continuing with pharmacological interventions, an ultrasound assessment of diaphragmatic contractility indicates it increases with caffeine administration. We know this is true in the adult population, and this confirms similar results in the premature population (6).

***“An ultrasound assessment of diaphragmatic contractility indicates it increases with caffeine administration.”***

Nitric oxide (iNO) use in the premature population is controversial. Although Dr. Roberta Ballard showed a decrease in chronic lung disease with early administration of iNO (7), these results have not been replicated, and using iNO in the preterm population is not recommended (8). A recent study showed that infants in hypoxic respiratory failure who respond favourably to iNO have better outcomes (9). This debate is not over.

That smoking during pregnancy is a bad thing has been known for decades. An evaluation of lung function at five years of age showed a decrease in function in children whose mothers smoked during their gestation, and that risks are decreased with maternal vitamin C supplementation (10).

***“An evaluation of lung function at five years of age showed a decrease in function in children whose mothers smoked during their gestation, and that risks are decreased with maternal vitamin C supplementation”***

As the use of non-invasive ventilation (NIV) increases, the PMA of babies receiving it as a first-line mode of respiratory support has decreased. The likelihood of requiring surfactant administration increases with lower PMA, but many of these babies (particularly those >25 weeks PMA) will not require an endotracheal tube. While the "INSURE" method allows for first-line use of NIV, it still requires intubation and subjects the baby to potential pulmonary injury and the physiological effects of ETT placement. Using "less invasive" means of surfactant administration has increased dramatically, but laryngoscopy is required to pass a catheter through the vocal cords. The physiological effects of laryngoscopy are well known, particularly if no medications are

**NEONATOLOGY TODAY is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.**

**Please submit your manuscript to: [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)**

given to mitigate them, and a clinician with this skill is required. In the NICU, this is not usually a problem (we hope!), but this may not be the case in tertiary hospitals.

Using a laryngeal mask (LMA) for surfactant administration is effective in the patient population studied and does not require laryngoscopy (11). LMAs are relatively easy to insert; however, the smallest LMAs are too big for tiny babies. This may change. However, a group from India reported the successful use of a size 1 LMA on a 1335-gram former 28-week PGA baby for surgery (12).

When extubating babies to nasal CPAP or other NIV modes, we have been advised to use a CPAP level equal to the mean airway pressure (MAP) prior to extubation. A recent study indicates greater success using pressure 2-3 cm H<sub>2</sub>O higher than pre-extubation MAP (13). I suggest therefore re-evaluating what MAP is appropriate to extubate from since as NIV pressure increases, the difficulty in maintaining that pressure also increases.

---

***“ Blood loss due to testing in infants <28 weeks PMA is significant, equal to 24-30% of circulating blood volume ”***

---

Lastly, blood loss due to testing in infants <28 weeks PMA is significant, equal to 24-30% of circulating blood volume (14). Bloodwork is often done without considering the necessity, significantly contributing to the need for transfusions. Before transfusing, infants may be subject to an increased risk of anemia-related sequelae such as necrotizing enterocolitis (14).

For example, serial blood gases are often ordered "for metabolic reasons" on stable babies in room air or low CPAP and 21% oxygen. If metabolic acidosis is present, it will often resolve without treatment and trigger more blood gases "just to be sure." Casting a large net will catch a few fish and much nothing; the catch is not worth the effort.

I have treated many infants of Jehovah's Witness parents. Very little bloodwork is drawn on these babies (even when intubated) with no apparent detrimental effect. Non-invasive monitoring can usually be followed to guide ventilation without routine blood gases. When bloodwork is ordered, many tests can be run on the same sample. Coordination and communication between those asking for tests can reduce the number of pokes and the volume of blood taken, and clinicians should know the minimum amount of blood required for any tests.

---

***“When bloodwork is ordered, many tests can be run on the same sample. Coordination and communication between those asking for tests can reduce the number of pokes and the volume of blood taken, and clinicians should know the minimum amount of blood required for any tests.”***

---

May is Mother's Day month, and in northern regions heralds the return of flowers and greenery. I wish all the mothers out there a happy Mother's Day and urge everyone to stop occasionally and smell those flowers.

**References:**

1. Graham R. RAM® Pressures: What You See is Not What You Get. Neonatology Today [Internet]. 2020 Oct [cited 2023 Apr 5]. Available from: [https://neonatologytoday.org/Archive/PDF\\_paper/NeonatologyToday\\_2020\\_10\\_15\\_10\\_37\\_40.pdf](https://neonatologytoday.org/Archive/PDF_paper/NeonatologyToday_2020_10_15_10_37_40.pdf)
2. Miner, Lonnie MD, LDS Hospital, Intermountain Health, PAS presentation Apr 30, 2023: Comparison of Non-Invasive Interfaces for Neonatal Respiratory Support Using Bubble Continuous Positive Airway Pressure in an Artificial Model of a Neonatal Airway,.
3. [www.neonatologytoday.net](http://www.neonatologytoday.net) April 2023 p.74-80
4. Srivatsa B, Wesolowski A, Srivatsa KR, Bennett MM, Clark RH, Kupke KG. Transpyloric Feeding is Associated With Improved Oxygenation Compared With Gastric Feeding Among Nonintubated Extremely Low Birth Weight Infants. J Pediatr. 2023 Apr;255:175-180.e1. doi: 10.1016/j.jpeds.2022.11.025. Epub 2022 Dec 1. PMID: 36462688.
5. Sullivan, Brynne A., MD, MSCR, University of Virginia School of Medicine, PAS presentation April 28, 2023: Dexmedetomidine improves respiratory stability in critically ill preterm infants without cardiovascular compromise
6. Dani C, Fusco M, Manti S, Marseglia L, Ciarcià M, Leonardi V, Corsini I, Gitto E. Effects of caffeine on diaphragmatic activity in preterm infants. Pediatr Pulmonol. 2023 May 5. doi: 10.1002/ppul.26439. Epub ahead of print. PMID: 37144862.
7. Ballard RA, Truog WE, Cnaan A, Martin RJ, Ballard PL, Merrill JD, Walsh MC, Durand DJ, Mayock DE, Eichenwald EC, Null DR, Hudak ML, Puri AR, Golombok SG, Courtney SE, Stewart DL, Welty SE, Phibbs RH, Hibbs AM, Luan X, Wadlinger SR, Asselin JM, Coburn CE; NO CLD Study Group. Inhaled nitric oxide in preterm infants undergoing mechanical ventilation. N Engl J Med. 2006 Jul 27;355(4):343-53. doi: 10.1056/NEJMoa061088.
8. Askie LM, Ballard RA, Cutter GR, Dani C, Elbourne D, Field D, Hascoet JM, Hibbs AM, Kinsella JP, Mercier JC, Rich W, Schreiber MD, Wongsiridej PS, Subhedar NV, Van Meurs KP, Voysey M, Barrington K, Ehrenkranz RA, Finer NN; Meta-analysis of Preterm Patients on Inhaled Nitric Oxide Collaboration. Inhaled nitric oxide in preterm infants: an individual-patient data meta-analysis of randomized trials. Pediatrics. 2011 Oct;128(4):729-39. doi: 10.1542/peds.2010-2725. Epub 2011 Sep 19. PMID: 21930540; PMCID: PMC3387905.
9. Boly TJ, Dagle JM, Klein JM, Rios DR, McNamara PJ, Giesinger RE. Response categorization and outcomes in extremely premature infants born at 22-26 weeks gestation that received inhaled nitric oxide for hypoxic respiratory failure. J Perinatol. 2023 Mar;43(3):324-331. doi: 10.1038/s41372-022-01582-4. Epub 2022 Dec 12. PMID: 36509816; PMCID: PMC10173872.
10. McEvoy CT, et al. JAMA Pediatrics, 2023 ; 177 : 16-24

11. Zapata HA, Fort P, Roberts KD, Kaluarachchi DC, Guthrie SO. Surfactant Administration Through Laryngeal or Supraglottic Airways (SALSA): A Viable Method for Low-Income and Middle-Income Countries. *Front Pediatr.* 2022;10:853831. doi:10.3389/fped.2022.853831
12. Velankar P, Joshi M, Sahu P. Use of laryngeal mask airway in premature infant. *Indian J Anaesth.* 2013 Nov;57(6):634-5. doi: 10.4103/0019-5049.123354. PMID: 24403639; PMCID: PMC3883414./
13. Khalid L, Al-Balushi S, Manoj N, Rather S, Johnson H, Strauss L, Dutta S, Mukerji A. Toward Optimal High Continuous Positive Airway Pressure as Postextubation Support in Preterm Neonates: A Retrospective Cohort Study. *Am J Perinatol.* 2022 Oct 1. doi: 10.1055/a-1925-8643. Epub ahead of print. PMID: 35977710./
14. Narvey M, Khashu M. It is high time we reduce “routine” blood work in neonatal units. *Front Pediatr.* 2023;11:1147512. doi:10.3389/fped.2023.1147512

*Disclosures: The author receives compensation from Bunnell Inc for teaching and training users of the LifePulse HFJV in Canada. He is not involved in sales or marketing of the device nor does he receive more than per diem compensation. Also, while the author practices within Sunnybrook H.S.C. This paper should not be construed as Sunnybrook policy per se. This article contains elements considered “off label” as well as maneuvers, which may sometimes be very effective but come with inherent risks. As with any therapy, the risk benefit ratio must be carefully considered before they are initiated.*

**NT**

## TAKE THE NECESSARY STEPS TO ELIMINATE INEQUITIES



ONCEUPONAPREEMIEACADEMY.COM

©2020 BY ONCE UPON A PREEMIE ACADEMY.

Corresponding Author



Rob Graham, R.R.T./N.R.C.P.  
Advanced Practice Neonatal RRT  
Sunnybrook Health Science Centre  
43 Wellesley St. East  
Toronto, ON  
Canada M4Y 1H1  
Email: [rcgnrcp57@yahoo.ca](mailto:rcgnrcp57@yahoo.ca)  
Telephone: 416-967-8500



Readers can also follow

**NEONATOLOGY TODAY**

via our Twitter Feed

@NEOTODAY



Perinatal Advisory Council:  
Leadership, Advocacy and Consultation

### CONTINUING MEDICAL EDUCATION

The Continuing Education Department at PAC/LAC is pleased to consider requests to be a joint provider of your CME activity. PAC/LAC is actively involved in direct and joint-providership of multiple continuing education activities and programs and works with our partners to ensure the highest standards of content and design. PAC/LAC is the recipient of the 2018 Cultural & Linguistic Competency Award. This award recognizes a CME provider that exemplifies the goal of integrating cultural and linguistic competency into overall program and individual activities and/or a physician who provides leadership, mentorship, vision, and commitment to reducing health care disparities

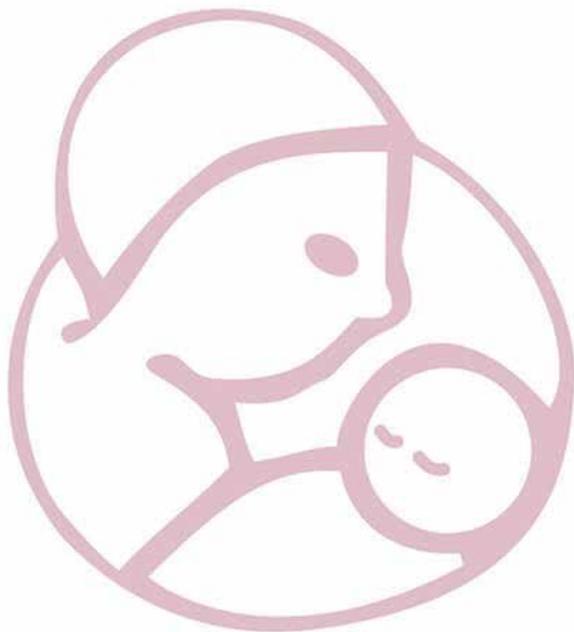
PAC/LAC is an accredited provider of continuing education by Accreditation Council for Continuing Medical Education / Institute for Medical Quality, the California Board of Registered Nursing, the California Association of Marriage and Family Therapists, the National Commission for Health Education Credentialing, and the American Association for Respiratory Care.

To inquire about Continuing Education Joint-Providership opportunities for your event please visit our website and complete the online request form.

PAC/LAC offers continuing education for:

- Continuing Medical Education (CME)
- California Registered Nurses (CEU)
- Licensed Clinical Social Workers (LCSW)
- Licensed Marriage and Family Therapists (LMFT)
- Licensed Professional Clinical Counselors (LPCC)
- Licensed Educational Psychologists (LEP)
- Certified Health Education Specialists (CHES)
- Continuing Respiratory Care Education (CRCE)

[www.paclac.org](http://www.paclac.org)



**PAC/LAC's core values** for improving maternal and child health have remained constant for over 30 years – a promise to lead, advocate and consult with others.

#### Leadership

Providing guidance to healthcare professionals, hospitals and healthcare systems, stimulating higher levels of excellence and improving outcomes for mothers and babies.

#### Advocacy

Providing a voice for healthcare professionals and healthcare systems to improve public policy and state legislation on issues that impact the maternal, child and adolescent population.

#### Consultation

Providing and promoting dialogue among healthcare professionals with the expectation of shared excellence in the systems that care for women and children.

**NEONATOLOGY TODAY** is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)



Thirteen-year-old Emily Rose Shane was tragically murdered on April 3, 2010 on Pacific Coast Highway in Malibu, CA. Our foundation exists to honor her memory.

# In Loving Memory

August 9, 1996 - April 3, 2010



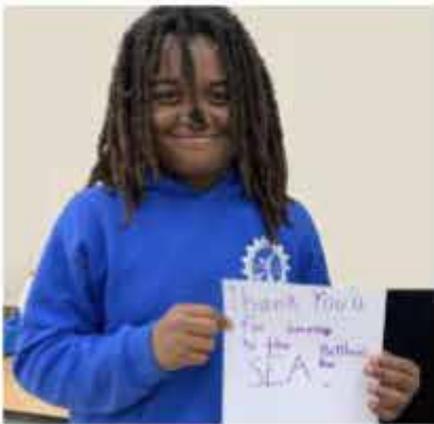
Each year, the Emily Shane Foundation SEA(Successful Educational Achievement) Program provides academic and mentoring support to over 100 disadvantaged middle school students who risk failure and have no other recourse. We have served over 700 children across Los Angeles since our inception in the spring of 2012. Due to the COVID-19 outbreak, our work is in jeopardy, and the need for our work is greatly increased. The media has highlighted the dire impact online learning has caused for the very population we serve; those less fortunate. **We need your help now more than ever to ensure another child is not left behind.**

Make a Difference in the Life of a Student in Need Today!

Please visit [emilyshane.org](http://emilyshane.org)

## Sponsor a Child in the SEA Program

The average cost for the program to provide a mentor/ tutor for one child is listed below.



1 session_____	\$15
1 week _____	\$30
1 month_____	\$120
1 semester_____	\$540
1 year_____	\$1,080
Middle School_____	\$3,240

The Emily Shane Foundation is a 501(c)3 nonprofit charity, Tax id # 27-3789582. Our flagship SEA (Successful Educational Achievement) program is a unique educational initiative that provides essential mentoring/tutoring to disadvantaged middle school children across Los Angeles and Ventura counties. All proceeds directly fund the SEA Program, making a difference in the lives of the students we serve.

# The Village Son



## A Life's Journey

Iranian village to a university professor in the United States of America in this memoir. As a boy, his unruly behavior was sedated by scholastic challenges as a remedy. At age twelve, he left home for junior high school in a provincial capital. At first, a lack of self-esteem led him to stumble, but he soon found the courage to tackle his subjects with vigor. He became more curious about the world around him and began to yearn for a new life despite his financial limitations. Against all odds, he became one of the top students in Iran and earned a scholarship to study medicine in Europe. Even though he was culturally and socially naïve by European standards, an Italian family in Rome helped him thrive. The author never shied away from the challenges of learning Italian, and the generosity of Italy and its people became part and parcel of his formative years. By the time he left for the United States of America, he knew he could accomplish whatever he imagined.

Houchang D. Modanlou

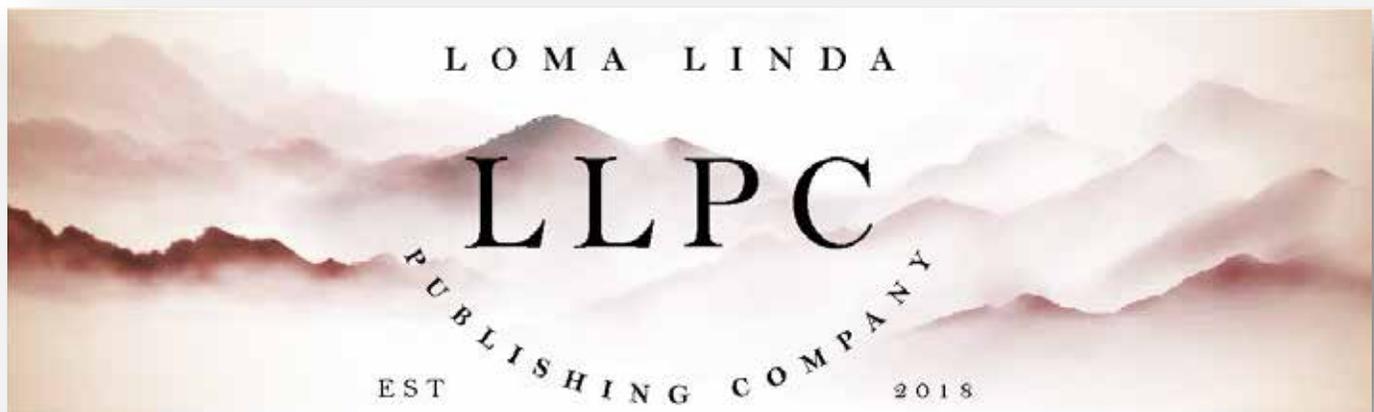
Paperback  
USD 24.99

# There's new information and rulings on safe sleep. Are you ready to speak with your patients?



Bring First Candle's Straight Talk for Infant Safe Sleep program to your hospital so that everyone is up to date on the latest information from the AAP on safe sleep and the CPSC on safe products.

For more information contact Barb Himes  
at [barb@firstcandle.org](mailto:barb@firstcandle.org)



National Network  
of NICU  
Psychologists

[www.nationalperinatal.org/psychologists](http://www.nationalperinatal.org/psychologists)

COVID-19

## FREE RESOURCES for your NICU

- Helping Children and Families Cope
- Bonding with Your Baby
- Caregivers Need Care Too



## Postpartum Revolution

@ANGELINASPICER



Readers can also follow

**NEONATOLOGY TODAY**

via our Twitter Feed

@NEOTODAY

### Neonatology Today's Digital Presence

Neonatology Today's now has a digital presence. The site is operational now and defines the future look of our digital web presence. By clicking on this <https://www.neonatologytoday.org/web/>, researchers can download individual manuscripts both in digital format and as part of the original PDF (print journal). While the PDF version of Neonatology Today will continue in its present form, we envision that the entire website will be migrated to this format in the next several months. We encourage you to take a look, "kick the wheels," and let us know where we still need to improve.. We are working towards making the website more functional for subscribers, reviewers, authors and anyone else. Although we have not yet applied for inclusion in the National Library of Medicine Database (Pub-Med), this new format meets several of the important metrics for this ultimate goal. As of December, 2020, NT has its own account with Cross-Ref and will assign DOI to all published material.

As we indicated last month, we look forward to a number of new features as well.

1. An online submission portal: Submitting a manuscript online will be easier than before. Rather than submitting by email, we will have a devoted online submission portal that will have the ability to handle any size manuscript and any number of graphics and other support files. We will have an online tracking system that will make it easier to track manuscripts in terms of where they are in the review process.
2. Reviewers will be able to review the manuscript online. This portal will shorten the time from receipt of review to getting feedback to the submitting authors.
3. An archive search will be available for journals older than 2012.
4. A new section called news and views will enable the submission of commentary on publications from other journals or news sources. We anticipate that this will be available as soon as the site completes the beta phase
5. Sponsors will be able to sign up directly on the website and submit content for both the digital and PDF issues of Neonatology Today.

Neonatology Today will continue to promote our Academic True Open Model (ATOM), never a charge to publish and never a charge to subscribe.

If there are any questions about the new website, please email Dr. Chou directly at:

[fu-sheng.chou@neonatologytoday.net](mailto:fu-sheng.chou@neonatologytoday.net)

# Summit Highlights Scope of Research and Activities to Cut Sudden Unexplained Infant Death

Alison Jacobson



Saving babies. Supporting families.

**First Candle's efforts to support families during their most difficult times and provide new answers to help other families avoid the tragedy of the loss of their baby are without parallel.**

***"...Seattle Children's and Microsoft SIDS Research Summit, which has emerged as an opportunity for researchers, data scientists, medical, health, and social service professionals worldwide to convene and share latest findings as well as emerging and successful practices."***

During the last week of April, I had the opportunity to participate and present at the 6th Seattle Children's and Microsoft SIDS Research Summit, which has emerged as an opportunity for researchers, data scientists, medical, health, and social service professionals worldwide to convene and share latest findings as well as emerging and successful practices.

The Summit is the outgrowth of a SIDS death; following the 2004 loss of his son a few days after he was born, John Kahan, Vice President, Chief Data Analytics Officer at Microsoft, helped raise more than \$200,000 over a two year-period for SIDS research at Seattle Children's Research Institute. Kahan went on to found the Aaron Matthew SIDS Research Guild of Seattle Children's. Microsoft and Seattle Children's co-host the annual event.

***"...the necessity of infant death investigations to carefully and thoroughly uncover the factors that could have contributed to a sleep-related death, being aware of how socio-economic challenges and structural racism can frame the circumstances."***

Microsoft has also donated a research tool and cloud platform to Seattle Children's that enables raw data on infant births and sudden deaths from the Centers for Disease Control and Prevention to be analyzed for correlations.

Research presented at the conference indicates an ongoing exploration into brainstem function, genetics, and the role of serotonin, as well as whether there could be a link between SIDS and the diaphragm.

Dr. Rachel Moon of the University of Virginia School of Medicine, and lead author of the American Academy of Pediatrics Task Force's 2022 updated recommendations on infant safe sleep, discussed the Study of Attitudes and Factors Effecting PREterm infant care Practices (SAFE PREP), an NICHD-funded project to examine the prevalence of adherence to AAP recommended infant care practices and reductions in Sudden Unexplained Infant Death (SUID). The results of this study will be published in the near future.

Kindra Ahmann of the Pierce County Health Department told of the necessity of infant death investigations to carefully and thoroughly uncover the factors that could have contributed to a sleep-related death, being aware of how socio-economic challenges and structural racism can frame the circumstances.



**Did you know that premature and low birth weight babies have a 4x greater risk for SIDS?**

**At First Candle we're educating parents, grandparents and caregivers about safer sleep to make sure all babies reach their first birthday. Learn more at [firstcandle.org](http://firstcandle.org)**

With regard to products, Dr. Fern Hauck of the University of Virginia School of Medicine and Dr. Marisa Abbe of Children's Health System of Texas reviewed the PepiPod®, (1) a baby basket modeled on the Māori wahakura, which is being used increasingly in New Zealand as part of a campaign to reduce the overall SUID rate 86 percent by 2025, a reduction from 44 to six deaths per year.

---

***“This led to a discussion regarding the banning by the U.S. Consumer Products Safety Commission of in-bed sleepers that do not meet its safety criteria and the concern that this will have dangerous consequences when parents continue to bed share intentionally or accidentally when they fall asleep ”***

---

This led to a discussion regarding the banning by the U.S. Consumer Products Safety Commission of in-bed sleepers that do not meet its safety criteria and the concern that this will have dangerous consequences when parents continue to bed share intentionally or accidentally when they fall asleep.

First Candle's presentation was an overview of our community-led initiative, Let's Talk Community Chats and our commitment to addressing the role of structural racism in the disparate rates of infant mortality among Black infants. (2) While many of the presenters discussed the global concern about the stagnant rate of SUID here in the U.S., few acknowledged the widening maternal and infant mortality gap among Black families.

---

***“First Candle's presentation was an overview of our community-led initiative, Let's Talk Community Chats and our commitment to addressing the role of structural racism in the disparate rates of infant mortality among Black infants.”***

---

As worthwhile as the Summit was, we believe every health conference must have community members, public health providers, doulas, caregivers, and non-profit organizations who can lift up the voices of their families and detail their lived experiences. While medical research is necessary, we must ensure that the family is centered.

Representation in research matters. The context of the questions asked matters.

References:

1. <https://www.rnz.co.nz/news/te-manu-korihī/332959/govt-to-fund-pepi-pods-for-every-family-that-needs-it>

2. <https://firstcandle.org/lets-talk-community-chats/>

**Disclosure:** *The author is the Executive Director and Chief Executive Officer of First Candle, a Connecticut-based not-for-profit 501(c)3 corporation.*

**NT**

Corresponding Author



Alison Jacobson  
Executive Director  
Chief Executive Officer  
First Candle  
21 Locust Avenue, Suite 2B  
New Canaan, CT 06840  
Telephone: 1-203-966-1300  
For Grief Support: 1-800-221-7437  
Email: [Alison@firstcandle.org](mailto:Alison@firstcandle.org)  
[www.firstcandle.org](http://www.firstcandle.org)

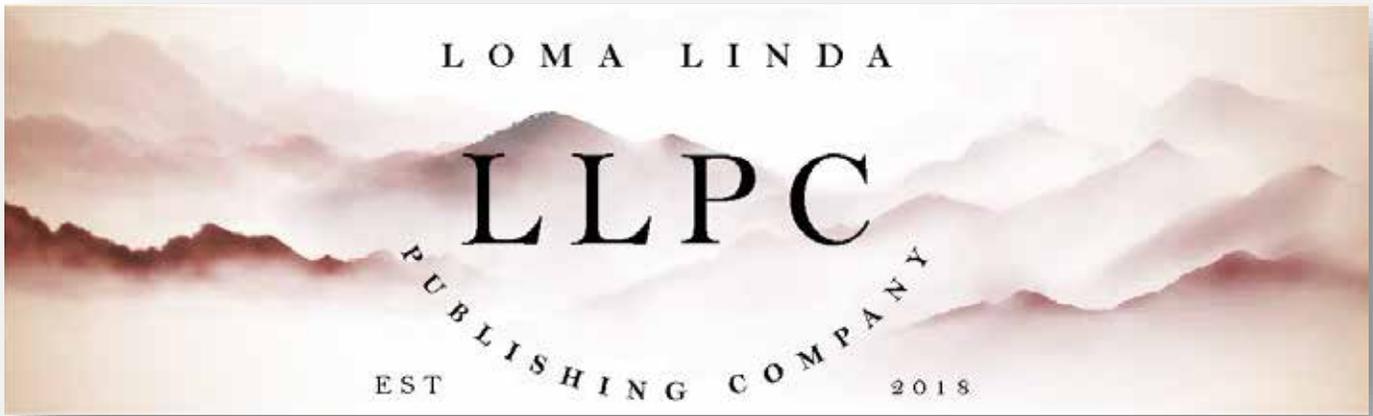
#### About First Candle

First Candle, based in New Canaan, CT, is a 501c (3) committed to eliminating Sudden Unexpected Infant Death while providing bereavement support for families who have suffered a loss. Sudden Unexpected Infant Death (SUID), which includes SIDS and Accidental Suffocation and Strangulation in Bed (ASSB), remains the leading cause of death for babies one month to one year of age, resulting in 3,500 infant deaths nationwide per year.

**New subscribers are always welcome!**

**NEONATOLOGY TODAY**

**To sign up for a free monthly subscription,  
just click on this box to go directly to our  
subscription page**



Supporting NICU Staff so they can support families



Providing online education that is...

- Story-Driven
- Trauma-Informed
- Evidence-Based



The preeminent provider of compelling perinatal education on psychosocial support created through interprofessional collaboration

[www.mynicunetwork.org](http://www.mynicunetwork.org)



The only worldwide monthly publication exclusively serving Pediatric and Adult Cardiologists that focus on Congenital/ Structural Heart Disease (CHD), and Cardiothoracic Surgeons.



**Subscribe Electronically**  
Free on the Home Page

[www.CongenitalCardiologyToday.com](http://www.CongenitalCardiologyToday.com)

# COPING WITH COVID-19

KEEP PATIENTS UP-TO-DATE WITH CHANGES IN POLICIES SO THEY KNOW WHAT TO EXPECT. LISTEN TO THEIR CONCERNS.



Provide culturally-informed and respectful care.

TELL PARENTS HOW YOU WILL KEEP THEM AND THEIR BABIES SAFE DURING THEIR NICU STAY.



Use technology like video chat apps to include family members who can't visit the NICU.

[myNICUnetwork.org](http://myNICUnetwork.org)



National Perinatal Association  
NICU Parent Network

My Perinatal Network and My NICU Network are products of a collaboration between NPA and NPN.

## TOP 10

### RECOMMENDATIONS FOR THE PSYCHOSOCIAL SUPPORT OF NICU PARENTS



Essential evidence-based practices that can transform the health and well being of NICU families and staff

based on the National Perinatal Association's Interdisciplinary Recommendations for Psychosocial Support of NICU Parents

#### 1 PROMOTE PARTICIPATION

Honor parents' role as primary caregiver. Actively welcome parents to participate during rounds and shift changes. Remove any barriers to 24/7 parental involvement and avoid unnecessary separation of parents from their infants.



#### 2 LEAD IN DEVELOPMENTAL CARE

Teach parents how to read their baby's cues. Harness your staff's knowledge, skills, and experience to mentor families in the principles of neuroprotection & developmental care and to promote attachment.



#### 3 FACILITATE PEER SUPPORT

Invest in your own NICU Parent Support program with dedicated staff. Involve veteran NICU parents. Partner with established parent-to-parent support organizations in your community to provide continuity of care.



#### 4 ADDRESS MENTAL HEALTH

Prioritize mental health by building a team of social workers and psychologists who are available to meet with and support families. Provide appropriate therapeutic interventions. Consult with staff on trauma-informed care - as well as the critical importance of self-care.



#### 5 SCREEN EARLY AND OFTEN

Establish trusting and therapeutic relationships with parents by meeting with them within 72 hours of admission. Follow up during the first week with a screening for common maternal & paternal risk factors. Provide anticipatory guidance that can help normalize NICU distress and timely interventions when needed. Re-screen prior to discharge.



#### 6 OFFER PALLIATIVE & BEREAVEMENT CARE

Support families and NICU staff as they grieve. Stay current with best practices in palliative care and bereavement support. Build relationships with service providers in your community.

#### 7 PLAN FOR THE TRANSITION HOME

Set families up for success by providing comprehensive pre-discharge education and support. Create an expert NICU discharge team that works with parents to find specialists, connect with service providers, schedule follow-up appointments, order necessary medical supplies, and fill Rx.



#### 8 FOLLOW UP

Re-connect with families post-discharge. Make follow-up calls. Facilitate in-home visits with community-based service providers, including Early Intervention. Partner with professionals and paraprofessionals who can screen families for emotional distress and provide timely therapeutic interventions and supports.

#### 9 SUPPORT NICU CARE GIVERS

Provide comprehensive staff education and support on how to best meet families' psychosocial needs, as well as their own. Acknowledge and address feelings that lead to "burnout."



#### 10 HELP US HEAL

Welcome the pastoral care team into your NICU to serve families & staff.

[SUPPORT4NICUPARENTS.ORG](http://SUPPORT4NICUPARENTS.ORG)

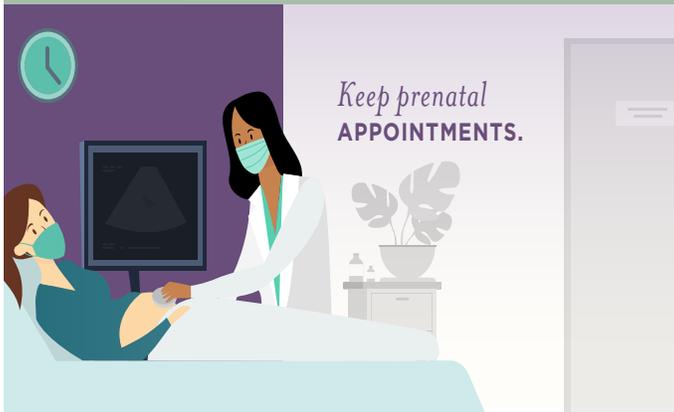
## The PREGNANT MOM'S Guide To Staying SAFE DURING COVID-19



Maintain at least A 30-DAY SUPPLY OF YOUR MEDICATIONS.



Keep prenatal APPOINTMENTS.



Talk to your health care provider about STAYING SAFE DURING COVID-19.

LEARN MORE >

**NCJIH** National Coalition for Infant Health  
Protecting Access for Premature Infants through Age Two

## SUPPORTING KANGAROO CARE

SKIN-TO-SKIN CARE DURING COVID-19



GET INFORMED ABOUT THE RISKS + BENEFITS

work with your medical team to create a plan

GET CLEAN WASH YOUR HANDS, ARMS, and CHEST

with soap and water for 20+ seconds. Dry well.



PUT ON FRESH CLOTHES

change into a clean gown or shirt.



IF COVID-19 + WEAR A MASK

and ask others to hold your baby when you can't be there



**National Perinatal Association**

[nicuparentnetwork.org](http://nicuparentnetwork.org)  
[nationalperinatal.org/skin-to-skin](http://nationalperinatal.org/skin-to-skin)

**NPN**  
NICU PARENT NETWORK

New subscribers are always welcome!

## NEONATOLOGY TODAY

To sign up for a free monthly subscription, just click on this box to go directly to our subscription page



Position available for Neonatal Nurse Practitioner (NNP)

Excellent practice opportunity for a NNP in an established Los Angeles neonatal practice. The Neonatal Hospitalist Group (NHG) is interviewing for an NNP to join the practice. The practice includes four NICU's in the Burbank and Glendale area. Call is from home with excellent work life balance. If you are interested, please email Robert Gall, MD, at [robertgallmd@gmail.com](mailto:robertgallmd@gmail.com).

Readers can also follow

## NEONATOLOGY TODAY

via our Twitter Feed

@NEOTODAY

# Protecting your baby from Respiratory Viruses:

## What parents need to know this RSV and flu season



RSV (Respiratory Syncytial Virus) and flu infections affect the lungs and can cause serious breathing problems for children and babies.

Certain diagnoses can make children and babies more vulnerable for serious complications - including prematurity, chronic lung disease, heart conditions.



You can limit the spread of viruses by wearing a mask, washing your hands with soap & water, and using alcohol-based hand sanitizer.

The fewer germs your baby is exposed to, the less likely they are to get sick. Limit visitors. Avoid crowds. Stay away from sick people.



Immunizations save lives. Stay up-to-date with your family's flu and COVID-19 vaccinations. This helps stop the spread of deadly viruses.

Babies older than 6 months can get a flu shot. There is no vaccine for RSV, but monthly antibody shots during RSV season can help protect them.



[www.nationalperinatal.org/rsv](http://www.nationalperinatal.org/rsv)

# eLearning Courses

Health and Racial in the NICU

## Meet Our Faculty



+ Jenné Johns, MPH  
Once Upon A Premie Academy



+ Deidre McDaniel, MSW, LCSW  
Health Equity Resources and Strategies



+ Dawn Godbolt, Ph.D.  
National Birth Equity Collaborative



+ Dalia Feltman, MD, MA, FAAP  
Univ. of Chicago Pritzker School of Medicine



+ Chavis A. Patterson, Ph.D.  
Children's Hospital of Philadelphia



+ Terri Major- Kincade, MD, MPH  
Pediatrician and Neonatologist



+ Shanté Nixon  
Connect2NICU



+ Ashley Randolph  
Glo Premies



**REGISTER TODAY**

[OnceUponAPremieAcademy.com](https://OnceUponAPremieAcademy.com)

## Health and Racial Equity + On-Demand Continuing Education

The first and only virtual training academy focused on delivering health and racial equity educational programs for perinatal and neonatal healthcare professionals. Our purpose is to raise awareness and offer real-time solutions for addressing health and racial equity.

# Raising Global Awareness of RSV

Global awareness about respiratory syncytial virus (RSV) is lacking. RSV is a relatively unknown virus that causes respiratory tract infections. It is currently the second leading cause of death – after malaria – during infancy in low- and middle-income countries.

The RSV Research Group from professor Louis Bont, pediatric infectious disease specialist in the University Medical Centre Utrecht, the Netherlands, has recently launched an RSV Mortality Awareness Campaign during the 5<sup>th</sup> RSV Vaccines for the World Conference in Accra, Ghana.

They have produced a personal video entitled “*Why we should all know about RSV*” about Simone van Wyck, a mother who lost her son due to RSV. The video is available at [www.rsvgold.com/awareness](http://www.rsvgold.com/awareness) and can also be watched using the QR code on this page. Please share the video with your colleagues, family, and friends to help raise awareness about this global health problem.





# *8th World Congress of Pediatric Cardiology and Cardiac Surgery*

AUGUST 27 – SEPTEMBER 1, 2023 | WASHINGTON D.C.

## Program Guide



[www.WCPCS2023.org](http://www.WCPCS2023.org)



# 8th World Congress of Pediatric Cardiology and Cardiac Surgery

AUGUST 27 – SEPTEMBER 1, 2023 | WASHINGTON D.C.

In 2023, for the first time ever, the World Congress of Pediatric Cardiology and Cardiac Surgery will be held in the continental United States of America. The 2023 WCPCCS promises to be the most comprehensive, up-to-date and technologically advanced meeting ever designed for Pediatric and Congenital Heart Disease.



---

## SUBSPECIALTY TRACKS

---

Cardiac Surgery • Ambulatory Cardiology • Cardiac Catheterization • Multimodal Imaging • Cardiovascular Nursing • Rheumatic Heart Disease  
Adult Congenital Heart Disease • Advocacy • Cardiac Intensive Care • Cardiovascular Disease in the Neonate • Cardiac Anesthesia • Neurodevelopment  
Heart Failure and Transplantation • Echocardiography • Administration & Leadership • Basic and Translational Science • Pulmonary Hypertension  
Global Cardiac Health • Electrophysiology • Quality Improvement • Fetal Cardiology • Special Sessions for Trainees and Junior Faculty  
Big Data, New Technology & Artificial Intelligence • Cardiopulmonary Bypass, ECMO & Mechanical Circulatory Support

---

## EXECUTIVE COMMITTEE

---

**Gil Wernovsky, MD & Jeffrey P. Jacobs, MD**  
Co-Chairs, 8th World Congress  
of Pediatric Cardiology and Cardiac Surgery

**Mitchell I. Cohen, MD**  
Chair, Scientific Committee

**David S. Cooper, MD, MPH**  
Chair, Institutional, Societal,  
and Industry Relations Committee

**Kathryn M. Dodds, MSN, CPNP**  
Chair, Nursing &  
Interdisciplinary Committees

---

Join our mailing list at  
**[WCPCCS2023.org](https://www.wcpccs2023.org)**



Connect and learn  
**[#WCPCCS2023](https://twitter.com/WCPCCS2023)**



## Table of Contents

<b>Introduction . . . . .</b>	<b>104</b>	<b>Main Program . . . . .</b>	<b>133</b>
<b>Two-Day Academies –</b>		Monday, August 28, 2023 . . . . .	134
<b>August 26–27, 2023 . . . . .</b>	<b>109</b>	Tuesday, August 29, 2023 . . . . .	146
Mobassaleh Symposium: Sudden Cardiac Death		Wednesday, August 30, 2023 . . . . .	158
in the Young . . . . .	110	Thursday, August 31, 2023. . . . .	167
CHD Nursing Academy. . . . .	112	Friday, September 1, 2023 . . . . .	174
Pediatric Cardiology for the Primary Care		<b>Invited Faculty. . . . .</b>	<b>176</b>
Practitioner. . . . .	114	<b>Why a Global Initiative? . . . . .</b>	<b>186</b>
Grown-Up Pediatric Heart Disease for the Adult		<b>Leadership and Organizing Team . . . . .</b>	<b>190</b>
Cardiologist . . . . .	116	<b>Scientific Committee. . . . .</b>	<b>199</b>
International PDA Symposium 2023 . . . . .	118	<b>Abstracts . . . . .</b>	<b>204</b>
<b>Pre-Conferences. . . . .</b>	<b>120</b>	<b>Special Features: Anatomy and</b>	
Nomenclature and Cardiac Networks United . . . . .	121	<b>Technology Center of the Future. . . . .</b>	<b>205</b>
World Society for Pediatric and Congenital		Multi-dimensional Anatomy Lab. . . . .	207
Heart Surgery . . . . .	122	Digital Futures Technology Hub . . . . .	208
3DI3. . . . .	123	<b>Communications and Marketing Team. . . . .</b>	<b>210</b>
Neonatal Heart Society . . . . .	124	<b>Relations Committee. . . . .</b>	<b>213</b>
Pediatric Cardiac Intensive Care Society . . . . .	125	<b>Institutional, Societal and</b>	
Pedirhythm <sup>x</sup> . . . . .	126	<b>Industry Relations Committee . . . . .</b>	<b>214</b>
ISACHD. . . . .	127		
CNOC. . . . .	128		
PHTS . . . . .	129		
American Society of Echocardiography . . . . .	130		
Fetal Heart Society . . . . .	131		
Children’s Heart Link. . . . .	132		



# Introduction



## Invest a Week in Your Career. The Results Will Last a Lifetime.

Worldwide, there are hundreds of societal and educational organizational meetings annually which provide education, research, and advocacy regarding pediatric and congenital heart disease. These meetings are typically selective in scope and goal, are regional, country or pathology specific, and if on an international platform, solely focused on a very limited agenda of pathologies discussed. The World Congress of Pediatric Cardiology and Cardiac Surgery (WCCPCS) on the other hand, is the only global meeting which encompasses the broadest clinical format, with top experts from around the world and thought leaders from individual national and international societies, who come together only every 4 years to share the newest and most ground-breaking techniques, technologies, and advanced medical innovations.

The World Congress of Pediatric Cardiology and Cardiac Surgery (WCPCCS) is an international meeting, designed with the primary objective of promoting the sharing of ideas to improve cardiac care for children across the globe. The WCPCCS is the most comprehensive global meeting to advance the care of children and young adults with pediatric and congenital cardiovascular disease.

The 8th WCPCCS will bring together thousands of physicians, nurses, scientists, the medical industry, administrative stakeholders, and technology leaders from around the globe to collaborate and develop innovative and sustainable models of care for children and young adults with congenital and acquired heart disease.

Separate pediatric cardiology (est. 1980) and cardiac surgery (est. 1989) meetings were combined to form the current collaborative structure in 1993. Dr. Gil Wernovsky, a pediatric cardiologist and cardiac intensivist in Washington DC and Dr. Jeffrey Jacobs, a cardiovascular surgeon in Florida first had the vision to bring this historic meeting to the USA in 2009. In 2015, after six years of extensive research and planning, and competing against seven other countries, the International Steering Committee awarded the bid to host the 8th WCPCCS to the USA. This historic meeting, held every four years and considered the “Olympics of Our Field,” will occur in our nation’s capitol, Washington DC August 27th – September 1st, 2023. A more detailed history of the WCPCCS may be found at [www.wcpccs2023.org](http://www.wcpccs2023.org) This meeting represents the hard work and planning of our entire team for over 14 years, including a 2-year postponement due to the COVID pandemic.



See [www.wcpccs2023.org](http://www.wcpccs2023.org) for more information, registration, hotel reservations and abstract submission details.



The excitement and anticipation from colleagues in our field is palpable. As of May 5th, 2023, we have received abstract submissions of new science from 60 countries outside of the USA. Faculty have been chosen from 76 countries around the globe to share important international perspectives.

Perhaps the most important principle of our meeting (borrowed from the National Pediatric Cardiology Quality Improvement Collaborative) is that “Everybody teaches, everybody learns”. From the beginning of this initiative, we have not wavered from our mission, vision, and core values:

Vision: To improve the global standard for pediatric and congenital cardiac care.

Mission: To organize the most comprehensive, technologically sophisticated, scientific forum ever convened for this patient population and their caregivers, in order to improve the duration and quality of life for neonates, infants, children, and adults with pediatric and congenital cardiovascular disease.

## Core Values

- Economic, Ethnic, Gender and Geographic Diversity
- Advocacy for Patients and Families Across the Globe, at the Educational, Institutional, Governmental, and Economic Levels
- Training the Next Generation of Health Care Providers
- Seamless Sharing of Best Practices
- Interdisciplinary Collaboration
- Inter-Institutional Collaboration
- International Collaboration



See [www.wcpccs2023.org](http://www.wcpccs2023.org) for more information, registration, hotel reservations and abstract submission details.



## Goals

- To create the most technologically advanced, state-of-the-art World Congress to date, featuring a Scientific Program that is unique and unparalleled.
- To bring together non-governmental organizations and patient/family advocacy groups in a “Global Village” to share best practices and develop strategies for improved and sustainable access to patient care in low- and middle-income countries.
- To use the scientific presentations to create “Enduring Materials,” providing up-to-date online education for caregivers in low- and middle-income countries.

## Special Features

- 16 International Societies and Postgraduate Courses have cancelled their annual meetings and partnered with the WCPCCS, embedding their scientific content to create the largest meeting of its kind, indeed the WCPCCS represents 16 meetings in one!
- Five Highly focused 2-day “Academies” and 14 1-day “Pre-Conferences” for important, highly specialized topics prior to the meeting.
- A Multi-Dimensional Anatomy Lab (first of its kind, see below) integrating historical pathologic heart specimens, traditional angiography, echo and cross-sectional imaging, newer approaches to 3D printing, surgery and/or catheter intervention planning, as well as state-of-the-art virtual and augmented reality.
- Digital Futures and Technology (first of its kind, see below) featuring hands-on sessions with academic centers and tech industry partners. There will be scheduled demonstrations and presentations from global experts in artificial intelligence, machine learning, augmented, virtual and extended reality, applied visual effects, and gamification/simulation.
- Showcasing new technology and medical therapies in a large, multidisciplinary exhibit hall (350,000 square feet)
- Convening work groups of international experts to develop Consensus Statements and White Papers to address start-up and sustainability of pediatric cardiovascular programs in the developing world, as well as up to date (2023) workforce needs assessments for all subspecialties present.
- Creation of a “Global Cardiac Health and Advocacy Village” in the Exhibit Hall, featuring representatives of patient and family advocacy groups and other grass roots organizations, as well as foundations that provide clinical care at no cost to patients and their families (“Mission Trips”).
- An “Abstract Competition” where the best abstracts of 17 different scientific tracks are presented to the large global audience, where using audience response technology, the delegates will vote for the “Best Abstract of the World Congress”



See [www.wcpccs2023.org](http://www.wcpccs2023.org) for more information, registration, hotel reservations and abstract submission details.



## Conference Logistics

### Registration Fees, Hotel Accommodations and Other Logistics

Careful consideration and attention have been paid by the executive committee to the concerns of delegates regarding the cost to attend the 2023 WCPCCS congress. We consider this week-long convention separate and apart from the more typical 2–3 day meetings of national or international scientific societies. Indeed, this is the most comprehensive meeting in our field, of 5-7 days duration; this is an investment in one's career rather than a short couple of days away from work. Importantly, compared to prior World Congresses in Barcelona (2017), Cape Town (2013) and Cairns (2009), the cost of 2023 WCPCCS is unchanged per credit hour (adjusted for inflation). In addition, significantly reduced registration fees are available for attendees from low- and middle-income countries as defined by the World Bank. We have made a special goal to aid individuals in need of financial assistance or who seek lower-cost alternatives in housing, registration costs and other ancillary expenses during the congress.

- **Food** – During the congress, coffee and lunch breaks will be provided, as well as complimentary access to sponsored breakfast and dinner symposia. During leisure time, Washington, D.C. has a vast assortment of restaurant options at every price point, including modest but delicious cuisine from around the world.
- **Accommodations** – Hotel choices in Washington, D.C. are plentiful and varied. Visitors will have no trouble finding accommodations to suit every taste and budget. Choices ranging from one-star (hostel) to 5-star luxury accommodations are available within a short distance to the Walter E. Washington Convention Center, transportation centers, and all major tourist points of interest.
- **Transportation** – During leisure time, Washington DC has a variety of low-cost transportation options, including the DC Connector bus and the Metro (subway) which runs throughout the city. Both are easy and cost-efficient modes of transportation. Many sites are within easy walking distance of congress hotels.
- **Tourism** – Washington, D.C. offers hundreds of venues, parks, monuments, and tours that are either free or at very low cost to visitors. Delegates will have a multitude of options available to them during the congress, many of which are within walking distance to hotels and the convention center.
- **Breastfeeding Room** – Walter E. Washington Convention Center (DC Convention Center) has a nursing mother's Mamava lactation pod, a freestanding, mobile suite for mamas to pump or breastfeed. Great for traveling moms in attendance. It's located on the lower level of concourse A.
- **Prayer/Quiet Rooms** – Two prayer/quiet rooms will be available during the World Congress from 7:00 am to 6:00 pm – one room will be provided with chairs and one room will feature an open space designed for attendees who will be using mats or rugs.
- **Friends of Bill W. Room** – A room will be provided from 7:00 am to 6:00 pm for those delegates who wish to gather informally, as necessary.



*8th World Congress of  
Pediatric Cardiology and Cardiac Surgery*

# Two-day Academies



## Saturday-Sunday, August 26-27, 2023

### Mobassaleh Symposium: Sudden Cardiac Death in the Young

Saturday: 8:00am – 10:00am

#### Mobassaleh Symposium: Who's at Risk for Sudden Cardiac Death?

- Epidemiology of SCD in the young: from cradle to graduation
- The primary provider's approach to identifying the "healthy" youngster at risk.
- Interpreting the non-invasive electrical recordings
- Ventricular ectopy in the young: When to worry?
- Interpreting pertinent imaging studies: The gray zone
- A debate: Every youngster with WPW pattern requires invasive testing (pro)
- A debate: Every youngster with WPW pattern requires invasive testing (con)

Saturday: 10:30 am – 12:30 pm

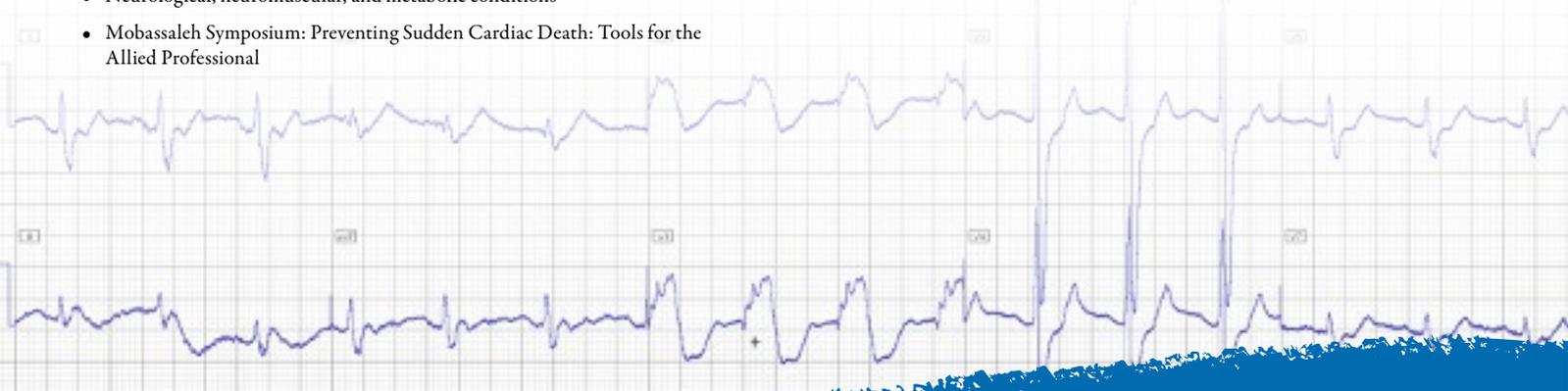
#### Mobassaleh Symposium: Primary Electrical Disease: Risk Stratification & Therapy

- A primer on interpreting genetic testing as an aid to diagnosis and risk
- A primer on exercise testing as an aid to risk analysis and treatment considerations
- Individualized medicine for the patient with long QT syndrome beta blockers and beyond
- Provocative testing and therapy considerations for patients with Brugada syndrome. Who? How? When?
- Advances in our understanding of CPVT
- Idiopathic VF, J wave syndromes: Can they really be diagnosed in the young?

Saturday: 1:30 pm – 3:30 pm

#### Mobassaleh Symposium: Sudden Cardiac Arrest in Acquired Cardiac Conditions

- Sudden death and "the itis" (peri, myo, endo)
- Kawasaki's disease and other acquired coronary conditions
- Tropical diseases and sudden death
- Life threatening events related to performance enhancing drugs, stimulants, & vaping
- Sudden death due to aortic pathology
- Neurological, neuromuscular, and metabolic conditions
- Mobassaleh Symposium: Preventing Sudden Cardiac Death: Tools for the Allied Professional
- Syncope: When to Worry?
- Growing up with an arrhythmia: Can I play?
- The nuts and bolts of WPW
- ICD's: When to implant?
- Providing family support after SCA
- Sudden death awareness in the community: an international perspective





## Saturday-Sunday, August 26-27, 2023

### Mobassaleh Symposium: Sudden Cardiac Death in the Young *Continued*

Saturday: 4:00 pm – 6:00 pm

#### Mobassaleh Symposium: Congenital Heart Disease and Sudden Cardiac Arrest

- Yet another decade with the atrial switch for D-TGA
- Ebstein's Anomaly: Spectrum of disease, spectrum of risk
- #TOF#Risk#SCA
- Left sided valvular disease: When to worry and what to do?
- The patient with a functionally single ventricle: The new kid on the block
- Congenital coronary artery anomalies/bridges: Is there finally data?

Sunday: 8:00 am – 10:00 am

#### Sudden Cardiac Arrest and Primary Cardiomyopathies

- The sarcomere, the cytoskeleton, the desmosome: So many proteins, so little time... Making sense of it all
- Newer risk assessment strategies and better therapies for HCM
- ARVD -> ARVC -> AVC: A moving target
- Paving the rough and rigid roads in LVNC & restrictive cardiomyopathy
- Sudden death in the young patient with dilated cardiomyopathy: How do we reconcile the adult experience
- The role of ICD's in primary electrical disease and primary cardiomyopathy

Sunday: 10:30 am – 12:30 pm

#### An International Review of National Screening Programs: Are We Keeping Children Safe?

- Screening in Israel
- Screening in Pakistan
- Screening in Central/South America
- Screening in China/Hong Kong
- Screening in New Zealand
- Screening in Italy
- Screening in Denmark
- Panel Discussion

Sunday: 1:30 pm – 3:30 pm

#### Mobassaleh Symposium: Genetics of Channelopathies: A Reappraisal

- CLinGen reappraisal of LQTS genes
- ClinGen reappraisal of SQTS and CPVT genes
- ClinGen reappraisal of Brugada syndrome genes
- CLinGen reappraisal of ARVC
- ClinGen reappraisal of HCM
- Polygenic etiology of inherited arrhythmia syndromes

Sunday: 5:30 pm – 8:00 pm (Optional)

#### Opening Ceremony and Reception of the 8th World Congress of Pediatric Cardiology and Cardiac Surgery



Saturday-Sunday, August 26-27, 2023

## CHD Nursing Academy

Saturday: 10:30 am – 12:30 pm

### Nursing CHD Academy: The Building Blocks of Congenital Heart Disease

- What Is Normal?
- Presentation, Diagnosis, Initial Management
- What Happens in the OR?
- Impact of Cardiopulmonary Bypass: What is LCOS?
- The 1st 24 Hours: Hemodynamic Monitoring/Vasoactive Medications
- Post Operative Arrhythmias
- Temporary Pacing
- Pain, Sedation, Delirium
- Cardiopulmonary Interactions

Saturday: 1:30 pm – 3:30 pm

### Nursing CHD Academy: Congenital Heart Defects: Part 1

- Patent Ductus Arteriosus
- Coarctation of the Aorta
- Atrial Septal Defects
- Total Anomalous Pulmonary Venous Return
- Ventricular Septal Defects
- Atrioventricular Septal Defects/Atrioventricular Canal Defects

Saturday: 3:30 pm – 5:30 pm

### Nursing CHD Academy: Congenital Heart Defects: Part 2

- IAA
- TOF
- TOF/MAPCAS
- Truncus
- D-TGA/ASO
- L-TGA/Double Switch/Rastelli

Sunday: 8:00 am – 10:00 am

### Nursing CHD Academy: Congenital Heart Defects Part 3: Single Ventricle

- Tricuspid Atresia
- Pulmonary Atresia/Intact Ventricular Septum
- HLHS and Variants
- Stage I Norwood
- Interstage Management
- Bidirectional Glenn
- Fontan Operation
- Nutrition, Feeding, and Growth Issues





## Saturday-Sunday, August 26-27, 2023

### CHD Nursing Academy *Continued*

#### Sunday: 10:30 am – 12:30 pm

- Nursing CHD Academy-Neurodevelopmental Concerns
- Neurodevelopmental Issues
- Modifiable and Non-Modifiable Factors Impacting Outcomes
- Palliative Care and CHD: The Scope
- Post Intensive Care Syndrome
- Emotional Health Issues
- Transition and ACHD Care
- A Patient Perspective

#### Sunday: 1:30 pm – 4:00 pm

#### Nursing CHD Academy: Multidimensional Anatomy Lab

- TBD

#### Stabilization of the Newborn with Complex CHD

- Strategies in the Delivery Room for Newborns with Prenatally Diagnosed Complex CHD
- Stabilization of the Neonate with Left Sided Heart Disease: Those With and Without a Prenatal Diagnosis
- Stabilization of the Neonate with d-TGA
- When is ECMO the Treatment of Choice in the Critically Ill Preoperative Neonate?
- Monitoring in the Preoperative Neonate
- Timing of Surgery 1: New Insights Into the Transitional Circulation in Neonates with Single Ventricle
- Timing of Surgery 2: Cerebral Oxygen Delivery in the Preoperative Neonate
- Evaluation of Other Organ Systems
- Surgeons Perspective: What do I Need? What Don't I Need?
- The Best Way To Stabilize is the Operate Within Hours of Birth: Update on Umbilical Cord Blood for CPB Priming

#### Sunday: 5:30 pm – 8:00 pm (Optional)

#### Opening Ceremony and Reception of the 8th World Congress of Pediatric Cardiology and Cardiac Surgery





Saturday-Sunday, August 26-27, 2023

## Pediatric Cardiology for the Primary Care Practitioner

Saturday: 8:00am – 10:00am

### The Basics

- The Patient's History
- Family History -It's all in the Details.
- The Patient's Examination
- Heart Murmurs - Distinguishing Innocent From Pathologic
- ECG, Echo, or Referral?
- Who Should Provide the Medical Home For Cardiac Children

Saturday: 10:30 am – 12:30 pm

### When To Refer?

- Approach to Chest Pain
- Approach to Syncope
- Approach to Palpitations
- Concerning Family History
- Cardiomyopathy
- Heart Failure
- ADD/ADHD - Is Treatment Different in Cardiac Patients?

Saturday: 1:30 pm – 3:30 pm

### My Job As The Primary Care Provider: CHD Potentially Escaping Fetal and/or Newborn Screening

- Atrial Septal Defects
- Aortic Stenosis
- Pulmonary Stenosis
- Patent Ductus Arteriosus
- Ventricular Septal Defects
- Coarctation of the Aorta
- Vascular Rings

Saturday: 4:00 pm – 6:00 pm

### Infections and Inflammation of the Heart - What the Primary Care Provider Needs to Know

- COVID and the Heart
- Post-vaccine Myocarditis and Long Covid in Kids
- Myocarditis/Pericarditis
- Endocarditis
- Lyme Disease
- Kawasaki Disease
- Rheumatic Heart Disease



Saturday-Sunday, August 26-27, 2023

## Pediatric Cardiology for the Primary Care Practitioner

*Continued*

Sunday: 8:00 am – 10:00 am

### What You Need to Know from The Cardiologist's Report

- The Office Letter
- Echocardiography
- CT and MRI
- Fetal echocardiography
- Exercise Stress Testing
- Cardiac Cath

Sunday: 10:30 am – 12:30 pm

### Pediatric Cardiology Potpourri

- Obesity: Scope of the Problem
- Hypertension
- Hypercholesterolemia: Recommendations Now and Moving Forward
- Neurodevelopment and CHD
- Multidisciplinary Care for the Syndromic Child with CHD
- Exercise, Nutrition - Important or Overrated?
- The Pediatrician's Important Role in the Child with Arrhythmia

Sunday: 1:30 pm – 3:30 pm

### Pediatric Cardiology for the Primary Care Practitioner: Screening Children for Heart Disease

- Current Status of Newborn Pulse Oximetry
- ECGs - Now, Never, Whenever?
- Screening for Sudden Cardiac Death Prevention
- Screening and Treatment Guidance for Peds Dyslipidemias
- Genetic Syndromes and the Heart
- Fetal Echocardiography and Screening

Sunday: 5:30 pm – 8:00 pm (Optional)

### Opening Ceremony and Reception of the 8th World Congress of Pediatric Cardiology and Cardiac Surgery



## Saturday-Sunday, August 26-27, 2023

### Grown-Up Pediatric Heart Disease for the Adult Cardiologist

Saturday: 8:00am – 10:00am

#### Practical Care of the Pregnant Patient with (mWHO IV) Cardiovascular Disease

- Maternal cardiovascular risk classification: An Overview
- High Risk Pregnancy: A Multi-Disciplinary Approach to Success
- Left Heart Obstruction: Location Matters
- Cardiomyopathy and PPCM with residual ventricular dysfunction
- Aortopathy in Pregnancy

Saturday: 10:30 am – 12:30 pm

#### Overview of Heart Failure in Adults with Congenital Heart Disease

- Assessment for heart failure in the ACHD Patient: A Practical Approach
- Basic management of heart failure in ACHD: Acute decompensated HF
- Basic management of heart failure in ACHD: Chronic HF therapy
- Heart Failure and Transplant Referral: When is the right time?
- Case Presentation: A real-life example of heart failure management

Saturday: 1:30 pm – 3:30 pm

#### Assessing Surgical Risk for Non-Cardiac Surgery in the ACHD Patient

- General cardiovascular risk considerations for the Adult CHD patient
- Adult CHD lesion-specific cardiac risk
- Adult CHD lesion-specific extracardiac risk
- Shunt-related Havoc in the Perioperative Setting: Assessing Hemodynamics
- Case Presentation: Putting it all together: Adult CHD Pre-operative risk stratification in non-cardiac surgery.

Saturday: 4:00 pm – 6:00 pm

#### Grown-up Pediatric Heart Disease Potpourri

- Management of the adult late after pediatric Kawasaki Disease
- Sexual health and contraception in young adults with CHD
- Exercise restrictions in ACHD: Yes, No or Maybe
- Primer on anticoagulation in ACHD: valves, conduits, and single ventricles
- Managing obesity in ACHD: The unintended consequence (of pediatric cardiology)

Sunday: 8:00 am – 10:00 am

#### Acute Care Pearls in the ACHD Patient

- Acute care of the Eisenmenger Patient: The Basics
- Acute care of the Single ventricle S/P Fontan Palliation
- Acute care of the DTGA with Atrial Switch/LTGA: The Failing Systemic RV
- Acute care of the TOF patient
- Acute Care Case: Putting Knowledge into Practice



## Saturday-Sunday, August 26-27, 2023

### Grown-Up Pediatric Heart Disease for the Adult Cardiologist *Continued*

Sunday: 10:30 am – 12:30 pm

#### Case Based Approach to Septal Defect Care

- The Nuts & Bolts of Septal Defects: Anatomic Review
- Diagnosis of Septal Defects: An Imaging Approach
- The straightforward atrial-level shunt: An Interventionalist Perspective
- Percutaneous VSD Closure: Ready for Prime-time?
- Percutaneous closure of Sinus Venosus ASD: The New Kid On the Block

Sunday: 1:30 pm – 3:30 pm

#### What did you learn? Test Your Knowledge with ACHD Board Style Trivia

Sunday: 5:30 pm – 8:00 pm (Optional)

#### Opening Ceremony and Reception of the 8th World Congress of Pediatric Cardiology and Cardiac Surgery





## Saturday-Sunday, August 26-27, 2023

### Advanced Management of the PDA in Newborns

Saturday: 8:00 am – 10:30 am

#### Introduction And Opening Remarks

#### Management Of PDA In Preterm Infants

- Mechanisms for Ductal Patency and Closure
- Consequences of Prolonged Ductal Patency
- Echocardiographic Assessment for Hemodynamic Significance
- Decision to Treat
- Prophylactic Treatment – For whom and when?
- Early rescue: medical closure vs. Transcatheter approach
- Late rescue: Try more medications? Is it too late already?
- Introduction to Transcatheter PDA Closure
- Questions and Discussions

Saturday: 10:45 am – 12:15 pm

#### The Transcatheter Approach to PDA Closure

- Acute Outcomes of Transcatheter PDA Closure
- Bedside Transcatheter PDA Closure – This is the way!
- How to make the Procedure Available for all NICUs?
- The Memphis Experience – What have we learned so far?
- How do we bridge the Divide?
- Questions and Discussions

Saturday: 1:00 pm – 3:45 pm

#### Case Discussion

#### Debate 1: To treat or not to treat: Therapeutic nihilism vs. Early medical management

- Pro: PDA is an innocent bystander – Leave the PDA alone!
- Con: PDA is a pathology – Treat when clinically indicated!
- Rebuttals and Discussion
- PDA and BPD: Any relation or just a coincidence

#### Debate 2: Medical vs Transcatheter PDA Closure in Preterm

- Pro: Early medical closure should always be first line
- Con: TC PDA closure is definitive and will replace medical closure
- Rebuttals and Discussion

#### Debate 2: Medical vs Transcatheter PDA Closure in Preterm

- Pro: Early medical closure should always be first line
- Con: TC PDA closure is definitive and will replace medical closure
- Rebuttals and Discussion

#### Debate 3: Transcatheter PDA Closure in Preterm – Bedside vs. Cath Lab

- Pro: Bedside is the best
- Con: Cath Lab is the safest
- Rebuttals and Discussion



Saturday-Sunday, August 26-27, 2023

## Advanced Management of the PDA in Newborns *Continued*

Saturday: 3:45 pm – 5:00 pm

### PDA Closure in Premature Infants – The way Forward

- Update on the PIVOTAL Trial
- Consensus Statement from the PDA Symposium/World Congress
- Panel Discussion

Sunday: 8:00 am – 12:00 pm

### Interventional Track: Transcatheter PDA Closure in Premature infants

- Device Overview – Amplatzer Piccolo Occluder
- Device Overview – Microvascular Plug
- Device Overview – KA Microplug Set
- Device Sizing and Positioning
- Device Embolization – Retrieval Techniques
- Keeping the patient safe during the procedure
- Questions and Discussions

### Transcatheter PDA Closure in Premature Infants – What Next?

- Why transcatheter PDA closure is not the preferred therapy
- How to perform Echo Guided Bedside Closure
- How do I perform the procedure in multiple NICUs
- How did I convince my Neonatologists to refer early
- Can we agree on a treatment algorithm?
- Change of Topic – Update on the COMPASS Trial
- Questions and Discussions

OR

Sunday: 8:00 am – 12:00 pm

### Hemodynamics Of The Extremely Premature Infant

- Optimizing The Hemodynamic Transition From The Delivery Room Through 1st Day Of Life
- The Anatomy And Physiology Behind Altered Cerebral Auto-Regulation
- Diagnosis And Treatment Of Hypotension In The Extremely Premature
- The Artificial Placenta is Almost Here, Should we be Excited or Terrified??
- The Long-Term Impact Of Prematurity On The Adult Heart

### Neonatal Heart Society (NHS):

- POCUS By The Neonatal ICU Practitioner
- What Differentiates Targeted Neonatal Echo (TNE) From Point Of Care Ultrasound (POCUS)?
- Why “State Of The Art” Management Of PH Must Include Transthoracic
- Neonatal ECHO
- What Is The Role Of TNE In The Asphyxiated Newborn?
- Novel Methods For Assessing Ventricular Function
- How To Develop A Targeted Neonatal Echo Program In Resource Limited NICUs?
- Group Discussion

### Cardiovascular Implications In Patients With Congenital Diaphragmatic Hernia (CDH)

- Fetal Predictors Of Postnatal Outcomes
- Fetal Endotracheal Occlusion (FETO) For Severe Disease; Will This Become Standard Of Care?
- What Is The Role Of Pulmonary Vasodilators In CDH?
- Is Congenital Diaphragmatic Hernia A Ductal Dependent Lesion?
- When Is The Right Time To Decannulate The Patient On ECMO?
- Group Discussion

Sunday: 5:30 pm – 8:00 pm (Optional)

Opening Ceremony and Reception of the 8th World Congress of Pediatric Cardiology and Cardiac Surgery



# Pre-Conferences



## Saturday, August 26, 2023



8:00 am – 10:00 am

### Nomenclature Of Paediatric And Congenital Heart Disease: Session 1

- History Of The International Society For Nomenclature Of Paediatric And Congenital Heart Disease (ISNPCHD)
- The “International Paediatric And Congenital Cardiac Code” (IPCCC) And The International Classification Of Disease (ICD-11)
- The “International Paediatric And Congenital Cardiac Code” (IPCCC) And The International Classification Of Health Interventions (ICHI)
- Nomenclature And Anatomy Of The Right Ventricle
- Nomenclature And Anatomy Of Ventricular Septal Defects
- Nomenclature And Anatomy Of The Aortic Valve
- The Challenges Of Building Consensus

10:00 – 10:30 BREAK

10:30 am – 12:30 pm

### Nomenclature Of Paediatric And Congenital Heart Disease: Part 2 - Advanced Concepts

- History Of The IPCCC ICD-11 Congenital Heart Atlas
- Demonstration Of The IPCCC WEBSITE And The IPCCC ICD-11 Congenital Heart Atlas
- Morphology Is BEST For Demonstrating Nomenclature.
- Echocardiography Is BEST For Demonstrating Nomenclature.
- Angiography Is BEST For Demonstrating Nomenclature.
- Advanced Imaging (CT And MRI) Is BEST For Demonstrating Nomenclature.
- Surgical Photography Is BEST For Demonstrating Nomenclature.

12:30 – 1:30 LUNCH BREAK

1:30 pm – 3:30 pm

### Cardiac Networks United: Part 1

- The Society of Thoracic Surgeons Congenital Heart Surgery Database
- The Congenital Cardiac Anesthesia Society Module of The Society of Thoracic Surgeons Congenital Heart Surgery Database
- The European Congenital Heart Surgery Association (ECHSA) Congenital Database
- The World Database for Pediatric and Congenital Heart Surgery (WDPCHS)
- The Congenital Heart Surgeons’ Society (CHSS) Database
- Pedimacs – Database of Pediatric Mechanical Circulatory Support
- Multi-Societal Database Committee for Pediatric and Congenital Heart Disease

4:00 pm – 6:00 pm

### Cardiac Networks United: Part 2

- Cardiac Networks United Overview
- The Pediatric Cardiac Critical Care Consortium (PC<sup>4</sup>) & The Cardiac Arrest Prevention Project
- Pediatric Acute Care Cardiology Collaborative (PAC<sup>3</sup>) & The Health Equity Module
- The Cardiac Neurodevelopmental Outcome Collaborative (CNOC) – The power of collaboration to advance critical long term outcomes
- The COMPASS Trial
- National Institute for Cardiovascular Outcomes Research (NICOR)
- Data for Patients and Families



Sunday, August 27, 2023

## World Society for Pediatric and Congenital Heart Surgery

8:00 – 10:00

### World Society For Pediatric And Congenital Heart Surgery With Asian Association For Pediatric And Congenital Heart Surgery: TGA & CC-TGA

- Arterial Switch For High-Risk Coronary Anatomy Patterns In D-TGA
- The Role Of Nikaidoh Operation And Double Root Translocation For D-TGA
- Indications And Different Management Strategies For LVOTO In D-TGA, VSD And D-TGA, IVS.
- Anatomic Repairs For CC-TGA
- Role And Outcomes Of Physiologic Repairs For CC-TGA
- Management Strategies For Systemic RV Failure And Systemic AV Valve Regurgitation In CC-TGA

10:00 – 10:30 BREAK

10:30 – 12:30

### World Society For Pediatric And Congenital Heart Surgery With The Society Of Thoracic Surgeons (STS): The Atrioventricular Junction

- Overview Of Different Repairs For CAVC
- Atrioventricular Septal Defect With Conotruncal Anomalies
- Surgical Decision Making And Management Of Unbalanced AV Canal
- AV Valve Repair In Single Ventricle
- Ebstein's Disease: The Cone Repair And Beyond
- The Role Of Bidirectional Cavopulmonary Anastomosis For Ebstein's Malformation

12:30 – 1:30 LUNCH BREAK

1:30 – 4:00

### Stabilization Of The Newborn With Complex CHD

- Strategies In The Delivery Room For Newborns With Prenatally Diagnosed Complex CHD
- Stabilization Of The Neonate With Left Sided Heart Disease: Those With And Without A Prenatal Diagnosis
- Stabilization Of The Neonate With D-TGA
- When Is ECMO The Treatment Of Choice In The Critically Ill Preoperative Neonate?
- Monitoring In The Preoperative Neonate
- Timing Of Surgery 1: New Insights Into The Transitional Circulation In Neonates With Single Ventricle
- Timing Of Surgery 2: Cerebral Oxygen Delivery In The Preoperative Neonate
- Evaluation Of Other Organ Systems
- Surgeons Perspective: What Do I Need? What Don't I Need?
- The Best Way To Stabilize Is To Operate Within Hours Of Birth: Update On Umbilical Cord Blood For CPB Priming

OR

1:30 – 4:00

- Business Meeting





Sunday, August 27, 2023

## 3DI3: Multimodality Imaging For Interventional Catheterization And Surgical Planning

8:00 – 10:00

### Part 1

- 3D Imaging 101: From DICOM To STL To 3D Printing And CFD
- Debate: 3D Printing Is Here To Stay
- Debate: Who Needs 3D Printing When We Have Extended Reality?
- 4D Flow MRI To Optimize Coarctation Intervention
- How I Interpret The Screening Reports For Self-Expanding TPVR
- CFD To Optimize Hepatic Flow Distribution In Fontan Circulation
- 3D Planning For Percutaneous Potts Shunts

10:00 – 10:30 BREAK

10:30 – 12:30

### Part 2

- Debate: 3DRA Is Essential For Congenital Intervention
- Debate: Who Needs 3DRA When You Can Use 3D Image Fusion?
- Taped Case: 3D Image Fusion
- State-Of-The-Art 3D TEE For Interventional Catheterization Guidance
- Update On Tools For Interventional Cardiac MR
- Taped Case: ICMR
- CFD Assessment Of Branch Pulmonary Artery Intervention

12:30 – 1:30 LUNCH BREAK

1:30 – 4:00

### Stabilization Of The Newborn With Complex CHD

- Strategies In The Delivery Room For Newborns With Prenatally Diagnosed Complex CHD
- Stabilization Of The Neonate With Left Sided Heart Disease: Those With And Without A Prenatal Diagnosis
- Stabilization Of The Neonate With D-TGA
- When Is ECMO The Treatment Of Choice In The Critically Ill Preoperative Neonate?
- Monitoring In The Preoperative Neonate
- Timing Of Surgery 1: New Insights Into The Transitional Circulation In Neonates With Single Ventricle
- Timing Of Surgery 2: Cerebral Oxygen Delivery In The Preoperative Neonate
- Evaluation Of Other Organ Systems
- Surgeons Perspective: What Do I Need? What Don't I Need?
- The Best Way To Stabilize Is To Operate Within Hours Of Birth: Update On Umbilical Cord Blood For CPB Priming





Sunday, August 27, 2023

## Neonatal Heart Society (NHS)

8:00 – 10:00

### Hemodynamics Of The Extremely Premature Infant

- Optimizing The Hemodynamic Transition From The Delivery Room Through 1st Day Of Life
- The Anatomy And Physiology Behind Altered Cerebral Auto-Regulation
- Diagnosis And Treatment Of Hypotension In The Extremely Premature
- The Artificial Placenta is Almost Here, Should we be Excited or Terrified??
- The Long-Term Impact Of Prematurity On The Adult Heart

10:00 – 10:30 BREAK

10:30 – 12:30

### Cardiovascular Implications In Patients With Congenital Diaphragmatic Hernia (CDH)

- Fetal Predictors Of Postnatal Outcomes
- Fetal Endotracheal Occlusion (FETO) For Severe Disease; Will This Become Standard Of Care?
- What Is The Role Of Pulmonary Vasodilators In CDH?
- Is Congenital Diaphragmatic Hernia A Ductal Dependent Lesion?
- When Is The Right Time To Decannulate The Patient On ECMO?
- Group Discussion

12:30 – 1:30 LUNCH BREAK

1:30 – 4:00

### Stabilization Of The Newborn With Complex CHD

- Strategies In The Delivery Room For Newborns With Prenatally Diagnosed Complex CHD
- Stabilization Of The Neonate With Left Sided Heart Disease: Those With And Without A Prenatal Diagnosis
- Stabilization Of The Neonate With D-TGA
- When Is ECMO The Treatment Of Choice In The Critically Ill Preoperative Neonate?
- Monitoring In The Preoperative Neonate
- Timing Of Surgery 1: New Insights Into The Transitional Circulation In Neonates With Single Ventricle
- Timing Of Surgery 2: Cerebral Oxygen Delivery In The Preoperative Neonate
- Evaluation Of Other Organ Systems
- Surgeons Perspective: What Do I Need? What Don't I Need?
- The Best Way To Stabilize Is To Operate Within Hours Of Birth: Update On Umbilical Cord Blood For CPB Priming

OR

8:00 – 10:00

### Neonatal Heart Society (NHS): POCUS By The Neonatal ICU Practitioner

- What Differentiates Targeted Neonatal Echo (TNE) From Point Of Care Ultrasound (POCUS)?
- Why "State Of The Art" Management Of PH Must Include Transthoracic Neonatal ECHO
- What Is The Role Of TNE In The Asphyxiated Newborn?
- Novel Methods For Assessing Ventricular Function
- How To Develop A Targeted Neonatal Echo Program In Resource Limited NICUs?
- Group Discussion





Sunday, August 27, 2023

## Pediatric Cardiac Intensive Care Society (PCICS)

8:00 – 10:00

### Getting A Job: CV, Mentoring And Interviewing

- Panel Discussion #1
  - ▷ What Makes A Good CV
  - ▷ What Is A Good Interview
  - ▷ Expectations Of Junior Faculty
- Panel Discussion #2
  - ▷ Finding A Mentor
  - ▷ Being A Good Mentee
  - ▷ Pitfalls Of A Mentor/Mentee Relationship
  - ▷ Going From Mentee To Mentor
- Q & A

10:00 – 10:30 BREAK

10:30 – 12:30

### Training Pathways In The USA: Should I Be Dual Boarded, And What's On The Horizon?

- What I Would Do Differently And What I Would Not Change (Panel)

12:30 – 1:30 LUNCH BREAK

1:30 – 4:00

### Stabilization Of The Newborn With Complex CHD

- Strategies In The Delivery Room For Newborns With Prenatally Diagnosed Complex CHD
- Stabilization Of The Neonate With Left Sided Heart Disease: Those With And Without A Prenatal Diagnosis
- Stabilization Of The Neonate With D-TGA
- When Is ECMO The Treatment Of Choice In The Critically Ill Preoperative Neonate?
- Monitoring In The Preoperative Neonate
- Timing Of Surgery 1: New Insights Into The Transitional Circulation In Neonates With Single Ventricle
- Timing Of Surgery 2: Cerebral Oxygen Delivery In The Preoperative Neonate
- Evaluation Of Other Organ Systems
- Surgeons Perspective: What Do I Need? What Don't I Need?
- The Best Way To Stabilize Is To Operate Within Hours Of Birth: Update On Umbilical Cord Blood For CPB Priming





Sunday, August 27, 2023

## Pedirhythm<sup>x</sup>

8:00 – 10:00

### Management Of Ventricular Arrhythmias

- What Really Is A “Structurally Normal” Heart: Diagnostic Work-Up And Challenges?
- Clinical Presentation And ECG-Diagnosis
- VT In Asymptomatic Patients: Treat Or Not To Treat?
- Symptomatic VT: Drug Or Ablation?
- Ventricular Arrhythmias In Myocarditis
- Outflow Tract Pvc: Are They Really Innocent... Patterns That Make Us Worry
- Malignant Mitral Valve Prolapse

10:00 – 10:30 BREAK

10:30 – 12:30

### (CIED) Cardiac Implantable Electronic Devices

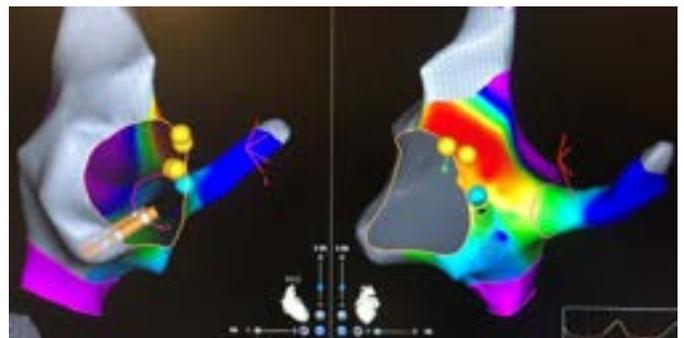
- Smart Bells And Whistles – Underutilized Programming Features In Pacemakers And Defibrillators Specifically For Pediatric Patients
- Optimizing Resynchronization Therapy In Congenital Heart Disease – Variables That Impact Electromechanical Synchrony
- Device Implantation In ACHD: Tips, Tricks, And Lessons Learned
- Advances In Device Miniaturization And Novel Implantation Techniques
- Remote Monitoring In Cardiac Rhythm Management Devices
- Choosing Your ICD Hardware: Patient And Disease Characteristics To Consider
- What Is On The Horizon For Devices

12:30 – 1:30 LUNCH BREAK

1:30 – 4:00

### Ablations That Are Really Hard: Tips From The Experts

- Outflow-Tract Arrhythmia With Left-Sided Origin/Aortic Cusp Ablations
- Para-Hisian Accessory Pathways
- AVNRT With A Non-Responding “Typical” Slow-Pathway-Region
- “Epicardial” Inferoseptal Accessory Pathways
- Idiopathic LV- Fascicular- Tachycardia (ILVT)
- “Unusual” Accessory Connections: Mahaim-Fibers; PJRT, Fasciculo-Ventricular Connections and More
- Focal Atrial Tachycardias
- Pulmonary Vein Isolation—It’s Not Just For Adults Anymore





Sunday, August 27, 2023

## International Society For Adult Congenital Heart Disease (ISACHD)

8:00 – 10:00

### ACHD Is A Global Concern

- Welcome To The ISACHD Pre-Conference
- ACHD Research Around The Globe: Insights From The APPROACH-IS Consortium
- Global ARCH: Patient Empowerment Around The Globe
- ACHD Program Building: Perspective Of Higher-Resourced Countries
- ACHD Program Building: Perspective Of Lower-Resourced Countries
- Developing ACHD Expertise In Africa
- Reflections: What ISACHD Can Offer The Global ACHD Community

10:00 – 10:30 BREAK

10:30 – 12:30

### Pushing The Limits While Recognizing Limitations

- PAH And Shunt: To Close Or Not To Close?
- AV Replacement In Fontan?
- Mechanical Support For Advanced ACHD Heart Failure
- Valve Procedures In Pregnancy - Who, How And When?
- Presentation Of Cyanotic CHD In Adulthood: Can I Modify Natural History By Surgery?
- Ebstein Valve Surgery: When Is The RV Too Sick?
- The New Frontier: The Role Of Artificial Intelligence In ACHD

12:30 – 1:30 LUNCH BREAK

1:30 – 4:00

### Helping Patients With ACHD Live Full Lives

- Reflecting On A "Normal" Life
- "I Want To Run A 10K" - Aspiring To A Physically Active Life With CHD
- The Adrenaline Junkie: What Do I Say To My Patient Who Wants To Jump Out Of A Plane?
- Engaging Adolescents: The Next Generation Of ACHD
- It's Not Easy Being A Grown-Up: Supporting Independence & Resilience In Young Adults With CHD
- WHO Class IV And Wanting To Continue Pregnancy: What Have We Learned
- Advance Care Planning: "When Am I Going To Die?"



Sunday, August 27, 2023



Cardiac Neurodevelopmental Outcome Collaborative

## Cardiac Neurodevelopmental Outcome Collaborative (CNOC)

8:00 – 10:00

### Neurodevelopment At Key Transition Points - Risks And Opportunities

- Risks And Opportunities: Neurodevelopment At Key Transition Points
- Parent Perspective On Perioperative Transitions
- Key Transitions In The Perioperative Period, Birth To Discharge
- Benefits And Bias In Neurodevelopmental Evaluation For Children With CHD
- Parent Perspective On The Preschool Years
- Key Transitions In The Preschool Age Child - Explosive Growth And Shifting Expectations
- Patient/Parent Perspective On The Teenage/Transition Years
- Key Transitions In Adolescence - Shifting Towards Independence
- Patient Perspective On Adulthood
- Key Transitions And Challenges In Adulthood

10:00 – 10:30 BREAK

10:30 – 12:30

### Redefining Neuroprotection And Intervention Across The Lifespan In CHD

- Introduction: Thinking Beyond Operative Factors For Neuroprotection
- Neuroprotection In The Presurgical Period In Children With CHD
- Neuroprotection In The Post-Operative Period In Children With CHD
- Neurodevelopmental And Family Intervention In Infancy And Early Childhood In Children With CHD
- Neuropsychological And Psychological Interventions In School Age Children With CHD
- Interventions For Adolescents And Adults With CHD
- Interventions To Reduce The Impacts Of Health Disparities In Neurodevelopmental Care In CHD

12:30 – 1:30 LUNCH BREAK

1:30 – 4:00

### Debates In Cardiac Neurodevelopment

- Debate 1: Neurodevelopmental Disorders In CHD Cannot Be Modified By Interventions
- Debate 1: Neurodevelopmental Disorders In CHD Can Be Modified By Interventions
- Debate 2: All Children And Families With CHD Should See The ND Team
- Debate 2: Children And Families With CHD Should Be Triaged Before Visiting The ND Team
- Debate 3: Neuroimaging Should Be A Standard Part Of Clinical Care In CHD
- Debate 3: Neuroimaging Is Most Informative To Research Questions
- Debate 4: The ICU Should Be Structured With All Cardiac Patients On One Team To Maximize ND Outcomes In Individuals With CHD
- Debate 4: The ICU Should Be Structured With Segmented ICU Model Based On Age To Maximize ND Outcomes In Individuals With CHD



Sunday, August 27, 2023

## Pediatric Heart Transplant Society (PHTS)

8:00 – 10:00

### Optimizing Cardiac Donors

- Donor Availability Around The World
- Size Matching
- Donor Management: What Should We Really Worry About
- Donation After Cardiac Death
- Remote Donors: How Far Can We Go?
- Management Of Primary Graft Dysfunction
- Xenotransplantation

10:00 – 10:30 BREAK

10:30 – 12:30

### Heart Failure And Transplant Across The Lifespan In CHD

- Case Presentation: Newborn With HLHS, Moderate RV Dysfunction, And Severely Depressed RV Function
  - Why I Would Place A VAD
  - Why I Would Not Place A VAD
- Case Presentation: 22-Month-Old S/P Bidirectional Glenn With Refractory Heart Failure And Highly Sensitized
  - Why I Would Transplant Across A Positive Crossmatch
  - Why I Would Use Desensitization Therapy
- How I Approach MCS In This Patient Population
- Ethical Approach: When Do Co-Morbidities Preclude Transplant?

12:30 – 1:30 LUNCH BREAK

1:30 – 4:00

### PHTS: Heart Failure And Transplant Across The Lifespan In CHD - The Failing Fontan

- How I Approach Medical Therapy
- Mechanical Support For The Systemic Ventricle
- Mechanical Support For The Fontan Circulation
- Approach In Resource Limited Areas
- Multi-Organ Transplant In Congenital Heart Disease
- Current And Future Anti-Coagulation Strategies For Pediatric VADs
- What Will Trials Of Medical Therapy Tell Us?



Presented with the American Society  
of Echocardiography

Sunday, August 27, 2023

## Special Topics in Echocardiography

8:00 – 10:00

### VSDs: Why All The Fuss?

- Morphology Of VSDs: The Borders Approach
- Morphology Of VSDs: The Geographic Approach
- Echocardiography Of VSDs: The Borders Approach
- Echocardiography Of VSDs: The Geographic Approach
- VSDs: Do Other Modalities Add To The Diagnosis?
- VSDs: Surgical Implications Of Borders And Geography
- VSDs: Reaching Consensus

10:00 – 10:30 BREAK

10:30 – 12:30

### Double Outlet Right Ventricle (DORV): War And Peace

- Morphology Of DORV: The 50% Rule Rules
- Morphology Of DORV: It's All About The Conus
- Echocardiography Of DORV: The 50% Rule Rules
- Echocardiography Of DORV: It's All About The Conus
- Multimodality Imaging For DORV: The Rules Don't Matter
- DORV: What Does The Surgeon Need To Know For Successful Septation?
- DORV: Reaching Consensus

12:30 – 1:30 LUNCH BREAK

1:30 – 4:00

### Unusual Variants Of Complex CHD: Clinical Presentation And Outcomes (Case-Based Talks)

- Left Ventricular Outflow Tract Obstruction: Not A Pretty Picture
- Extraordinary Coronaries: Anomalies In CHD
- Corrected Transposition Of The Great Arteries: Not Correct At All
- Single Ventricles: Strange Tales Of Woe
- Stranger Than Fiction: Unusual Systemic And Pulmonary Vein Anomalies
- Memorable Mitral Valve Disorders: Dysplasia, Straddling, Arcade, And Others
- Criss-Cross Hearts And Other Abnormal Connections





Sunday, August 27, 2023

## Fetal Heart Society (FHS)

8:00 – 10:00

### Beyond CHD: Cardiac Development And Fetal Physiology

- Cardiovascular And Placental Development
- Transitional Physiology
- Prenatal Genetics, Testing, Implications
- Extracardiac Malformations That Impact The Cardiovascular System: What You Need To Know
- Fetal Heart Failure: Mechanisms, Assessment And Management
- Fetal Ductal Constriction: Etiology, Assessment And Management
- First Trimester Fetal Echo: Insight Into Cardiac Development

10:00 – 10:30 BREAK

10:30 – 12:30

### Fetal Cardiac Imaging: The Basics And Advanced

- Building Blocks: Segmental Anatomy Made Simple
- The Basics 1: Review Of Common 4-Chamber Abnormality Anatomy
- The Basics 2: Review Of Common Outflow Tract Abnormality Anatomy
- Predicting The Future: Is It Ductal Dependent?
- Predicting The Future: Can This Be A Two-Ventricle Repair?
- Predicting The Future: Will This Fetus Be Sick In The Delivery Room?
- Round Table Discussion

12:30 – 1:30 LUNCH BREAK

1:30 – 4:00

### Care Of The Family Following A Prenatal Diagnosis Of CHD

- Conveyance And Compassion: Challenges In Counselling Following Prenatal Diagnosis Of CHD
- Fetal CHD: Psychological Influence On Families And Impact On Quality Of Life
- Trauma-Informed Care: Insights And Application
- Impact Of Prenatal Diagnosis Of CHD From Detection To Treatment And Beyond: A Parent's Perspective
- Debate: Palliative Care Is No Longer A Reasonable Option (Pro)
- Debate: Palliative Care Is No Longer A Reasonable Option (Con)
- Palliative Care Fundamentals (10 Min) And Moderated Round Table Discussion



Developed with Children's Heart Link

Sunday, August 27, 2023

## Pediatric And Congenital Heart Surgery In Africa: Practical Solutions For Closing The Gap.

8:00 – 10:00

### Part 1 - Defining The Gap

- What Do We Really Know: Data From GBD Study
- What Do We Really Know: Survey Data
  - ▷ Obstacles 1: Financing
  - ▷ Obstacles 2: Supply Chain
  - ▷ Obstacles 3: Education/Training Of Workforce
  - ▷ Obstacles 4: Nursing Empowerment/Retention
  - ▷ Obstacles 5: Outcomes/Quality Improvement
- Pediatric And Congenital Heart Surgery In Africa: Practical Solutions For Closing The Gap. Part 2 - Real World Solutions
- Research As A Tool For Programmatic Growth
- Vendor Partnerships
- Patient Perspective Roundtable - Interviewer
  - ▷ Patient 1
  - ▷ Patient 2
  - ▷ Patient 3
- Policy Maker Roundtable - Interviewer
  - ▷ Policy Maker 1
  - ▷ Policy Maker 2
- Panel Discussion

10:00 – 10:30 BREAK

10:30 – 12:30

### Part 2 - Real World Solutions

- Research As A Tool For Programmatic Growth
- Vendor Partnerships
- Patient Perspective Roundtable
- Policy Maker Roundtable

12:30 – 1:30 LUNCH BREAK

1:30 – 4:00

### Part 3 - Workshop To Define Action Items.

- Breakout 1: Financing And Supply Chain
- Breakout 2: Workforce And Infrastructure
- Breakout 3: Academics: Training And Research
- Breakout 4: Patient Selection, Follow-Ups, Quality Improvement
- Breakout 5: Advocacy, Policy, Regionalization



*8th World Congress of  
Pediatric Cardiology and Cardiac Surgery*

# Main Program

*Faculty Assignments Will Be Complete June, 2023*



# Monday, August 28



## Monday, August 28, 2023

Block 1: 7:30 – 9:15 AM

### Landmark Lectures

- Chasing Excellence: "Peak Performance of Quarterbacks, Pilots and Surgeons."
  - ▷ Joseph A. Dearani, MD (USA)
- Developing Paediatric Cardiac Treatment Services in Low Income Countries – Who Has What Roles?
  - ▷ Sir Shakeel Qureshi, MBChB, MRCP (United Kingdom)
- The Top 5 Papers of 2023 – A Landmark Year for Heart Research.
  - ▷ David Celermajer, AO, FAA, FAHMS (Australia)
- Integrating Psychology Within ACHD Programs: The Time is Now.
  - ▷ Adrienne Kovacs PhD, CPsych (Canada)

### PediRhythmx Taped Electrophysiology Cases: Session #1

- Mustard Ablation
- SVT Ablation in a Patient with Tetralogy of Fallot
- VT Ablation
- SVT Ablation (PJRT)

Break and Visit Exhibits and Posters: 9:15 am – 10:15 am





## Monday, August 28, 2023 *Continued*

Block 2: 10:15 am – 12:30 pm

### World Society For Pediatric And Congenital Heart Surgery With The European Congenital Heart Surgeons Association (ECHSA): Tetralogy Of Fallot (TOF), Pulmonary Atresia With Ventricular Septal Defect (PA-VSD), Major Aortopulmonary Collateral Arteries (MAPCAs), Pulmonary Conduits

- Classical Trans-Infundibular Repair For TOF
- Transatrial-Transpulmonary Repair Of TOF
- Single-Stage Repair For PA With VSD And MAPCAs
- Multi-Stage Repair For PA With VSD And MAPCAs
- Indications For Placement Of Pulmonary Valves And Conduits For Pulmonary Regurgitation Following Repair Of TOF
- Update On Late Outcomes Of Different Pulmonary Valves And Conduits
- AATS TOF Study

### Opening Plenary In General Pediatric Cardiology: Hypertrophic Cardiomyopathy-More Than Just Being Thick

- Exploring The Genotype-Phenotype Association
- Imaging HCM: Thick, Stiff, Scar?
- Medical Options For Obstruction And Diastolic Dysfunction
- Predicting Sudden Cardiac Death
- ICD Now Or Wait?
- Surgical Options For HCM
- Competitive Sports: Let 'Em Play?

### Childhood Heart Disease And The Global Health Agenda

- What Is The Current Burden Of Heart Disease In Children?
- Why 90% Of The World's Children Still Don't Have Access To Pediatric Cardiac Care? Is It Really 90%?
- Financing Pediatric Cardiac Care In The World - Where Are We Today And Where Do We Need To Get?
- Are We Solving The Problem? What Progress Have We Made?
- Becoming Advocates - How, What And Who Should We Partner With?
- Eyes Wide Open: Can Aswan Be Replicated In Other Parts Of Africa?
- Global Preventative Cardiology: Can We Reduce The Burden Of Cardiovascular Disease For The Next Generation?
- Leveraging Combined RHD And CHD Diagnosis And Treatment To Optimize Capacity In LMIC
- Global Progress In RHD Control Since The 2018 Global Resolution On RHD: How To Advocate For A Disease Of Global Inequity

### ACHD: Reaching Everyone

- ACHD Burden Around The Globe: Leveling The Playing Field And Provision Of Global, Holistic Care
- Do Current ACHD Clinical Guidelines Translate To Low Resources Countries?
- ACHD Nursing: Perspective Of Lower-Resourced Countries
- ACHD Nursing: Perspective Of Higher-Resourced Countries
- Rural Access To ACHD Care
- ACHD EP-Perspective From Asia: Bringing Technologies Across High And Low Resourced Regions.
- Addressing The Aging ACHD Population
- Advancing The Field Through Organized Patient-Provider Partnerships
- Engaging The Next Generation Of Clinicians

### Pediatric Echocardiography: Where It Started, Where It's Going

- The History Of Pediatric Echocardiography
- Quality Initiatives In Echocardiography Across The Globe
- From M-Mode To Strain: Have We Gotten Better At Assessing Function?
- Z-Scores Explained: Why, Which Ones, Where, And How?
- Study Interpretation And Reporting: The Role Of Artificial Intelligence
- The Role Of Hand-Held Echo In Screening And Global Pediatric Cardiovascular Health
- Intra-Procedural 3D Echo: It's Time Has Come



## Monday, August 28, 2023 *Continued*

### Block 2: 10:15 am – 12:30 pm *Continued*

#### Team Science: Communication And Teamwork In The CICU

---

- Complex Teams And Communication Conundrums
- Crucial Conversations
- Psychological Safety
- Interdisciplinary Team Education
- Authority Gradients
- Implicit Bias/Recruitment
- Clinical Decision Making And Articulating The Cognitive Burden

#### New Technology And Artificial Intelligence In Electrophysiology

---

- Predictive Analytics – Determining Who Will Develop Arrhythmias Before They Happen
- Mobile Health Technology Will Better The Lives Of EP Patients And The Health Care Team
- Technology Is A Useful Servant But A Dangerous Master: Keeping The “Art” Of Medicine In The Era Of Big Data And AI
- Leveraging Dramatic Advances In Informatics To Understand Arrhythmic Disease
- Deep Learning In Pharmacogenomics: Using The Right Drug, Right Patient, Right Dose, Right Time
- Harnessing Big Data Without Getting Buried By It
- Artificial Intelligence: Where Is Its Place In Congenital EP?
- New Technology For Image Incorporation Guiding EP Interventions

#### Hemodynamics Of Septic Shock In The Neonate

---

- What Vital Signs Don't Tell Us About Our Patient's Hemodynamics?
- LV Systolic Or Diastolic Function; Which Is More Important To Monitor?
- Low Systemic Vascular Resistance; How To Regulate Vascular Tone And Integrity?
- Fluid Resuscitation In Septic Shock, When Is It Too Much Of A Good Thing?
- Inotropes, Lusitropes, Pressors, And Steroids; Why Are We All Doing It So Differently?
- When (And Why) I Ignore The “Surviving Sepsis Campaign” That I Helped Create

#### The State Of The Art In Cardiac Neurodevelopment Part 1: Where Have We Been?

---

- History Of Neuroprotection And Neurodevelopment In CHD
- Brain Development In Children With CHD
- Neuropsychological Outcomes In Children With Cardiac Disease
- Psychosocial Outcomes In Children With Cardiac Disease

#### Cardiac Anesthesia: A Tale Of Two Ventricles

---

- Pathophysiology Of Low Cardiac Output State
- Low Cardiac Output State: Monitoring
- Heart-Lung Interaction: What Is The Best Ventilation Strategy?
- Right And Left Ventricle Interactions: Differences And Similarities Between The 2 Ventricles
- Diastolic Dysfunction
- Severe Pulmonary Hypertension
- Inotropes: When, What And Why?
- Fluids: When, What And Why?



## Monday, August 28, 2023 *Continued*

Block 2: 10:15 am – 12:30 pm *Continued*

### Heart Failure, Transplantation And VAD: Case Presentations

- Case Presentation: Infant With DCM And Heart Failure
- What Heart Failure Therapies Would I Use And Why?
- What Biomarkers Would I Use To Predict Outcome?
- Surgical Options
- Discussion
- Case Presentation: 8-Year-Old With RCM And Heart Failure
- How I Would Approach This Patient Medically
- How I Would Approach This Patient Surgically
- Discussion

### Opening Plenary In Fetal Cardiology

- The Perennial Question: Does Fetal Diagnosis Improve Outcome?
- Fetal Cardiac Therapies: Maternal Considerations
- Does Congenital Heart Disease Impact Fetal Growth And Organ Development?
- Management Of Fetal Bradyarrhythmias: STOPBLOQ Trial
- Management Of Fetal Tachyarrhythmias: FAST Registry & Trial Update
- Use Of Advanced Fetal Multimodal Imaging To Plan Delivery
- Optimizing Outcomes For All: Deciding When To Wait And When To Deliver The Fetus With CHD - Obstetrical Perspective
- Optimizing Outcomes For All: Deciding When To Wait And When To Deliver The Fetus With CHD - Cardiologist Perspective

### Atrial Septal Defects And Atrial Septal Communications

- Formal Heart Specimen Demonstration
- Informal Hands On With Specimens
- Imaging Correlation

**LUNCH BREAK – Visit the Exhibits and Visit the Posters: 12:30 pm – 2:00 pm**





## Monday, August 28, 2023 *Continued*

### Small Group Lunch Sessions: 12:45 pm – 1:45 pm

#### Training the Next Generation of Imagers

---

- CTA Is So Easy To Do: Should We Give Up on Scanning Veins and Arteries?
- Tissue Doppler Imaging: When Should We Use It in Children?
- Echo Simulators: Do They Help Improve Competence?

#### Diversity in the Workforce: Now and In the Future

---

- The Gender Gap In CT Surgery
- The “Only” In The Room: Opportunities For Bringing Change In Medicine Through Enhanced Diversity
- Unforgiven Debt, The First-Generation Medical Trainee

#### Big Data & CHD: Moving Beyond Traditional Registries

---

- Cardiac Networks United - Integrating Registry Data Across The USA.
- Registry-Based Clinical Trials
- Real-Time Registry Modules
- Supporting Collaborative Learning & Quality Improvement

#### Round Table Lunch: Recruiting Top Talent Physicians

---

- Join an Expert Panel for a Lively, Interactive Discussion

#### Principles of Quality Improvement

---

- The Basic Building Blocks Of Quality Improvement In A Congenital Heart Program
- Transforming A Congenital Heart Program By Focusing On Quality And Outcomes
- Using Data To Drive Local Improvement Efforts And Quality Outcomes.

#### Anatomy Lab: Using 3D Echo for Management of CHD

---

- Join our Expert Group of Morphologists and Imagers in the Lab!



*From the 7th World Congress of Pediatric Cardiology and Cardiac Surgery, Barcelona 2017*



## Monday, August 28, 2023 *Continued*

Block 4: 2:00 pm – 4:15pm

### World Society For Pediatric And Congenital Heart Surgery With Sociedad Latina De Cardiología Y Cirugía Cardiovascular Pediátrica: Left Heart Obstructions

- Critical Aortic Stenosis
- Critical Coarctation
- Interrupted Aortic Arch
- Surgical Treatment Of Complex LVOTO
- Indications For Biventricular Repair For HLHS
- The Ross Procedure
- Supravalvar Aortic Stenosis

### Nursing Opening Plenary: Building Resilience In Patients, Families, And Ourselves

- A Sense Of Coherence: What Does Not Kill You Makes You Stronger?
- Moral Distress, Burnout, And Uncertainty: Who Is At Risk?
- Impact Of Social Determinants Of Health On Healthcare Outcomes
- A Story Of Resilience: What We Can Learn From Patients And Families
- Building A Care Model That Develops And Promotes Wellness
- The Importance Of Parental Resiliency
- Organizational Resilience
- Why Are Cardiac Professionals So Heartless When It Comes To Self-Care?

### Preventative Cardiology: Part 1

- Obesity And Hypertension In Latin America: Current Perspectives
- Pediatric Cardio-Oncology: Epidemiology, Screening, Prevention, And Treatment
- Psychological Counseling Is Important Prevention In Our Cardiac Patients
- Metabolic Syndrome: Bridging The Gap From Childhood To Adulthood.
- The Future: Creating A Metabolic Signature For CHD Patients
- Telehealth Is The New Answer To Preventing Premature Atherosclerotic Disease
- Health Behavior, Healthy Eating - Need To Treat The Family
- Rationale And The Creation Of Best Practices For Pediatric Cardiology Prevention Programs

### Inflammatory Heart Disease: Part 1

- Acute Pericarditis: Diagnosis & Management
- Chronic Recurrent Pericarditis: Diagnosis & Management
- Myocarditis: Etiology And Pathophysiology
- Myocarditis: Acute Managements
- Myocarditis: Long Term Management And Outcomes
- Update On COVID-19 Vaccine Myocarditis
- What's New In Endocarditis

### The Fetal And Neonatal Brain In CHD

- Case Presentation By Junior Faculty
- Genetic Determinants Of Brain Development In CHD
- Fetal Circulatory Physiology And Brain Health In CHD: The Cardiologist's Perspective
- The Developing Neonatal Brain And Neurodevelopmental Outcome: The Neurologist's Perspective
- Maternal Stress And Brain Development In CHD
- Perinatal Cerebrovascular Hemodynamics And Outcome
- Patterns Of Perioperative Brain Injury In CHD
- Evaluation Of The Neonatal Brain: Before & After Surgery



## Monday, August 28, 2023 *Continued*

### Block 4: 2:00 pm – 4:15 pm *Continued*

#### Arrhythmias In ACHD: A Conundrum

- Any News On Antiarrhythmic Drugs?
- Oral Anticoagulation In ACHD?
- Imaging For Risk Stratification Of Sudden Cardiac Death In Contemporary Patients: New Insights
- Ventricular Arrhythmias In ACHD – The Dynamics Of Arrhythmogenesis
- VT-Ablation In Tetralogy Of Fallot: A Model For Potentially Prognostic Treatment?
- ICD Therapy In ACHD: Room For Improvement
- Moving Beyond Just Simple Pulmonary Vein Isolation In ACHD
- Managing Arrhythmias In The Pregnant ACHD Patient

#### Examining The Evidence: What Do We Really Know About RHD?

- Patient Story - Hear My Voice -Story #1
- Patient Story - Hear My Voice -Story #2
- Patient Story - Hear My Voice -Story #3
- The History Of RF/RHD: Where Does Our Evidence Come From?
- Just Improve Living Conditions: The Evidence Base For Primordial Prevention Of RHD
- Just Treat Strep Throat: The Evidence Base For Primary Prevention Of RHD
- Secondary Prophylaxis Is Key: The Evidence That Penicillin Prophylaxis Prevents RHD
- When Should We Consider Oral Penicillin For RHD Prophylaxis? Emerging Evidence And Recommendations
- Medical Management Of RHD And Its Complications: What Is The Evidence For Our Current Practice?

#### Medical Management Of Heart Failure In The ICU

- Junior Faculty Presentation #1
- Junior Faculty Presentation #2
- Overview Physiologic /Monitoring /Diagnosis
- Imaging In Acute Heart Failure - What We Need To Know
- Kidneys, Lungs And End Organs In ACHF
- Post Op Acute Heart Failure In CHD - Surgeons View (Prevention - Protection Included)
- Medical Treatment Of LCOS And Cardiogenic Shock
- Surgical Treatment Of Cardiogenic Shock And Devices
- Moving Heart Failure Research Forward In The Cardiac Critical Care Unit

#### Imaging Of The Right Ventricle In Congenital Heart Disease

- The Right Ventricle: Why Is It Different? Why Is It Vulnerable?
- The Volume-Loaded RV: Predicting Failure
- The RV In Pulmonary Hypertension
- The Dysynchronous Right Ventricle
- The Systemic RV In A Biventricular Circulation
- The Systemic RV In Functionally Single Ventricle Circulation
- The Small RV: When To Quit, When To Recruit
- Ebstein Anomaly Of The Tricuspid Valve: What Matters To The Cardiologist And To The Surgeon?

#### Cardiac Catheterization On A Global Scale: Regional Challenges And Opportunities

- Lectures In Honor Of Kanishka Ratnayaka: Establishing Pediatric Cath In East Africa
- Developing A Pediatric Cath Lab In East Africa - View From Africa
- Developing A Pediatric Cath Lab In East Africa - View From NGO
- Lessons Learned For Developing Sustainable Interventional Programs Around The World
- Global Collaborative Efforts
- Cathchat, Remote Teaching And Learning Platform For Interventional Paediatric Cardiac Catheterization In Low Resource Environments
- IQIC Cath Registry: Role Of International Cardiac Catheterization Quality Collaboratives
- Clinical Challenges In LMICS
- Need For Hemodynamic Cath In Older Patients With Left To Right Shunts
- Utilization Of Interventional Devices In LMIC: Challenges And Opportunities
- Role Of Interventional Cath In RHD





## Monday, August 28, 2023 *Continued*

### Block 4: 2:00 pm – 4:15 pm *Continued*

#### Achieving Our Right To Health: Advocacy For Change

---

- High Quality CHD And RHD Care As A Human Right
- Gender, Income, And Racial Disparities In CHD Care
- Leveraging Government Health Funding: The Kenya Mended Hearts Model
- Beyond Screening To Surveillance
- From Advocacy To Activism: Protest As A Tool For Change
- Public/Private Partnerships In Mexico
- When Governments Fail: CHD In Lebanon

#### Discovery & Beyond For Basic & Translational Scientists

---

- Pediatric Cardiology: Discovery To Translation
- Training The Next Generation Of Translational Researchers
- Biobanks For Sustainable Research In CHD
- Stem Cell Platforms For Regenerative Medicine
- From Concept To: Three Decades Understanding Congenital AV Block

#### Driving Interdisciplinary Excellence In Heart Center Teams

---

- Planning For The Future: Leveraging The APP Role
- Driving Operational And Clinical Excellence With Interprofessional Heart Teams
- Mitigating Fears And Stressors Of Trainees And Junior Faculty
- Investing In Nursing, Matters To Patient Outcomes
- Opportunities For Improvement: Building On Mistakes
- A Backwards Look To The Future: What I Think Will Ultimately Drive Excellence

#### Implementing Quality Improvement In The Cath Lab

---

- Can Cath Lab Standards Be Applied Globally?
- You Improve What You Measure: Past, Present, And Future Of Outcome Metrics
- The Collective Wisdom: Benefits And Gaps In Current Registries.
- Panel And Audience Discussion: Registries And Outcome Metrics – What Is The Perception In The Community?
- Keeping Patient's Safe: Sedation Vs General Anesthesia
- Anesthesia: We Have A Problem!
- Periprocedural Risk Scoring: Development And Implementation
- Human Engagement: A Key Element In Quality Improvement

#### The Pediatric Heart Network (PHN) And Pediatric Cardiac Genetics Consortium (PCGC): Past Successes And Future Directions

---

- PHN Resources For The Community
- Landmark PHN Trials
- Current PHN Priorities
- The Future Of The PHN And Pediatric Cardiovascular Research
- De-Novo Variants And Neurologic Outcomes In Congenital Heart Disease
- Opportunities For Collaborative Investigation Of The Impact Of Genetics On Clinical Outcomes In CHD: A Large-Scale Database Integrating Electronic Health Records With Genomic Data
- Genomic Analysis Of 11,000 CHD Patients Identifies A Core Set Of CHD Genes
- Future International Collaborations To Understand The Heterogeneity Of Congenital Heart Disease

#### In The Anatomy Lab: Ventricular Septal Defects

---

- Formal Heart Specimen Demonstration
- Informal Hands On With Specimens
- Imaging Correlation



## Monday, August 28, 2023 *Continued*

### Block 4: 2:00 pm – 4:15 pm *Continued*

#### Common Syndromes With CHD: Critical Information In 2023

---

- Williams Syndrome
- Down Syndrome
- Turner Syndrome
- DiGeorge Syndrome
- Noonan Syndrome
- Alagille Syndrome

### Break and Visit Exhibits and Posters: 4:15 pm – 4:45 pm

### Block 5: 4:45 pm – 6:15 pm

#### Management Of the PDA in Very Tiny Babies: Does it Need Closure? If So, How?

---

- Why Is There So Much Controversy Around Preemie PDA Management?
- Top 5 Things That Drive Me Crazy About Neonatologist's Management Of The Ductus
- Defining The Hemodynamically Significant PDA: Imaging Considerations Before, During, And After Closure
- After Decades Of Success Are We Really Abandoning Surgical Ligation Of Preemie PDA?
- Is Catheter-Based Closure All Its Cracked Up To Be Or Is It Just The Shiniest New Toy In Our Toybox?

#### Rethinking Hypoplastic Left Heart Syndrome

---

An interactive panel of experts, where each speaker presents one slide with their perspective: what should we keep doing, what should we start doing, and what should we stop doing? The discussion to follow is likely to raise more questions than it answers!

- The Early Days of the Norwood Operation
- Fetal Considerations
- Preoperative Care
- Surgical Management
- Anesthetic Management
- Postoperative Care
- HLHS and the Brain
- Follow-Up Strategies
- Evolving Role of Cath
- Adults with HLHS
- Patient and Family Perspectives
- Given Current Outcomes, Is Comfort Care Still an Ethical Option?

#### Adult Congenital Heart Disease: Where Is the Evidence?

---

- Prevention Of Thromboembolic Events In Fontans: Warfarin, NOAC, ASA Or Nothing?
- Transition Programs: Do They Actually Reduce Gaps In CHD Care?
- Coronary Artery Anomalies: When To Refer To The Surgeon?
- Sudden Death In Subaortic RV: What Is The Role Of ICD In Primary Prevention
- Pulmonary Vasodilators In Fontans: Really?
- Pushing The Envelope: Controversies In Therapy For Shunt-Mediated PAH



## Monday, August 28, 2023 *Continued*

### Block 5: 4:45 pm – 6:15 pm *Continued*

#### Around The World In 90 Minutes: Using Registries, Surveys, Big Data To Track CHD Outcomes (Developed with the Centers for Disease Control and Prevention)

- Intro To Using Registries, Surveys, And Big Data To Track Long-Term Outcomes In CHD
- Clinical #1: Pediatric Cardiac Care Consortium
- Clinical #2: Australian And New Zealand Fontan Registry – Long-Term Clinical Outcomes Of Fontan Patients >16 Years Old And In Care
- Clinical #3: Cardiac Networks United
- Clinical #4: PROTEA CHD Registry
- Survey #1: CH STRONG – The Multi-Center Survey Re: Long-Term ACHD Outcomes In United States Coordinated By CDC
- Survey #2: APPROACH IS – International Multicenter Project On Patient-Reported Outcomes From 16 Countries
- Population #1: Quebec Registry Of CHD
- Population #2: Using The Danish Health Register For CHD Research

#### A Roundtable Discussion on Prevention, Research, Advocacy and Policy: Applying Solutions to Health Inequities in the USA and Globally

- A Comprehensive, Interdisciplinary Session With 14 Moderators And Panelists.

#### Health Systems and Pediatric Heart Disease

- Epidemiology: When Is The Right Time To Establish A CHD Program?
- Public Health Policy: How The Government Sets Priorities In Pediatric Cardiac Care
- Doing The Math: Capital Costs, Coverage Of Services, Pricing Of Supplies
- Pediatric Cardiac Services Guidelines: The Global Initiative For Children's Surgery
- Lessons Learned From The Lancet Commission On Global Surgery And The National Surgical, Obstetric And Anesthesia Plans

#### Surgical Videos Session 1

- Six Video Presentations With Discussion And Audience Participation

#### Anatomy Lab: Integration of 3D Printing and Advanced Visualization for Interventional and Surgical Planning



*Photo from the 6th World Congress of Pediatric Cardiology and Cardiac Surgery – Cape Town 2013*



*8th World Congress of*  
Pediatric Cardiology *and* Cardiac Surgery

**Tuesday, August 29**



## Tuesday, August 29, 2023

Block 5.5: 7:00 am – 7:30 am

### Pediatric Cardiac Research Initiative in Imaging to Support Mentoring: (PRIISM) SESSION #1

- Introduction to PRIISM
- How can I use Big Data and Registries for CHD Research? – Panel Discussion

Block 6: 7:30 am – 9:15 am

### Landmark Lectures

- Lessons Learned from Multicenter Collaborative Studies
  - Jane Newburger MD, MPH (USA)
- The Long Road to a Life-Saving Therapy: Catheter Ablation for Cardiac Arrhythmias
  - Edward P. Walsh MD (USA)
- 2023 Leadership Insights To Create a More Inclusive Work Environment.
  - Patricia Hickey PhD, MBA, RN, CHPQ, NEA-BC, FAAN (USA)
- Title TBD
  - Katarina Hansesus MD (Sweden)

### Featured Plenary Session of the 8th World Congress of Pediatric Cardiology and Cardiac Surgery: The Great Debates in Rheumatic Heart Disease - Where Should we Invest?

- Let's Put Our Eggs In One Basket And Invest In A Strep A Vaccine (Pro)
- Let's Put Our Eggs In One Basket And Invest In A Strep A Vaccine (Con)
- Echocardiographic Screening Is The Best Tool We Have To Reduce Global RHD Morbidity And Mortality (Pro)
- Echocardiographic Screening Is The Best Tool We Have To Reduce Global RHD Morbidity And Mortality (Con)
- Improved Tertiary Care For RHD Is The Best Approach To Save Lives (Pro)
- Improved Tertiary Care For RHD Is The Best Approach To Save Lives (Con)

### The Effects of Pain, Analgesia and Sedation on the Neonatal Brain

- The Toxic Effects Of Sedation And Analgesia In The Developing Brain: What's The Current Evidence?
- Medication And Hypotension: Which Is To Blame For Adverse Outcomes?
- Anesthesia Toxicity And Neurodevelopmental Outcomes In Neonates With Congenital Heart Disease
- Long Term Effects Of Neonatal Pain
- Building A Toolbox For Pain Management In The ICU

Break and Visit Exhibits and Posters: 9:15 am – 10:15 am





## Tuesday, August 29, 2023 *Continued*

Block 7: 10:15 am – 12:30 pm

### Nursing Science: Oral Abstracts

---

### Heart Failure, Transplantation And VAD: Oral Abstracts

---

### Rheumatic Heart Disease Oral Abstracts

---

### World Society For Pediatric And Congenital Heart Surgery With The Congenital Heart Surgeons' Society (CHSS): Congenital Coronary Arterial Abnormalities

---

- Lessons Learned From The CHSS AAOCA Registry
- Surgical Techniques For Repair Of AAOCA
- Surgical Management Of ALCAPA
- Coronary Bypass Surgery In Patients With CHD
- PA-IVS: Indications For One And Half And Biventricular Repair
- RV Dependent Coronary Circulation And LV Dependent Coronary Circulation
- Challenging Coronary Abnormalities That I Have Seen Over The Course Of My Career

### Channelopathies For The Ambulatory Cardiologist

---

- Investigating Sudden Cardiac Death: History, Family Tree, Genetic Autopsy
- Variants Of Unknown Significance (VUS): Now What?
- Syncope- When Should I Think Of Ion Channel Disease?
- Prolonged QTc On The ECG: When Should I Do Genetic Testing?
- PVCs - When Should I Think Of Catecholaminergic Polymorphic Ventricular Tachycardia?
- Genotype Positive-Phenotype Negative- Now What?
- Early Repolarization On The ECG- Any Consequences?
- My Look To The Future: Precision Medicine For Channelopathies

### Connective Tissue Disorders

---

- The Genetics Of Aortopathies
- Medical Management In 2023
- Building A Multidisciplinary Aortopathy Clinic
- Echocardiography In Aortic Aneurysmal Disease
- Advanced Imaging Of The Thoracic Aortic Aneurysm Patient
- Surgical Indications And Strategies In Aortopathy
- Aortopathy Associated With Congenital Heart Disease
- Aortopathies As A Model For Rare Cardiovascular Disease Research

### Multimodal Imaging Of Aortic Coarctation & Tetralogy Of Fallot

---

- Aortic Coarctation: Fetal CMR Evaluation
- Aortic Coarctation: 4D Flow In Aortic Assessment
- Aortic Coarctation: Computational Flow Dynamics In Aortic Assessment
- Aortic Coarctation: Finite Element Analysis And Stent Deployment - Lessons From TAVR
- TOF: Biventricular Myocardial Adaptation In Patients With Repaired Tetralogy Of Fallot: Mechanistic Insights From Magnetic Resonance Imaging - Tissue Phase Mapping
- TOF And MRI: The End Of The Golden Years Of Volume Assessment, What's Next?
- TOF: Computational Modeling And Simulation
- TOF: Imaging Predictors For Survival In Tetralogy Of Fallot



## Tuesday, August 29, 2023 *Continued*

### Block 7: 10:15 am – 12:30 pm *Continued*

#### Non-PPHN: Pulmonary Hypertension In The Neonate

- Case Presentation
- Pulmonary Hypertension In The Neonate: How To Use The Guidelines (WHO/NICE/NICHHD)
- Life-Threatening PPHN Refractory To Nitric Oxide: Proposal For A Rational Therapeutic Algorithm
- Beyond Ultrasound: Advanced And Invasive Diagnostics For The Neonate With PH
- Chicken Or The Egg: Pulmonary Hypertension And Congenital Heart Disease
- One Disease, Two Pathologies: Chronic Lung Disease And Pulmonary Hypertension
- Pulmonary Vein Stenosis; A Rare Disease Or Rarely Diagnosed?
- PH In Resource Limited Settings; What To Do When I Can't Follow The Guidelines?
- PPHN And The Perinatal Environment

#### The State Of The Art In Cardiac Neurodevelopment Part 2: New Frontiers

- Cardiovascular Genetics And Neurodevelopmental Outcomes
- Health Disparities In Neurodevelopmental Outcomes In CHD
- A Novel Team Approach To Neurodevelopmental Follow-Up In Complex CHD
- Development Trajectories In Children With Heart Disease
- Supporting Neurodevelopment In Children With CHD: A Nursing Perspective
- Navigating Neurodevelopmental Needs In Children With Heart Disease: Patient And Parent Perspectives
- Quality Of Life In Congenital Heart Disease Survivors

#### The Power Of Patient/Provider Partnerships

- Patient And Family Engagement: Beyond Checking The Boxes
- The Basics Of Patient-Centered Research: How To Do It Right
- CHD, Transparency, And Public Reporting
- Access To Care: The Congenital Heart Public Health Consortium
- The Remedy Study: From Subjects To Participants
- Promoting Quality: ACHD Program Accreditation
- Round Table Discussion: How Do We Go Beyond "Checking The Boxes?"

#### Quality Improvement On A Global Scale

- Improving The Quality Of The Team: Developing A Perfusion Course For LMICs - The IQIC Experience In Latin America
- Improving The Quality Of The Team: Training Perfusionists To Improve Quality Of Care
- Measuring What Matters Most: Value-Based Care - The ICHOM CHD Standard Set
- Panel Discussion
- Leveraging Our Data And Networks: Quality Improvement On A Global Scale - The Story Of The IQIC
- Leveraging Our Data And Networks: Reducing Average Ventilation Time In The PCICU By 30%
- Leveraging Our Data And Networks: Quality Improvement Programs In Resource-Limited Settings
- Improving Quality By Maintaining And Supporting The Multidisciplinary Team In A Public-Private Partnership





## Tuesday, August 29, 2023 *Continued*

### Block 7: 10:15 am – 12:30 pm *Continued*

#### Recent Advances In Pediatric Cardiac Anesthesia

---

- Hematocrit, FIO<sub>2</sub>, And Temperature On Cardiopulmonary Bypass
- Anesthetic Management For VAD/ECMO Coming For Noncardiac Procedures
- Perioperative Blood Management
- Role Of POCUS In The Cardiac OR
- Technology And Monitoring Advances
- Can We Measure Cardiac Output With The Ventilator?
- Recruitment Maneuvers In Patients With Congenital Heart Disease
- ERAS And Local/Regional Anesthetic In Cardiac Surgery

#### Electrophysiology In Cardiomyopathies: What Is New? (With Latin American Heart Rhythm Society)

---

- Current Status Of Pediatric Electrophysiology In Latin America:
- Role Of The Electrophysiologist In Managing Restrictive Cardiomyopathy And Left Ventricular Non-Compaction
- Unusual And Atypical Cardiomyopathies (Purkinje Cell And Others)
- Treatment Of Atrial And Ventricular Arrhythmias In Dilated Cardiomyopathy: What To Ignore And What To Treat?
- Bringing The Bench To The Bedside: Lessons I Have Learned On Arrhythmias
- Dilated Cardiomyopathy: Do Adult ICD Guidelines Apply To Pediatrics?
- Arrhythmogenic Right Ventricular Cardiomyopathy: Evaluation And Management In Children

#### Sexual & Reproductive Health In Adults With CHD

---

- I Have Congenital Heart Disease And This Is My Pregnancy Story
- Prioritizing The Patient Voice
- Risk Stratification In Patients Desiring Pregnancy
- Aortic Concerns In Turner Syndrome: What Are The Risks During Pregnancy?
- Management Of Pulmonary Hypertension In Pregnancy
- Regional Variation: Results From The ROPAC Registry On CHD Pregnancy Outcomes
- Complex Pregnancy Program Building: Focus On Developing Nations
- Transgender Health Care In ACHD

#### Challenges In Administration

---

- Leadership And Workforce Challenges In Interprofessional Heart Teams
- Building A Heart Center: Restructuring And Leading Change
- Dealing With Difficult Team Member Behaviors
- Is A Longitudinal Mind–Body Skills Program Feasible And Effective For Pediatric Cardiac Staff?
- Cultivating Culture, Engagement, And Teamwork In Your Heart Center
- Challenge And Satisfaction Of Forming A New Hospital

#### In The Anatomy Lab: Atrioventricular Septal Defects

---

- Formal Heart Specimen Demonstration
- Imaging Correlation
- Informal Hands On With Specimens

#### What's New In Perfusion?

---

- Strategies To Minimize Blood Usage
- ECMO Transport
- The Quest For The Perfect CPB Prime
- The Trials And Tribulations Of Establishing And Maintaining An ECMO Program
- Perfusion Considerations For The Complex Adult Congenital Patient
- AMSECT Standards And Guidelines; Acceptance And Application
- Perfusion Technique For An 800g Premature Neonate Undergoing Repair Of TGA
- Global Perspectives: Interactive Discussion Focusing On Current Topics In Pediatric Perfusion Practice Worldwide.



## Tuesday, August 29, 2023 *Continued*

Block 7: 10:15 am – 12:30 pm *Continued*

### Basic And Translational Science In Congenital Cardiac Disease

---

- Brain: Bench To Bedside
- Does Anesthesia Impact Your Immune System?
- Connecting The Research Laboratory To The Operating Theater 1
- Connecting The Research Laboratory To The Operating Theater 2
- Connecting The Research Laboratory To The Operating Theater 3
- Extraordinary Measures (My View)
- Extraordinary Measures (My View)

### Hot Topics In ECMO

---

- Cardiac ECMO: Where Are We Now
- Technology And Innovation In ECMO
- ECMO For The Postoperative Single Ventricle
- ECPR: Indications, Clinical Decision Making And Ethics
- Rehabilitation And Mobility On ECMO
- Disparities And Inequities In ECMO Clinical Decision Making
- ECMO In Low Resource Countries
- Hematologic Emergencies On ECMO



Plenary Session from the 7th World Congress of Pediatric Cardiology and Cardiac Surgery Barcelona 2017



## Tuesday, August 29, 2023 *Continued*

**LUNCH BREAK – Visit the Exhibits and Visit the Posters: 12:30 pm – 2:00 pm**

**Small Group Lunch Sessions: 12:45 pm – 1:45 pm**

### Training The Next Generation: Invasive Hemodynamics

- Hemodynamic Concepts Of ACHD: Definition And Method Of Assessment
- How To Assess Shunts And Calculate PVR: Doing Things Right
- Invasive Hemodynamics In Single Ventricle Physiology: Impact On Decision Making
- Valvular Interventions: Role Of Invasive Hemodynamics

### Bringing Basic And Translational Science To The Bedside And OR - Part 1: Tissue Engineering

- Tissue Engineered Vascular Grafts
- Tissue Engineered Heart Valves
- Regenerative Therapy For Hypoplastic Left Heart Syndrome

### Surgical Videos Session 2

- VSD Repair In Children With Severe Pulmonary Hypertension And Elevated PVR By The Double Or Traditional Patch Technique
- Cryopreserved Valved Femoral Vein Homografts For Right Ventricular Outflow Tract Reconstruction In Infants
- My Favorite Operation

### Nightmare Cases In Electrophysiology

- Four Cases and Audience Discussion

### Strep And Sustenance: An Interactive Case-Based Rheumatic Heart Disease Discussion For Resource Limited Settings

- Case 1: When To Wait, When To Repair, When To Replace. Severe RHD In The Very Young
- Case 2: Mixed Valve Disease In The Young, Considerations For Optimizing Outcomes
- Case 3: Determining Optimal Management Of RHD In A Young Woman

### Quality Improvement And Enhancing Safety In CPB

- How Can Perfusion EMR Systems Improve Outcomes And Decrease Variability?
- The Pedi Perform Learning Network, Where Are We?
- Global Perspectives: Interactive Discussion Focusing On Pediatric Perfusion Quality Improvement And Perfusion Practice Worldwide

### In The Anatomy Lab: Computational Modeling For CHD: Anatomy And Physiology Integration

### Health Care Primer For Big Data And Artificial Intelligence

- History Of Artificial Intelligence
- Introduction To Big Data
- Machine Learning
- Deep Learning
- Convolutional Network
- Federated Learning
- Data Sharing
- What Is Next In Artificial Intelligence?



## Tuesday, August 29, 2023 *Continued*

Block 9: 2:00 pm – 4:15 pm

NICU, PICU, CICU, ECMO: Oral Abstracts

---

Cardiac Catheterization: Oral Abstracts

---

Electrophysiology: Oral Abstracts

---

World Society For Pediatric And Congenital Heart Surgery With The American Association For Thoracic Surgery (AATS): Transplantation, Ventricular Assist Devices, And Extracorporeal Membrane Oxygenation

---

- Update On Pediatric Heart Transplantation And Mechanical Bridge To Heart Transplant
- Update On Pediatric Lung And Heart-Lung Transplantation
- Pediatric ECMO: Overview Of Indications And Clinical Experience
- Pediatric VAD's: Overview Of Indications And Clinical Experience
- Total Artificial Heart In Infants
- Ventricular Assist Devices For Single Ventricle
- Pediatric Mechanical Circulatory Support: The Future

Exercise: Restrictions And Prescriptions

---

- Adiposity In CHD: Is It More Than Just Fast Food
- Exercise Prescription: Risk For Me Or The Patient
- Exercise Training In CHD: Guidelines And Evidence
- Determining Risk: Exercise Testing.....Who, When, And What
- Connection Between Exercise And Improved Mental Health
- Exercise And CHD: Unique Physiologic Benefits & CV Risk Reduction
- Exercise And CHD: Using Shared Decision Making In The Clinic
- Sports Participation Should Be Based On Individual Functional Hemodynamics Not Lesion Based

Inflammatory Heart Disease: Part 2

---

- What's New In Etiology And Pathophysiology Of Kawasaki Disease
- Treatment In The Acute Phase Of Kawasaki Disease
- Long-Term Management Of Kawasaki Disease
- Chagas Disease
- Lyme Disease
- Human Immunodeficiency Virus (HIV)
- COVID-19 And The Athlete
- MIS-C





## Tuesday, August 29, 2023 *Continued*

### Block 9: 2:00 pm – 4:15 pm *Continued*

#### Cardiac Nursing: Improving Outcomes And Care

---

- Empowering Nurses To Improve Quality And Patient Safety
- Technology And Safety: ECLS And ECPR Education And Competency
- Improving The Quality Of Care In Developing Countries
- Nurse Led Collaboration: The C4-MNP (Consortium Of Congenital Cardiac Care-Measurement Of Nursing Practice) Experience
- Data Driven Strategies For Mitigating Risks And Improving Quality
- Cardiac Arrest Prevention
- Education Of Cardiac Nurses: Global Challenges And Opportunities
- A Role For Patients And Families In Outcomes Improvement

#### Cardiac Catheterization In ACHD

---

- Pushing The Limits In Transcatheter Interventions For Aortic Coarctation. When And When Not To Stent?
- Transcatheter Interventions For Atrioventricular Valve Dysfunction Are Here To Stay - Who Wins, Who Loses?
- Transcatheter RV Outflow Tract Rehabilitation: Which Device For Which Patient?
- Transcatheter Mechanical Support For Heart Failure
- Transcatheter Closure Of Sinus Venosus Defect – Can We Do It? Yes, We Can! Who? Why? How? When?
- Invasive Fontan Hemodynamics – Uncovering The Hidden Truth Of The Fontan Response To Exercise
- Failing Fontan Circulation - Cardiac Rehab Begins In The Cath Lab
- Upstream Management Of Congenital Aortic Valve Stenosis: Role Of TAVR In ACHD Patients?

#### New And Emerging Echocardiographic Modalities

---

- Frontiers And Innovation: Where Is Echo Going?
- High Frame Rate Imaging: Fast And Furious?
- 3D Printing From Echo Datasets: Virtual And Extended Reality
- Pediatric Stress Echocardiography: Evolving Techniques And Indications
- Deep Learning And AI In ECHO
- Echocardiographic-Fluoroscopic Fusion Imaging: Application In CHD Interventions
- Intracardiac Flow Imaging By Echocardiography: Are We There Yet?
- Myocardial Work: The Holy Grail Of Ventricular Performance?

#### Practical Practice In ACHD: How I Do It

---

- How Do I Manage The Failing Subaortic RV?
- How Do I Risk Stratify For Sudden Arrhythmic Death?
- How Do I Care For Patients And Families At The End Of Life?
- How Do I Assess For Pulmonary Hypertension In CHD
- How Do I Titrate Pulmonary Hypertension Therapy?
- What Are The Red Flags For Procedures In Patients With Cognitive Deficits?
- How Do I Support Mental Health In The Inpatient Setting?
- How Do I Support Patients With Low Health Literacy?
- How Do I Prevent Loss To Follow-Up?

#### Pulmonary Hypertension: Basics & Beyond In 2023

---

- How To Make The Correct Diagnosis Of Pediatric PAH
- Echocardiographic Evaluation Of The Pediatric PAH Patient
- Catheterization Of The Pediatric Patient With Severe PAH: Tips And Pitfalls
- Operability In Congenital Heart Disease With Pulmonary Hypertension
- Prognostic Markers In Pediatric PAH
- What Have We Learned From Registries In Pediatric PAH
- Genetics Of PAH
- Managing PH In A Large Country With Diverse Resources
- New And Emerging Medical Therapies



## Tuesday, August 29, 2023 *Continued*

Block 9: 2:00 pm – 4:15 pm *Continued*

### Global Perspectives On Cardiac Neurodevelopment

- Strategies For Abbreviated Neurodevelopmental Screening In CHD
- Strategies To Support Development When Multidisciplinary Neurodevelopmental Evaluation Is Not Available
- Health Related Quality Of Life And Family-Centered Care: Perspectives For Low-Middle Income Countries
- USA Perspective
- Canadian Perspective
- Indian Perspective
- Asian Perspective
- European Perspective
- Mexican Perspective
- Australia/New Zealand
- Middle Eastern Perspective
- Parent Perspective

### Providing Comprehensive And Available Imaging On A Global Scale

- Starting A Fetal Echo Program From Scratch
- Global Perspectives On Impact Of Prenatal Diagnosis On Planning And Outcomes
- Novel Modes Of Teaching Imaging Skills – What Has The Pandemic Taught Us
- Task Shifting To Non-Physician Health Care Workers – Expanding The Reach Of Ultrasound Across The Globe
- Using Telemedicine To Close Gaps In Echocardiography Availability In LMICs
- Echocardiography Screening For Rheumatic Heart Disease – What Have We Learned?
- Artificial Intelligence For Echocardiography Image Acquisition And Diagnosis Of Rheumatic Heart Disease

### Multimodal Imaging Of Single Ventricle, DORV And TGA

- Single Ventricle: Multimodal Imaging In The Decision Making For Biventricular Conversion
- Single Ventricle: Hybrid Cath-MRI In Single Ventricle: Lessons Learnt
- Single Ventricle: Myocardial Mechanics And Fibrosis In Single Ventricle Care
- Single Ventricle: Lymphography
- Double Outlet RV: How Has Imaging Improved Anatomical Knowledge?
- Double Outlet RV: 3D Printed Models, VR And Advanced Visualization: What Surgeons Want To Know
- Multimodality Assessment Of Postoperative TGA

### In The Anatomy Lab: Tetralogy Of Fallot

- Formal Heart Specimen Demonstration
- Imaging Correlation
- Informal Hands On With Specimens





## Tuesday, August 29, 2023 *Continued*

Break and Visit Exhibits and Posters: 4:15 pm – 4:45 pm

Block 10: 4:45 pm – 6:15 pm

### Delivering Congenital Cardiac Surgical And Intensive Care Services On A Global Scale

---

- Disparities In Cardiac Surgery: Advocating For 6 Billion People Without Access To Care
- Overcoming Systemic Challenges To Develop A Multidisciplinary Team
- A Public-Private And Patient Partnership To Develop A Cohesive Pediatric Cardiac Team
- Challenges Of Building And Maintaining A Surgical Team In Resource-Limited Setting
- Teamwork In Low Socioeconomic Countries
- Education And Training At Global Scale
- Improving The Preoperative Condition Of Neonates And Infants - A Special Challenge Of Low-Resource Settings
- Cardiac Surgery In The Developing World: Matching Patient Selection To Longitudinal Care.

### Surgery And Cath In Tiny Babies: Why?, When?, How?

---

- Which Is More Important For A Successful Operation, Weight Or Gestational Age?
- What To Do With All Those Other Immature Organs; Pearls To Avoid A Bad Situation
- ECMO In Neonates: Advances And Outcomes
- Unique Challenges Of Catheter Intervention In The LBWB: A Nursing Perspective
- Transcatheter Approaches To Augmenting Pulmonary Blood Flow In LBW Infants
- Neonates Coming For A Cardiac Procedure: Anesthetic Considerations
- Hemostatic Profile Of Low-Birth-Weight Babies: Is Weight Or Gestational Age More Important?

### Featured Plenary Session On Neurodevelopment In Children And Adults With CHD

---

- Cardiac Neurodevelopmental Outcomes Collaborative: Leadership Update #1
- Cardiac Neurodevelopmental Outcomes Collaborative: Leadership Update #2
- Present Research Aims From The Registry Or RFA
- Looking Ahead: Where Should We Be In 10 Years? (R13)
- The Annual Newburger-Bellinger Lecture

### Arrhythmias: The “Benign (And Not-So Benign)” In Children

---

- Normal Heart & The Bradycardia I Should Worry About
- ECG Findings: What Not To Miss!
- My Sixth Sense Approach To The Concerning Faint
- Preexcitation In The “Asymptomatic Patient” - Management In 2023
- Things I Learned As An Electrophysiologist On The Treadmill
- Antiarrhythmic Management Of SVT: In Whom And How?

### Update From The Centers For Disease Control: Effect On The Young Heart From COVID-19 And Other Infectious Diseases (Developed With The CDC)

---

- COVID #1: COVID Considerations Among Children With Congenital Heart Disease
- COVID #2: Multisystem Inflammatory Syndrome
- COVID #3: Myocarditis
- Global Health: How Does The Centers For Disease Control And Prevention Prevent And Control Disease?
- Global Health #1: Chagas
- Global Health #2: Lyme Carditis



## Tuesday, August 29, 2023 *Continued*

### Teamwork, Culture Change, And Strategy

---

- Belonging
- I Was The Problem
- The Role Of The PICU Director In Keeping The Squad Happy
- Surgical Leadership 1
- Military Leadership
- Shared Governance
- Ubuntu: Holistic Care
- Calling Out Bad Behavior
- Surgical Leadership 2

### In The Anatomy Lab: Image Fusion And Overlay

---





*8th World Congress of  
Pediatric Cardiology and Cardiac Surgery*

**Wednesday, August 30**



## Wednesday, August 30, 2023

Block 10.5: 7:00 am – 7:30 am

### Pediatric Cardiac Research Initiative in Imaging to Support Mentoring: (PRIISM Session 2) Putting Therapies to the Test

- Introduction to PRIISM
- How can I successfully initiate a CHD clinical trial?
- Panel Discussion

Block 11: 7:30 am – 9:15 am

### Landmark Lectures

- The Great Orchestra of the Christmas Charity Fund. Thirty years of Saving Children's Lives in Poland.
  - Bohdan Maruszewski, MD (Poland)
- Equity for All: It's Time for a Population Health Approach to Pediatric and Congenital Heart Disease.
  - Bistra Zheleva (USA)
- Looking to Our Past to Plan the Future
  - David Wessel MD (USA)
- Pediatric Cardiac Anesthesiologists: An Endangered Species
  - Susan Nicolson MD (USA)

### Conversations With Our Nursing Giants: Advice To Myself If I Started Over

- Patricia Hickey PhD, MBA, RN, CHPQ, NEA-BC, FAAN
- Martha AQ Curley RN, PhD, FAAN
- Nancy Pike PhD, RN, CPNP-AC/PC, FAHA, FAAN
- Sandra Staveski MS, PhD, RN, APRN, CPNP-AC
- Jean Connor PhD, RN, CPNP, FAAN
- Karen Uzark PhD, RN
- Kathleen Mussatto PhD, RN

### PediRhythmx Taped Electrophysiology Cases Session #2

- Exceptional Approach For (Hybrid-) Ablation Of Exceptional Accessory Pathways
- Epicardial Ablation
- Hybrid Surgical Ablation Of VT In TOF Re-Do-Surgery
- SVT

Break and Visit Exhibits and Posters: 9:15 am – 10:15 am

*Embedded  
Societies &  
Post-Graduate  
Courses*





## Wednesday, August 30, 2023 *Continued*

Block 12: 10:15 am – 12:30 pm

### Adult Congenital Heart Disease: Oral Abstracts

---

### Cardiac Anesthesia: Oral Abstracts

---

### Fetal Cardiology: Oral Abstracts

---

### World Society For Pediatric And Congenital Heart Surgery With African Society For Pediatric And Congenital Heart Surgery: Global Initiatives

---

- The Development Of The World Society
- World University For Pediatric And Congenital Heart Surgery
- The World Journal For Pediatric And Congenital Heart Surgery
- The World Database For Pediatric And Congenital Heart Surgery
- World Society Focus On Africa: Status Of Neonatal And Infant Cardiac Surgery
- Global Council For Education In Congenital Heart Surgery

### Ethical Issues In Pediatric And Congenital Cardiac Care

---

- Innovation In Fetal Interventions: Is There An Ethical Conundrum?
- Ethical Considerations In The Evolution In Care For Trisomy 13 And 18
- Identifying Health Inequities In Cardiac Critical Care In USA: What Is To Be Done?
- Candidacy Versus Cannulas? The Ethics Of ECMO Candidacy Decisions
- Xenotransplantation Revisited
- Is It Ethical To Offer CHD Surgery In Resource Limited Settings
- Artificial Intelligence In Cardiac Care: Do We Risk Algorithmic Paternalism?

### Featured Topics In Cardiac Nursing: Challenging Cases And Issues From Around The World

---

- Eight Challenging Cases to Be Discussed By An Expert Panel

### Developmental Care For Inpatients With CHD

---

- A Parent's Perspective: What I Wish I Knew Earlier
- Why Care About Developmental Care?
- Back To Basics: Human Touch, Holding, And Skin-To-Skin Care
- Infants Talk To Us: Behavioral Assessment And Cue-Based Care
- Developmentally Supportive Feeding And Nutrition
- Supporting The Older Child In The ICU: Sleep, Mobility, Exercise, Academics, And Emotional Support
- Family-Centered Care: Have We Arrived?

### Ambulatory Cardiology Debates

---

- Exercise Should Be A Prescription For All Forms Of Congenital Heart Disease (PRO)
- Exercise Should Be A Prescription For All Forms Of Congenital Heart Disease (CON)
  - Audience Voting/Discussion
- Pediatric Exertional Chest Pain Requires Echocardiography (PRO)
- Pediatric Exertional Chest Pain Requires Echocardiography (CON)
  - Audience Voting/Discussion
- Pediatric Stress Testing: Underappreciated Or Less Than Adequate (PRO)
- Pediatric Stress Testing: Underappreciated Or Less Than Adequate (CON)
  - Audience Voting/Discussion
- Dysautonomia Is Best Managed By The Cardiology Team (PRO)
- Dysautonomia Is Best Managed By The Cardiology Team (CON)
  - Audience Voting/Discussion



## Wednesday, August 30, 2023 *Continued*

### Block 12: 10:15 am – 12:30 pm *Continued*

#### The Administrator-Physician Dyad

---

- The Service Line - What Is It? Can It Work?
- Optimizing The Relationship Between The Central Administration And The Physician Staff - Obstacles, Challenges, And Solutions
- The Leadership Triad - Cardiologist, Surgeon, And Administrator - How To Make It Work
- Helping Administrators Understand What We Do - All Intensivists Are Not Equal
- Building Trust Amongst Stakeholders And Optimizing The Culture In The Heart Center
- Synergy Between Cardiology Leadership And Administrative Leadership - How To Make Ostensible Competing Interests Work And How To Promote Synergy
- Why Can't We All Get Along? Natural Areas Of Contention And Tricks To Solve This
- The Five Dysfunctions Of A Team And How Cardiology-Administrative Leadership Can Make It Functional

#### Outpatient Echocardiography Potpourri

---

- Utility Of Telemedicine In Pediatric Echocardiography
- POCUS: Is The Stethoscope Really Dead?
- Long-Term Cardiac Functional Surveillance After Chemotherapy And Immunotherapy
- Screening For Rheumatic Heart Disease: A Long Road Ahead
- Sequelae Of COVID Infection And Vaccines: What Does Echo Tell Us?
- Restrictive, Hypertrophic, And Non-Compaction Cardiomyopathies: What Is Abnormal?
- Imaging Of The Fontan Patient In Clinic: What Should We Be Looking For?

#### Local Solutions To Address Global Disparities

---

- Population Health Approach To CHD - Reaching SDG 3 By Addressing Infant Mortality
- Academics And Research: The Forgotten Component Of Capacity Building
- NGO Partnerships For Building Capacity
- Home-Grown Capacity
- South To South Collaboration
- Developing A National Plan For Pediatric Cardiac Services
- Workforce Planning - Training The Next Generation Of Pediatric Cardiac Professionals
- Innovative Financing

#### The Emerging Science For RHD Control

---

- RHD Registries - What Have We Learned From PURE And INVICTUS?
- RHD Is Largely Genetic: What Do The Facts Support?
- The Pathogenesis Of ARF, What Have We Learned?
- Can Immunomodulators Improve Outcomes In Acute Rheumatic Fever?
- Scalable Patient-Facing Supports To Improve Prophylaxis Adherence
- The Host Response To RHD - What Have We Learned About The Pathways To Progression?
- Omics Holds Potential To Develop A Biological Signature For Acute Rheumatic Fever
- Practical Approaches To Improve ARF Diagnosis In The Community

#### Improving Transplant Longevity And Health Related Quality Of Life

---

- Contraindications To Transplant
- Not A Transplant Candidate At Our Center, What's Next?
- Race, Ethnicity & Transplant Outcomes Around The World
- Social Support Is The Most Important Factor In Transplant Success
- Re-transplantation Is Not Common: Why Is That?
- Best Practices In Teen Care And Transition
- Balancing Hope And Realism In Discussing Transplant Survival
- Montage Of Transplant Experience



## Wednesday, August 30, 2023 *Continued*

Block 12: 10:15 am – 12:30 pm *Continued*

### Nuts And Bolts Of Pediatric Electrophysiology Devices

---

- Leadless Pacemakers
- Subcutaneous ICDs: Who, When And Why
- Single Chamber Versus Dual Chamber Pacing: A New Look At An Old Problem
- Specific Device Programming For Pediatrics/CHD
- Lead Location In Single Ventricular Lead Pacing
- Physiologic (His And Left Bundle) Pacing: Who And When
- The Adult Patient With Congenital AV Block: Does Everybody Need A Device?
- Strategies For Life-Long Pacing/ICD: Lead Extractions, Recanalizations, ...

### Challenging Topics In Pulmonary Hypertension

---

- What Do We Know About Reversibility Of PH In CHD?
- Oral Therapy In Pediatric PAH
- IV/SQ Therapy In Pediatric PAH
- PAH In Single Ventricle Heart Disease
- Management Of The Acute And Chronic Failing Right Ventricle
- Atrial Septostomy In PAH
- Potts Shunt In Pediatric PAH
- Lung Transplant In Pediatric PAH

### The Relationship Of Quality, Data, Value, Provider Buy-In And Safety

---

- Leveraging Quality And Safety To Achieve Value
- Merging Big Data And Quality Improvement - Two Great Things But Do They Go Great Together?
- Economics Of Quality Improvement: The Business Case For Quality
- Data Stewardship: Development Of Local Dashboards
- Developing An Infrastructure To Deliver High Reliable Care To Ensure Patient Safety
- Parents And Patients As Partners In Improving Cardiac Outcomes
- Bedside Nursing Impact On Quality And Patient Outcomes
- The Role Of Transparency In Achieving Improved Outcomes

### Transposition Of The Great Arteries

---

- Formal Heart Specimen Demonstration
- Informal Hands-On Specimens
- Imaging Correlation





## Wednesday, August 30, 2023 *Continued*

**LUNCH BREAK – Visit the Exhibits and Visit the Posters: 12:30 pm – 1:45 pm**

**Small Group Lunch Sessions: 12:40 pm – 1:40 pm**

### Training the Next Generation in Research

- Join 4 International Experts for an Interactive Session on How to Get Started and How to Sustain Cardiovascular Research

### Complex Arrhythmia Management (Audience Participation with the Experts)

- Lone Atrial Fibrillation In An Adolescent
- Monomorphic Non-Sustained VT in Post-Operative Chd: Is It Significant?
- Tachycardia Induced Cardiomyopathy
- Syncope With No Identifiable Relation To Arrhythmia

### How To Best Optimize Neurodevelopmental Care? A Round Table Lunch For Occupational And Physical Therapists; Speech And Language Pathologists, Child Life Specialists And Others

- Speech and language pathologists
- Occupational Therapists
- Physical Therapists
- Child Life

### Decision Making in Pediatric Cardiology-Deconstructing Dogma: Part I

- Moderator (Honorary Contrarian) and Five Panelists:
  - ▷ What is the Data That A Child with a VSD, Mild Aortic Prolapse And Mild Aortic Regurgitation Should Undergo Surgery?
  - ▷ What is the Data That A Child with a Mild Aortic Coarctation Should Undergo Intervention?
  - ▷ What Is The Data That A Patient With A Non-intramural Anomalous Right Coronary Should Undergo Surgery?
  - ▷ Should An Asymptomatic Child With An Aberrant Left Subclavian Undergo Surgery?

### Surgical Videos Session 3

- How I Do The Arterial Switch Operation
- How I Place A Pediatric VAD
- Fetal Surgery For Intrapericardial Teratoma
- How I Perform Neonatal Aortic Arch Repair

### In The Anatomy Lab - Fast Track Methods and Application of AI to VR





## Wednesday, August 30, 2023 *Continued*

Block 14: 1:45 pm – 4:00 pm

Echocardiography: Oral Abstracts

---

Nursing Clinical Inquiry: Oral Abstracts

---

Neurodevelopment: Oral Abstracts

---

Multimodal Imaging: Oral Abstracts

---

Cardiac Surgery - WSPCHS Special Lectures And  
Presidential Address

---

- Adib Jatene Lecture
- Richard and Stella Van Praagh Lecture
- Presidential Address



Evaluation And Management Of Non-Rheumatic Mitral Valve Disease

---

- Welcome And Hybrid (Patient/Physician) POV On Mitral Disease
- Case Presentation: Balanced Atrioventricular Septal Defect
  - ▷ Preoperative Imaging: Leverage The 3D Probe!
  - ▷ How To Reconstruct A Common Atrioventricular Valve
  - ▷ Late Outcomes Of Left Atrioventricular Valve Regurgitation And Subsequent Repair
- Case Presentation: Shone's Syndrome With Dominant Mitral Stenosis
  - ▷ When To Take The Patient To The Operating Room
  - ▷ Imaging To Decide Adequacy Of Left-Sided Heart Structures In Infants And Children
  - ▷ Postoperative Considerations In Young Patients Following Mitral Stenosis Repair
- Case Presentation: Young Adult With Progressive Mitral Regurgitation
  - ▷ Leverage Multimodality Imaging: Get Quantitative!
  - ▷ Inside The Surgeons Mind: When To Repair/Replace
  - ▷ Postoperative Considerations In Patients With Mitral Regurgitation

Hidden Gems: Three Things You Shouldn't Miss From My Sub-Subspecialty

---

- The Fetal Report
- The Extended Monitor
- The Cath Report
- The Treadmill
- The Echo
- The Genetic Test
- The Surgical Op Note
- The ICU Discharge Note

Special Considerations In ACHD: From The Operating Room to the Intensive Care Unit

---

- How Do I Stratify Perioperative Risks?
- Communication Challenges: Perioperative Risks And Care Directives!
- Adult Or Pediatric Hospital For My 30-Year-Old Fontan Revision?
- Late Presentation Of Congenital Heart Disease: Challenges And Strategies!
- Challenges In Resource-Limited Settings
- Revision Of Revision Surgery
- Heart Failure Treatment: What Can The Surgeon Contribute?
- Early Recovery After ACHD Surgery: Fast-Tracking



## Wednesday, August 30, 2023 *Continued*

### Block 14: 1:45 pm – 4:00 pm *Continued*

#### Hybrid Approaches In 2023

- The Hybrid Approach To Hypoplastic Left Heart & Other Complex CHD
- The Hybrid Approach To Transcatheter Heart Valves In Complex CHD
- Anesthetic Consideration For Simultaneous Catheterization And Magnetic Resonance Imaging
- Anesthesia For Hybrid Procedures
- Imaging Of The Hybrid In Hypoplastic Left Heart And Its Variants: Considerations And Complications
- Surgical Implications When Considering Hybrid Therapies.
- Hybrid Palliation For Hypoplastic Left Heart Should Only Be Offered In High Volume Centers: Pro
- Hybrid Palliation For Hypoplastic Left Heart Should Only Be Offered In High Volume Centers: Con

#### Heart Failure Vs. Electrophysiology: Case Presentations And Management Decisions From My Lens

- Case Presentation: 12-Year-Old With Dilated Cardiomyopathy and Compensated Heart Failure, Non-sustained Ventricular Tachycardia (10 Beats At Rate Of 150 BPM EF 20%) - What Would You Do?
  - Electrophysiology Perspective
  - Heart Failure Perspective
  - Panel With Audience Participation
- Case Presentation: 6-Year-Old With Dilated Cardiomyopathy, EF 35%, Compensated Heart Failure On ACE Inhibitor, Beta Blocker And Aldactone With Sinus Tachycardia 110 BPM: Would You Add Ivabradine?
  - Electrophysiology Perspective
  - Heart Failure Perspective
  - Panel With Audience Participation
- Case Presentation: 12-Year-Old With Congenital Complete Heart Block, DDD Pacemaker Since 8-Years-Old, Now With EF 48%. What Would You Do?
  - Electrophysiology Perspective
  - Heart Failure Perspective
  - Panel With Audience Participation
- Case Presentation: 16-Year-Old With Hypertrophic Cardiomyopathy, Septal Thickness 2.2 cm, No Major Risk Factors And Late Gadolinium Enhancement On MRI 20%. What Would You Do?
  - Electrophysiology Perspective
  - Heart Failure Perspective
  - Panel With Audience Participation

#### Hot Topics In Fetal Cardiology

- Late-Breaking Updates In Fetal Cardiology: Most Important Discoveries And Innovations In The Past 5 Years
- Fetal MRI: Value In Assessing Structure And Blood Flow
- Artificial Intelligence: Utility In Clinical Practice
- Maternal-Placental Influences And The Impaired Fetal Environment: Impact On Outcomes
- Oxygen Therapy In Fetal CHD: Fact Or Fiction?
- Gene Therapy—Fact Or Fiction?
- The Artificial Placenta—Fact Or Fiction?

#### Hot Topics In New Technology And Artificial Intelligence

- Wearable Biosensors In Children
- Streaming Critical Physiologic Data
- Clinical Deterioration And Machine Learning
- Clinical Stability And The Norwood
- Prediction And Beyond
- Biosensors And Artificial Intelligence
- Neural Networks And Fetal CHD
- Machine Learning And CHD



## Wednesday, August 30, 2023 *Continued*

### Block 14: 1:45 pm – 4:00 pm *Continued*

#### Quality Improvement In The CICU

- Background: Quality Improvement In The CICU (Available Registries, Overview, Collaboration)
- Implementation Science In Quality Improvement And Why It Fails (Gaps, Challenges, Personalities)
- Standardizing Care And Preventing Harm: A Nursing Perspective
- Evidence Based Guidelines: When And How To Use Them And When To Deviate
- The Balancing Measures To QI: Parental, Legal And Ethical
- How Families Can Use Quality And Transparency For Decision Making
- QI In Limited Resource Countries (Transport, Stabilization, Beds, Triaging)

#### Providing Seamless Care Across Wide Distances

- Use Of Telemedicine For Expanded Access To Clinical Cardiac Services: Uganda Case Study
- Mhealth-Based Registry To Improve Compliance With Cardiac Medications In Low- And Middle-Income Countries
- Miniaturized Ultrasound And Task Shifting For Echocardiography Screening Of Rheumatic Heart Disease
- The Virtual Pediatric Cardiac Intensive Care Unit
- A Mobile Auscultation Technology To Screen For Heart Murmurs In Children In Remote Areas
- Utilization Of Artificial Intelligence To Enhance Ultrasound And Clinical Diagnostics Around The Globe
- Care Across The Northern Lights
- How Can Hospitals And Physicians Promote And Develop The Pediatric Cardiac Nursing Staff?
- Advanced Nursing Roles In LMICs - Is This The Solution To The ICU Workforce Shortage In Low-Resource Settings?

#### Empowering Patients And Families To Thrive: Education And Support

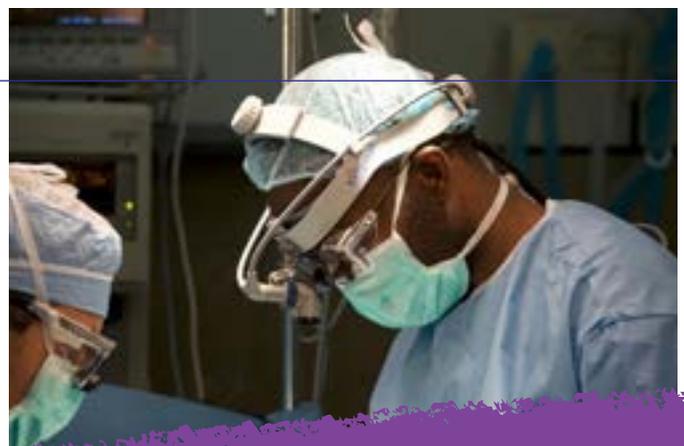
- The Principles Of Shared Decision-Making
- Patient Education In LMICs: Challenges And Opportunities
- Bridging The Gap: The Pedi Project
- Empowering Patients with Rheumatic Heart Disease In Uganda
- Partnering For Life-Long Care: #Findachd - Canada
- Fighting Stigma In India
- Round Table: Education And Support: What Do We Share? How Do We Differ?

#### Hands On ECMO Primer

- Fundamentals And Physiology Of ECMO Support
- Administrative Obstacles Of ECMO: Running A Contracting ECMO Service
- Components ECMO Circuit
- Cannulation Techniques For ECMO
- Anticoagulation And Blood Management
- Extra-Corporeal Cardiopulmonary Resuscitation
- Ethical Considerations Of ECMO Support: When To Stop

#### In The Anatomy Lab: Double Outlet Right Ventricle

- Formal Heart Specimen Demonstration
- Imaging Correlation
- Informal Hands On With Specimens





*8th World Congress of*  
Pediatric Cardiology *and* Cardiac Surgery

Thursday, August 31



# Thursday, August 31, 2023

Block 15: 4:15 pm – 6:15 pm

## Heterotaxy/Isomerism: Who's Side Are You On?

- Cardiac Anomalies
- Genetics Of Abnormalities Of Sidedness
- Non-Cardiac Anomalies
- Primary Ciliary Dyskinesia
- Twin AV Nodes Or No Nodes -An EP Approach To Atrial Isomerism
- Long Term Outcomes

## Preventative Cardiology: Part 2

- Pediatric Cardio-Oncology: Epidemiology, Screening, Prevention, And Treatment
- Psychological Counseling Is Important Prevention In Our Cardiac Patients
- Metabolic Syndrome: Bridging The Gap From Childhood To Adulthood.
- The Future: Creating A Metabolic Signature For CHD Patients
- Telehealth Is The New Answer To Preventing Premature Atherosclerotic Disease
- Healthy Behavior, Healthy Eating - Need To Treat The Family
- Rationale And The Creation Of Best Practices For Pediatric Cardiology Prevention Programs

## Anatomy Lab - Planning Simulation And Education In VR Environments

### International Seminars:

- Adult Congenital And Pediatric Cardiology Section (ACPC) Of The American College Of Cardiology (ACC)
- African Society For Pediatric and Congenital Heart Surgery (ASPCHS) and Pan African Society Of Cardiology (PASCAR)
- Asia-Pacific Pediatric Cardiac Society (APPCS)
- Association for European Paediatric and Congenital Cardiology (AEPC)
- Cardiac Society Of Australia And New Zealand (CSANZ)
- Gulf Heart Group – Fetal Cardiology
- Pan Arab Congenital Heart Disease Association (PACHDA)
- Pediatric Cardiac Society Of India (PCSI)
- Sociedad Latina Cardiología y Cirugía Cardiovascular Pediátrica

4:30 pm – 5:30 pm Sponsored Nursing Reception





## Thursday, August 31, 2023 *Continued*

Block 15.5: 7:00 am – 7:30 am

### Pediatric Cardiac Research Initiative in Imaging to Support Mentoring: (PRIISM 3)

#### Quantifying Self Improvement

- Introduction To PRIISM
- How Do I Translate Quality Initiatives Into Research?
- Panel Discussion

Block 16: 7:30 am – 9:15 am

#### Landmark Lectures

- Final Common Pathways Associated With Cardiomyopathies And Arrhythmias
  - ▷ Jeffrey Towbin MD, MS (USA)
- Learning From History (So We're Not Doomed To Repeat It)
  - ▷ Roberta Williams MD, MACC (USA)
- A Change Of Heart: From Genetics Of Congenital Heart Disease To New Therapeutics
  - ▷ Deepak Srivastava MD (USA)
- Weaving Healthcare For The Forgotten Ones In Macondo
  - ▷ Nestor Sandoval MD (Colombia)

### Ventricular Arrhythmias Following Repair of Tetralogy of Fallot (in Association with the European Association of Paediatric Cardiologists)

- Who Is At Risk For SCD Following Repair Of Tetralogy: The Latest On Risk Factors And Scoring Systems
- How To Choose Candidates For EPS And Catheter Ablation: Who And When?
- How To Perform Catheter Ablation Of VT In TOF? – Prognostic Value?
- Evolution Of Surgery For TOF Over The Last 4 Decades: Impact On Ventricular Arrhythmia?
- Primary Prevention ICDs- Endocardial Or S-ICD?

#### Anatomy Lab: Heterotaxy/Isomerism

- Formal Heart Specimen Demonstration
- Informal Hands On With Specimens
- Imaging Correlation

Break and Visit Exhibits and Visit Posters: 9:15 am – 10:15 am

Block 17: 10:15 am – 12:30 pm

#### Ambulatory And General Cardiology: Oral Abstracts

#### Cardiac Surgery And Cardiopulmonary Bypass: Oral Abstracts

#### Basic And Translational Science: Oral Abstracts

#### Global Cardiac Health: Oral Abstracts





## Thursday, August 31, 2023 *Continued*

### Block 17: 10:15 am – 12:30 pm *Continued*

#### Cardiac Nursing: Care Across The Lifespan - Providing A Continuum Of Care

---

- The Scope And Challenges Of CHD
- CHD Care In Norway: A “Continuous” Team Approach
- Single Ventricle Interstage Monitoring: Where We Are Today
- Challenges Of CHD Care In China
- Transition: Stepstones Project
- Adult Care, And Long-Term Outcomes
- A Role For Palliative Care
- The Journey

#### Arrhythmias In The Intensive Care Unit

---

- PACs And PVCs In Critically Ill Patients, When To Worry?
- Pre-Operative Arrhythmia Management Before Upcoming Cardiac Surgery
- New Antiarrhythmic Medications And Their Role In The ICU
- Temporary And Permanent Pacemakers In The Post Operative Setting: Placement And Use
- Controversies In The Management Of Fetal SVT
- Neonatal Arrhythmias: Acute And Chronic Management
- Refractory Arrhythmias In The ICU: Two Case Presentations With Audience Participation

#### Imaging In Adults With CHD: Anticipating The Future

---

- Beyond Ejection Fraction; New Ways Of Assessing Ventricular Motion In Congenital Heart Disease
- Establishing Consensus On Multimodality Aortic Measurements
- Best Techniques Using Today’s Tools To Assess Systolic Function Of The Subaortic Right Ventricle For Clinical Decision Making
- MRI For EP Devices: Is It Safe And Worthwhile?
- 4D Flow By Cardiac MRI: Does It Help?
- High Frame Rate Echo: The Future Is Fast Approaching!
- MRI Lymphangiography In Failing Fontans: How And Why?
- Multiparametric Mapping By Cardiac MRI; What Does This Mean And How This Might Individualize Care

#### Delivering An Arrhythmia Care Model In Low-And Middle-Income Countries

---

- Tele-Electrophysiology – Bringing Modern Pediatric Electrophysiology To The Developing World - Can We Do It?
- Implementing A Genetic Counseling Program For Channelopathies In Low- And Middle-Income Countries
- Cardiac IED-Related Infections And Cardiac IED Reuse In Low- And Middle-Income Countries
- Low Tech, High Impact Arrhythmia Screening: Can We Apply Cost-Effectiveness Lessons In Low- And Middle-Income Countries
- Starting And Sustaining A Pediatric Electrophysiology Service In Low- And Middle-Income Countries: Lessons Learned
- What I Need The Most: How The International Community Could Make A Difference In My Country
- Practical Solutions To Providing Electrophysiology Care In Low-Resource Settings

#### Response To Who Resolution - Perspectives From Global Experts And Dragons Den - Research Proposals From Emerging Scientists

---

- Response From Latin America
- Response From Asia
- Response From Africa
- Response From Pacific
  - ▷ Panel Discussion
- Dragon’s Den
  - ▷ Research Project 1
  - ▷ Research Project 2
  - ▷ Research Project 3



## Thursday, August 31, 2023 *Continued*

### Block 17: 10:15 am – 12:30 pm *Continued*

#### Hot Topics In Cardiac Transplantation

- Waitlist Strategies To Ensure Success After Transplant
- Beyond Calcineurin-Inhibitors: Novel Approaches To Immunosuppression
- Cell Free DNA, Can We Leave The Biopome At Home?
- Heart Transplant In Genetic Syndromes
- Cardiac Allograft Vasculopathy: Controversies In Diagnosis And Treatment
- Management Of Acute And Chronic Antibody-Mediated Rejection
- Transplantation After Single Ventricle Surgery
- End-Stage Care Of The Transplanted Patient

#### Update On Fetal Interventions For CHD

- The Fetus With Critical Aortic Stenosis: Pre- Or Post-natal Valvuloplasty?
  - Fetal
  - Postnatal
- The Fetus With Hypoplastic Left Heart And Intact Or Severely Restrictive Foramen Ovale: Pre- Or Post-natal Intervention?
  - Fetal
  - Postnatal
- The Fetus With Critical Pulmonary Stenosis or Pulmonary Atresia with Intact Ventricular Septum: Pre- Or Post-natal Valvuloplasty?
  - Fetal
  - Postnatal
- Maternal-Fetal Anesthesia During Fetal Interventions
- Practical Challenges Building A Fetal Cardiac Intervention Program

#### It's Not All About The Heart: Cutting Edge Management Of Non-Cardiac Disease In The CICU

- Renal Disease
- Lung Disease
- Gastrointestinal
- Infectious Disease
- Vascular Problems
- Lymphatic Dysfunction
- Airway Anomalies

#### Multimodal Imaging Of Valvular Heart Disease & Coronary Arteries

- Valvular Heart Disease: Multimodal Assessment Of Aortic Regurgitation And Stenosis
- Valvular Heart Disease: Planning Atrioventricular Valve Surgery - Future Perspectives
- Valvular Heart Disease: Imaging Developments For Structural Interventions
- Valvular Heart Disease: Multimodal Evaluation Of The Mitral Valve
- Coronary: Multimodal Evaluation Of Myocardial Ischemia And Viability
- Coronary: Assessment Of Transplant Coronary Vasculopathy And Coronary Sequelae Of Kawasaki Disease
- Coronary: Anomalous Origins - First Do No Harm?
- Coronary: Coronary Evaluation In Covid Kawasaki

#### Acute Persistent Pulmonary Hypertension In The Newborn: State Of The Art Management

- Have All The “BPD Collaboratives” Moved The Needle?
- What To Do When Inhaled Nitric Oxide (iNO) Is Not Enough...Or Not Available?
- When Is The Right Time To Start iNO In The Extremely Premature?
- Acute Pulmonary Hypertension And Hypoxic Ischemic Encephalopathies: Are The Benefits Of Cooling Mitigated By The Risk Of ECMO?
- In A Baby With Acute Pulmonary Hypertension, When Should I Start Looking For Zebras?
- How To Aide A Failing Right Ventricle
- How Should We Define “Successful” Management Of PPHN?



## Thursday, August 31, 2023 *Continued*

Block 17: 10:15 am – 12:30 pm *Continued*

### Supporting Neurodevelopment In The Outpatient Setting

- The Ideal Model: Guidelines For Outpatient Neurodevelopmental Follow-Up
- Why Is It Important? The Impact Of Neurodevelopmental Evaluation
- How Do You Fund It: Financial Support For Cardiac Neurodevelopment
- Advocating For the School Aged Child
- Including Parents In Developmental Care
- Assessment And Support Of Emotional Health In The Medical Setting
- It Takes A Village: Parent Organizations And Advocacy

### In The Anatomy Lab: Conduction System (Normal & Abnormal Hearts)

- Imaging Correlation
- Informal Hands On With Specimens

LUNCH BREAK – Visit the Exhibits and Visit the Posters: 12:30 pm – 2:00 pm

Small Group Lunch Sessions: 12:40 pm – 1:40 pm

- The National Pediatric Cardiology Quality Improvement Collaborative - 18 Years Of Progress
- Collaboration To Improve Surgical Outcomes In The Norwood Procedure
- Improvement In Single Ventricle Outcomes Through Shared Practices Among ICU And Inpatient Teams
- Improvements In Single Ventricle Mortality And Nutrition And Growth Through Collaboration
- Parents As Partners In Improving Single Ventricle Outcomes

### Advanced Techniques In Perfusion

- Novel Techniques In ABO Incompatible Transplants
- Beyond The Electronic Record – Using Electronic Charting To Improve Practice
- Integrating New Technology To Improve Patient Safety For CPB
- Lactate Management In Pediatric CPB

### Surgical Videos Session 4

- Complex Biventricular Conversion
- How I Repair Tetralogy
- Mitral Valve Replacement Using A Handmade Construct
- Surgery For Cardiac Tumors

### Optimal Organ Protection: Monitoring, Detection And Prevention

- Protecting The Myocardium
- Protecting The Brain
- Protecting The Nephrons

### Decision Making In Pediatric Cardiology-Deconstructing Dogma: Part II

- Moderator (Honorary Contrarian) and Five Panelists:
- Case Presentations:
  - ▷ What is the DATA that a Qp/Qs > 2:1 Is An Indication For Surgery,
  - ▷ The Silent Ductus Should Be Closed
  - ▷ Can We Please Stop Using Mild To Moderate, Moderate To Severe? You Measured It Didn't You?

### Anatomy Lab - Intraoperative EP Mapping





## Thursday, August 31, 2023 *Continued*

Block 19: 2:00 pm – 5:00 pm

### Best Abstract Competition

- Best Abstract In Cardiac Surgery and Cardiopulmonary Bypass
- Best Abstract In General Pediatric Cardiology
- Best Abstract in Cardiac Anesthesia
- Best Abstract in Nursing Science
- Best Abstract in Multimodal Imaging
- Best Abstract in Basic and Translational Science
- Best Abstract in Echocardiography
- Best Abstract in Global Cardiac Health
- Best Abstract in Fetal Cardiology
- Best Abstract in Adult Congenital Heart Disease
- Best Abstract in Nursing Clinical Inquiry
- Best Abstract in Electrophysiology
- Best Abstract in Neurodevelopment
- Best Abstract in Cardiac Catheterization
- Best Abstract in Heart Failure, Transplantation and Ventricular Assist Devices
- Best Abstract in ECMO, Neonatal Intensive Care, and Cardiac Intensive Care
- Best Abstract in Rheumatic Heart Disease

1:45 pm – 3:45 pm

### PICS Nightmare Cases

- Four Difficult Cases Will Be Presented And Discussed

3:45 pm – 5:00 pm

### Pathways To Increase Access And Adoption Of 3D Modeling Technologies

## World Congress Special Evening Event



**Miami Marlins vs. Washington Nationals**

Nationals Park, Approximately 6 pm | Details to Follow





*8th World Congress of  
Pediatric Cardiology and Cardiac Surgery*

**Friday, September 1**



## Friday, September 1, 2023

Block 20: 8:00 am – 10:30 am

### Closing Plenary Session #1: Tetralogy of Fallot

- Management Before Repair (A Global View)
- Variations In Surgical Approaches
- Post-Op Tetralogy of Fallot Repair And Managing Restrictive Physiology
- Preserving The Pulmonary Valve-Reality Or A Pipe Dream?
- Residual Lesions And Reinterventions
- Sudden Cardiac Death Risk Stratification
- A Proactive And Prescriptive Approach To Ablation for Ventricular Tachycardia Following Repair of Tetralogy of Fallot
- My Approach To Long Term Surveillance - Imaging, Exercise, Pregnancy
- Quality Of Life In Patients Following Repair of Tetralogy Of Fallot

Break and Visit Exhibits: 10:30 am – 11:00 am

Block 21: 11:00 am – 1:15 pm

### Closing Plenary Session: Transposition of the Great Arteries

- Fetal Physiology
- Preoperative Physiology And Management
- The Arterial Switch Operation: Past And Present
- Update On The Arterial Switch Operation In The First Hours Of Life Using Autologous Umbilical Cord Blood
- Use Of 3D Models Of Congenital Heart Disease As An Education Tool Following the Arterial Switch Operation (And Other CHD)
- Cross Sectional Imaging After The Arterial Switch
- The Boston Circulatory Arrest Study At 30 Years of Age
- Uh-Oh: Evaluation Of The Coronary Arteries And Myocardial Innervation
- Preventative Maintenance and Future Directions



*From our exhibit at the 7th World Congress in Barcelona, 2017. Note the date – prior to the pandemic – which caused the meeting to be delayed two years.*



# Invited Faculty



## Invited Faculty

### A

Moustafa Abdle Raheem (Egypt)  
Haifa Abdul Latiff (Malaysia)  
Riad Abou Zahr (Saudi Arabia)  
Jamil Abouhosn (USA)  
Jane Aceng (USA)  
Iki Adachi (USA)  
Anu Agrawal (USA)  
Farhan Ahmad (Pakistan)  
Humera Ahmed (United Kingdom)  
Vera Aiello (Brazil)  
Teiji Akagi (Japan)  
Nana Akyaa Yao (Ghana)  
Dimpna Calila Albert-Brotons (Saudi Arabia)  
Armando Alfaro Ramirez (Costa Rica)  
Rafa Alfonso (Canada)  
Zohair AlHalees (Saudi Arabia)  
Fatima Ali (Pakistan)  
Sulafa Ali (Sudan)  
Alaa Aljiffry (USA)  
Kiona Allen (USA)  
Nelson Alphonso (Australia)  
Bahaaldin Alsoufi (USA)  
Gabriel Altit (Canada)  
Carolyn Altman (USA)  
Zahid Amin (USA)  
Antonio Amodeo (Italy)  
Rogerio Andalaft (Brazil)  
Jason Anderson (USA)  
Jeffrey Anderson (USA)  
Jennifer Andrews (USA)  
Annette Ansong (USA)  
Shafkat Anwar (USA)  
Leah Apalodimas (USA)  
Kathryn Armstrong (Canada)  
Aimee Armstrong (USA)  
Rima Arnaout (USA)  
Philip Arnold (United Kingdom)  
Bhawna Arya (USA)  
Alfred Asante-Korang (USA)  
Amir Ashrafi (USA)  
Ritu Asija (USA)  
Joseph Atallah (Canada)  
Andrew Atz (USA)  
Tim Au (USA)  
Tangeni Auula (Namibia)  
Eric Austin (United Kingdom)  
Earl Austin (USA)  
Estela Azeka (Brazil)

### B

Sonya Babu-Narayan (United Kingdom)  
Emile Bacha (USA)  
Carl Backer (USA)  
Eun-Jung Bae (Republic of Korea)  
Frederique Bailliard (USA)

David Bailly (USA)  
Carissa Baker-Smith (USA)  
Sowmya Balasubramanian (USA)  
Molly Ball (USA)  
Guilherme Baptista de Faria (USA)  
Yaniv Bar-Cohen (USA)  
Aliessa Barnes (USA)  
David Barron (Canada)  
Sheena Basemera (Uganda)  
Amy Basken (USA)  
Brian Bateson (USA)  
Anjan Batra (USA)  
Cheyenne Beach (USA)  
David Bearl (USA)  
Andrea Beaton (USA)  
Virginie Beausejour-Ladouceur (Canada)  
Pedro Becker (Chile)  
Lee Beers (USA)  
Marie Béland (Canada)  
Emre Belli (France)  
Melania Bembea (USA)  
Alan Benheim (USA)  
Monica Benjamin (Argentina)  
Solange Benjamin (USA)  
Lee Benson (Canada)  
Alberto Berardi (Italy)  
Rudolphus Berger (Netherlands)  
John Berger (USA)  
Stuart Berger (USA)  
Lisa Bergersen (USA)  
Darren Berman (USA)  
Rebecca Beroukhim (USA)  
Charlie Berul (USA)  
John Derek Best (Australia)  
Misha Bhat (Sweden)  
Areesh Bhatti (Pakistan)  
Shazia Bhombal (USA)  
Dilli Bhurtel (USA)  
Paolo Bianchi (Italy)  
David Bichell (USA)  
Maria Angelica Binotto (Brazil)  
Einat Birk (Israel)  
Adrienne Bischoff (USA)  
Benjamin Black (USA)  
Sara Bleich (USA)  
Mark Bleiweis (USA)  
Nico Blom (Netherlands)  
Gillian Blue (Australia)  
Elizabeth Blume (USA)  
Prashant Bobhate (India)  
Martin Bocks (USA)  
Beatrice Bonello (United Kingdom)  
Damien Bonnet (France)  
Drissi Boumzebra (Morocco)  
Elisa Bradley (USA)  
Scott Bradley (USA)  
Ewa-Lena Bratt (Sweden)  
Christopher Breuer (USA)

Craig Broberg (USA)  
Elizabeth Broden (USA)  
Julie Brothers (USA)  
Kelsey Brown (USA)  
Morgan Brown (USA)  
Martina Brueckner (USA)  
Ronny Buechel (Switzerland)  
Anica Bulic (Canada)  
Catherine Bull (USA)  
Michael Burch (England)  
Redmond Burke (USA)  
Greg Burkman (USA)  
Kristin Burns (USA)  
Jane Burns (USA)  
Jennifer Butcher (USA)  
Samantha Butler (USA)  
Barry Byrne (USA)

### C

Allison Cabalka (USA)  
Amanda Cai (USA)  
Patrick Callahan (USA)  
Louise Callow (USA)  
Edward Callus (Italy)  
Gonzalo Calvimontes (Guatemala)  
Margarita Camacho (Costa Rica)  
Luiz Caneo (Brazil)  
Bryan Cannon (USA)  
Charles Canter (USA)  
Massimiliano Cantinotti (Italy)  
Sherrill Caprarola (USA)  
Marcelo Cardarelli (USA)  
Mario Carminati (Italy)  
Michael Carr (USA)  
Enrique Carrion-Vargas (Puerto Rico)  
Kerri Carter (USA)  
Frank Casey (United Kingdom)  
Adam Cassidy (USA)  
Ari Cedars (USA)  
David Celermajer (Australia)  
Alpay Celiker (Turkey)  
Scott Ceresnak (Canada)  
Jorge Cervantes-Salazar (Mexico)  
Sarah Chambers Gursun (USA)  
Alice Chan (USA)  
Titus Chan (USA)  
Nikhil Chanani (USA)  
Stephanie Chandler (USA)  
Anthony Chang (USA)  
Julia Charlton (Canada)  
Paul Checchia (USA)  
Sara Cherny (USA)  
Yiu Fai Cheung (Hong Kong (SAR China))  
Tom Chin (USA)  
Isaac Chinnappan (USA)  
Devyani Chowdhury (USA)  
Mark Chubb (USA)



## Invited Faculty *Continued*

Sandy Chung (USA)  
Sertac Çiçek (USA)  
Paolo Ciliberti (Italy)  
Nathalie Claessens (Netherlands)  
Robert Clancy (USA)  
Julie Cleuziou (Germany)  
Jim Cnota (USA)  
Jennifer Co-Vu (USA)  
Meryl Cohen (USA)  
Mitchell Cohen (USA)  
Scott Cohen (USA)  
Steven Colan (USA)  
Lucas Collazo (USA)  
Kathryn Collins (USA)  
Tom Collins (USA)  
George Comitis (South Africa)  
Vanessa Connell (Australia)  
Chad Connor (USA)  
Jean Connor (USA)  
Andrew Cook (United Kingdom)  
Stephen Cook (USA)  
David Cooper (USA)  
Rachael Cordina (Australia)  
Rafael Correa (Colombia)  
John Costello (USA)  
Serena Counsell (United Kingdom)  
Stephany Cox (USA)  
Paul Critser (USA)  
Elizabeth Crowe (Australia)  
Adrian Crucean (United Kingdom)  
Clifford Cua (USA)  
Bettina Cuneo (USA)  
Blanche Cupido (South Africa)  
Martha Curley (USA)  
Bruna Cury Borim (Brazil)

### D

Yves D'Udekem (USA)  
Jose Pedro Da Silva (USA)  
Nagib Dahdah (Canada)  
Shyamala Dakshinamurti (Canada)  
Aarti Dalal (USA)  
Michiel Dalinghaus (Netherlands)  
Sanjay Daluvoy (USA)  
Stephen Daniels (USA)  
Mark Danton (United Kingdom)  
Andrew Davis (Australia)  
Claire Davis (South Africa)  
Rik De Decker (South Africa)  
Natasja de Groot (Netherlands)  
Katya De Groote (Belgium)  
Caridad De La Uz (USA)  
Sarah de Loizaga (USA)  
Barbara Deal (USA)  
Peter Dean (USA)  
Joseph Dearani (USA)  
K. Barry Deatruck (USA)

William Decampli (USA)  
Brynn Dechert-Crooks (USA)  
Maria del Cerro (Spain)  
Pedro Del Nido (USA)  
María Blanca del Valle (Mexico)  
Dennis Delany (USA)  
Shashank Desai (USA)  
Lajja Desai (USA)  
Shri Deshpande (USA)  
Nina Deutsch (USA)  
Elizabeth Dewitt (USA)  
Alyssa DeWyer (USA)  
Meghan Didier (USA)  
Robert DiGeronimo (USA)  
Gerhard-Paul Diller (Germany)  
Christin Diller (USA)  
Vivian Dimas (USA)  
James DiNardo (USA)  
Anne Dipchand (Canada)  
Adriana Dobrzycka Bechara (USA)  
Kathryn Dodds (USA)  
Anudeep Dodeja (USA)  
Nicola Doherty (Northern Ireland)  
Mary Donofrio (USA)  
Yoav Dori (USA)  
Johannes Douwes (Netherlands)  
Laura Downey (USA)  
Karrie Downing (USA)  
Fabrizio Drago (Italy)  
Karen Dryden-Palmer (Canada)  
Lizhong Du (China)  
Anne Dubin (USA)  
Phuoc Duong (United Kingdom)  
Kritvikrom Durongpisitkul (Thailand)  
Waldarez Dutra (Brazil)  
John Dykes (USA)

### E

Karen Eagleson (Australia)  
Michael Earing (USA)  
Talya Ebel (USA)  
Frank Edwin (Ghana)  
Pirooz Eghtesady (USA)  
Benjamin Eidem (USA)  
Nadia El idrissi Slitine (Morocco)  
Maiy El Sayed (Egypt)  
Nibras El Sherif (USA)  
Adel ( Mohamed-Adel ) Elgamal (Egypt)  
Justin Elhoff (USA)  
Maria Elizari (Argentina)  
Sitaram Emani (USA)  
Mark Engel (South Africa)  
Maurice Enriquez-Sarano (USA)  
Carolina Escudero (Canada)  
Susan Etheridge (USA)  
Lucy Eun (Republic of Korea)  
Melanie Everitt (USA)

Danny Eytan (Israel)

### F

Toakase Fakakovikaetau (Tonga)  
Kanwal Farooqi (United Kingdom)  
Joanna Fazio (USA)  
Brian Feingold (USA)  
Eric Feins (USA)  
Matthew Fenton (United Kingdom)  
Kathleen Fenton (USA)  
Matthew Files (USA)  
Jeffrey Fineman (USA)  
Annabel Finucane (New Zealand)  
Anna Fisk (USA)  
English Flack (USA)  
Craig Fleishman (USA)  
Jennifer Fogel (USA)  
Mark Fogel (USA)  
Rami Fogelman (Israel)  
Natalie Forshaw (USA)  
Justine Fortkiewicz (USA)  
Gwendolyn Fosse (USA)  
Amanda Fowler (USA)  
Jeremy Fox (USA)  
María Fraga (USA)  
Katrien Francois (Belgium)  
Rodney Franklin (United Kingdom)  
Charles Fraser (USA)  
Britt Elin Fredriksen (Norway)  
Vicki Freedenberg (USA)  
Jay Fricker (USA)  
Mark Friedberg (Canada)  
Kevin Friedman (USA)  
Richard Friedman (USA)  
Beatriz Furlanetto (Brazil)

### G

Michael Gaies (USA)  
Anne Gallagher (Canada)  
Jay Gangemi (USA)  
Peter Gaskin (USA)  
Gladwell Gathecha (Kenya)  
Lasya Gaur (USA)  
J. William Gaynor (USA)  
Roman Gebauer (Germany)  
Bob Geggel (USA)  
Bruce Gelb (USA)  
Thomas Gentles (New Zealand)  
Renelle George (USA)  
Michael Gewitz (USA)  
Nancy Ghanayem (USA)  
Joumana Ghandour Atallah (Lebanon)  
Alessandro Giardini (United Kingdom)  
Regan Giesinger (USA)  
Salil Ginde (USA)  
Caren Goldberg (USA)



## Invited Faculty *Continued*

Allan Goldman (Ireland)  
Elizabeth Goldmuntz (USA)  
Michael Goldsmith (USA)  
Sergio Golembeck (USA)  
Cecilia Gonzalez Corcia (Canada)  
Eva Goossens (Belgium)  
Vaisakh Gopakumar (United Kingdom)  
Sebastian Goreczny (Poland)  
Kara Goss (USA)  
Stafford Grady (USA)  
Claudia Grau (Brazil)  
William Greeley (USA)  
Gail Green (USA)  
Adele Greyling (South Africa)  
Erin Gris (USA)  
Lars Grosse-Wortmann (USA)  
Peter Gruber (USA)  
Hong Gu (China)  
Janus Freyr Gudnason (Iceland)  
Kristine Guleserian (USA)  
Yigit Guner (USA)  
Saurabh Gupta (India)  
Michelle Gurvitz (USA)

### H

Sebastian Haas (Germany)  
Walid Habre (Switzerland)  
Benjamin Hale (USA)  
Dan Halpern (USA)  
Robert Hamilton (Canada)  
Bridy Hamilton (USA)  
James Hammel (USA)  
Shannon Hamrick (USA)  
Melina Handley (USA)  
Frank Hanley (USA)  
Katarina Hanseus (Sweden)  
Ashraf Harahsheh (USA)  
Victoria Harris (Canada)  
Tondi Harrison (USA)  
Babar Hasan (Pakistan)  
Amanda Hauck (USA)  
Joachim Hebe (Germany)  
Audrey Hebert (Canada)  
Holly Hedrick (USA)  
Jane Heggie (Canada)  
Jenna Heichel (USA)  
Heather Henderson (USA)  
Ulrike Herberg (Germany)  
Lazaro Hernandez (USA)  
Gabrielle Hessling (Germany)  
Edward Hickey (USA)  
Patricia Hickey (USA)  
Ziyad Hijazi (USA)  
Kevin Hill (USA)  
Vibeke Hjortdal (Denmark)  
George Hoffman (USA)  
Seth Hollander (USA)

Signe Holm Larsen (Denmark)  
Byron Holt (USA)  
Ralf Holzer (USA)  
Rachel Hopper (USA)  
Jürgen Hörer (USA)  
Lisa Hornberger (Canada)  
Ari Horton (Australia)  
Stephen Horton (Australia)  
Taylor Houlihan (USA)  
Lucile Houyel (France)  
Daphne Hsu (USA)  
Marina Hughes (United Kingdom)  
Christopher Hugo-Hamman (South Africa)  
James Huhta (USA)  
Syed Adil Husain (USA)  
Tarique Hussain (USA)  
Nazia Hussein (USA)  
Suzy Hutchinson (United Kingdom)

### I

Salim Idriss (USA)  
Dawn Ilardi (USA)  
Ilias Iliopoulos (USA)  
Frank Ing (USA)  
Dunbar Ivy (USA)  
Krishna Iyer (India)  
Parvathi Iyer (India)

### J

Jeffrey Jacobs (USA)  
Roni Jacobsen (USA)  
Edgar Jaeggi (Canada)  
James Jagers (USA)  
Priya Jagi (India)  
Cynthia James (USA)  
Sue Jameson (USA)  
Jan Janousek (Czech Republic)  
Robert Jaquiss (USA)  
Marcelo Jatene (Brazil)  
Aamir Jeewa (Canada)  
John Jefferies (USA)  
Anusha Jegatheeswaran (Canada)  
Kathy Jenkins (USA)  
Anitha John (USA)  
Jonathan Johnson (USA)  
Richard Jonas (USA)  
Pei-Ni Jone (USA)  
Melissa Jones (USA)  
Thomas Jones (USA)  
Anna Joong (USA)  
Christopher Jordan (USA)  
Ignacio Juaneda (Argentina)  
Amy Juraszek (USA)  
Lindsey Justice (USA)  
Henri Justino (USA)  
Robert Justo (Australia)

### K

Baturine Flavia Kamalemba (Uganda)  
Rishi Kamaleswaran (USA)  
Jenneke Kammeraad (Netherlands)  
Anna Kamp (USA)  
Geetha Kandavello (Malaysia)  
Supaluck Kanjanauthai (Thailand)  
Ronald Kanter (USA)  
Paul Kantor (USA)  
Mahesh Kappanayil (India)  
Tevfik Karagoz (Turkey)  
Tara Karamlou (USA)  
Tom Karl (USA)  
Sharon Karr (USA)  
Ganesan Karthikeyan (India)  
Nadine Kasparian (USA)  
Nicholas Kassabaum (USA)  
Christine Katusiime (Uganda)  
Ann Kavanaugh-mchugh (USA)  
Joseph Kay (USA)  
Vanna Kazazian (Canada)  
Robertta Keller (USA)  
Damien Kenny (Ireland)  
Naomi Kertesz (USA)  
Sachin Khambadkone (United Kingdom)  
Abigail Khan (USA)  
Amber Khanna (USA)  
Nee Scze Khoo (Canada)  
Michael Khoury (Canada)  
Adrienne Kilgore-Walton (USA)  
Yuli Kim (USA)  
Jeffrey Kim (USA)  
James Kimber (USA)  
Naoyuki Kimura (Japan)  
John Kinsella (USA)  
James Kirklín (USA)  
Roxanne Kirsch (Canada)  
Alex Kline (USA)  
Darren Klugman (USA)  
Jolanda Kluijn (Netherlands)  
Daisuke Kobayashi (USA)  
Josh Koch (USA)  
Lazaros Kochilas (USA)  
Peter Koenig (USA)  
Shigetoyo Kogaki (Japan)  
Le Minh Koi (Vietnam)  
Igor Konstantinov (Australia)  
László Környei (Hungary)  
Martin Kostelka (Germany)  
Adrienne Kovacs (Canada)  
Rich Krasuski (USA)  
Ulrich Krausse (Germany)  
Eric Kreiger (USA)  
Christian Kreutzer (Argentina)  
Jacqueline Kreutzer (USA)  
Thomas Kriebel (Germany)



## Invited Faculty *Continued*

Gregor Krings (Netherlands)  
Ganga Krishnamurthy (USA)  
Tomasz Ksiazczyk (Poland)  
Peter Kubuš (Czech Republic)  
Raman Kumar (India)  
Shelby Kutty (USA)  
Sit Yee Kwok (Hong Kong (SAR China))

### L

Laila Ladak (Pakistan)  
Wyman Lai (USA)  
John Lamberti (USA)  
Luke Lamers (USA)  
Julia Lampe-Van den Dool (Netherlands)  
Kyle Landry (USA)  
Andrew Landstrom (USA)  
Michael Landzberg (USA)  
Peter Lang (USA)  
Damien LaPar (USA)  
Javier Lasa (USA)  
Beatrice Latal (Switzerland)  
Sabrina Law (USA)  
Ian Law (USA)  
John Lawrenson (South Africa)  
Aimee Layton (USA)  
Chul Lee (Republic of Korea)  
Jennifer Lee-Summers (USA)  
Stephanie Levasseur (USA)  
Daniel Levi (USA)  
Rebecca Leverson (USA)  
Victor Levy (USA)  
Mark Lewin (USA)  
Xiaoyan Li (China)  
Jennifer Li (USA)  
Daniel Licht (USA)  
Claudia Lidroneta Katz (Brazil)  
Catherine Limperopoulos (USA)  
Hui Lin (USA)  
Christopher Lindblade (USA)  
Steven Lipshultz (USA)  
Amy Lisanti (USA)  
Sherard Little (Jamaica)  
Jin-Fen Liu (China)  
Petru Liuba (Sweden)  
Tracy Livecchi (USA)  
Cecelia Lo (USA)  
Andreas Loepke (USA)  
Yue-Hin Loke (USA)  
Justin Long (USA)  
Patricia Longmuir (Canada)  
Rohit Loomba (USA)  
Rodrigo Lopez (Chile)  
Cecilio De La Cruz Lopez (USA)  
Keila Lopez (USA)  
Angela Lorts (USA)  
barry love (USA)  
Jimmy Lu (USA)

Peter Lwabi (Uganda)

### M

Andrew Mackie (Canada)  
Malani Madhavan (USA)  
Sreehari Madhavankutty Nair (India)  
Erin Madriago (USA)  
Vanessa Madrigal (USA)  
Nicolas Madsen (USA)  
Yasuki Maeno (Japan)  
Douglas Mah (USA)  
Kevin Maher (USA)  
Balakrishnan Mahesh (USA)  
William Mahle (USA)  
Rudolph Mair (Austria)  
Sunil Malhotra (USA)  
Lindsey Malloy-Walton (USA)  
Alice Maltret (France)  
Almudena March (Mexico)  
Pietro Marchese (Italy)  
Luciana Marcondes (New Zealand)  
Jan Marek (United Kingdom)  
Ariane Marelli (Canada)  
Bradley Marino (USA)  
Michael Mark (USA)  
Audrey Marshall (Canada)  
Gerard Martin (USA)  
Hugo Martinez (USA)  
Manuel Martinez-Selles (Spain)  
Jose Diogo Martins (Portugal)  
Bohdan Maruszewski (Poland)  
Eva Marwali (Indonesia)  
Christopher Mascio (USA)  
Shiraz Maskatia (USA)  
Christopher Mastropeitro (USA)  
Sinat Mathew (United Arab Emirates)  
Sandra Mattos (Brazil)  
Fhumulani MavisMulaudzi (South Africa)  
Constantine Mavroudis (USA)  
Constantine Mavroudis (USA)  
Thomas Maxey (USA)  
Joseph May (USA)  
Bronagh Mcalinden (Australia)  
Mary McBride (USA)  
Michael McBride (USA)  
Melissa McCradden (Canada)  
George McDaniel (USA)  
Lidja McGrath (USA)  
Colin McMahan (Ireland)  
Patrick McNamara (USA)  
Brad McQuilkin (USA)  
Folkert Meijboom (Netherlands)  
Cody Meissner (USA)  
Jon Meliones (USA)  
Laura Mercer-Rosa (USA)  
Luc Mertens (Canada)  
Carlos Mery (USA)

Bret Mettler (USA)  
Leonardo Miana (Brazil)  
Shanna Milko (USA)  
Steven Miller (Canada)  
Nathan Miller (USA)  
Owen Miller (United Kingdom)  
Rebecca Miller (USA)  
Thomas Miller (USA)  
Wanda Miller-Hance (USA)  
Laura Miller-Smith (USA)  
Maria Miszczak Knecht (Poland)  
Seema Mital (Canada)  
Yoshihide Mitani (Japan)  
Michael Mitchell (USA)  
Christina Miyake (USA)  
Shelley Miyamoto (USA)  
Aya Miyazaki (Japan)  
Diego Moguillansky (USA)  
Muhammad Mohsin (Pakistan)  
Shazia Mohsin (Pakistan)  
Thomas Möller (Norway)  
Hlengiwe Moloi (South Africa)  
Jose Moltedo (Argentina)  
Mona Momeni (Belgium)  
Anita Moon-Grady (USA)  
Jeremy Moore (USA)  
Lisa Moore (USA)  
David Morales (USA)  
Nikki Moreland (New Zealand)  
Victor Morell (USA)  
Gareth Morgan (USA)  
Samira Morhy (Brazil)  
Shaine Morris (USA)  
Sarah Morton (USA)  
Jim Morwood (India)  
Ralph Mosca (USA)  
Kara Motonaga (USA)  
Pablo Motta (USA)  
Katie Moynihan (USA)  
Matthias Mueller (Germany)  
Dana Mueller (USA)  
Babu Muhamed (USA)  
Mary Mullen (USA)  
Michael Mulreany (USA)  
Yogeswary Muniandy (Malaysia)  
Juan-Carlos Muniz (USA)  
Ricardo Munoz (USA)  
Raghav Murthy (USA)  
Kathy Mussatto (USA)  
John Musuku (Zambia)  
Julius Mwita (Botswana)

### N

Hani Najm (USA)  
Doreen Nakagaayi (Uganda)  
Bruno Nascimento (Brazil)  
Viviane Nasr (USA)



## Invited Faculty *Continued*

Shobha Natarajan (USA)  
Tsvetoslav Naydenov (Bulgaria)  
Emma Ndagire (Uganda)  
Lavinia Ndemutilla Ndinangoye (Namibia)  
Karli Negrin (USA)  
Timothy Nelson (USA)  
Jennifer Nelson (USA)  
Jane Newburger (USA)  
Ruth Ngwaro (USA)  
Quan Ni (USA)  
Talha Niaz (USA)  
Jeremy Nicolarsen (USA)  
Susan Nicolson (USA)  
Masaki Nii (Japan)  
Gabrielle Norrish (United Kingdom)  
William Novick (USA)  
Hopewell Ntsinjana (South Africa)  
David Nykanen (USA)  
Siri Ann Nyernes (Norway)

### O

Matthew O'Connor (USA)  
Clare O'Donnell (New Zealand)  
Edward O'Leary (USA)  
Jennifer O'Neil (USA)  
James O'Brien (USA)  
Erwin Oechslin (Canada)  
Vanessa Ogueri (USA)  
Conor Ohallorhan (USA)  
Richard Ohye (USA)  
Emmy Okello (Uganda)  
Michael Oketcho (Uganda)  
Molly Oldeen (USA)  
Melissa Olen (USA)  
Laura Oliveri (USA)  
Olutoyin Olutoye (USA)  
Uvie Onakpoya (Nigeria)  
Alexander Opotowsky (USA)  
Cynthia Ortinau (USA)  
Matthew Oster (USA)  
Fatma Ouarda Torgeman (Tunisia)  
David Overman (USA)

### P

Christian Paech (Germany)  
Alexis Palacios-Macedo (Mexico)  
Ashok Panigrahy (United States Minor Outlying Islands)  
Ioannis Papagiannis (Greece)  
Michael Papdakos (United Kingdom)  
Andrew Papez (USA)  
Stephen Paridon (USA)  
Kinjal Parikh (USA)  
Sara Pasquali (USA)  
Rob Pass (USA)

Neil Patel (United Kingdom)  
Angira Patel (USA)  
Sheetal Patel (USA)  
Jason Patregnani (USA)  
Lacie Patterson (USA)  
Thomas Paul (Germany)  
Dorothy Pearson (USA)  
Gail Pearson (USA)  
Carlos Pedra (Brazil)  
David Peng (USA)  
Dan Penny (USA)  
Ericka Perez Albrecht (Bolivia)  
Gianluigi Perri (Italy)  
Tanya Perry (USA)  
Christopher Petit (USA)  
Shabnam Peyvandi (USA)  
Andreas Pflaumer (Australia)  
Thomas Pickardt (Germany)  
Diane Pickles (USA)  
Nancy Pike (USA)  
Nelangi Pinto (USA)  
Andrew Pitkin (USA)  
Christian Pizarro (USA)  
Kari Plant (USA)  
Nancy Poirier (Canada)  
Uri Pollak (Israel)  
Terence Prendiville (USA)  
Marc Priest (USA)  
James Priest (USA)  
Robert Przybylski (USA)  
Michael Puchalski (USA)  
Jafesi Pulle (Uganda)  
Kriti Puri (USA)  
Kuberan Pushparajah (United Kingdom)

### Q

Katty Quezada (Chile)  
James Quintessenza (USA)  
Shakeel Qureshi (United Kingdom)

### R

Budi Rahmat (Indonesia)  
Alireza Raissadati (USA)  
Anna Ralph (Australia)  
Sandhya Ramlogan (USA)  
Muncera Rasheed (Pakistan)  
Rob Raylman (USA)  
James Reagor (USA)  
Leigh Reardon (USA)  
Darshan Reddy (South Africa)  
Yavini Reddy (South Africa)  
Charitha Reddy (USA)  
Prakash Regmi (Nepal)  
Zdenka Reinhardt (United Kingdom)  
Bo Remenyi (Australia)

Kate Restaino (USA)  
John Rhodes (USA)  
Maria Ricci Bartol (Canada)  
Christine Riley (USA)  
Diana Robertshaw (United Kingdom)  
Alex Robertson (United Kingdom)  
Mark Rodefald (USA)  
Fred Rodriguez (USA)  
Peter Paul Roeleveld (Netherlands)  
Lisa Roelle (USA)  
Lindsay Rogers (USA)  
Caitlin Rollins (USA)  
Jack Rome (USA)  
David Rosenthal (USA)  
Tami Rosenthal (USA)  
Erika Rosenzweig (USA)  
Ferran Roses-Noguer (Spain)  
Shelagh Ross (Canada)  
Joseph Rossano (USA)  
Anthony Rossi (USA)  
Stephen Roth (USA)  
Abraham Rothman (USA)  
David Rubenstein (USA)  
Nancy Rudd (USA)  
Harish Rudra (USA)  
Mark Russell (USA)  
Joselyn Rwebembera (Uganda)  
Jack Rychik (USA)

### S

Annamarie Saarinen (USA)  
Craig Sable (USA)  
Ritu Sachdeva (USA)  
Anjali Sadhwani (USA)  
Anurag Sahu (USA)  
Arwa Saidi (USA)  
Kisaburo Sakamoto (Japan)  
Arash Salavitarab (USA)  
Jorge Salazar (USA)  
Taariq Salie (South Africa)  
Joshua Salvin (USA)  
Cyrus Samai (USA)  
Duminda Samarasinghe (Sri Lanka)  
Renee Sananes (Canada)  
Shubhayan Sanatani (Canada)  
Joan Sanchez de Toledo (Spain)  
George Sandor (Canada)  
Nestor Sandoval (Colombia)  
Juan Pablo Sandoval (Mexico)  
Amy Sanyuhumbi (USA)  
Jacqueline Sanz (USA)  
Anita Saraf (USA)  
Shyam Sathanandam (USA)  
Amy Sato (Canada)  
Rashmin Savani (USA)  
Jill Savla (USA)



## Invited Faculty *Continued*

Anita Saxena (India)  
Melanie Scala (USA)  
Emma Scanlan (United Kingdom)  
Claudia Scanzoni (Venezuela)  
Tina Schade Willis (USA)  
Marc Schecter (USA)  
Mark Scheurer (USA)  
Ehrenfried Schindler (Germany)  
Frank Scholl (USA)  
Steven Schwartz (Canada)  
Bryanna Schwartz (USA)  
Chloe Searchinger (USA)  
Aurelio Secinaro (Italy)  
Michael Seckeler (USA)  
Farsha Sedaghat (USA)  
Mike Seed (Canada)  
Elisabeth Seidel-Mlczoc (Austria)  
Shawn Sen (USA)  
Skaistė Sendžikaitė (Lithuania)  
Nishant Shah (United Arab Emirates)  
Maully Shah (USA)  
Divya Shakti (USA)  
Gurleen Sharland (United Kingdom)  
Lara Shekerdeman (USA)  
Sam Shemie (Canada)  
Libby Sherwin (USA)  
Fenny Shidhika (Namibia)  
Martha Naambo Shiimi (Namibia)  
Amanda Shillingford (USA)  
Gary Sholler (Australia)  
Billie Short (USA)  
Stanford Shulman (USA)  
Jennifer Silva (USA)  
Eric Silver (USA)  
Norman Silverman (USA)  
Candice Silversides (Canada)  
Massimo Silveti (Italy)  
Lyudmil Simeonov (Bulgaria)  
John Simpson (United Kingdom)  
Lynn Simpson (USA)  
Kanchana Singappulli (Sri Lanka)  
Sanjeev Singh (India)  
Yogen Singh (United Kingdom)  
Simran Singh (USA)  
Pranava Sinha (USA)  
Kothandam Sivakumar (India)  
Sivakumar Sivalingam (Malaysia)  
Ben Sivirajan (Canada)  
Justin Skowno (Australia)  
Liz Smith (United Kingdom)  
Jodi Smith (USA)  
Lindsey Smith Taillie (USA)  
Melissa Smith-Parrish (USA)  
Christopher Smyser (USA)  
Andressa Mussi Soares (Brazil)  
Jinyoung Song (Republic of Korea)  
Erica Sood (USA)

Neil Spencely (United Kingdom)  
Diane Spicer (USA)  
Nancy Spinner (USA)  
Deepak Srivastava (USA)  
Shubhika Srivastava (USA)  
Cecilia St. George-Hyslop (Canada)  
James St. Louis (USA)  
Jeremiah Staffell-Mwangi (Switzerland)  
Sandra Staveski (USA)  
Andrew Steer (Australia)  
Robin Steinhorn (USA)  
Elizabeth Stephens (USA)  
Jean Storey (USA)  
Karen Stout (USA)  
Lillian Su (USA)  
Ram Kumar Subramanyan (USA)  
Lubega Sulaiman (Uganda)  
Victoria Surma (USA)  
Denise Suttner (USA)  
Lana Svjetlana Tisma-Dupanovic (USA)  
Lorna Swan (Switzerland)  
Joanna Szymkiewicz - Dangel (Poland)

### T

Sarah Tabbutt (USA)  
Shinichi Takatsuki (Japan)  
Christopher Talluto (USA)  
Reina Tan (USA)  
Weiyi Tan (USA)  
Ronn Tanel (USA)  
Menglin Tang (China)  
Paul Tannous (USA)  
Andrew Taylor (United Kingdom)  
Michael Taylor (USA)  
Christo Tchervenkov (Canada)  
Sarah Teele (USA)  
Leila Ternera (Colombia)  
Edythe Tham (Canada)  
William Thompson (USA)  
Seda Tierney (USA)  
Joseph Timpa CCP, FPP (USA)  
Deanna Todd Tzanetos (USA)  
Jeffrey Towbin (USA)  
Karin Tran-Lundmark (Sweden)  
Justin Tretter (USA)  
John Triedman (USA)  
Martin Tristani-Firouzi (USA)  
Dongngan Truong (USA)  
Sabrina Tsao (Hong Kong (SAR China))  
Gerald Tulzer (Austria)  
Joseph Turek (USA)  
Gerardo Tusman (Argentina)  
Oktay Tutarel (Germany)  
Mark Twite (USA)  
Wayne Tworetzky (USA)

### U

Michelle Udine (USA)  
Elaine Urbina (USA)  
Karen Uzark (USA)  
Orhan Uzun (United Kingdom)

### V

Balu Vaidyanathan (India)  
Anne Marie Valente (USA)  
Israel Valverde Perez (Spain)  
Andrew Van Bergen (USA)  
Catharina van Doorn (United Kingdom)  
George Van Hare (USA)  
Grace van Leeuwen (Qatar)  
Caleb Varner (USA)  
Surendranath Veeram Reddy (USA)  
Gruschen Veldtman (Saudi Arabia)  
David Vener (USA)  
Amy Verstappen (USA)  
Dominique Vervoort (Canada)  
Unnikrishnan Vettickal Sasi (India)  
Francis Veyckemans (France)  
Vladamiro Vida (Italy)  
Trisha Vigneswaran (United Kingdom)  
Olivier Villemain (Canada)  
Casey Vogel (USA)  
Inga Voges (Germany)  
Susan Vosloo (South Africa)

### W

Philip Wackel (USA)  
Scott Walker (USA)  
Michelle Wallace (USA)  
Mark Walsh (Ireland)  
Edward Walsh (USA)  
Jou-Kou Wang (Taiwan (Province of China))  
Kendra Ward (USA)  
Stephanie Ware (USA)  
Reginald Washington (USA)  
David Watkins (USA)  
Robert Webster (USA)  
Sam Weinstein (USA)  
Robert Weintraub (Australia)  
Dany Weisz (Canada)  
Ken-Pen Weng (Taiwan (Province of China))  
David Werho (USA)  
Gil Wernovsky (USA)  
David Wessel (USA)  
Timothy Willens (USA)  
Heather Williams (USA)  
Patricia Williams (USA)  
Robert Williams (USA)  
William Wilson (Australia)  
Nigel Wilson (New Zealand)



## Invited Faculty *Continued*

Neil Wilson (United Kingdom)  
Melissa Winder (USA)  
David Winlaw (USA)  
Kristy Wolfe (Canada)  
Brian Wolfe (USA)  
Kelly Wolfe (USA)  
Joshua Wolovitz (USA)  
Joyce Woo (USA)  
Jo Wray (United Kingdom)  
Mei-Hwan Wu (Taiwan (Province of China))  
Fred Wu (USA)  
Rosemary Wyber (Australia)

### Y

Satoshi Yasukochi (Japan)  
Illya Yemets (Ukraine)  
Anji Yetman (USA)  
Christopher Yilgwan (Nigeria)  
Betul Yilmaz (USA)  
Deane Yim (Australia)  
Shi-Joon Yoo (Canada)  
Jun Yoshimoto (Japan)  
Diana Young (Canada)  
Luciana Young (USA)  
Putri Yubbu (Malaysia)  
Koichi Yuki (USA)

### Z

Luis Zabala (USA)  
Christopher Zachary (USA)  
Evan Zahn (USA)  
Martin Zahorec (Slovakia)  
Ali Zaidi (USA)  
Rosanna Zanai (Italy)  
Steven Zangwill (USA)  
Jill Zender (USA)  
Dominica Zentner (Australia)  
Hao Zhang (China)  
Bistra Zheleva (USA)  
Paulo Zielinsky (Brazil)  
Leisl Zuhlke (South Africa)





*8th World Congress of  
Pediatric Cardiology and Cardiac Surgery*

# About the Conference



## Why a Global Initiative?

### The Need for Medical Education, Research, and Quality Improvement Activities

An estimated 45 million children die or are crippled annually by treatable or preventable heart disease in low- and middle-income countries.

Efforts at reducing mortality among children under 5 years of age have been the focus of significant international attention for decades, beginning with the convention on the rights of the child and accelerating in 2000 with the Millennium Development Goals, with goal 4 being to reduce the under-5 mortality rate by two-thirds. This work continued with the United Nations' adoption of the Sustainable Development Goals, specifically Sustainable Development Goal 3, which aims to end preventable deaths of newborns and children under 5 years of age. All countries aimed to reduce neonatal mortality to at most 12 per 1000 live births and under-5 mortality to at most 25 per 1000 live births. These efforts have been largely targeted at prevention and treatment of communicable diseases, owing to the number of affected children and the relatively low cost, low technology, and experience required to do this work. Overall, progress has been achieved with a reduction in global mortality.

Pediatric heart disease, both congenital and acquired, remains a major health problem in low- and middle-income countries, and have largely been left to non-governmental organizations to address. Although excellent outcomes can be achieved even with low-cost cardiovascular care in challenging environments, health systems have shied away from setting up CHD and RHD heart centers, most likely because of perceived challenges around cost, technology, availability of trained personnel, and the expertise required to affect change.

According to the 2010 global burden of disease, injuries, and risk factors study, ~302,000 infants died from congenital anomalies, which accounted for 6% of all infant deaths, with 96% of these occurring in low- and middle-income countries. About 28% of all major congenital anomalies are heart defects.

Most CHDs are not diagnosed before birth, owing to lack of antenatal or early postnatal screening. Early diagnosis of simple lesions could result in early referral and treatment before the onset of irreversible sequelae. Other factors that contribute include limitations in the existing infrastructure, lack of resources, low numbers of appropriately trained healthcare workers, and a general lack of awareness of heart disease in children. Meeting these challenges requires clinical evidence pertinent to the local settings, an adequate number of well-trained personnel, improvement in nursing and medical education, research, and quality improvement activities. Again, it is estimated that 45 million children and young adults die or are crippled annually by potentially treatable or preventable cardiac disease. Educating government and community leaders about prevention and treatment of paediatric heart disease is imperative



## Poor Access and Lack of Adequately Trained Staff

**“The resources to treat CHD are both inadequate and seriously maldistributed. The World Society for Paediatric and Congenital Heart Surgery Manpower Survey noted that about 75% of the world’s population have no access to cardiac surgery, and that the distribution of cardiac surgeons was very unbalanced.”**

The global burden of congenital heart disease, Julien Hoffman, Cardiovascular Journal of Africa, Vol 24, No 4, May 2013  
Submitted 11/3/13, accepted 17/4/13, Cardiovasc J Afr 2013; 24: 141–145 www.cvja.co.za, DOI: 10.5830/CVJA-2013-028

Mortality from congenital heart disease (CHD) has decreased over the last few decades in high income countries. However, both CHD and acquired heart disease (AHD), mostly Rheumatic Heart Disease (RHD) remain important problems in low and middle-income countries (LMIC). The reason for the high mortality is multifactorial and varies between countries. However, some common factors include:

- Lack of access to primary and specialized centers
- Lack of adequately trained physicians and nurses
- Financial constraints and suboptimal coverage
- Absence of specialized units
- Lack of basic healthcare, and
- Low awareness

Over the years, healthcare providers and institutions in high income countries have developed different strategies to improve the care of patients with CHD in LMIC. These strategies include:

- Referring patients to other countries for care.
- Periodic visits of cardiac specialists to LMICs to diagnose, care for, and/or operate on patients with CHD.
- Training of physicians and staff in their home countries and abroad.
- Development of local programs.



“By 2020, 7 of 10 deaths in developing countries are predicted to be due to noncommunicable diseases—the majority of which would be due to preventable cardiovascular diseases (CVDs). Section IV.A.5 (a) of the Accreditation Council for Graduate Medical Education’s Program requirements for graduate medical education (GME) in cardiovascular disease recommends that fellows-in-training (FITs) must demonstrate competence in the practice of health promotion, disease prevention, diagnosis, care, and treatment of patients of each sex, from adolescence to old age, during health and all stages of illness. However, there is an unmet and unrecognized need for U.S. cardiology fellowship programs to offer an opportunity to incorporate global health training in cardiology during the 36 months of core training.

A unique aspect of the U.S. GME program is the systematic integration of physicians trained outside of the United States (international medical graduates) into the post-graduate medical training programs alongside American medical graduates, often creating a melting pot of shared knowledge. More than 25% of the 797 positions for cardiovascular disease in the 2014 match were filled by non-U.S. international medical graduates. This tremendous pool of shared cultures and diversities is an asset that can be tapped when formulating and implementing a national global health training policy.

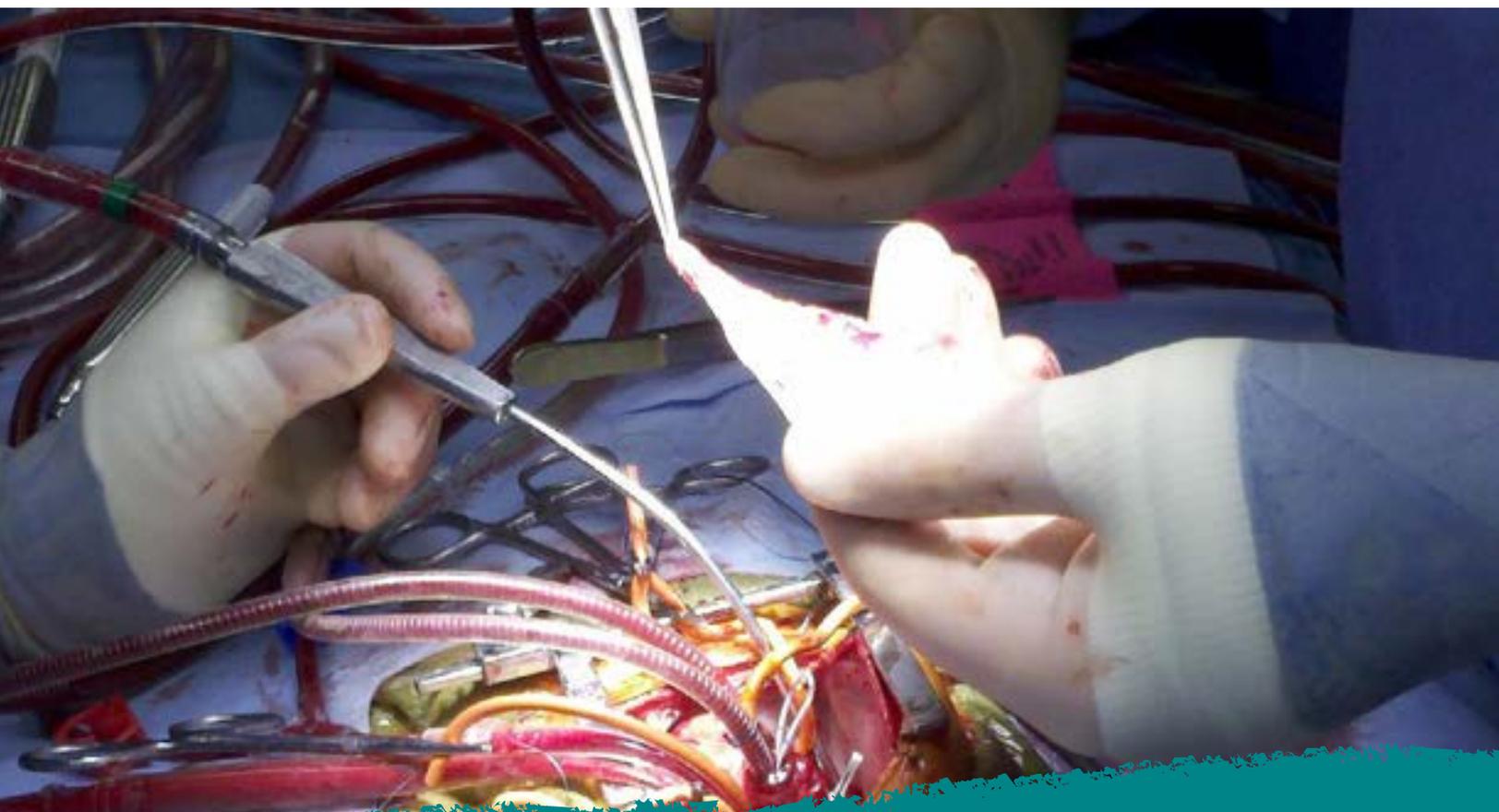
Improving access of low- and middle-income countries to CVD diagnostics, U.S. cardiology FITs (senior and subspecialty fellows) are uniquely positioned to take their technical and procedural skills to the proverbial “bedside” of the patients in low- and middle-income countries where there is still significant physician shortage (e.g., in India: 6.5 physicians/10,000 population vs. 14.2/10,000 population worldwide). This will require partnership and collaborations among nongovernmental organizations, member associations, and academic institutions.”

Specifically, the World Congress of Pediatric Cardiology and Cardiac Surgery (WCPCCS) is the major international scientific event for the global pediatric cardiac community, providing an opportunity for specialists from around the globe to gather and highlight and review the previous four years of research and technological developments in surgical techniques, basic sciences, translational and clinical research, and advanced therapeutic interventions. This critical meeting provides an ideal meeting place for a global coalition of doctors, nurses, and health scientists from around the world, who use research and technological development to provide better care for babies, children, and adults with congenital and acquired cardiac disease. The international faculty now includes over 1000 members and offers exceptional scientific programs, across the different cardiac disciplines, from research, interventions, imaging, and non-invasive procedures through to critical care and surgical procedures.



The WCPCCS supports the notion that all children with cardiac disease should not to be denied the benefits of medical science, and our vision is to use this Congress as a platform to spread cardiac care ideas and techniques to caregivers of those children in regions without access. It is an occasion to emphasize the glaring inadequacies in delivery of cardiac care in many countries, and to use this global forum to find creative humanitarian solutions to develop new services in resource-poor environments. Of course, while the limitations to developing cardiac care in the presence of financial, managerial, and human resource constraints are problems shared with colleagues from all nations, poorer nations carry a heavier burden and our Congress offers health policy planners, health system managers, and health economists a unique forum to find health systems solutions necessary to initiate, develop, and improve cardiac care for children in less robust medical environments.

Numerous international societies and institutions have shared the vision that the WCPCCS is the defining international event in the lives of those committed to helping children with cardiac disease and adults with congenital cardiac disease. The prior World Congresses have been successful in bringing together delegates from hundreds of countries across varying different healthcare environments, for stimulating educational meetings where individuals can network and learn from one another. The World Congresses have been effective in fostering a collegial spirit between the many specialties involved in children's heart health, providing a range of opportunities for trainees and established practitioners to upgrade skills, cooperate, and collaborate for the good of all children with cardiac diseases around the world. Additionally, this Congress will specifically benefit children and young adults in this country by bringing global educators here to the United States, many for the first time.





## Leadership and Organizing Team



**Gil Wernovsky, MD, FAAP, FACC Co-Chairman**

Senior Consultant in Cardiac Critical Care and Pediatric Cardiology

Children's National Hospital

Professor of Pediatrics

George Washington University School of Medicine and Health Sciences

[gwernovsky@childrensnational.org](mailto:gwernovsky@childrensnational.org)

Dr. Wernovsky attended Brandeis University, receiving a BS degree in 1978 in Anthropology and Music. He attended Pennsylvania State University College of Medicine, receiving his MD in 1982, completed a Pediatric Residency at New York Hospital (now known as Weill Cornell Medical Center) in 1985, and his Pediatric Cardiology Fellowship at Boston Children's Hospital in 1988, with a focus on Cardiac Intensive Care. He was Associate Medical Director of the Cardiac Intensive Care Unit in Boston from 1988-1994.

Dr. Wernovsky moved to the Children's Hospital of Philadelphia in 1995, where he was Medical Director of one of the first Pediatric Cardiac Intensive Care Units in the USA. He was promoted to Professor of Pediatrics at the University of Pennsylvania School of Medicine in 2004, was Associate Chief of the Division of Cardiology, and developed one of the first Cardiac Neurodevelopmental Follow-Up Programs in 2008, where he was the medical director from 2008-2012. He was a Staff Cardiologist and the Director of Patient and Family Centered Care of the Heart Program at Nicklaus Children's Hospital from 2014-2016

Currently, Dr. Wernovsky is an Attending Cardiologist at Children's National Hospital, working in both the Cardiac Intensive Care Unit and General Cardiology Inpatient Service. He is a member of the NeuroCardiac Critical Care Team, one of the only few programs of its kind in the World.

He is a Professor of Pediatrics at the George Washington University School of Medicine and Health Sciences. His clinical and research interests include the inpatient care of newborns and infants with critical congenital heart disease and acute mechanical support of the failing circulation. For the past 35 years, he has also focused on improving duration and quality of life for his patients, specifically the long-term functional outcomes following surgery for complex congenital heart disease, such as transposition of the great arteries, tetralogy of Fallot and forms of single ventricle such as hypoplastic left heart syndrome. He was awarded the prestigious 2015 Newburger-Bellinger Award for his career contributions to the field of Neurodevelopment in Children with Heart Disease.

He was a study physician in the landmark Boston Circulatory Arrest Study from 1987-1992, and was the Principal Investigator of the international PRIMACORP study from 2002-2003, at the time the largest multicenter trial in pediatric cardiac intensive care. He is currently a co-investigator for an ongoing NIH-funded clinical trial investigating the safety and efficacy of the intraoperative delivery of mesenchymal stromal cells for neuroprotection during cardiac surgery.



He was the Editor-in-Chief of the 4th Edition of Anderson's Pediatric Cardiology, the most read textbook in the field of Pediatric Cardiology, has edited 5 additional textbooks and 13 periodicals, and has published over 300 peer-reviewed manuscripts, book chapters and reviews. He has an H-index of 94 and his work has been cited over 28,000 times. He was listed as the 2nd most cited author in the entire congenital heart disease literature from 1990-2020, and as the 1st most cited author in "The 100 most influential articles in congenital heart disease in 2000-2020: A bibliometric analysis."

He was the Co-Chair of the Perioperative Working Group of the Pediatric Heart Network, National Institutes of Health in 2009, and a Member of the Special Emphasis Panel for review of NHLBI Pediatric Heart Network Clinical Research Centers in 2016. Dr. Wernovsky has been the course director for over 100 post graduate educational seminars, including the annual "CHOP Cardiology meeting" from 1998-2012.

He has been internationally recognized as a Master Educator, and has been on the faculty at Cornell University College of Medicine, Harvard Medical School, University of Pennsylvania School of Medicine, Florida International University and George Washington University of Medicine and Health Sciences. He was recently awarded the 2021 Maria Serratto Master Educator Award by the Section on Pediatric Cardiology and Cardiac Surgery of the American Academy of Pediatrics. The Master Educator Award is presented each year to a pediatric cardiologist or cardiothoracic surgeon who exemplifies excellence in the areas of education, mentorship and/or leadership. He has lectured and been a visiting professor in countless institutions and post-graduate courses throughout the world. He has participated in the training and mentoring of over 300 fellows in pediatric cardiology, cardiac surgery, neonatology, critical care medicine, and cardiac anesthesia, in addition to countless residents and medical students.

He is a founding member of:

- Pediatric Cardiac Intensive Care Society (1996)
- International Society of Pediatric Mechanical Circulatory Support (2009)
- World Society for Pediatric and Congenital Cardiac Surgery (2010)
- Cardiac Neurodevelopmental Outcomes Collaborative (2016)
- Congenital Heart Academy (2020)
  - The CHA has presented over 100 webinars free of charge in 2020-2022 during the Coronavirus pandemic to over 26,000 unique attendees in over 120 countries <https://www.youtube.com/c/CongenitalHeartAcademy>

In 1992, Dr. Wernovsky was a participating cardiologist and intensivist for a mission trip to Bratislava, Slovakia sponsored by Project Hope. The program in Bratislava has remained sustainable for 30 years, has become one of the best in Europe, and has been a model of NGO-sponsored charitable missions\*. Along with others, Dr. Wernovsky returned for multiple visits to Bratislava, as well as ongoing education with the team for the next 20 years. He has also participated in NGO missions to Jamaica and Costa Rica; all three of these programs continue to be sustainable and successful.



Finally, Dr. Wernovsky just celebrated his 40th wedding anniversary with his “high school sweetheart” and is a proud father of two and grandfather of three. He is an avid music lover; composes and performs music, and co-founded the Baby Blue Sound Collective, a musical group of pediatric heart surgeons and cardiologists who perform at medical meetings and raise money for pediatric cardiac charities.

\* <https://www.openmedicalinstitute.org/blog/2022/05/10/30th-anniversary-of-the-pediatric-cardiac-center-in-bratislava-slovakia/>



**Jeffrey P. Jacobs, M.D., FACS, FCCP Co-Chairman**

Professor of Surgery and Pediatrics

University of Florida

[jeffreyjacobs@ufl.edu](mailto:jeffreyjacobs@ufl.edu)

Dr. Jacobs is a Diplomate of the American Board of Surgery and the American Board of Thoracic Surgery. He also has the Congenital Heart Surgery Certificate from the American Board of Thoracic Surgery. He is also a Fellow of the American College of Surgeons (FACS), the American College of Cardiology (FACC), and the American College of Chest Physicians (FCCP). He is a member of The American Association for Thoracic Surgery (AATS), The Society of Thoracic Surgeons (STS), The European Association for Cardio-Thoracic Surgery (EACTS), The Southern Thoracic Surgical Association (STSA), The Congenital Heart Surgeons’ Society (CHSS), and The European Congenital Heart Surgeons Association (ECHSA). He is founding Secretary of The World Society for Pediatric and Congenital Heart Surgery (WSPCHS).

Dr. Jacobs received his bachelor’s degree from the University of Miami and his medical degree from the University of Miami School of Medicine through the Honors Program in Medicine, a combined 6-year BS/MD program. He graduated as a Doctor of Medicine with Distinction in Research 1988. He then completed a five-year residency in General Surgery followed by a two-year residency in Thoracic and Cardiovascular Surgery at the University of Miami/Jackson Memorial Medical Center. Dr. Jacobs spent an additional year at the University of London in England training in pediatric cardiothoracic surgery at Great Ormond Street Hospital for Sick Children; this Pediatric Cardiac Surgery Fellowship was through the Overseas Doctors Training Scheme of The Royal College of Surgeons of England.

Dr. Jacobs is a Professor of Surgery and Pediatrics in the Congenital Heart Center at University of Florida and UF Health Shands Children’s Hospital. He has been a Professor at University of Florida since 2020. Previously, he served as a cardiac surgeon at Johns Hopkins All Children’s Hospital from 1998 – 2019, and a Professor of Surgery and Pediatrics at Johns Hopkins University. He performs both pediatric and adult congenital cardiothoracic surgery and has performed over 4200 operations. From 2007 till 2018, he was the Director of the Johns Hopkins All Children’s Hospital Heart Transplantation Program, which performed over 180 pediatric heart transplants and specialized in high-risk pediatric cardiac transplantation. He was Director of the Andrews/Daicoff Cardiovascular Program at Johns Hopkins All Children’s Hospital from 2013 – 2018 and Chief of Cardiovascular Surgery and Co-Director of Johns Hopkins All Children’s Heart Institute from 2015 – 2018.



Dr. Jacobs is Editor in Chief of *Cardiology in the Young*, one of the most widely read journals dedicated to pediatric and congenital cardiac care (2013 – present). He is also Associate Editor for the *World Journal for Pediatric and Congenital Heart Surgery*, one of the most widely read journals dedicated to pediatric and congenital cardiac surgery (2009 – present) and Deputy Editor for *Annals of Thoracic Surgery*, one of the most widely read journals dedicated to thoracic and cardiovascular surgery (2022 – present). Personally, he has authored nearly 700 peer reviewed publications, over 60 book chapters, and 9 books.

Although his primary professional activity is as a clinical cardiothoracic surgeon, caring for children and young adults with cardiovascular disease, Dr. Jacobs has expertise and interest in health care quality measurement, outcomes analysis, public reporting, and longitudinal follow-up. He is recognized as an international pioneer in linking and leveraging databases to share best practices and improve outcomes globally.

- Member of the Society of Thoracic Surgeons Workforce on National Databases (2006 – 2021)
  - Workforce Chair from 2015 – 2019.
- Chair of the Society of Thoracic Surgeons Congenital Heart Surgery Database Task Force (2006 – 2014)
- Chair of the Society of Thoracic Surgeons Longitudinal Follow-up and Linked Registries (LFLR) Task Force (2007–2015)
- Chair of the Society of Thoracic Surgeons Public Reporting Task Force (2009– 2015).
- He has held multiple leadership positions including
- Past-President (2019) of the Southern Thoracic Surgical Association.
- Founding Chair of the Congenital Heart Surgeons' Society (CHSS) Committee on Quality Improvement and Outcomes.
- Founding Secretary of The World Society for Pediatric and Congenital Heart Surgery (WSPCHS)
- Working Group Leader of the Heart/Heart Surgery Working Group for U.S. News America's Best Children's Hospitals rankings.
- Founding member of The International Society for Nomenclature of Paediatric and Congenital Heart Disease (ISNPCHD); including serving as President from 2017 – 2021.
  - ISNPCHD has developed the terminology and definitions for the congenital and pediatric cardiac nomenclature for the eleventh revision of the International Classification of Diseases (ICD-11)
- Since 2010, Dr. Jacobs has served on the American Medical Association Current Procedural Terminology (CPT) Advisory Committee (2010 – 2025), as a representative of The Society of Thoracic Surgeons (STS)



For 18 years (2001 – 2018), Dr. Jacobs served as Chair of The Annual International Symposium on Congenital Heart Disease with Echocardiographic, Anatomic, Surgical, and Pathologic Correlation. This annual symposium was one of the largest multidisciplinary meetings in the world for congenital cardiac disease. In 2009, 2010, 2011, and 2012, this meeting was co-sponsored by The American Association for Thoracic Surgery (AATS). Following these clinical, academic and international leadership positions, Dr. Jacobs is Co-Chair of the 2023 World Congress of Pediatric Cardiology and Cardiac Surgery.

Dr. Jacobs performs both pediatric and adult cardiac and thoracic surgery and enjoys providing individual attention to both patients and their families. He spends his leisure time with his wife Stacy and their children.



**Mitchell I. Cohen, MD, FACC FHRS – Scientific Chair 8th World Congress**

Chief, Pediatric Cardiology  
Director, Pediatric Arrhythmia Services  
Inova Children's Hospital  
mitchcohenmd@gmail.com

Dr. Cohen is the current Co-Director of the Heart Center and Chief of Pediatric Cardiology at Inova LJ Murphy Children's Hospital. Dr. Cohen graduated from Temple University School of Medicine and then completed a pediatric internship, residency, cardiology fellowship, and subspecialty training in pediatric electrophysiology at the Children's Hospital of Philadelphia and the University of Pennsylvania School of Medicine. Dr. Cohen remained on faculty at the Children's Hospital of Philadelphia and University of Pennsylvania School of Medicine for 7 years before relocating to Arizona where he became Co-Director of the Heart Center at Phoenix Children's Hospital for more than a decade.

While in Arizona Dr. Cohen helped establish and grow the heart center from a community hospital to one that was performing more than 600 open heart surgeries, 1,000 interventional cardiology procedures, and began doing heart transplants and became the leading provider of mechanical circulatory support services for children with advanced heart failure in the Southwest. During Dr. Cohen's tenure in Arizona the program rapidly expanded from 9 pediatric cardiologists to over 25 with US News World Rankings going from the upper 40s to the low teens. In addition, Dr. Cohen helped shape the Electrophysiology Program to one of the busiest in the country and helped establish EP outreach. Clinics throughout the state as well as in New Mexico.

In 2015, Dr Cohen became Professor of Pediatrics at the University of Arizona School of Medicine where he not only spent countless hours with medical students helping them build a career in clinical research, but also sat on the Admissions Committee for the University of Arizona Medical School. He is board certified in pediatric cardiology, adult congenital heart disease and pediatric electrophysiology by the International Board of Heart Rhythm Examiners.



In October 2017, Dr. Cohen was heavily recruited to come back east and help build the pediatric heart program and electrophysiology program in Northern Virginia at Inova Children's Hospital. He has performed more than 4,000 EP studies and catheter ablations and has families travelling from numerous states to seek his clinical advice and care. Over the last 5 years Dr Cohen has helped shape the cardiac program at Inova that now boasts close to 20 pediatric cardiologists and 3 cardiac surgeons.

Dr Cohen has long been active in clinical research. His research interests address long-term outcomes of children with cardiovascular implantable electronic devices, genotype specific therapies for patients with channelopathies, WPW, and late arrhythmic outcomes in adults with congenital heart disease. He has been on numerous RO1 and K8 grants as well as partnered with industry for clinical research. Dr Cohen has been active in numerous societies including the Heart Rhythm Society, American College of Cardiology and the American Heart Association. He has served on the Scientific Clinical Documents Committee where has been an author on 6 nationally published guidelines including: The Management of Asymptomatic WPW, Syncope, Arrhythmias with Adults with Congenital Heart Disease, Pediatric Pacemakers.

Dr. Cohen's most prestigious accomplishment was his time as the President of the Pediatric and Congenital Electrophysiology Society, where he helped expand PACES into an international society with a global image and brand. PACES is now the international voice caring for children and adults with CHD who have arrhythmias. Dr. Cohen continues to serve as a scientific advisor for the SADS (Sudden Arrhythmia Death Syndromes) Foundation and is the current pediatric liaison on the ACC Electrophysiology Section Leadership Council.

He has been a Visiting Professor of Pediatric Cardiology at Children's Mercy, Duke University and Primary Children's Hospital. Dr Cohen has more than 100 published papers, lectured over 250 times throughout the world and has mentored pediatric residents interested in cardiology. Dr Cohen is the Associate Editor for Pediatric Electrophysiology for both Cardiology in the Young and World Society of Congenital Heart Surgery Journal.

On a global level Dr Cohen has participated in medical missions to both Nicaragua and Jamaica and in 2011 performed the first pediatric ablations in Jamaica. He was the scientific program chair for the 7th World Congress of Pediatric Cardiology and Cardiac Surgery Meeting in Barcelona in 2017 and has assumed that role for a 2nd time and is now the Scientific Program Chair for the 2023 8th World Congress in Pediatric Cardiology and Cardiothoracic Surgery.

However, what Dr Cohen is most proud of is his family. Dr Cohen has been married for over 30 years to the same girl (Maileen) he went with to his high school prom. Dr Cohen has two amazing kids (no longer kids) – Jamie (24) and Jordan (27) both grew up playing competitive soccer and baseball respectively in Arizona before they each graduated Duke University. Jordan recently graduated medical school at the University of Miami and just began his residency in anesthesiology with hopes of becoming a pediatric cardiac anesthesiologist. Jamie works in strategic communications for an international firm in Washington DC and plans to go to business school next year. Dr. Cohen is always about his patients first and foremost and helping to promote his junior cardiology faculty.



**David S. Cooper, MD, MPH, MBA (candidate)**

Chair: Institutional, Societal and Industry Relations Committee

Medical Director, The Heart Institute

Medical Director, Cardiac Intensive Care Unit

Medical Director, Cardiac Anesthesia Recovery Unit

Cincinnati Children's Hospital Medical Center

Professor of Pediatrics

University of Cincinnati College of Medicine

Dr Cooper is board certified in Pediatrics, Pediatric Cardiology and Pediatric Critical Care. He is currently the Medical Director of the Heart Institute and Cardiac Intensive Care Unit at Cincinnati Children's Hospital Medical Center. Prior to this he served as the Medical Director of the Cardiac ECLS program, co-Director of the Center for Acute Care Nephrology and Chief Safety Officer for the Heart Institute. For the last 19 years, his career has focused on the care of critically ill neonates, infants, children, and adults with complex congenital heart disease with a particular interest in how care in the intensive care unit can impact morbidity. His research work has focused on anticoagulation, extracorporeal support, acute/chronic kidney injury, teamwork and performance and patient outcomes. He has authored over 150 peer reviewed publications and multiple textbook chapters. He serves as an editor for the textbook on pediatric cardiac critical care (Critical Heart Disease in Infants and Children – 3rd Edition).

Dr. Cooper is the President of the Pediatric Cardiac Intensive Care Society (PCICS); he has had an extensive relationship with the PCICS since 2001. He has been actively involved in the PCICS meetings since 2005, serving as the PCICS program co-director from 2008-2012 and program director in 2014-2016. Moreover, he has helped lead multiple initiatives surrounding the transformation of the society into a more responsive, modern-day organization, including serving as the Treasurer from 2013-2022 and on the Board of Directors since 2011. His efforts on behalf of the PCICS were recognized with the PCICS Service Award in 2020. He remains active in the Extracorporeal Life Support Organization (ELSO) both in North America and abroad serving as its program director from 2008-2011. Additionally, he has broad involvement with the Pediatric Cardiac Critical Care Consortium (PC4), including the development of the PC4 CICU database that is used to track and improve outcomes for patients with critical cardiac disease across North America.

Dr. Cooper was co-chair of the critical care track for the 7th World Congress of Pediatric Cardiology and Cardiac Surgery, held in Barcelona in 2017, and is the Chair of the Institutional, Societal and Industry Relations Committee for the 2023 8th World Congress of Pediatric Cardiology and Cardiac Surgery.



**Kathryn Dodds, RN, MSN, CRNP – Chair: Interdisciplinary Committee**

Clinical Manager: Fontan FORWARD Program

Faculty/Lecturer

University of Pennsylvania School of Nursing

Pediatric Acute Care Nurse Practitioner Program

dodds@chop.edu

Kathryn has been a nurse at CHOP since 1989 when she started as a new nursing school graduate in the Cardiac Intensive Care Unit. During her clinical work, in 1994, she graduated with a Masters Degree from the University of Pennsylvania, in the first acute care nurse practitioner program in the country. She was then hired as the first nurse practitioner within the cardiac program at CHOP in 1996.

She has worked in all aspects of the cardiac program including cardiac surgery, cardiology, transplant, and helped develop the cardiac center referral program – one of the largest of its kind in the world. She is also one of the founding members of the Single Ventricle Survivorship Program at CHOP, and is now manager of the Fontan FORWARD multidisciplinary team, responsible for the inpatient and outpatient management of patients with single ventricle congenital heart disease. This program was the first of its kind in the world and has evaluated over 600 patients after the Fontan operation. Kathryn's clinical and research interests have focused on the consequences and impact of single ventricle physiology. She has been an invited speaker nationally and internationally.

Kathryn has been part of the faculty and teaching in the graduate pediatric acute care and critical care nurse practitioner program at The University of Pennsylvania School of Nursing since 2005. She also lectures for Drexel University's Pediatric Nurse Practitioner Program, Jefferson University's Neonatal Nurse Practitioner Program, and the Acute Care Nurse Practitioner program at UCSF. Kathryn is committed to the education, training, and mentorship of tomorrow's pediatric nurse practitioners in acute care.

Kathryn has been part of the organizing committee for the CHOP Annual Update on Pediatric and Congenital Cardiovascular Disease, celebrating its 25th annual conference this year (Cardiology 2022), since 2000. She has planned the nursing program and been responsible for the nursing credit hours for this meeting for 22 years.

On a national level, Kathryn is currently on the medical advisory board of Mended Little Hearts and is part of the Quality Improvement Team for the Fontan Outcomes Network.

Kathryn is committed to the care of patients and families with congenital heart disease. She has most recently been awarded the 2022 Tita Hutchens Award and the National Heart Hero of the Year Award by Mended Little Hearts, Inc.



## Conference Organizers



### **Christina Mannices, Director**

Christina Mannices is the Manager, Continuing Medical Education at The Children's Hospital of Philadelphia. She has nineteen years of experience in continuing medical education and thirty years of experience in the hotel and restaurant industry.

As Manager of Continuing Medical Education at The Children's Hospital of Philadelphia, she is responsible for overseeing the accredited status of The Children's Hospital of Philadelphia with the Accreditation Council for Continuing Medical Education (ACCME) and managing the Department of Continuing Medical Education and Conference Center. She manages a CME staff of seven; oversees the planning/coordination of all medically-related education events; collaborates with other departments on several Outreach Committees to market the department/division and make them more visible regionally and nationally; and manages forty-five conference budgets yearly totaling revenue of 1.3 million. She is also responsible for managing the Conference Center scheduling, marketing, audio visual, maintenance, and environmental services.

Prior to joining The Children's Hospital of Philadelphia in 1999, she was restaurant general manager for a large dining company and managed a few hotel restaurants in Philadelphia. She has also managed several university food service operations.

Christina graduated from the School of Hotel and Restaurant Management at Widener University with a Bachelor of Science degree. She attends the annual ACCME accreditation Workshops and MPI Conferences.

Christina Mannices manages one of the largest pediatric cardiac meetings in the United States, the Annual Postgraduate Course in Pediatric Cardiovascular Disease, organized by The Children's Hospital of Philadelphia which is entering its 25th year.



### **Melodye Farrar, Director**

Melodye Farrar, MAEd, CHCP, CMP-HC is the Director of Continuing Professional Development at the University of Virginia School of Medicine, a joint accreditor, providing continuing education for the healthcare team. UVA provides a wide variety of educational and performance/quality improvement opportunities in primary care, medical specialties and interprofessional care that incorporate cutting edge research, faculty expertise to address: population health issues, complex clinical and health care challenges, optimum clinician and team performance, lifelong learning and the education continuum.

Previously, Melodye served as the Director of Continuing Medical Education at Johns Hopkins All Children's Hospital, a teaching and research hospital, and a U.S. News & World Report Best Children's Hospital. For nearly 20 years there, she



directed a large clinical educational program that supports more than 50 pediatric specialties. In this role, she served as the past director for the World Society for Pediatric Congenital Heart Surgery. Prior to joining Johns Hopkins, she managed educational teams as vice president of two large medical education companies.

Melodye holds a master's degree in adult education from the University of South Florida, and a bachelor's in communication from Florida State University. Her advanced certifications include: Certified Healthcare CPD Professional (CHCP), Certified Meeting Professional in Healthcare (CMP-HC), and a graduate certificate in Leadership in Human Resource Development.

## Scientific Committee

### Adult Congenital Heart Disease

---

#### Track Chairs

- Craig Broberg (USA)
- Luke Burchill (Australia)
- Geetha Kandavello (Malaysia)
- Adrienne Kovacs (USA)
- Erwin Oechslin (Canada)

#### Committee Members

- Jamil Aboulhosn (USA)
- Maria Elizari (Argentina)
- Sue Fernandes (USA)
- Edward Hickey (USA)
- Anitha John (USA)
- Paul Khairy (Canada)
- Leila Ladak (Pakistan)
- Clare O'Donnell (New Zealand)
- Jolien Roos-Hesselink (Netherlands)
- Christopher Talluto (USA)
- Daniel Tobler (Switzerland)

### Administration

---

#### Track Chairs

- Patricia Hickey (USA)
- Kay Stewart-Huey (USA)
- David Wessel (USA)

#### Committee Members

- Stuart Berger (USA)
- Robert Crone (USA)
- Martin Elliott (United Kingdom)
- Allain Fraise (United Kingdom)
- Allan Goldman (United Kingdom)
- Jim Kirklin (USA)
- Tom Lee (USA)
- Stephen Roth (USA)
- Robert Shaddy (USA)

### Advocacy

---

#### Committee

- Stacey Lihn (USA)
- Jodi Smith (USA)
- Amy Verstappen (USA)

### Artificial Intelligence, New Technology & Big Data

---

#### Track Chairs

- David Axelrod (USA)
- Anthony Chang (USA)
- Kevin Maher (USA)
- Sara Pasquali (USA)

#### Committee Members

- Eichanan Bruckheimer (Israel)
- Rodney Franklin (United Kingdom)
- Michael Gaies (USA)
- Kimberly Gauvreau (USA)
- Joao Lima (USA)
- Mjaye Mazwi (Canada)
- Ryan Moore (USA)
- Spyro Mousses (USA)
- Jai Nahar (USA)
- Jennifer Silva (USA)



## Anesthesia

---

### Track Chairs

- Walid Habre (Switzerland)
- Viviane Nasr (USA)
- Mark Twite (USA)

### Committee Members

- Roseberg Albores Figueroa (Mexico)
- Philip Arnold (United Kingdom)
- Nina Deutsch (USA)
- David Faraoni (Canada)
- Mariane Maroun (Lebanon)
- Justin Skowno (Australia)
- James Spaeth (USA)
- David Vener (USA)
- Rosanna Zanai (Italy)

## Basic Science

---

### Track Chairs

- Connie Bezzina (Netherlands)
- Martina Brueckner (USA)
- Barry Byrne (USA)

### Committee Members

- Allen Everett (USA)
- Bruce Gelb (USA)
- Marc Hitz (Germany)
- Seema Mital (Canada)
- James Priest (USA)
- Sushma Reddy (USA)
- Isao Shiraishi (Japan)
- Deepak Srivastava (USA)
- Hiroyuki Yamagishi (Japan)

## Cardiac Intensive Care

---

### Track Chairs

- Nikhil Chanani (USA)
- Bruna Cury (Brazil)
- Melissa Jones (USA)

### Committee Members

- Qalab Abbas (Pakistan)
- Kiona Allen (USA)
- Ritu Asija (USA)
- Jason Buckley (USA)
- David Cooper (USA)
- Christin Diller (USA)
- Robin Horak (USA)
- Jeannie Koo (USA)
- Graeme McClaren (Australia)
- Guillermo Moreno (USA)
- Peter Roeveld (Netherlands)
- Joshua Salvin (USA)
- Deanna Tzanetos (USA)
- Marin Záhorec (Slovakia)
- Jill Zender (USA)

## Cardiac Surgery

---

### Track Chairs

- Jim Kirklin (USA)
- Giovanni Stellin (Italy)
- Christo Tchervenkov (Canada)

### Committee Members

- Zohair Al-Halees (Saudi Arabia)
- Emile Bacha (USA)
- Drissi Boumzebra (Morocco)
- John Calhoon (USA)

- Jorge Cervantes (Mexico)
- Sertaç Çiçek (Turkey)
- Yves D'Udekem (USA)
- Joseph Dearani (USA)
- Frank Edwin (Ghana)
- Adel Eigamal (Egypt)
- Sitaram Emani (USA)
- Kirsten Finucane (New Zealand)
- Joe Forbess (USA)
- Jose Fragata (Portugal)
- Hani Hajm (USA)
- Jürgen Hörer (Germany)
- Krishna Iyer (India)
- Jeffrey Jacobs (USA)
- Marcelo Jatene (Brazil)
- Christian Kreuzer (Argentina)
- Bret Mettler (USA)
- Jennifer Romano (USA)
- Kisaburo Sakamoto (Japan)
- Nestor Sandoval (Colombia)
- George Sarris (Greece)
- James Tweddell (USA)
- Susan Vosloo (South Africa)
- Hao Zhang (China)

## Cardiovascular Disease in the Neonate

---

### Track Chairs

- Amir Ashrafi (USA)
- John Cleary (USA)
- Victor Levy (USA)

### Committee Members

- Zohra Banoo (South Africa)
- Silvia Fernandez Jonusas (Argentina)
- Martin Kluckow (Australia)



- Masaki Osaki (Japan)
- Felipe Santelices (Chile)
- Istvan Seri (Hungary)

## Cardiac Catheterization

---

### Track Chairs

- Ziyad Hijazi (Qatar)
- Ralf Holzer (USA)
- Damien Kenny (Ireland)

### Committee Members

- Felix Berger (Germany)
- Allison Cabalka (USA)
- John Cheatham (USA)
- Maiy El Sayed (Egypt)
- Tom Jones (USA)
- Jacqueline Kreutzer (USA)
- Carlos Pedra (Brazil)
- Jou-Kou Wang (Taiwan)
- Evan Zahn (USA)

## Echocardiography

---

### Track Chairs

- Meryl Cohen (USA)
- Leo Lopez (USA)
- Jan Marek (United Kingdom)

### Committee Members

- Carrie Altman (USA)
- Piers Barker (USA)
- Yiu-Fai Cheung (Hong Kong)
- George Comitis (South Africa)
- Folkert Meijboom (Netherlands)

- Luc Mertens (Canada)
- Nelangi Pinto (USA)
- Megan Sherwood (Australia)
- John Simpson (United Kingdom)
- Adressa Soars (Brazil)
- Satochi Yasukochi (Japan)
- Luciana Young (USA)

## Electrophysiology

---

### Track Chairs

- Bryan Cannon (USA)
- Joachim Hebe (Germany)
- Gabrielle Hessling (Germany)
- Elizabeth Stephenson (Canada)

### Committee Members

- Charles Berul (USA)
- Nico Blom (Netherlands)
- Alpay Çeliker (Turkey)
- Mitchell Cohen (USA)
- Susan Etheridge (USA)
- Rami Fogelman (Israel)
- Roman Gebauer (Germany)
- Adele Greyling (South Africa)
- Tevfik Karagöz (Turkey)
- Laszlo Korynei (Hungary)
- Aya Miyazaki (Japan)
- Jose Moltedo (Argentina)
- Ferrán Rosés Noguer (Spain)
- Maully Shah (USA)
- Jon Skinner (New Zealand)
- Sabrina Tsao (Hong Kong)
- George Van Hare (USA)
- Katja Zeppenfeld (Netherlands)

## Fetal Cardiology

---

### Track Chairs

- Mary Donofrio (USA)
- Anita Moon-Grady (USA)
- Jack Rychik (USA)

### Committee Members

- Alfred Abuhamad (USA)
- Sarah Chambers-Gurson (USA)
- Jim Cnota (USA)
- Ulrike Herberg (Germany)
- Christopher Lindblade (USA)
- Gurleen Sharland (United Kingdom)
- Gary Shollere (Australia)
- Gerald Tulzer (Austria)
- Paulo Zielinsky (Brazil)

## Global Cardiac Health & Rheumatic Heart Disease

---

### Track Chairs

- Christopher Hugo-Hamman (South Africa)
- David Overman (USA)
- Craig Sable (USA)
- Bistra Zheleva (USA)

### Committee Members

- Armando Alfaro (Costa Rica)
- Andra Beaton (USA)
- Marcello Cardarelli (USA)
- Josie Everett (USA)
- Sherard Little (Jamaica)



- Frank Molloy (United Kingdom)
- Jeremiah Mwangi (United Kingdom)
- William Novick (USA)
- Rob Raylman (USA)
- Nestor Sandoval (Colombia)
- Anita Saxena (India)
- Emma Scanlon (United Kingdom)
- Liesl Zühlke (South Africa)

## Heart Failure, Transplantation, Ventricular Assist Devices

---

### Track Chairs

- Daphne Hsu (USA)
- William Mahle (USA)
- David Morales (USA)
- Joseph Rossano (USA)

### Committee Members

- Antonio Amodeo (Italy)
- Estela Azeka (Brazil)
- Wendy Book (USA)
- Michael Burch (United Kingdom)
- Michiel Dalinghaus (Netherlands)
- Shripasad Deshpande (USA)
- Robert Jacquiss (USA)
- Aamir Jeewa (Canada)
- Johnathan Johnson (USA)
- Shigetoyo Kogake (Japan)
- Shelley Miyamoto (USA)
- Robert Weintraub (Australia)
- Steven Zangwill (USA)

## Members-at-Large

---

### Committee Members

- Mark Bleiweis (USA)
- Elisa Bradley (USA)
- Jonathan Chen ( USA)
- Lucas Collazo (USA)
- Yves D’Udekem (USA)
- Joe Forbess (USA)
- Elizabeth Goldmuntz (USA)
- Roxanne Kirsch (USA)
- Ron Lacro (USA)
- Bret Mettler (USA)
- Laura Olivieri (USA)
- Steven Paridon (USA)
- Andrew Redington (USA)
- Elizabeth Stephens (USA)
- Sarah Teele (USA)
- Ali Zaidi (USA)

## Multimodal Imaging

---

### Track Chairs

- Shelby Kutty (USA)
- Andrew Taylor (United Kingdom)
- Israel Valverde (Spain)

### Committee Members

- Haifa Abdul Latiff (Malaysia)
- Sonya Babu-Narayan (United Kingdom)
- Timothy Cohen (Canada)
- David Danford (USA)
- Mark Fogel (USA)
- Tal Geva (USA)
- Hopewell Nitsinjana (South Africa)

- Sergio Uribe (Chile)
- Alistair Young (New Zealand)

## Neurodevelopment

---

### Track Chairs

- Frank Casey (Northern Ireland)
- Bradley Marino (USA)
- Jacqueline Sanz (USA)

### Committee Members

- Jon Beca (New Zealand)
- Adam Cassidy (USA)
- J. William Gaynor (USA)
- Bea Latal (Switzerland)
- Daniel Licht (USA)
- Amy Jo Lisanti (USA)
- Keila Lopez (USA)
- Shabnam Peyvandi (USA)
- Florencia Ricci (Canada)
- Mike Seed (Canada)
- Erica Sood (USA)
- Gil Wernovsky (USA)
- Jo Wray (United Kingdom)



## Nursing

---

### Track Chairs

- Kathryn Dodds (USA)
- Cecilia St. George Hyslop (Canada)
- Sandra Staveski (USA)

### Committee Members

- YangJing Bai (China)
- Derek Best (Australia)
- Louise Callow (USA)
- Jean Connor (USA)
- Anida Elias (Malaysia)
- Britt Elin Fredriksen (Norway)
- Philip Moons (Belgium)
- Nancy Pike (USA)
- Diana Robertshaw (United Kingdom)
- Unnikrishnan Vs (India)

## Outpatient Cardiology

---

### Track Chairs

- Stuart Berger (USA)
- Stafford Grady (USA)

### Committee Members

- Carissa Baker Smith (USA)
- Mitchell Cohen (USA)
- Jane Newburger (USA)
- Geoff Rosenthal (USA)

## Perfusion

---

### Track Chairs

- Molly Oldeen (USA)
- Jim Reagor (USA)
- Tami Rosenthal (USA)

### Committee Members

- Ashley Hodge (USA)
- Bradley Kulat (USA)
- Alex Robertson (United Kingdom)
- Joseph Timpa (USA)

## Pulmonary Hypertension

---

### Track Chairs

- Jeffrey Fineman (USA)
- Dunbar Ivy (USA)

### Committee Members

- Antonio Augusto Lopes (Brazil)
- Rolf Berger (Netherlands)
- John Berger (USA)
- Prashant Bobhate (India)
- Maria Del Cerro (Spain)
- Kong Gu (China)
- Yoshihide Mitani (Japan)
- Erika Rosenzweig (USA)

## Quality Improvement

---

### Track Chairs

- Jeffrey Anderson (USA)
- Katie Bates (USA)
- Krishna Kumar (India)

### Committee Members

- Kate Brown (United Kingdom)
- Eva Goossens (Belgium)
- Babar Hassan (Pakistan)
- Mashall Jacobs (USA)
- Kathy Jenkins (USA)
- Tara Karamlou (USA)
- Alex Palacios (Mexico)
- Ronn Tanel (USA)
- Dongnan Truong (USA)
- Karen Uzark, (USA)



## Abstracts



**Chair: David J. Goldberg, M.D.**

Dr. Goldberg completed his pediatric residency and Chief Residency at Yale – New Haven Hospital in 2005, and his fellowship in Pediatric Cardiology at Children’s Hospital of Philadelphia in 2008. Following his fellowship, Dr. Goldberg joined the Division of Pediatric Cardiology at the Perelman School of Medicine and the Children’s Hospital of Philadelphia (CHOP) where he is now an Associate Professor of Pediatrics.

Dr. Goldberg currently serves as the Associate Director of the Cardiac Care Unit at Children’s Hospital, and he is an active member of the echocardiography lab. His research interests include single ventricle heart disease, particularly the Fontan circulation, and he recently served as the co-Principal Investigator of the internationally Fontan Udenafil Exercise Longitudinal Trial.

Dr. Goldberg has been the director of abstracts and on the organizing committee for the Annual Update on Pediatric and Congenital Cardiovascular Disease since 2008.



**Co-Chair: Kurt R. Schumacher, M.D., M.S.**

Associate Professor of Pediatrics, Division of Pediatric Cardiology  
Director, Pediatric Heart Transplant Program  
Congenital Heart Center, C.S. Mott Children’s Hospital, University of Michigan

With clinical research that focuses on long term outcomes in children and adults who have palliated congenital heart disease, Kurt Schumacher has contributed to the understanding and treatment of heart failure after surgical treatment of congenital heart disease. His primary focus has been on complications of Fontan circulation, the final surgical palliation of single ventricle heart disease. His work also focuses on avoidance of heart failure and improving physical and psychological health in children with heart conditions.

Dr. Schumacher is a member of the Congenital Heart Center at C.S. Mott Children’s Hospital, a world leader in the care of children with heart disease, where he is a cardiac intensivist and medical director of the Pediatric Heart Transplant Program.

Dr. Schumacher earned his M.D. from the University of Michigan Medical School and completed pediatrics residency at the University of North Carolina. He completed fellowship in pediatric cardiology and advanced training in both heart failure/transplantation and cardiac intensive care at the University of Michigan. He earned his M.S. in clinical research design and statistical analysis at the University of Michigan School of Public Health. He is the Associate Director of the Congenital Heart Center’s highly active Michigan Congenital Heart Outcomes Research and Discovery (M-CHORD) clinical research unit and is the director of the Pediatric Cardiac Critical Care Consortium (PC4) Data Coordinating and Analytic Center.



## Special Features: Anatomy and Technology Center of the Future

### Lead Faculty:



#### **Justin Tretter MD, Co-Director Multi-Dimensional Anatomy Lab**

Dr. Justin Tretter is a pediatric cardiologist and non-invasive cardiac imager at the Cleveland Clinic, with unique training under the mentorship of Professor Robert Anderson as a cardiac morphologist. He is the Director of Advanced Cardiac imaging and Co-director of the Congenital Aortic Valve Procedural Planning Center for Cleveland Clinic Children's, and Director of Cardiac Morphology for the Cleveland Clinic. He has specific interest and expertise in understanding detailed and clinically relevant cardiac anatomy to guide personalized imaging-based procedural approaches.



#### **Shelby Kutty MD, Co-Director Multi-Dimensional Anatomy Lab**

Dr. Shelby Kutty is the director of Pediatric and Congenital Cardiology, the co-director of the Blalock-Taussig-Thomas Heart Center, and the Helen B. Taussig Professor of the Johns Hopkins School of Medicine. He serves as Chair of Cardiovascular Analytic Intelligence Initiative, and also holds appointments at the Johns Hopkins Bloomberg School of Public Health.

Dr. Kutty trained in pediatrics, cardiology, and cardiac imaging in India, Australia, Canada, and the United States. He earned his master's degree in healthcare management from Harvard University and is an Aresty Scholar of the Wharton School at the University of Pennsylvania. Prior to joining Johns Hopkins, he was a professor of pediatrics and internal medicine at the University of Nebraska Medical Center College of Medicine, where he was named Vice Chair for Pediatrics and Assistant Dean for Research and Development in 2017.

Dr. Kutty is one of the foremost authorities in multimodality cardiovascular imaging, including echocardiography, magnetic resonance, and computed tomography. His areas of academic interest have focused on myocardial function, therapeutic ultrasound, and cardiovascular outcomes, as well as an important role in developing guidelines and standards for contrast echocardiography



**Ryan A. Moore MD, MSc; Digital Futures Lead**

Dr. Ryan Moore is an Associate Professor at Cincinnati Children’s Hospital and Director of Cincinnati Children’s Digital Health Innovation. Dr. Moore also specializes in cardiac cross-sectional imaging (MRI/CT) and advanced 3D modeling, visualization, and digital interactivity including 3D printing, virtual/augmented reality (VR/AR), and game engine-enhanced virtual surgical planning. His team has spearheaded work in virtual surgical planning for congenital heart surgeries, virtual implantation of mechanical circulatory support devices in pediatric and young adults, and virtual transplantation and Artificial Intelligence (AI) model development to expand the pediatric heart and lung transplant donor pools. He recently founded Cincinnati Children’s Digital Experience Technologies which serves as the institution’s innovation hub for development of AR/VR/gaming and interactive 3D modeling to provide novel AR/VR experiences, 3D modeling/printing, and medical gaming/simulations. Recently, he led development of a VR-based “Congenital Heart Surgical Metaverse” in partnership with cardiothoracic surgeon, Dr. David L.S. Morales. Drs. Moore and Morales are actively deploying this exciting new technology in several participating institutions, including international partners like Sheba Medical Center in Israel. Dr. Moore has also created a great deal of digital content for patient-family-provider education including the “Heartpedia” mobile application, the “Surgical Animate” mobile application and its accompanying surgical animations, and most recently “Hank the Heart” Children’s book – which includes age-specific health literacy animations and interactive games designed to help kids with CHD better understand their complex medical conditions. Dr. Moore will be leading the Digital Futures Technology Hub with an international team of experts in Digital Health Innovation.





## #1 A First of Its Kind: The Multi-Dimensional Anatomy Lab

Cardiac anatomy forms the building blocks to properly understand the form and resulting function and physiology in patients with congenital heart disease, additionally serving the basis to guide cardiac intervention and surgical repair.

Our understanding of cardiac anatomy has historically been based on investigations from autopsied heart specimens, 2-dimensional imaging, and intraoperative inspection. With the turn of the 21st century, however, has come an explosion in the application of advanced imaging and digital technology, bringing with it increasing and improved use of three- and four-dimensional imaging and the application of augmented and virtual reality.

In the developed world, these techniques have now become increasingly common place to visualize the complex 3-dimensional cardiac anatomy of various congenital lesions in the living patient, with the increased ability to not only plan but also simulate interventional and surgical procedures.

The Multi-Dimensional Cardiac Anatomy Lab will highlight this historical advance at the 8th World Congress of Pediatric Cardiology and Cardiac Surgery. This lab will be open throughout the World Congress from August 26th – September 1st, 2023, featuring hands-on sessions with heart specimens, 3D and 4D imaging and reconstructions using various vendor software, and augmented and virtual reality. In addition, there will be scheduled demonstrations and presentations from global experts in anatomy, morphology, imaging, and surgery. The lab will additionally feature opportunities to explore surgical simulation with expert-guided instructions covering common surgical repairs in congenital heart disease.





## #2 Digital Futures Technology Hub

- Augmented and Virtual Reality, Surgical Metaverse, Applied Visual Effects
- Gamification of Clinical Simulations, Interactive Artificial Intelligence and Machine Learning

Through an international team of Digital Health Innovation experts, the Digital Futures Technology Hub will serve as an interactive experience for participants to test and trial the latest cutting-edge technology. The highlighted sessions include – AR/VR Surgical Metaverse, Gamification and Simulations, Applied Visual Effects to CHD, and Interactive AI/(Machine Learning (ML) Use Cases.

- Surgical planning has recently undergone a paradigm shift as newer extended reality (XR) technologies have become rapidly implemented for preoperative, intraoperative and postoperative validation. In addition, there have been significant advances in the “metaverse” ideology, where surgeons can connect to each other via immersive technology (AR/VR) preoperatively/postoperatively, as well as utilizing enhanced virtual care platforms that can connect in real time during surgery. Participants will learn utilizing hands-on experience with XR technologies that allow for cardiologists and cardiac surgeons to interact with digital anatomic twins of patients, and virtual tools to advance surgical planning discussions and peer-to-peer consultations.
- CHD education has rapidly advanced in the digital transformation era, with adoption of newer “gamification” and immersive simulation techniques. Participants will learn utilizing and hands-on experience with advancing technologies that employ gamification and simulation principles into pediatric critical care (e.g., ICU simulations), cardiac anesthesia, cardiac surgery (e.g., surgical simulations) and nursing education. Examples include Body Interact Clinical Simulator, Surgical Science Simbionix Simulators, Medivis XR Anatomy, MediView XR30, Heartpedia VR, Stanford Heart, and Level Ex/Cardio Ex applications.
- Visual effects have long played a role in advancing the film and gaming industry. More recently, healthcare has started to adopt and implement various techniques to push forward several media-driven disciplines including 3D imaging, digital pathology, and intraoperative video feeds. Participants will utilize hands-on experience with visual effects technologies such as 3D photogrammetry for virtual path specimen creation, 3D imaging deep learning super sampling (DLSS) and cinematic rendering, and applying 8k resolution, 3D and microscopic technology to operating room cameras to enhance intraoperative visualization.
- AI/ML/DL has potential benefits in CHD, including discovery of new clinical markers, more precise classification of CHD phenotypes, as well as predicting disease progression, optimizing treatment plans and interventions. However, currently there are relatively few demonstrations of the use of machine learning techniques focused in clinical care. This session will enable participants to have hands-on experience with evolving AI/ML/DL technology, and learn how to implement these techniques into their patient care and research.



The Digital Futures Technology Hub will highlight cutting-edge technology at the 8th World Congress of Pediatric Cardiology and Cardiac Surgery. This tech hub will be open throughout the World Congress from August 26th – September 1st, 2023, featuring hands-on sessions with academic centers and tech industry partners. In addition, there will be scheduled demonstrations and presentations from global experts in AI/ML, AR/VR, applied visual effects, and gamification/simulation.





## Communications and Marketing Team Leadership



**Co-Chair: Grace Van Leeuwen, MD**

Pediatric Cardiology

Assistant Professor of Clinical Pediatrics at Weill Cornell Medicine - Qatar

Senior Attending - PCICU – Sidra Medicine

Co-Chair of Congenital Heart Academy

gracecvlb@gmail.com

Dr. Grace van Leeuwen is a Brazilian Pediatric Cardiologist and Cardiac Intensivist. She is assistant Professor of Clinical Pediatrics at Weill Cornell Medicine – Qatar. She has more than 10 years of experience in Pediatric Cardiac Critical Care, currently serving as a Senior Attending at Sidra Medicine's Pediatric Cardiac Intensive Care Unit in Qatar, where she is a member of the ethics committee and responsible for the Neonatal and Pediatric ECMO transport program.

Dr van Leeuwen is a Co- Chair of the Congenital Heart Academy and Co-chair of Marketing and Communication Committee of the 8th World Congress of Pediatric Cardiology and Cardiac Surgery 2023.

She is part of the editorial board of the ELSO education and the Congenital Heart Disease Journal, and is part of the ECMO working group for COVID19 at ELSO.

She has published several papers and book chapters on her field, including the Extracorporeal Life Support Organization (ELSO): 2020 Pediatric Respiratory ECMO Guidelines. She has led the development of the Cardiac and ECMO programs at Sabará Children's Hospital, her former place of work, in Brazil, being the only ECMO center in the country to have the ELSO award of excellence.

Her clinical and research interests include Pediatric Cardiac Intensive Care and ECMO, with special focus on education.

Dr van Leeuwen has been involved in several cardiac mission trips and other volunteer work for many years. She loves water sports, currently practicing dragon boat and wakesurf. She has a lovely son who will get married next year.



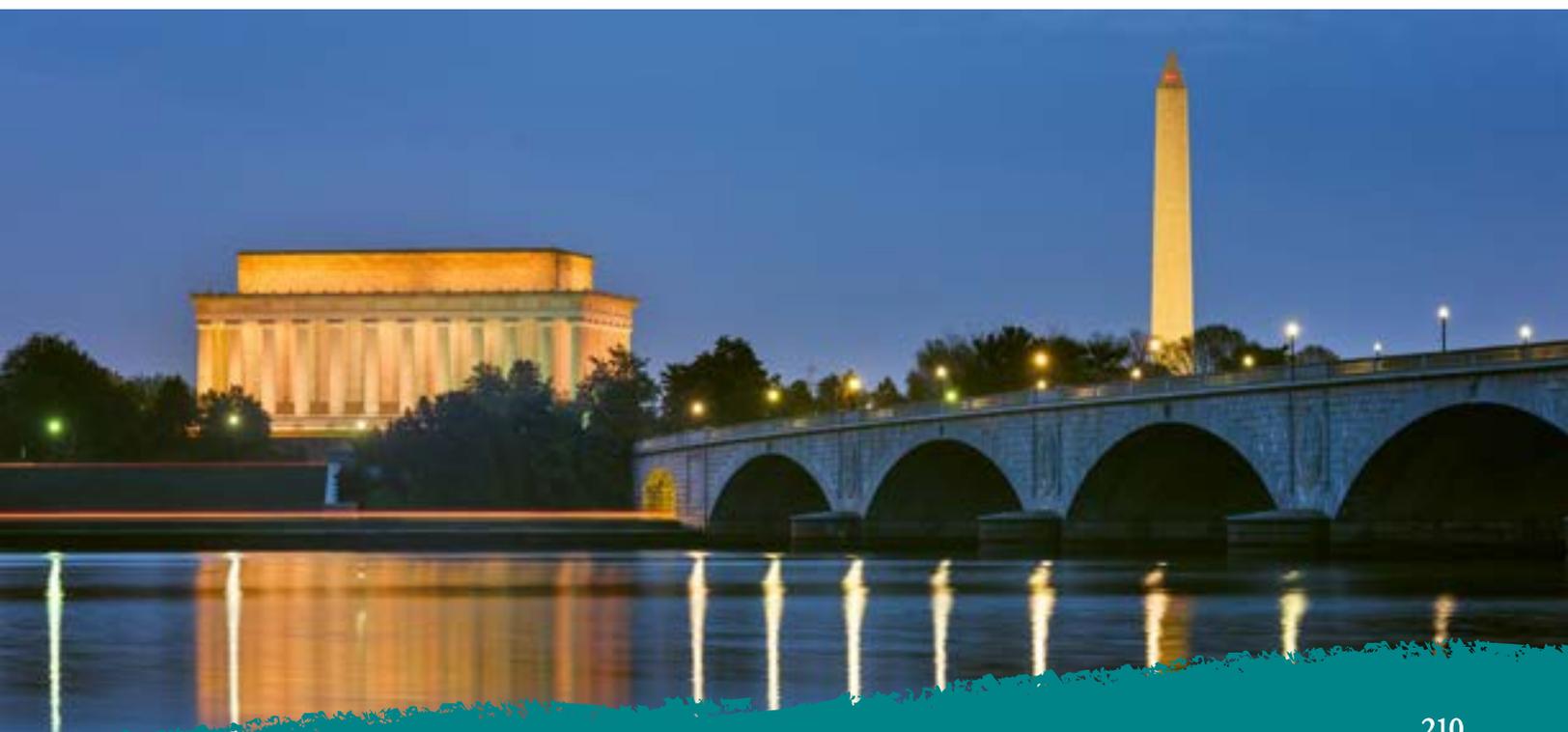
**Co-Chair: Jill Zender RN, MSN**

Nurse Practitioner  
Cardiac Intensive Care Unit  
Children's Health, Dallas  
jillzender1@gmail.com

Jill Zender is Pediatric Cardiac Intensive Care Nurse Practitioner at UT Southwestern/ Children's Health in Dallas, TX. She received her Bachelor of Science in Nursing from Otterbein University and has spent her 14 year career in the CICU. She has served in several roles in the CICU such as bedside nurse, clinical educator and, after obtaining her Master of Science Degree in Pediatric Acute Care Nurse Practitioner from University of Texas Arlington, she transitioned to a provider role. She is Co-Lead of the Heart Center Advanced Practice Provider Education Committee. Her academic interests include improving neurodevelopmental outcomes for infants with congenital heart disease. She has been part of creating a Developmental Care Team and helped to create a system to allow for family participation in Developmental Care Rounds during pandemic restrictions.

Jill is a member of The Pediatric Cardiac Intensive Care Society (PCICS) and has served on the Board of Directors since 2020. She is also Co-Lead of the PCICS Advanced Practice Provider Special Interest Group, Faculty on the PCICS APP Curriculum Course, and Co-Chair of the PCICS Connections Committee.

Jill is married with two very active school-aged boys. She enjoys any type of outdoor activities and spending time with friends and family.





## Communications and Marketing Committee

- Anas Abu Hazeem (United Arab Emirates)
- Salvatore Agati (Sicily)
- Teiji Akagi (Japan)
- Armando Alfaro (Costa Rica)
- Abdullah Alghubaishy (Saudi Arabia)
- Abdullah AlHuzaimi (Saudi Arabia)
- Sulafa KM Ali (Sudan)
- Amir Ashrafi (USA)
- Emre Belli (France)
- Tara Bharucha (United Kingdom)
- Mark Bleiweis (USA)
- Ewa-Lena Bratt (Sweden)
- Kelsey Brown (USA)
- Elio Caruso (Italy)
- Frank Casey (Northern Ireland)
- Paul Checchia (USA)
- Yiu-fai Cheung (Hong Kong)
- Mitchell Cohen (USA)
- David Cooper (USA)
- Manan Desai (India)
- Kathryn Dodds (USA)
- Molly Dreher (USA)
- Anita Duritrescu (Germany)
- Luke Eckersly (Canada)
- Melody Farrar (USA)
- Kirsten Finucane (New Zealand)
- Rami Fogelman (Israel)
- Ranni Goldwasser (Germany)
- Eva Goossens (Belgium)
- Sofia Grinenco (Argentina)
- Sayed Hamid Meky (Egypt)
- Cristen Hemmingway (USA)
- Ziyad Hijazi (Qatar)
- Irena Ivanac Vranesic (Croatia)
- Jeffrey Jacobs (USA)
- Sarah Kelly (USA)
- Eifif Khuffash (Ireland)
- Darren Klugman (USA)
- Jacqueline Kreutzer (USA)
- Ganga Krishnamurthy (USA)
- Krishna Kumar (India)
- Ajejandro Lopez-Magallon (Mexico)
- Christina Mannices (USA)
- Pamela Josue Marasigan (Qatar)
- Fernando Martins (Brazil)
- Demeke Mekonnen Mengistie (Ethiopia)
- Victoria Meskin (USA)
- Vivianne Mnawi (Tanzania)
- Victoria Molyneux (UK)
- Viviae Nasr (USA)
- Almudena Ortiz Garrido (Spain)
- Robert Pass (USA)
- Giles Peek (USA)
- Yulia Piskova (Ukraine)
- Peter Roeleveld (Netherlands)
- Jolanda Sabatino (Italy)
- Asma Salloo (South Africa)
- Christine Sawda (USA)
- Skaistė Sendžikaitė (Lithuania)
- Domenico Sirico (United Kingdom)
- Victoria Surma (USA)
- Aybala Tongut (Turkey)
- Justin Tretter (USA)
- Andreas Tulzer (Austria)
- Grace van Leeuwen (Qatar)
- David Werho (USA)
- Gil Wernovsky (USA)
- Sarah Wilson (USA)
- David Winlaw (Australia)
- Arianne Woodward (Australia)
- Justine Yap (Phillippines)
- Jill Zender (USA)



## Institutional, Societal and Industry Relations Committee Leadership



**Co-Chair: Shriprasad Deshpande, MBBS MS**

Medical Director, Heart Transplant and  
Advanced Cardiac Therapies Program  
Cardiac Intensivist  
Children's National Hospital  
Associate Professor of Pediatrics  
The George Washington University

Dr. Deshpande's clinical and research interests have included heart failure, mechanical circulatory support and transplant related research. He has led significant collaborative research that has focused on reducing the complications associated with ECMO circuits, improving the understanding of clotting complications in the circuit and improving the ability to support children requiring mechanical circulatory assistance over the long term.

He has also been part of the team that has developed blood-based testing – rather than invasive biopsies - for the detection of rejection in children who have undergone heart transplantation. This landmark research was supported by NIH/ NHLBI, and has led to the development of a commercial assay. He is part of many transplant-related drug trials and is also developing new methods for analyzing the biopsies in transplanted patients.

Dr. Deshpande has been invited to serve on writing committees for important guidelines and position statements from American Heart Association and the Extracorporeal Life Support Organization, as well as written chapters for important textbooks. He currently serves on various advisory boards including non-profits and healthcare startups. He is the current vice-president for the Pediatric Heart Transplant Society and will transition to President position at the end of 2 years.



**Co-Chair: Michael Fundora, MD**

Division of Pediatric Cardiology  
Sibley Heart Center Cardiology  
Assistant Professor of Pediatrics  
Emory University School of Medicine  
michael.fundora@emory.edu

Dr. Fundora began his professional career in marketing and finance, raising funds for tech startups, implementing international rebranding campaigns, and developing an Olympic bid for New York City.



After leveraging his skills to support a successful medical mission to Guatemala, he decided to take his talents into the medical field. His training focused on caring for children with congenital heart disease and after completing his training at Boston Children's Hospital and Harvard Medical School, he joined the faculty at Emory University School of Medicine.

Dr. Fundora's research is focused on optimizing healthcare delivery and healthcare workforce management. His research has been supported by the National Institutes of Health, National Science Foundation, and Emory University. His work has been featured in international meetings, medical journals and podcasts. In partnership with The Georgia Institute of Technology, Dr. Fundora continues to lead his work in advancing cutting edge research, and developing new technologies focused on optimizing workload in the Intensive Care Unit.

As a proud Hispanic and fluent Spanish speaker, Dr. Fundora has partnered with Johnson and Johnson to develop communication apps for limited English proficiency speakers and has continued his efforts to deliver safe and effective care internationally. He has brought his many talents to the World Congress as the Co-chair of the Finance and Industry Relations committee to form lasting industry partnerships and help make the World Congress a success as a landmark Global Event.



**Co-Chair: Lindsey Justice, DNP, APRN, CPNP-AC**

APP Clinical Manager for Cardiac Intensive Care Unit and  
Acute Care Cardiology

The Heart Institute, Cincinnati Children's Hospital Medical Center

Lindsey.Justice@cchmc.org

Dr. Justice is a nurse practitioner at in the Cardiac Intensive Care Unit (CICU) at Cincinnati Children's Hospital Medical Center (CCHMC). She received her Bachelor of Science in Nursing from the University of Kentucky, her Master of Science in Nursing from Rush

University, and her Doctor of Nursing Practice from the University of Cincinnati.

She pioneered the acute care Pediatric Nurse Practitioner role in the CICU at CCHMC and is now the Advanced Practice Provider (APP) Clinical Manager for both the CICU and the Acute Care Cardiology Unit.

She remains active in bedside clinical care, and her academic work centers around development and sustainability of CICU APP teams, professional growth and clinical advancement for APPs, and improvement of teamwork and communication processes in the CICU.

She is on the Board of Directors of the Pediatric Cardiac Intensive Care Society (PCICS), served as Treasurer for 2021-2022 and currently serves as Vice President. She has co-chaired the development and implementation of a CICU Advanced Practice Provider Curriculum, which includes a published book and multiple in-person curriculum review courses per year.



## Institutional, Societal and Industry Relations Committee Members

- Qalab Abbas (Pakistan)
- Amir Ashrafi (USA)
- Nico Blom (Netherlands)
- Jean Chatzky (USA)
- Bruna Cory (Brazil)
- Shri Deshpande (USA)
- Katie Dodds (USA)
- Rich Friedman (USA)
- Mike Fundora (USA)
- Lindsey Justice (USA)
- Tim Knilans (USA)
- Nageswara Koneti (India)
- Tina Mannices (USA)
- Ornella Milanese (Italy)
- Ryan Moore (USA)
- David Morales (USA)
- Ziyad Hijazi (USA)
- Hanoch Patt (USA)
- Kimberly Ray (USA)
- James Reagor (USA)
- Justin Tretter (USA)
- David Vener (USA)
- Gil Wernovsky (USA)



Corresponding Author



Gil Wernovsky MD, FAAP, FACC  
Senior Consultant in Cardiac Critical Care and Pediatric Cardiology  
Children's National Hospital  
Professor of Pediatrics  
George Washington University School of Medicine and Health Sciences  
Washington, DC  
<https://childrensnational.org/visit/find-a-provider/gil-wernovsky>  
<https://linkedin.com/in/gil-wernovsky-md-1096a0>  
Email: [gwernovsky@childrensnational.org](mailto:gwernovsky@childrensnational.org)

# National Perinatal Association PERINATAL MENTAL HEALTH

[nationalperinatal.org/position](http://nationalperinatal.org/position)  
[www.nationalperinatal.org/mental\\_health](http://www.nationalperinatal.org/mental_health)

## SCREEN DADS TOO

10% of fathers experience depression and anxiety during the perinatal period.



Educate. Advocate. Integrate.

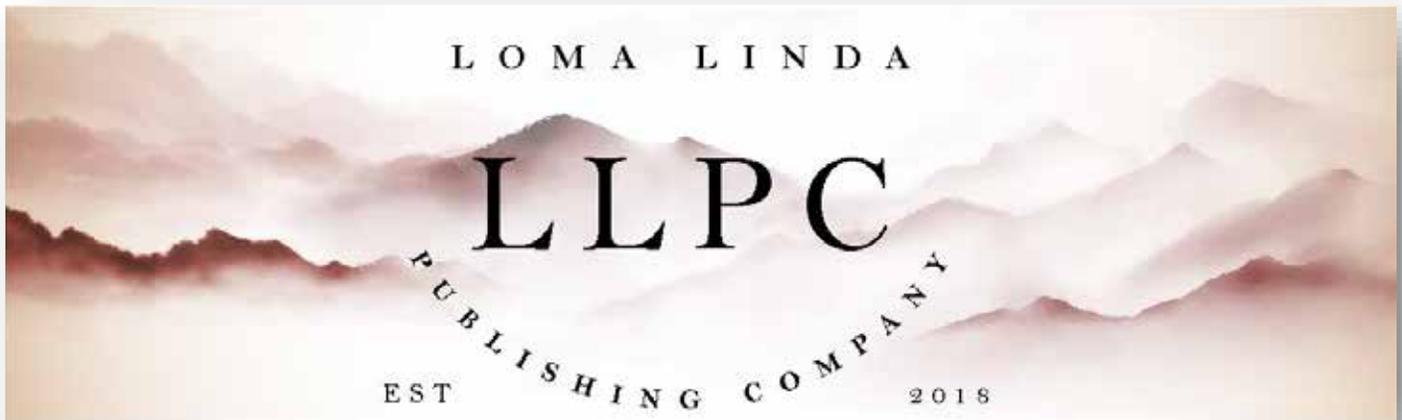


Readers can also follow

**NEONATOLOGY TODAY**

via our Twitter Feed

**@NEOTODAY**



## Neonatology Grand Round Series

Earn accredited CE while learning about pressing neonatology topics!



CENTER FOR RESEARCH, EDUCATION, QUALITY AND SAFETY



*Thirteen-year-old Emily Rose Shane was tragically murdered on April 3, 2010 on Pacific Coast Highway in Malibu, CA. Our foundation exists to honor her memory.*

*In Loving Memory*

*August 9, 1996 - April 3, 2010*



Each year, the Emily Shane Foundation SEA(Successful Educational Achievement) Program provides academic and mentoring support to over 100 disadvantaged middle school students who risk failure and have no other recourse. We have served over 700 children across Los Angeles since our inception in the spring of 2012. Due to the COVID-19 outbreak, our work is in jeopardy, and the need for our work is greatly increased. The media has highlighted the dire impact online learning has caused for the very population we serve; those less fortunate. **We need your help now more than ever to ensure another child is not left behind.**

Make a Difference in the Life of a Student in Need Today!

Please visit [emilyshane.org](http://emilyshane.org)

### Sponsor a Child in the SEA Program

The average cost for the program to provide a mentor/ tutor for one child is listed below.



1 session_____	\$15
1 week _____	\$30
1 month_____	\$120
1 semester_____	\$540
1 year_____	\$1,080
Middle School_____	\$3,240

*The Emily Shane Foundation is a 501(c)3 nonprofit charity, Tax id # 27-3789582. Our flagship SEA (Successful Educational Achievement) Program is a unique educational initiative that provides essential mentoring/tutoring to disadvantaged middle school children across Los Angeles and Ventura counties. All proceeds directly fund the SEA Program, making a difference in the lives of the students we serve.*

# Gravens By Design: Six Weeks that Changed the Preterm Infant Brain: Insights from the Family Nurture Intervention (FNI) Randomized Controlled Trials

Martha G Welch, MD, Robert J Ludwig, BA, Amie A. Hane, PhD, Michael M Myers. PhD

## Abstract:

Our group conducted two randomized controlled trials over 12 years between 2008 and 2020 (total n=261) comparing neonatal intensive care unit (NICU) standard care (SC) with SC plus Family Nurture Intervention (FNI) of infants 26 to 34 weeks GA. The intervention included ~6 hours per week (24 to 36 hours total) of facilitated mother-infant calming sessions aimed at dyadic "emotional connection" during the NICU stay. At approximately 35 weeks and 41 weeks postmenstrual age, we collected electroencephalographic (EEG) activity on the brains of all subjects using 128-lead nets. Analyses at near-term age showed dramatic changes in brain function on multiple measures in FNI vs. SC infants. Importantly, we found similar increased prefrontal cortical activity in a multisite replication trial of FNI-NICU. We have documented in 18 publications that FNI group infants had significantly better short- and long-term neurobehavioral functioning, autonomic health, and developmental trajectories. FNI dyads had significantly better autonomic regulation than SC dyads through five years. In this article, we discuss the key features of FNI that led to our results and the theoretical and clinical advances that grew out of the trials. We discuss how these insights can help improve preterm infant outcomes. We introduce new terminology and constructs that describe behavior and physiology and a new assessment tool that correlates with physiology to measure the mother/infant emotional relationship (Welch Emotional Connection Screen). Finally, we discuss the significance of our findings and how our insights might be incorporated into other NICU interventions and widespread standard NICU care.

**Keywords:** attachment; emotional connection; approach-avoidance; brainstem; instinct; state-trait; conditioned reflex; Infant development; autonomic conditioning

## Background:

Our group tested the efficacy of Family Nurture Intervention (FNI) in a level-4 neonatal intensive care unit (NICU) at New York Presbyterian Morgan Stanley Children's Hospital single site in a randomized controlled trial (RCT) between 2008 and 2012. We replicated the intervention in a multisite RCT (New York Presbyterian and UT San Antonio) between 2016 and 2020. FNI was designed to increase specific activities that enhance the emotional connection between mother and baby. (1) Our primary objective was to

determine whether repeated mother-infant calming sessions that included maternal emotional expression would improve the infant's developmental trajectory.

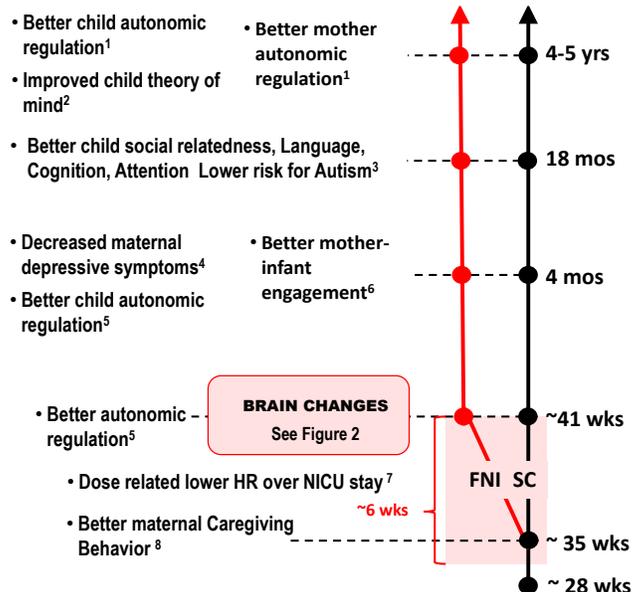


Figure 1 - Published findings from two RCTs of Family Nurture Intervention. FNI was conducted in level 4 NICUs. The intervention period is shown in blue. Note that findings included both behavioral and neurophysiological outcomes.

**“Our group tested the efficacy of Family Nurture Intervention (FNI) in a level-4 neonatal intensive care unit (NICU) at New York Presbyterian Morgan Stanley Children’s Hospital single site in a randomized controlled trial (RCT) between 2008 and 2012. We replicated the intervention in a multisite RCT (New York Presbyterian and UT San Antonio) between 2016 and 2020.”**

**NEONATOLOGY TODAY** is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)

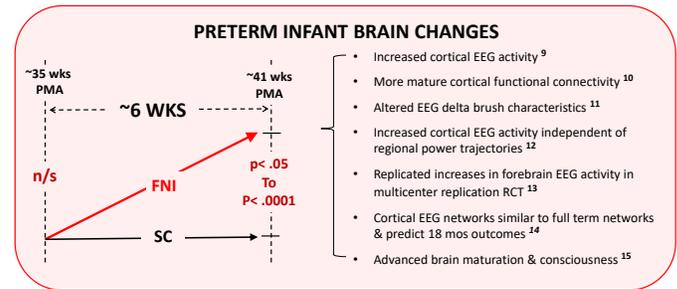
Thus far, our group has published 18 outcome papers comparing a group receiving Standard Care (SC) with a group receiving Standard Care plus FNI. Compared to controls, FNI infants showed significant improvement in neurobehavioral functioning, autonomic health, and development, FNI mothers showed significant improvement in depressive symptoms, and the dyad scored higher on relational and physiologic health at key assessment points through age 5 (**Figure 1**).

***“The most dramatic effect of the intervention was in changes in brain function (Figure 2). Fortuitously, our NICU was the beta site for developing high-density 128-lead nets, enabling us to collect a wealth of data.”***

The most dramatic effect of the intervention was in changes in brain function (**Figure 2**). Fortuitously, our NICU was the beta site for developing high-density 128-lead nets, enabling us to collect a wealth of data. At the beginning of the first trial, one of our neonatologists, who had been conducting EEG studies on preterm infants for decades, confidently stated, *“We will never see changes in EEG over six weeks in the NICU.”* When the first study showed significant increases in prefrontal cortex EEG activity after the six-week intervention period ( $p < .0001$ ), he not only conceded but advocated providing this intervention to all babies, even those born ultra early.

The large preterm infant data set attracted the attention of a world-renowned EEG expert Sampsa Vanhatalo, who was pioneering a new method for measuring infant brain networks. Using our EEG data from the first trial, Dr. Vanhatalo and his colleagues could show several large-scale, frequency-specific network effects of FNI, most extensively in the alpha frequency in frontocentral cortical regions. (2) The findings at term age were comparable to healthy full-term-born infants. Notably, the connectivity strength in this network correlated with the later neurocognitive performance of the FNI group at 18 months. These findings suggest that preterm brain development can be significantly improved by facilitating emotional connection between mother and infant. We are continuing to analyze data, and several more papers are in preparation.

***“These findings suggest that preterm brain development can be significantly improved by facilitating emotional connection between mother and infant. We are continuing to analyze data, and several more papers are in preparation.”***



**Figure 2 - Six weeks that changed the preterm infant brain.** In six weeks, between approximately 35 weeks and 41 weeks, we collected high-density 128-lead electroencephalographic (EEG) activity on the brains of all subjects. Analyses showed dramatic changes in brain function on multiple measures. Importantly, in a multisite replication trial of FNI-NICU, we found the same increases in prefrontal cortical EEG activity.

At this point in the follow-up of the FNI trial cohorts, we can confidently say that mother/infant dyads in the FNI group benefited significantly from the intervention. Additionally, because the intervention dose was relatively small, and the effects on the dyad persisted for so long, we feel it is essential to examine the factors we believe led to the results more closely. Therefore, in this article, we will address some crucial questions such as:

- What features of the intervention led to the outcomes?
- How is FNI different from other NICU interventions?
- What are the key biomarkers associated with the FNI changes?
- What are the biological mechanisms underlying FNI?
- Can FNI be integrated into standard NICU care?
- Is FNI scalable?

***“Mothers assigned to the FNI group agreed to attend at least four 1-hour intervention ‘calming sessions’ per week while in the NICU. Mothers who came to the NICU more frequently were encouraged to engage in intervention activities more often and for longer periods.”***

### What is Family Nurture Intervention

Mothers assigned to the FNI group agreed to attend at least four 1-hour intervention ‘calming sessions’ per week while in the NICU. Mothers who came to the NICU more frequently were encouraged to engage in intervention activities more often and for longer periods. Calming sessions between mother and infant included skin-to-skin contact, odor exchange, firm, sustained touch, eye contact, and oral communication. These activities are used regularly in other NICU interventions to improve infant and maternal outcomes. However, the key activity encouraged during the 60- to 90-minute FNI ‘calming sessions’ was *‘emotional expression’* between mother and baby accompanying sensorial contact in the isolette or during holding or skin-to-skin sessions. To our knowledge, FNI is the only intervention that focuses narrowly on emo-

tional expression as the critical element in changing the mother/baby's emotional relationship.

### The calming cycle

The central activity of FNI-NICU trials was the 'calming cycle' (see Figure 2). The phenomenon was first described in Holding Time. (3) Welch discovered that if the mother held the child until their upset was resolved regularly, communication between the two improved, upsets occurred less often, symptomatic behavior declined, and the emotional relationship and child development improved.

We applied the same theory in the NICU. The idea behind the NICU intervention is that repeated close physical and emotional communication between the mother and baby will result in calmer states of behavior and physiology (homeostasis) (Figure 3) and emotional connection.

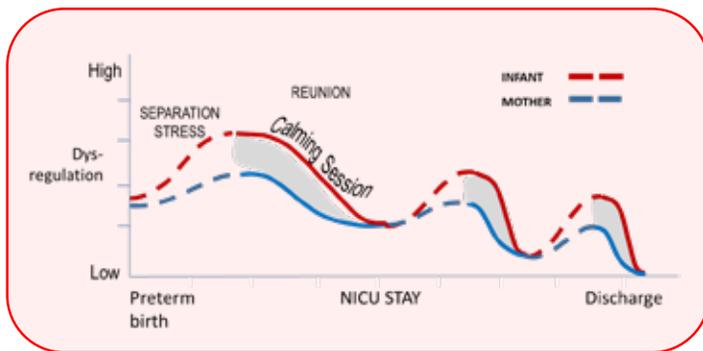


Figure 3 - The hypothesized NICU calming cycle. Separations increase upset and dysregulation in both the mother and the infant. One-hour calming sessions lead to calm behavior and calm physiology. Repeated sessions lead to more rapid reductions and lower absolute levels of upset and dysregulation in both the mother and the infant.

FNI focused on enabling mothers to engage in specified mother-infant interactions as early as possible after birth, within the constraints of the NICU environment. These interactions began while the infant was confined to the isolette, later during skin-to-skin or clothed holding, and near discharge during family sessions when strategies were developed to support the mother as she continued these interactions with her infant at home. The maternal-infant interactions included odor-cloth exchange, firm sustained touch, vocal soothing, eye contact, and emotional expression.

### Emotional expression

Due to the long-term hospitalization and uncertain prognosis of preterm infants, mothers experience strong negative emotions, such as fear, frustration, stress, anxiety, and guilt. Many strategies are now in place to support and help mothers cope with the NICU experience, such as Family Centered Care, Skin-to-skin Care, parent support and education programs, Interpersonal Therapy, spiritual care, NIDCAP, and telenursing. (4, 5) FNI employed some of these strategies. However, the central feature of the FNI-NICU method was helping the mother express strong emotions directly to the infant, which can be different from how she might express emotions and other social information to others in the variety of contexts that make up her everyday life. (6) To avoid confusion, the strategy employed in the FNI-NICU trials is called *Welch Emotional Expression (WEE)*.

Nurture specialists (NS), in this case, former NICU nurses, facilitate mother/infant emotional expression during 60 to 90-minute calming sessions. The NS did not attempt to teach or educate the mother about the intervention before she felt a connection with her infant. Instead, the NS helped the mother engage emotionally with her baby from the start. The first calming session typically took place at the isolette, on average, one week after birth. As early as the first session, the mother was encouraged to express deep emotions and feelings directly to her baby.

---

***“Sometimes the mother was emotionally blocked and had difficulty accessing her emotions with her baby. In these cases, the NS created as much privacy as possible for the mother and baby and suggested things the mother could say directly to her baby.”***

---

Sometimes the mother was emotionally blocked and had difficulty accessing her emotions with her baby. In these cases, the NS created as much privacy as possible for the mother and baby and suggested things the mother could say directly to her baby. For instance, the NS said to the mother, 'Tell your baby the birth story,' 'Tell your baby how you felt when you got pregnant,' 'How you felt when you were told the baby was going to be premature,' etc. The feeling of 'guilt' in NICU mothers is often overlooked. (5) One particularly effective prompt the NS used to help the mother release her emotions was to suggest the mother apologize to the baby and say something like: 'I am sorry for the separation and for the suffering you are going through.' This apology often prompted an emotional response from the mother and allowed the mother to cry.

---

***“Crying is one of the deepest, most powerful, and most therapeutic emotions a mother can express to her baby in the NICU. (7, 8) It is common for the mother to hold back crying.”***

---

Crying is one of the deepest, most powerful, and most therapeutic emotions a mother can express to her baby in the NICU. (7, 8) It is common for the mother to hold back crying. Sometimes, the mother is told not to cry by friends and staff, 'Everything is going to be OK.' Sometimes, the mother releases her emotions to the staff of family members. With FNI, crying with her infant was anticipated and welcomed. However, the NS told the mother to direct her emotions to the baby and let herself cry while holding her baby whenever she felt like it.

Such release of emotions by the mother while holding her baby prompted the baby's primary *orienting reflex* typically (9) (more on this phenomenon below). Orienting includes turning toward

the mother and making direct eye contact with her. When this happens, the mother typically feels an emotional connection to her baby, most often for the first time. The NS encouraged the mother to emotionally interact when touching her baby in the isolette or holding the baby during skin-to-skin or clothed holding. The nurture specialist encouraged the mother not to use her cell phone during her brief time with her baby. The mother was encouraged to direct her attention and emotional feelings to her baby—not to the nurture specialist, family members, or nursing staff.



Figure 4 - The key to Family Nurture Intervention in the NICU

The mother was also asked to speak or sing to her baby in her 'native' tongue (i.e., the language her grandmother spoke to her mother (or to her) when she was a baby). This is because the emotional content of expression between the mother and baby is most effectively conveyed in the primary language. (10, 11)

Our clinical observations confirm that once the mother releases her emotions to the infant, the infant becomes more available to the mother and responds behaviorally through eye contact and approach behaviors (Figure 4). This response from her baby profoundly moves the mother and prompts approach behaviors from the mother. The repeated emotional expression between the mother and infant during the NICU stay changes the dyad's emotional relationship and positively alters the infant's developmental trajectory and the mother's emotional well-being.

***“This response from her baby profoundly moves the mother and prompts approach behaviors from the mother. The repeated emotional expression between the mother and infant during the NICU stay changes the dyad’s emotional relationship and positively alters the infant’s developmental trajectory and the mother’s emotional well-being.”***

How does FNI differ from other NICU interventions?

FNI overlaps in some ways with many current mother-infant interventions implemented in the NICU that have been shown to improve some outcomes, such as kangaroo care (KC)(12), kangaroo mother care (13-15), developmental care (16-18), Parental emotional support by nurses (4), couplet care (19), to name a few. Such interventions have in common the importance of bringing the mother and preterm infant together as soon as possible following birth, assuming that proximity and contact will improve outcomes. Such proximity and contact are, of course, known to be necessary and critically important, but they do not assure an adaptive emotional relationship. FNI takes skin-to-skin contact a further step in engaging the mother and infant in emotional exchange. In addition, FNI differs substantially on the theoretical biological basis of the mother-infant relationship.

Some interventions, such as kangaroo mother care or develop-

***“FNI takes skin-to-skin contact a further step in engaging the mother and infant in emotional exchange. In addition, FNI differs substantially on the theoretical biological basis of the mother-infant relationship.”***

mental care, promote mother/infant 'co-regulation.' However, such interventions are equivocal regarding the mechanisms involved.

#### What is an emotional connection?

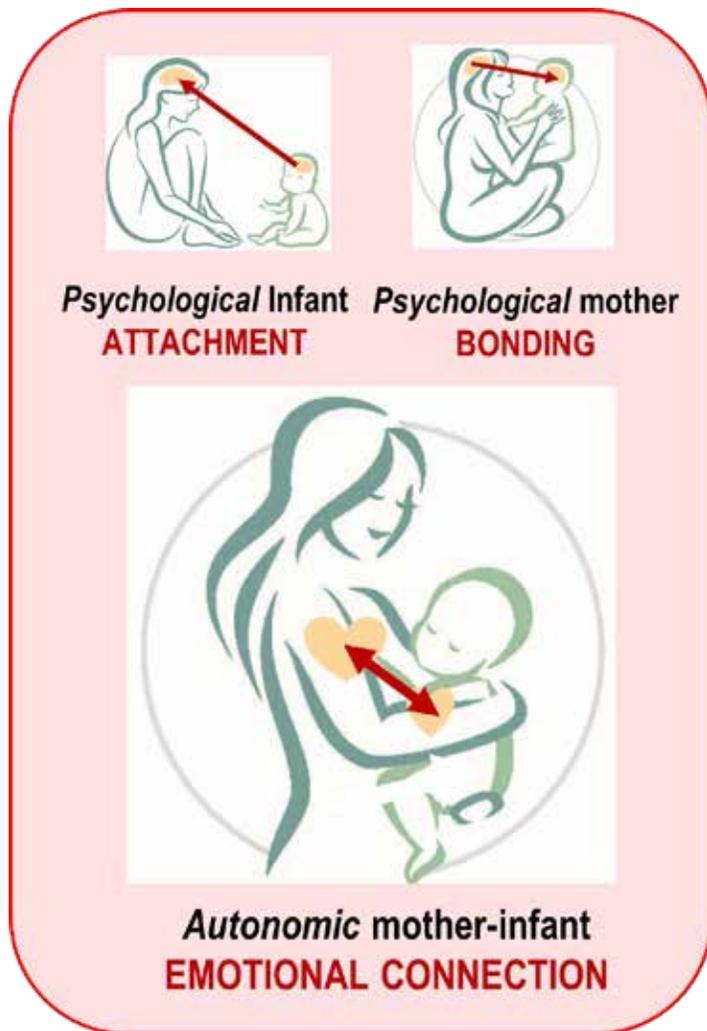
The most important concept that was supported by FNI-NICU trials is *emotional connection*. Emotional connection is an 'autonomic' construct—that is, it has to do with the autonomic nervous system, the nervous system that controls internal organs, especially the heart. Emotional connection describes the special biological relationship between a mother and a newborn infant. The emotional connection model differs from prevailing 'attachment' and 'bonding' models in how it views the early mother-infant *relationship*. The attachment model posits that the baby is born with behaviors toward a *mother figure*. (20, 21) Thus, the mother is not substantially differentiated from other caregivers.

In contrast, the emotional connection model holds that term and

***“In contrast, the emotional connection model holds that term and preterm babies are born with a special autonomic relationship with the mother that requires repeated mutual mother-infant learning and reinforcement.”***

preterm babies are born with a special *autonomic relationship* with the mother that requires repeated mutual mother-infant learning and reinforcement. The basics of emotional connection theory were articulated in the FNI study protocol (1), but the theory has been more thoroughly and carefully explicated since then. (10, 22-24)

Viewing the mother and infant relationship in terms of autonomic emotional connection requires rethinking the biological mechanisms mediating the phenomenon (**Figure 5**). Conventional constructs like attachment and bonding focus on cortical learning mechanisms. In contrast, emotional connection theory posits that mother/infant emotions are controlled by a highly conserved primitive learning mechanism outside of consciousness within the autonomic nervous system. A central tenet of emotional connection theory is that specialized primary cardiac reflexes form between mother and fetus via autonomic learning (conditioning) during gestation. (25) Pavlov termed this mechanism the conditional 'cardiac' or 'social' reflex. (26) 'Conditional' reflexes account for so-called mother and infant subconscious "*instinctive*" behaviors following birth. The term 'conditional' infers that the behaviors associated with the reflex depend on various environmental factors or conditions. For instance, in a normal birth, the social signaling between the mother and baby assures 'approach' behavioral responses. In preterm birth, however, the critical social signaling is disrupted between the two, often resulting in adversely conditioned '*avoidance*' behaviors.



The autonomic reflex construct originates in a phenomenon ini-

*Figure 5 – Emotional Connection vs. Attachment and Bonding. Note that emotional connection communication is heart-to-heart. Attachment and bonding are brain-to-brain.*

tially described by Pavlov in 1925 (27) when he described how a social relationship could profoundly impact the cardiac reflex (and associated behavior) below the conscious level. We have extended this basic concept to the mother-infant relationship and termed it the *autonomic socioemotional reflex (ASR)*. (25)

The term ASR applies specifically to neonatal mother-infant physiology related to the well-researched *orienting reflex*. (9) Orienting disorders are highly correlated with socioemotional pathologies in infants and children, such as social fear, anger, anxiety, depression, and autism. (28) Orienting stems from the activation of highly conserved autonomic defensive and appetitive motivational systems that evolved to sustain life (29) and assure species' survival. (30) In this respect, humans' mother/infant ASR orienting phenomenon does not differ significantly from the orienting reflex in other species.

---

***“The term ASR applies specifically to neonatal mother-infant physiology related to the well-researched orienting reflex. (9) Orienting disorders are highly correlated with socioemotional pathologies in infants and children, such as social fear, anger, anxiety, depression, and autism.”***

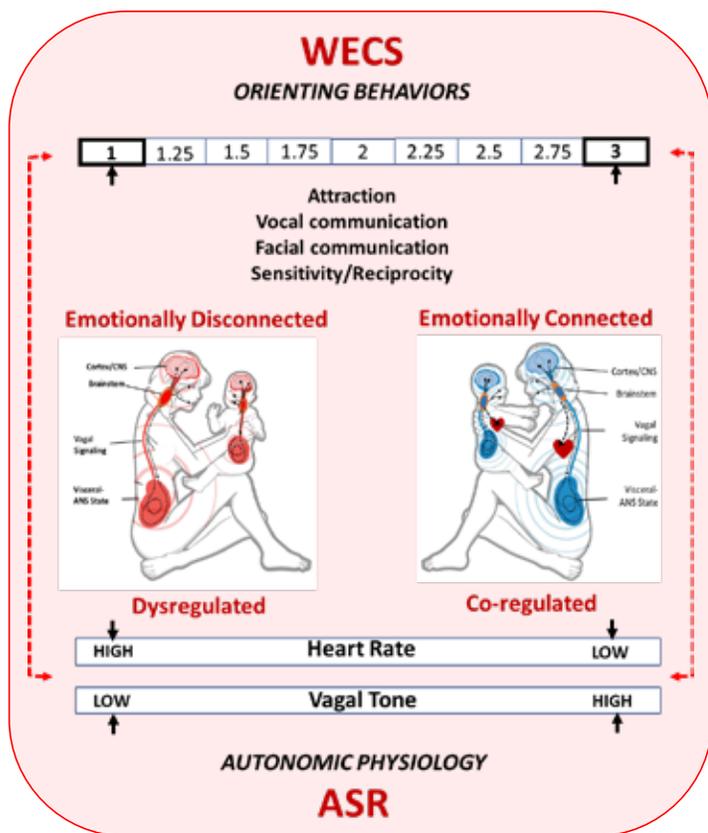
---

The ASR is theorized to correlate with the dyad's mutual autonomic '*states*' at the time of observation, as opposed to their assumed individual '*traits*.' Emotional connection theory predicts that negative *traits* are *states* created by negative environments. Therefore, if the baby's primary environmental signals are changed (e.g., through maternal emotional expression), then the baby's behavioral traits can be changed from negative to positive. This observation in the clinical practice of Welch's first iteration of FNI allowed us to reconsider mother/infant approach-avoidance behaviors considering and testing the theorized correlation between dyadic emotional behaviors and autonomic physiology, such as heart rate and heart rate variability. Emotionally '*disconnected*' behaviors would correlate with higher HR and lower HRV. Emotionally '*connected*' behavior would correlate with lower HR and higher HRV. We used face-to-face observation and later created the Welch Orienting LapCheck paradigm(31) to measure mother/infant behaviors before and after the FNI intervention to test the mother and infant's autonomic emotional reflex reaction to one another. Results confirmed that FNI was changing avoidance behaviors to mutual approach behaviors. (32)

**How do you measure the mother-infant emotional connection?**

The emotional connection behaviors require a special assessment. In the first FNI trial, we used conventionally validated assessment tools based on the attachment and bonding constructs. Such tools typically measure the separate *psychological* behaviors of the infant and mother but not the dyad's emotional *relationship*. As the trial progressed, we observed significant positive changes in the emotional relationship between the mother and the baby.

Based on her clinical observations in the 1970s, Welch had predicted that a few key behaviors could form the basis for a simple tool that would reliably assess the emotional relationship between mother and infant and identify dyads at risk for socioemotional disorders later in development. Such a tool could be used as a screen to identify dyads needing help and demonstrate the efficacy and effectiveness of an intervention. This led to the Welch Emotional Connection Screen (WECS) development. The process resulted in a subset of four observable mutual mother/infant behaviors: *attraction, vocal communication, verbal communication, and sensitivity/reciprocity*. Hane, an expert in coding approach behaviors, vocal rhythms, and mother-infant affect (33, 34), validated the WECS construct by comparing WECS behaviors using conventional labor-intensive observational coding software and correlating infant biobehavioral responses to the mother-infant in a still-face paradigm. (32)



As predicted, these behavioral subsets correlated with the mother and infant seeking a mutual approach to each other following *Figure 6 - WECS Behavior & ASR Physiology relationship*. Schematic showing the hypothesized mirror reflection of WECS behaviors and autonomic socioemotional reflex (ASR) physiology. The two sets of WECS behaviors at the opposite ends of a 9-point Likert scale are illustrated at the top of the figure. Shown at the bottom is cardiac physiology that correlates with WECS behaviors. Therefore, the WECS assessment serves as a quick and straightforward behavioral mirror reflection of autonomic physiology, which can inform immediate intervention.

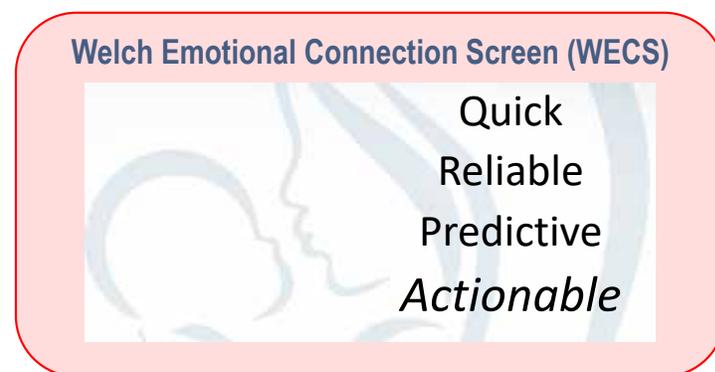
stress and the preterm infant's autonomic state physiology (cardiac response to stress)(32) (**Figure 6**). These data suggest that the mother/infant emotional connection is a behavioral mirror of the dyad's autonomic response to close physical face-to-face

proximity and a vital indicator of the dyad's emotional relationship at the time of observation. The clinical and practical advantage of the WECS is that it offers a fast, simple behavioral assessment screening measure that can assess risk for impaired socioemotional and relational health. FNI study results confirm the benefits of detecting and treating breaks in the early emotional connection between mother and infant.

### The practical utility of the WECS

NICU Emotional connection, as described here, provides NICU clinicians and researchers with a new framework for evaluating the mother-infant relationship. The WECS, because of its demonstrated accuracy and reliability, makes a useful additional tool in the NICU for clinicians and researchers (**Figure 7**). The ability to assess information quickly means that the information is 'actionable.' Clinicians practicing a wide range of mother-infant interventions, such as skin-to-skin care, developmental care, family-centered care, etc., can incorporate new ways to sensitively intervene that help the mother express her emotional feelings directly to her baby.

The FNI-NICU is not a prescribed intervention. There are many ways to help mothers open up to their babies and become emotionally connected. Instead, the insights gained from the trials should be taken as a guide for what to look for and what the goal should be. The trials have demonstrated what is possible.



### Post-NICU

The WECS is being incorporated into the clinical practice of col-*Figure 7 - Strengths of the WECS*

leagues in NICU follow-up clinics. The WECS is also being studied in the residency training program at Emory Developmental Pediatric. (35) O'Banion et al. showed that resident accuracy for identifying dyad emotional connection on the WECS improved significantly following brief training. As well, residents reported significantly changed beliefs about the importance of improving their ability to assess emotional connection and incorporating emotional connection assessment into pediatric practice.

We recently completed a novel family-based preschool intervention using the WECS to determine whether a parent-child home intervention, *E-Prep*, could improve classroom behavior. WECS scores of E-Prep children correlated with significant improvement in socioemotional and classroom behavior. (31)

### Summary:

The Family Nurture Interventions testify to the plasticity of preterm infant developmental mechanisms. (36) Following the intervention

over six weeks in the NICU, the brain network function of FNI infants resembled the function of term infants. As much as both SC and FNI received the same SC, we believe these changes resulted from facilitating the emotional connection between mother and infant.

A recent review of the literature confirms that despite a growing body of mother-infant research citing Bowlby's theoretical constructs of psychological 'attachment,' 'bonding,' and the associated variables, there is little agreement on the definitions of the constructs, as well as a lack of a comprehensive conceptual framework of antecedents and consequences of constructs that can guide empirical work. (37, 38) In addition, attachment treatment models have proved difficult to scale. (39) Conversely, there are notable shifts in current early intervention paradigms(40) and growing evidence supporting a new autonomic framework. Recent studies confirm the importance of a mother's breast odor and voice in enhancing the orientating response(40) and motivational seeking effect(41) on infants. (42) A recent study showed that modifying the position of mother-infant skin-to-skin care led to more overall communication between mother and preterm infant, a three-fold increase in vocalizations, more eye contact, and more smiling,(43) which suggests such proactive interventions help the mother and infant connect emotionally.

The emotional connection construct offers a new way of viewing the mother-infant relationship in the NICU. The FNI-NICU trials provide compelling evidence that the mother is more than an attachment *mother figure*. Rather, the mother-infant relationship should be considered an essential building block for future socioemotional relationships. The mother-infant emotional connection is and should be considered, foundational in overcoming the trauma of preterm birth and establishing healthy and adaptive development.

The field is currently at the threshold of significant discoveries regarding how the brainstem structure exerts varied and significant influences over brain function and behavior. (44)

Emotional connection theory provides a learning mechanism, a theory of change, and a set of testable hypotheses. The theory states that early relational behaviors between mother and newborn are learned through autonomic conditioning of autonomic socioemotional reflexes (ASRs) formed during gestation via autonomic co-conditioning that is stored as conditional reflexes within the dyad's autonomic nervous systems. These reflexes are preserved transnationally and can be used to monitor mother-infant relational health. The autonomic co-conditioning mechanism can be exploited to change the physiological/behavioral reflex response.

Importantly, including mother-infant emotional expression in other types of NICU intervention does not take further resources. Therefore, exploring this promising –and evidence-based pathway might benefit the field. In doing so, the fields of Neonatology and Pediatrics, in general, will attain a more holistic, foundational, and integrative approach to interventions and research, which could positively impact neonatal treatments and clinical outcomes. (45)

#### References:

1. Welch MG, Hofer MA, Brunelli SA, Stark RI, Andrews HF, Austin J, et al. Family nurture intervention (FNI): methods and treatment protocol of a randomized controlled trial in the NICU. *BMC Pediatr.* 2012;12:14. Epub 20120207. doi: 10.1186/1471-2431-12-14. PubMed PMID: 22314029;

PubMed Central PMCID: PMC394087.

2. Yrjola P, Myers MM, Welch MG, Stevenson NJ, Tokariev A, Vanhatalo S. Facilitating early parent-infant emotional connection improves cortical networks in preterm infants. *Sci Transl Med.* 2022;14(664):eabq4786. Epub 20220928. doi: 10.1126/scitranslmed.abq4786. PubMed PMID: 36170448.
3. Welch MG. *Holding Time: How to Eliminate Conflict, Temper Tantrums, and Sibling Rivalry and Raise Happy, Loving, Successful children.* New York, N.Y.: Simon & Schuster; 1988.
4. Maleki M, Mardani A, Harding C, Basirinezhad MH, Vaismoradi M. Nurses' strategies to provide emotional and practical support to the mothers of preterm infants in the neonatal intensive care unit: A systematic review and meta-analysis. *Womens Health (Lond).* 2022;18:17455057221104674. doi: 10.1177/17455057221104674. PubMed PMID: 35735784; PubMed Central PMCID: PMC9234836.
5. Wang LL, Ma JJ, Meng HH, Zhou J. Mothers' experiences of neonatal intensive care: A systematic review and implications for clinical practice. *World J Clin Cases.* 2021;9(24):7062-72. doi: 10.12998/wjcc.v9.i24.7062. PubMed PMID: 34540961; PubMed Central PMCID: PMC8409189.
6. Barrett LF, Adolphs R, Marsella S, Martinez AM, Pollak SD. Emotional Expressions Reconsidered: Challenges to Inferring Emotion From Human Facial Movements. *Psychol Sci Public Interest.* 2019;20(1):1-68. doi: 10.1177/1529100619832930. PubMed PMID: 31313636; PubMed Central PMCID: PMC6640856.
7. Craig AK, James C, Bainter J, Evans S, Gerwin R. Parental perceptions of neonatal therapeutic hypothermia; emotional and healing experiences. *J Matern Fetal Neonatal Med.* 2020;33(17):2889-96. Epub 20190108. doi: 10.1080/14767058.2018.1563592. PubMed PMID: 30585100; PubMed Central PMCID: PMC6594911.
8. Twohig A, Reulbach U, Figuerdo R, McCarthy A, McNicholas F, Molloy EJ. Supporting Preterm Infant Attachment and Socioemotional Development in the Neonatal Intensive Care Unit: Staff Perceptions. *Infant Ment Health J.* 2016;37(2):160-71. Epub 20160303. doi: 10.1002/imhj.21556. PubMed PMID: 26938792.
9. Ludwig RJ, Welch MG. Wired to Connect: The Autonomic Socioemotional Reflex Arc. *Front Psychol.* 2022;13:841207. Epub 20220624. doi: 10.3389/fpsyg.2022.841207. PubMed PMID: 35814106; PubMed Central PMCID: PMC9268160.
10. Welch MG, Ludwig RJ. Mother/Infant emotional communication through the lens of Visceral/Autonomic Learning and Calming Cycle Theory. In: Filippa M, Kuhn P, Westrup B, editors. *Early Vocal Contact and Preterm Infant Brain Development: Bridging the Gaps Between Research and Practice.* New York, NY: Springer International Publishing; 2017.
11. Dave S, Mastergeorge AM, Olswang LB. Motherese, affect, and vocabulary development: dyadic communicative interactions in infants and toddlers. *J Child Lang.* 2018;45(4):917-38. Epub 20180219. doi: 10.1017/S0305000917000551. PubMed PMID: 29457574.
12. Feldman R, Eidelman AI. Skin-to-skin contact (Kanga-

- roo Care) accelerates autonomic and neurobehavioural maturation in preterm infants. *Dev Med Child Neurol.* 2003;45(4):274-81. doi: 10.1017/s0012162203000525. PubMed PMID: 12647930.
13. Adejuyigbe EA, Agyeman I, Anand P, Anyabolu HC, Arya S, Assenga EN, et al. Evaluation of the impact of continuous Kangaroo Mother Care (KMC) initiated immediately after birth compared to KMC initiated after stabilization in newborns with birth weight 1.0 to < 1.8 kg on neurodevelopmental outcomes: Protocol for a follow-up study. *Trials.* 2023;24(1):265. Epub 20230410. doi: 10.1186/s13063-023-07192-5. PubMed PMID: 37038239; PubMed Central PMCID: PMCPCMC10088121.
  14. Linner A, Lode Kolz K, Klemming S, Bergman N, Lillieskold S, Markhus Pike H, et al. Immediate skin-to-skin contact may have beneficial effects on the cardiorespiratory stabilisation in very preterm infants. *Acta Paediatr.* 2022;111(8):1507-14. Epub 20220428. doi: 10.1111/apa.16371. PubMed PMID: 35466432.
  15. Group WHOIKS. Impact of continuous Kangaroo Mother Care initiated immediately after birth (iKMC) on survival of newborns with birth weight between 1.0 to < 1.8 kg: study protocol for a randomized controlled trial. *Trials.* 2020;21(1):280. Epub 20200319. doi: 10.1186/s13063-020-4101-1. PubMed PMID: 32188485; PubMed Central PMCID: PMCPCMC7081677.
  16. Lehtonen L, Gimeno A, Parra-Llorca A, Vento M. Early neonatal death: A challenge worldwide. *Semin Fetal Neonatal Med.* 2017;22(3):153-60. Epub 20170224. doi: 10.1016/j.siny.2017.02.006. PubMed PMID: 28238633.
  17. White RD, Lehtonen L, Reber KM, Phillips R. A pivotal moment in the evolution of neonatal care. *J Perinatol.* 2023;43(4):538-9. Epub 20220618. doi: 10.1038/s41372-022-01436-z. PubMed PMID: 35717458.
  18. Heon M, Aita M, Lavallee A, De Clifford-Faugere G, Laporte G, Boisvert A, et al. Comprehensive mapping of NICU developmental care nursing interventions and related sensitive outcome indicators: a scoping review protocol. *BMJ Open.* 2022;12(1):e046807. Epub 20220131. doi: 10.1136/bmjopen-2020-046807. PubMed PMID: 35105609; PubMed Central PMCID: PMCPCMC8808373.
  19. Klemming S, Lillieskold S, Westrup B. Mother-Newborn Couplet Care from theory to practice to ensure zero separation for all newborns. *Acta Paediatr.* 2021;110(11):2951-7. Epub 20210701. doi: 10.1111/apa.15997. PubMed PMID: 34146345.
  20. Ettenberger M, Bieleninik L, Epstein S, Elefant C. Defining Attachment and Bonding: Overlaps, Differences and Implications for Music Therapy Clinical Practice and Research in the Neonatal Intensive Care Unit (NICU). *Int J Environ Res Public Health.* 2021;18(4). Epub 20210210. doi: 10.3390/ijerph18041733. PubMed PMID: 33579015; PubMed Central PMCID: PMCPCMC7916808.
  21. Mcleod S. Attachment Theory: Bowlby and Ainsworth's theory explained 2023. Available from: <https://www.simplypsychology.org/attachment.html>.
  22. Welch MG. Calming cycle theory: the role of visceral/autonomic learning in early mother and infant/child behaviour and development. *Acta Paediatr.* 2016;105(11):1266-74. doi: 10.1111/apa.13547. PubMed PMID: 27536908.
  23. Welch MG, Ludwig RJ. Calming Cycle Theory and the Co-Regulation of Oxytocin. *Psychodyn Psychiatry.* 2017;45(4):519-40. doi: 10.1521/pdps.2017.45.4.519. PubMed PMID: 29244620.
  24. Ludwig RJ, Welch MG. Darwin's Other Dilemmas and the Theoretical Roots of Emotional Connection. *Front Psychol.* 2019;10:683. Epub 20190412. doi: 10.3389/fpsyg.2019.00683. PubMed PMID: 31031667; PubMed Central PMCID: PMCPCMC6473325.
  25. Ludwig RJ, Welch MG. How babies learn: The autonomic socioemotional reflex. *Early Hum Dev.* 2020;151:105183. Epub 20200913. doi: 10.1016/j.earlhumdev.2020.105183. PubMed PMID: 32971304.
  26. Gantt WH. Autonomic Conditioning. *Ann N Y Acad Sci.* 1964;117:132-41. doi: 10.1111/j.1749-6632.1964.tb48167.x. PubMed PMID: 14196636.
  27. Gantt WH, Newton JE, Royer FL, Stephens JH. Effect of person. 1966. *Integr Physiol Behav Sci.* 1991;26(2):145-60. doi: 10.1007/BF02691039. PubMed PMID: 1908697.
  28. Hedger N, Dubey I, Chakrabarti B. Social orienting and social seeking behaviors in ASD. A meta analytic investigation. *Neurosci Biobehav Rev.* 2020;119:376-95. Epub 20201015. doi: 10.1016/j.neubiorev.2020.10.003. PubMed PMID: 33069686.
  29. Boecker L, Pauli P. Affective startle modulation and psychopathology: Implications for appetitive and defensive brain systems. *Neurosci Biobehav Rev.* 2019;103:230-66. Epub 20190523. doi: 10.1016/j.neubiorev.2019.05.019. PubMed PMID: 31129237.
  30. Porges SW. *The Polyvagal Theory: Neurophysiological Foundations of Emotions, Attachment, Communication, and Self-Regulation.* New York: Norton; 2011.
  31. Welch MG, Ludwig RJ, Hane AA, Markowitz ES, Austin J, Jaffe ME, et al. Preschool-based Mother-child Emotional Preparation Program (E-Prep) Improves Emotional Connection, Behavior in Home and Classroom: A Randomized Controlled Trial. *J Child Fam Studies.* in review.
  32. Hane AA, LaCoursiere JN, Mitsuyama M, Wieman S, Ludwig RJ, Kwon KY, et al. The Welch Emotional Connection Screen: validation of a brief mother-infant relational health screen. *Acta Paediatr.* 2019;108(4):615-25. Epub 20180813. doi: 10.1111/apa.14483. PubMed PMID: 29959878.
  33. Hane AA, Fox NA, Henderson HA, Marshall PJ. Behavioral reactivity and approach-withdrawal bias in infancy. *Dev Psychol.* 2008;44(5):1491-6. doi: 10.1037/a0012855. PubMed PMID: 18793079; PubMed Central PMCID: PMCPCMC2575804.
  34. Hane AA, Fox NA. Ordinary variations in maternal caregiving influence human infants' stress reactivity. *Psychol Sci.* 2006;17(6):550-6. doi: 10.1111/j.1467-9280.2006.01742.x. PubMed PMID: 16771807.

35. O'Banion DD, Hane AA, Litsas D, Austin J, Welch MG. The Welch Emotional Connection Screen: Adapting observational methods to pediatric primary care via resident training. *Infant Behav Dev.* 2021;65:101629. Epub 20210821. doi: 10.1016/j.infbeh.2021.101629. PubMed PMID: 34425493.
36. DeMaster D, Bick J, Johnson U, Montroy JJ, Landry S, Duncan AF. Nurturing the preterm infant brain: leveraging neuroplasticity to improve neurobehavioral outcomes. *Pediatr Res.* 2019;85(2):166-75. Epub 20181016. doi: 10.1038/s41390-018-0203-9. PubMed PMID: 30531968.
37. Choate P, Tortorelli C. Attachment Theory: A Barrier for Indigenous Children Involved with Child Protection. *Int J Environ Res Public Health.* 2022;19(14). Epub 20220719. doi: 10.3390/ijerph19148754. PubMed PMID: 35886606; PubMed Central PMCID: PMC9319150.
38. Nakic Rados S, Hairston I, Handelzalts JE. The concept analysis of parent-infant bonding during pregnancy and infancy: a systematic review and meta-synthesis. *J Reprod Infant Psychol.* 2023:1-24. Epub 20230102. doi: 10.1080/02646838.2022.2162487. PubMed PMID: 36588501.
39. Wright B, Fearon P, Garside M, Tsappis E, Amoah E, Glaser D, et al. Routinely used interventions to improve attachment in infants and young children: a national survey and two systematic reviews. *Health Technol Assess.* 2023;27(2):1-226. doi: 10.3310/IVCN8847. PubMed PMID: 36722615; PubMed Central PMCID: PMC9900465.
40. Prechtl HFR. The directed head turning response and allied movements of the human baby. *Behaviour.* 1958;13:212-42.
41. Papousek H. Conditioned head rotation reflexes in infants in the first months of life. *Acta Paediatr (Stockh).* 1961;50:565-76. doi: 10.1111/j.1651-2227.1961.tb08047.x. PubMed PMID: 14483743.
42. Hym C, Forma V, Anderson DI, Provasi J, Granjon L, Huet V, et al. Newborn crawling and rooting in response to maternal breast odor. *Dev Sci.* 2021;24(3):e13061. Epub 20201205. doi: 10.1111/desc.13061. PubMed PMID: 33174352.
43. Buil A, Sankey C, Caeymaex L, Apter G, Gratier M, Devouche E. Fostering mother-very preterm infant communication during skin-to-skin contact through a modified positioning. *Early Hum Dev.* 2020;141:104939. Epub 20191216. doi: 10.1016/j.earlhumdev.2019.104939. PubMed PMID: 31855717.
44. Poe GR, Foote S, Eschenko O, Johansen JP, Bouret S, Aston-Jones G, et al. Locus coeruleus: a new look at the blue spot. *Nat Rev Neurosci.* 2020;21(11):644-59. Epub 20200917. doi: 10.1038/s41583-020-0360-9. PubMed PMID: 32943779; PubMed Central PMCID: PMC8991985.
45. Hidalgo-Mazzei D, Young AH, Vieta E, Colom F. Behavioural biomarkers and mobile mental health: a new paradigm. *Int J Bipolar Disord.* 2018;6(1):9. Epub 20180506. doi: 10.1186/s40345-018-0119-7. PubMed PMID: 29730832; PubMed Central PMCID: PMC6161977.
46. Porges SW, Davila MI, Lewis GF, Kolacz J, Okonmah-Obazee S, Hane AA, et al. Autonomic regulation of preterm infants is enhanced by Family Nurture Intervention. *Dev Psychobiol.* 2019;61(6):942-52. Epub 20190313. doi: 10.1002/dev.21841. PubMed PMID: 30868570.
47. Firestein MR, Myers MM, Feder KJ, Ludwig RJ, Welch MG. Effects of Family Nurture Intervention in the NICU on Theory of Mind Abilities in Children Born Very Preterm: A Randomized Controlled Trial. *Children (Basel).* 2022;9(2). Epub 20220218. doi: 10.3390/children9020284. PubMed PMID: 35205004; PubMed Central PMCID: PMC8870221.
48. Welch MG, Barone JL, Porges SW, Hane AA, Kwon KY, Ludwig RJ, et al. Family nurture intervention in the NICU increases autonomic regulation in mothers and children at 4-5 years of age: Follow-up results from a randomized controlled trial. *PLoS One.* 2020;15(8):e0236930. Epub 20200804. doi: 10.1371/journal.pone.0236930. PubMed PMID: 32750063; PubMed Central PMCID: PMC7402490.
49. Welch MG, Firestein MR, Austin J, Hane AA, Stark RI, Hofer MA, et al. Family Nurture Intervention in the Neonatal Intensive Care Unit improves social-relatedness, attention, and neurodevelopment of preterm infants at 18 months in a randomized controlled trial. *J Child Psychol Psychiatry.* 2015;56(11):1202-11. Epub 20150311. doi: 10.1111/jcpp.12405. PubMed PMID: 25763525.
50. Welch MG, Halperin MS, Austin J, Stark RI, Hofer MA, Hane AA, et al. Depression and anxiety symptoms of mothers of preterm infants are decreased at 4 months corrected age with Family Nurture Intervention in the NICU. *Arch Womens Ment Health.* 2016;19(1):51-61. Epub 20150301. doi: 10.1007/s00737-015-0502-7. PubMed PMID: 25724391.
51. Ludwig RJ, Grunau RE, Chafkin JE, Hane AA, Isler JR, Chau CMY, et al. Preterm infant heart rate is lowered after Family Nurture Intervention in the NICU: Evidence in support of autonomic conditioning. *Early Hum Dev.* 2021;161:105455. Epub 20210831. doi: 10.1016/j.earlhumdev.2021.105455. PubMed PMID: 34517207.
52. Hane AA, Myers MM, Hofer MA, Ludwig RJ, Halperin MS, Austin J, et al. Family nurture intervention improves the quality of maternal caregiving in the neonatal intensive care unit: evidence from a randomized controlled trial. *J Dev Behav Pediatr.* 2015;36(3):188-96. doi: 10.1097/DBP.000000000000148. PubMed PMID: 25757070.
53. Welch MG, Myers MM, Grieve PG, Isler JR, Fifer WP, Sahni R, et al. Electroencephalographic activity of preterm infants is increased by Family Nurture Intervention: a randomized controlled trial in the NICU. *Clin Neurophysiol.* 2014;125(4):675-84. Epub 20131017. doi: 10.1016/j.clinph.2013.08.021. PubMed PMID: 24140072.
54. Myers MM, Grieve PG, Stark RI, Isler JR, Hofer MA, Yang J, et al. Family Nurture Intervention in preterm infants alters frontal cortical functional connectivity assessed by EEG coherence. *Acta Paediatr.* 2015;104(7):670-7. Epub 20150413. doi: 10.1111/apa.13007. PubMed PMID: 25772627.
55. Welch MG, Grieve PG, Barone JL, Ludwig RJ, Stark RI, Isler JR, et al. Family nurture intervention alters relationships between preterm infant EEG delta brush characteristics and term age EEG power. *Clin Neurophysiol.* 2020;131(8):1909-16. Epub 20200608. doi: 10.1016/j.clinph.2020.05.020. PubMed PMID: 32599274.

56. Welch MG, Stark RI, Grieve PG, Ludwig RJ, Isler JR, Barone JL, et al. Family nurture intervention in preterm infants increases early development of cortical activity and independence of regional power trajectories. *Acta Paediatr.* 2017;106(12):1952-60. Epub 20170925. doi: 10.1111/apa.14050. PubMed PMID: 28850710.
57. Welch MG, Grieve PG, Stark RI, Isler JR, Ludwig RJ, Hane AA, et al. Family nurture intervention increases term age forebrain EEG activity: A multicenter replication trial. *Clin Neurophysiol.* 2022;138:52-60. Epub 20220305. doi: 10.1016/j.clinph.2022.02.018. PubMed PMID: 35358769.

*Disclosure: The authors have no stated conflicts of interest*

**NT**



*Amie Ashley Hane, PhD  
Professor of Psychology/Neuroscience and Public Health/Williams College,  
Williamstown, MA  
Visiting Associate Professor in Clinical Psychology/Columbia University Irving Medical Center  
Director WECS behavioral coding lab*

*Corresponding Author*



*Martha G Welch, MD  
Professor of Psychiatry in the Department of Pediatrics and in the Department of Pathology & Cell Biology) at Columbia University Irving Medical Center in New York City  
601 West End Ave, New York, NY 10024  
Email: [mgw13@cuimc.columbia.edu](mailto:mgw13@cuimc.columbia.edu)  
Phone: +1-917-747-4355.*



*Michael M. Myers, PhD.  
Professor of Behavioral Biology in Psychiatry & in Pediatrics/ Developmental Neuroscience, Columbia University Irving Medical Center, New York, NY  
Former Chief, Developmental Psychobiology, New York State Psychiatric Institute, New York, NY  
Extraordinary Professor, Department of Obstetrics, Stellenbosch University, South Africa*



*Robert J Ludwig BA  
Former Associate Director of the Nurture Science Program/ Columbia University Irving Medical Center  
Welch Legacy Program/ Columbia University Irving Medical Center.  
Principal author/emotional connection theory*



# COVID-19

## STOP THE SPREAD AT HOME

What to do when you or a loved one is infected.

### HYGIENE TIPS

- MOUTH**
  - Wear a face mask or face shield.
  - If in car, wear mask & put windows down.
  - NO cloth face masks for children younger than 2yrs.
  - Avoid kissing.
- EYES**
  - Wear protective eye gear (glasses)
- HANDS**
  - ALWAYS wash your hands
- CLOTHING**
  - Wear a jacket when dealing with infected.
  - DO NOT share clothing, sheets, or pillows.

### BATHROOM

- Sanitize EVERYTHING.
- Clean after every use.
- Patient gargle Listerine every morning & night.

### PROTECT

- If infected, notify everyone in contact from the past 10 days.
- Ask Dept. of Health for further assistant.
- Call 211 for FREE delivery services.

If you are feeling sicker, DON'T WAIT. Call your doctor immediately.

### SELF ISOLATION

- Sick should be separate from household.
- Room with window preferred.
- Aerate room 3x day.
- Create a room divider with sheet.
- Keep water and sanitation liquids near room.
- Don't cuddle with pets.
- Use SEPARATE utensils.
- Clean utensils separately.
- If sick avoid the kitchen.

### KITCHEN

- Use SEPARATE utensils.
- Clean utensils separately.
- If sick avoid the kitchen.



Visit Miora.org



# COVID-19

## DETENER LA PROPAGACION EN CASA

Qué hacer cuando usted o un ser querido está infectado.

### CONSEJOS DE HIGIENE

- BOCA**
  - Use una mascarilla o careta
  - Si está en el automóvil, use una máscara y baje las ventanas.
  - NO mascarillas de tela para niños menores de 2 años.
  - Evitar besos
- OJOS**
  - Use equipo de protección para los ojos (lentes)
- MANOS**
  - SIEMPRE lávate las manos
- ROPA**
  - Use una chaqueta cuando se trata de infectados.
  - NO comparta ropa, sábanas o almohadas.

### BAÑO

- Desinfecte TODO.
- Limpia después de cada uso
- El paciente hace gárgaras con Listerine todas las mañanas y noches.

### PROTEGER

- Si está infectado, notifique a todos los contactos de los últimos 10 días.
- Pídale al Departamento de Salud por más ayuda.
- Llame al 211 para obtener servicios de entrega GRATUITOS.

Si te sientes más enfermo, NO ESPERES. Llame a su médico de inmediato.

### ASLAMIENTO

- Los enfermos deben estar separados del hogar.
- Habitación con ventana preferida
- Alinea la habitación 3x al día
- Crear un separador de ambientes con sábanas.
- Mantener agua y líquidos de saneamiento cerca
- Mantenga una bolsa de basura en la habitación.
- Use utensilios SEPARADOS.
- Limpie los utensilios por separado.
- Si está enfermo, evite la cocina.

### COCINA

- Use utensilios SEPARADOS.
- Limpie los utensilios por separado.
- Si está enfermo, evite la cocina.



Visitar Miora.org



## Ways to Manage Covid 19 @ Home

### Household

- Stay 6 feet apart from others at all times.
- Wear protective covering over mouth and eyes (mask AND shield/goggles/glasses) when near others. (Do not put masks on children under 2 years old)
- Gargle with antiseptic mouthwash in the morning and evening.
- Wash hands 10-12x a day, before each meal for at least 20 seconds.
- Keep good ventilation throughout home. (open windows/doors) where possible
- Do not share towels, blankets, pillows with sick.
- Call 211 for assistance/free delivery of services.
- Wear protective clothing (jacket, gloves, mask) that can be removed after being around infected.

### Sick

- Self-isolate by staying in separate room with separate bathroom where possible. Don't go into shared spaces.
- Create a room divider with sheet, if shared space is unavoidable.
- Ventilate room with fresh air at least 3x per day.
- Keep water and sanitation products in room.
- Keep plastic garbage bag in room.
- Protect pets - don't cuddle.
- Notify contacts in last 10 days.
- Don't wait! Call doctor if symptoms get worse.

Stop the Spread at HOME Miora



## Maneras de manejar COVID-19 en casa

### Hogar

- Manténgase 6 pies de distancia de los demás en todo momento. Use una cubierta protectora sobre la boca y la máscara para los ojos y el protector / gafas / anteojos cuando esté cerca de otras personas. No ponga máscaras a niños menores de 2 años.
- Hacer gárgaras todas las mañanas y noches con productos de enjuague bucal antiséptico que contienen alcohol.
- Lavé la manos 10-11 veces al día, y antes de cada comida por lo menos 20 segundos.
- Mantenga Buena ventilación en toda la casa. Abra las ventanas y puertas cuando sea posible.
- No compartá toallas, cobijas, y almohadas con personas que estén infectados.
- Llame al 211 para obtener servicios de entrega gratuitos.
- Use ropa protectora, chaqueta, guantes, máscara que se pueda quitar después de estar cerca de infectados.

### Enfermo

- Aíslase permaneciendo en una habitación separada con baño separado. No vayas a espacios compartidos
- Si no se puede aislar crea un separador de ambiente con una sábana.
- Ventile la habitación con aire fresco por lo menos 3 veces al día.
- Mantenga agua y productos de saneamiento en la habitación.
- Mantenga una bolsa de basura en la habitación.
- Proteja a las mascotas, no las abraza.
- Notifique a todos los contactos de los últimos 10 días.
- No espere! Si se siente peor llame a su médico.

Detén la propagacion en CASA Miora



## WEAR A MASK

PROTECT PARENTS + BABIES

COVID-19

When we all wear masks...

We protect parents and babies.



Project Sweet Peas + National Perinatal Association

## USA UNA MASCARILLA

PROTEGER A LOS PADRES Y BEBÉS

COVID-19

Cuando todos usamos mascarillas ...

Protegemos a los padres y los bebés.



Project Sweet Peas + National Perinatal Association

---

# FCC TASKFORCE

---

## FCC Core Team

### Co-Chairs

Malathi Balasundaram, MD  
Colby Day, MD  
Keira Sorrells

### Program Manager

Caroline Toney-Noland, MSc



## Mission Statement

We exist to equip and support NICUs as they seek to begin or strengthen family-centered care in their unit.

## What is family-centered care?

Family-Centered Care (FCC) ensures that caregivers are active, engaged team members throughout their NICU journey and is a key factor in improving infant health and family mental health outcomes.

Be sure to visit our new website, [fcctaskforce.org](https://fcctaskforce.org), to view all past and upcoming webinars as well as shared resources.

Want to strengthen FCC in your NICU? Click this [link](#) or scan the QR code to join the FCC Taskforce.



[@FCCTaskforce](https://twitter.com/FCCTaskforce)



## Upcoming Webinars

---

### May 11, 11am-12:30pm PT

- "Family Engagement and QI" Dr. Meg Parker & Molly Wylie
- "VON Family Engagement QI Work Examples" Marybeth Fry & Lelis Vernon

### July 20, 11am-12:30pm PT

- "The I-Rainbow: A flexible, evidence-based care path for providing developmental care in the NICU" Dr. Melissa Scala & Dr. Eilish Byrne
- "Social Media: A Tool for Connecting with Families" Dr. Daphna Barbeau
- "How Mamma is Closing Gaps in Maternal Mental Health Care in NICUs" Maureen Fura, MPA, Mamma CEO & Founder

# WE NEED YOUR HELP,

*Your voice, Your expertise, Your support,*

*to raise awareness about the Alliance  
and our vision for supporting Black  
NICU Families.*

Black NICU Moms & Dads:

## TAKE THE SHORT SURVEY!

<https://preemie.us/BlackNICUFamilies>

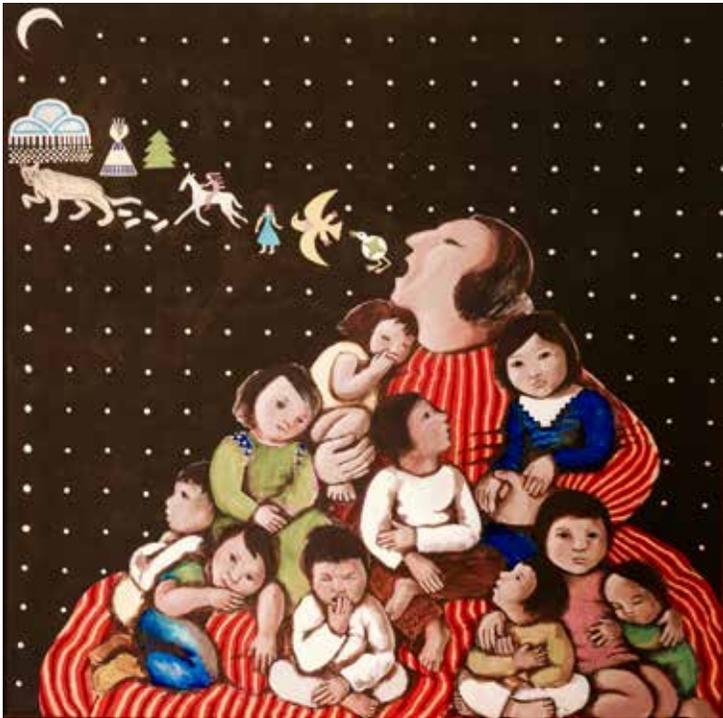


**alliance**

FOR BLACK NICU FAMILIES™

# Fragile Infant Forums for Implementation of IFCDC Standards: Key Cornerstone of the IFCDC Standards: Infant Mental Health

Joy V. Browne, Ph.D., PCNS, IMH-E



***“Engaging in a reflective stance regarding the impact of care on the baby’s and family’s experience individual experience assists the professional in implementing the principles included in IFCDC practice. (1) IMH considerations are vital in the conceptual model of how IFCDC should be implemented in intensive care.”***

Infant and family-centered developmental care (IFCDC) includes several guiding principles, one of which is the application of Infant Mental Health (IMH) to practice in intensive care. The emerging knowledge base of IMH clearly shows how early experiences affect babies’ social and emotional well-being and should be a major consideration in all caregiving. Within the field of IMH, the constructs of *regulation, relationships, and reflection* guide thinking about the optimal environment of care on 1) the baby’s organization/regulation, 2) the baby’s ability to be an active interactor, 3) the primary role of the m(other) on the baby’s organization, and 4) optimizing neurodevelopment. See Figure 1. Engaging in a reflective stance regarding the impact of care on the baby’s and family’s experience individual experience assists the professional

in implementing the principles included in IFCDC practice. (1) IMH considerations are vital in the conceptual model of how IFCDC should be implemented in intensive care. (2, 3, 4)

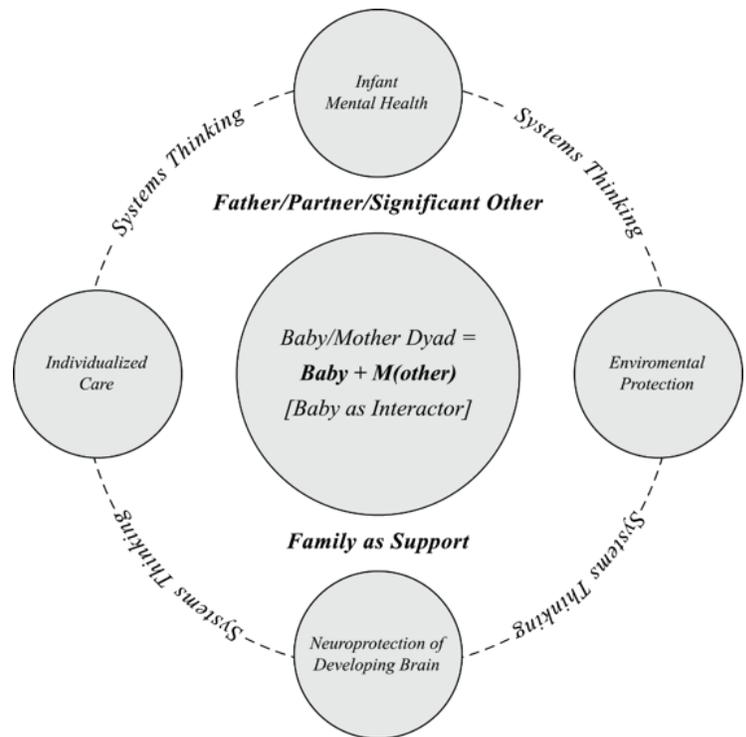


Figure 1

IMH is becoming more relevant to babies and young children’s social and emotional development. Intensive care professionals must understand and implement strategies to enhance rather than detract from optimal developmental outcomes. (5, 6) Implementation of appropriate IMH approaches should be provided in the context of the baby’s family, the family’s cultural and social orientation, and their caregiving preferences.

***“IMH approaches should be provided in the context of the baby’s family, the family’s cultural and social orientation, and their caregiving preferences.”***

## Historical aspects of IMH

IMH is now considered an essential consideration for robust infant and child development. Its roots come from a shift in focus from more adult-oriented psychodynamic approaches to seeing the baby and young child as unique within their caregiving relationships. Early studies by Selma Fraiberg (7), Donald Winnicott (8, 9), and Claire Britton (Winnicott) (10) recognized the impact of early childhood traumatic events as well as disturbed relationships

as affecting the young child's mental health and behavior. Interventions developed by those early investigators focused on understanding the infant and young child's world, beliefs, and fears. They recognized that as the child is dependent on others for both physical and emotional growth, a sensitive, nurturing relationship with the primary caregiver is essential for optimal outcomes.

---

***“They recognized that as the child is dependent on others for both physical and emotional growth, a sensitive, nurturing relationship with the primary caregiver is essential for optimal outcomes.”***

---

More recent emphases on early childhood social and emotional development have resulted in theoretical and practical foundations for IMH assessment, prevention, and intervention. Accumulating scientific evidence has pointed to the neurobehavioral and social, and emotional impact of early experiences and the protective nature of nurturing early relationships. (11, 12)

#### Defining IMH and its primary principles

IMH is typically defined as “the young child's capacity to experience, regulate and express emotions, form close and secure relationships and explore the environment and learn. These capacities are best accomplished in the caregiving environment, including family, community, and cultural expectations for young children. Developing these capacities is synonymous with healthy social and emotional development”. (13)

The field of IMH is “represented by multidisciplinary professionals of inquiry, practice, and policy concerned with alleviating suffering and enhancing the social and emotional competence of young children” (14), page 6. The guiding principles of IMH include the following:

- Infant-caregiver relationships are the primary focus of assessment and intervention
- IMH is a strengths-based discipline
- Caregivers' past and current experiences influence their relationship with their baby/child.
- As the field strives to delineate, establish, and sustain positive development for infants and young children, intervention should not only alleviate suffering in the short term but also attend to future development through nurturing relationships.

#### **Prevention, Promotion, and Treatment: Three Levels of Intervention:**

Primary IMH goals include promoting emotional well-being in young children and their families, reducing risk factors, and preventing and/or ameliorating emotional problems. Three levels of approaches describe awareness of what is necessary to support emotional well-being and the intensity of appropriate approaches to meet the goal of that particular level. The first level relates to all babies and children and addresses preventive services, including ensuring early nurturing relationships and environments for all babies and children within the context of their family's culturally relevant parenting practices. The second level includes promoting emotional well-being by helping to reduce identified risk factors

and includes more focused and nuanced approaches to enhance the child's regulation and relationships within the context of their caregiver(s). The third level indicates that babies, children, and their families have mental health or behavioral issues that need specific treatment. Many evidence-based interventions are now available when significant intervention is necessary.

---

***“Primary IMH goals include promoting emotional well-being in young children and their families, reducing risk factors, and preventing and/or ameliorating emotional problems.”***

---

Application of these three levels of intervention to intensive care assumes that professionals and hospital systems should provide care that prevents long-term social and emotional distress. (15) It assumes that all hospitalized babies and children will have safe, responsive, and nurturing care primarily provided by their family members and that the environments in which they receive care will be non-threatening and age-appropriate. Policies and procedures that minimize separation from their primary caregiver and strategies to minimize the effects of invasive procedures may be included in this level of prevention. Examples might be assuring comfortable accommodations for families to be with their baby; unrestricted access to be with their baby; assuring that painful procedures are minimized and/or that they have appropriate analgesia for painful and/or stressful procedures.

---

***“The level of promotion, however, is likely to apply to most babies and infants in intensive care. Due to the nature of the unfamiliar hospital setting, potentially overwhelming sensory environments, separation from their family, and invasive caregiving procedures by non-primary caregivers are likely.”***

---

The level of promotion, however, is likely to apply to most babies and infants in intensive care. Due to the nature of the unfamiliar hospital setting, potentially overwhelming sensory environments, separation from their family, and invasive caregiving procedures by non-primary caregivers are likely. These situations are also likely to be emergent and fast-paced, with little consideration of the potential for the baby to experience stressful and overwhelming traumatic events. Careful assessment of the baby's behavioral reaction to caregiving and their ability to use the help of the primary caregiver to regulate their responses appropriately is necessary. Specific strategies should be implemented to promote regulation and to assure positive interactions and relationships with their primary caregiver. At this level, the family members may also need significant support to interact positively with their baby. Examples of situations like these might be when babies have been in traumatic accidents and need immediate clinical approaches in order to provide stabilization. Another example might be if the

parent is separated from the baby for procedures and unable to regulate their behavior due to the cause of the baby's hospitalization. Application of infant and family-centered developmental care standards, competencies, and best practices guide how best to address many of these issues and thus promote more optimal immediate and long-term behavioral and developmental outcomes. <https://nicudesign.nd.edu/nicu-care-standards/>. (2, 3)

Treatment at the third level typically results from concerns of the professional staff or parent that the behavior of the baby and/or family is outside the expectations of the baby's age or condition. It also involves concerns about the parents' reactions to the intensive care situation. Examples include babies who cannot calm down and are irritable, regardless of typical calming strategies or those who become listless and "tuned out" and do not seem to be processing their experience appropriately for their age. Additional examples include parents needing third-level intervention when they exhibit extreme withdrawal, uncontrolled crying, anxiety, or difficulty managing their behavior. Mental health concerns should be addressed by a well-trained IMH professional with both baby and adult experience. Recommendations for mental health resources for parents are detailed in the Psychosocial Program Standards for NICU parents. (16, 17)

---

***“Understanding the subtle nuances of behavior and reactivity of the baby guides an understanding of their development and capacity for relationship, which further guides intervention.”***

---

#### **What about the baby?**

A typical question in IMH practice, particularly if interventions seem to be more focused on the caregivers or the system itself, is: “*What about the baby?*”. Much mental health supports focus on the mental health of the parent/caregiver rather than understanding the baby's experience. When starting with the baby, it is easy to understand that they focus on intervention and guidance for the caregiving environment. (6, 18) Understanding the subtle nuances of behavior and reactivity of the baby guides an understanding of their development and capacity for relationship, which further guides intervention. (6, 19, 20, 21) This allows for reflection on the baby's experience and what they need for regulation and support for relationship development. Keeping the baby in mind throughout the hospitalization and providing opportunities to support the primary caregiver to reflect on the baby's experience is a critical intervention strategy in IMH. (18)

---

***“The application of IMH practice highlights the necessity of addressing essential components of regulation, relationships, and reflective practice.”***

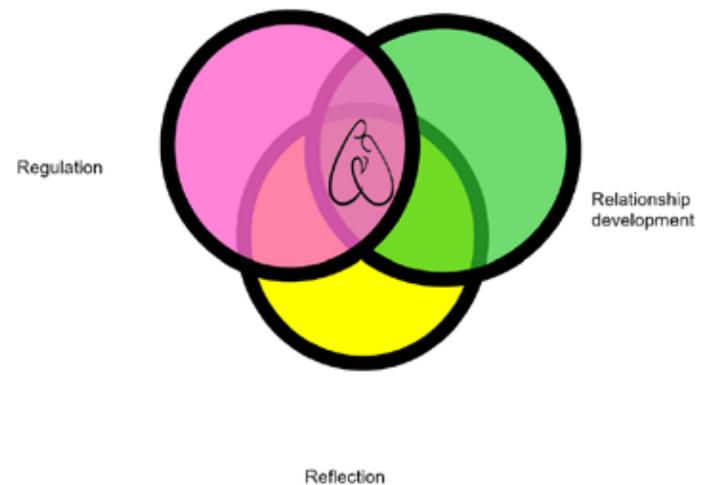
---

#### **Key elements for IMH practice in intensive care**

The application of IMH practice highlights the necessity of ad-

ressing essential components of *regulation, relationships, and reflective practice*. (1) These three complementary practices are best visualized in Figure 2.

#### **Relationship development**



**Figure 2**

“*Regulation*” applies to the baby's ability to regulate their behavior with the support of the primary caregiver, typically the m(other). In utero, the fetus is provided regulation through the mother's body and physiology. For typical births, the m(other's) body continues to promote the regulatory environment for the baby's physiology, arousal, sleep states, and motor behaviors. For babies in intensive care, equipment, medication, and caregiving interventions often become the regulating or dysregulating environment as most babies are separated from the m(other), even if briefly. IMH practices, therefore, should focus on ensuring that the m(other) is physically and emotionally available as constantly as possible, and until that occurs, provision of support for regulation of the baby's behavior and physiology is essential.

Another essential aspect of IMH practice includes the provision of a nurturing environment that lays a foundation for *sound relationship development*. All social and emotional development begins in infancy and depends on the baby's feeling safe and secure and that the familiar m(other) can meet their needs and respond to their distress. Providing opportunities for close, intimate, and supportive face-to-face interactions with familiar caregivers continues the familiarity with the mother's body after birth and allows for feelings of safety and regulated behavior. Studies have shown that promoting emotional exchanges between the baby and the mother has both short- and long-term benefits. (22, 23, 24) As relationships are a two-way street, understanding and supporting the primary caregiver's ability to provide a nurturing exchange can also be a focus of IMH intervention. As primary caregivers have their background and stressful experiences, including being in intensive care and having potential mental health issues, providing physical, psychosocial, and emotional support is imperative. (17)

*Reflecting on the baby's and caregiver's experience* provides a foundation for both best practices and sensitizing professional staff to the potential challenges to the baby's regulatory capacity and relationship development. Studies of parental reflective capacity clearly indicate that the child's mental health can be significantly and positively impacted when the parent can reflect on the child's experience. Reflection leads to insight and sensitivity to what the baby's world may be like enhancing individualized caregiving. Reflection and a reflective stance are robust and evidence-based practices that can enhance professional interactions and evaluate the success of their interventions on the dyad. Reflective practice

in a busy, intensive care unit is challenging if not practiced regularly and valued by the unit leadership. Providing education and opportunities for reflection individually or in groups can benefit the professional and the professional's practice with babies and their families. (1, 6)

---

***“IMH definition, principles, scientific inquiry, and clinical application can be used in caring for all babies and families, including those whose lives begin in intensive care.”***

---

#### **Conclusion:**

Applying IMH principles and practices in scientific and clinical settings allows for robust inquiry and practice. IMH definition, principles, scientific inquiry, and clinical application can be used in caring for all babies and families, including those whose lives begin in intensive care. (1, 5, 15) As a vital component of the IFCDC standards, competencies, and best practices for babies and families intensive care, IMH plays a significant complementary role. Application to intensive care should contribute to optimal outcomes for high-risk babies and their families. IMH approaches should be infused into all levels of care in hospital settings, particularly in intensive care, prevention, promotion, and treatment. The practice of IMH in intensive care should represent the key elements in support of physiologic and behavioral regulation, sound relationships with primary caregivers, and a reflective approach to caregiving.

#### **References:**

1. Browne JV. Infant mental health in intensive care: Laying a foundation for social, emotional and mental health outcomes through regulation, relationships and reflection. *Journal of Neonatal Nursing*. 2021;27(1):33-9.
2. Jaeger CB, Browne JV. The Science. In: Kenner C, McGrath JM, editors. *Developmental Care of Newborns and Infants: A Guide for Health Professionals*. Third ed: Wolters Kluwer; 2023. p. 1-17.
3. Jaeger CB, Browne JV. The infant and family-centered developmental care standards for babies in intensive care and their families. In: Kenner C, McGrath JM, editors. *Developmental Care of Newborns and Infants: A Guide for Health Professionals*. Philadelphia: Wolters Kluwer; 2023. p. 18-34.
4. Browne JV, Jaeger CB, Kenner C. Executive summary: standards, competencies, and recommended best practices for infant- and family-centered developmental care in the intensive care unit. *Journal of perinatology: official journal of the California Perinatal Association*. 2020;40(Suppl 1):5-10.
5. Givrad S, Hartzell G, Scala M. Promoting infant mental health in the neonatal intensive care unit (NICU): A review of nurturing factors and interventions for NICU infant-parent relationships. *Early human development*. 2021;154:105281.
6. Talmi A, Browne JV. Regulation, Relationships and Reflection: Developmental care in the NICU. In: Dempsey AG, Cole JCM, Saxton SN, editors. *Behavioral Health Services with High-Risk Infants and Families: Meeting the Needs of Patients, Families, and Providers in Fetal, Neonatal Intensive Care Unit and Neonatal Follow-up Settings*. New York: New York: Oxford University Press; 2022. p. 359-74.
7. Fraiberg S. *The Magic years: Understanding and Handling the Problems of Early Childhood*: Simon and Schuster; 1996. 303 p.
8. Winnicott DW. Primitive emotional development. *Int J Psychoanal*. 1945;26(3-4):137-43.
9. Winnicott DW. *Babies and their Mothers*. Reading, Massachusetts: Addison Wesley Publishing Co 1992.
10. Kanter J. The untold story of Clare and Donald Winnicott: How social work influenced modern psychoanalysis. *Clinical Social Work Journal*. 2000;28(3):245-61.
11. Shonkoff JP, Phillips DA, Committee on Integrating the Science of Early Childhood Development boC, Youth and Families. From Neurons to Neighborhoods: The Science of Early Childhood Development. New York National Academies Press; 2000. 612 p.
12. De Haan M, Gunnar MR. *Handbook of developmental social neuroscience*: Guilford Press; 2009.
13. Three Zt. Definition of infant mental health [[www.zerotothree.org](http://www.zerotothree.org)]. Arlington, VA,: Zero to Three; 2001
14. Zeanah CH. Infant Mental Health: The Science of Early Experience. In: Zeanah CH, editor. *Handbook of Infant Mental Health Fourth Edition*. New York: New York: The Guilford Press; 2019. p. 5-24.
15. Browne JV, Talmi A. Reflections on infant mental health practice, policy, settings, and systems for fragile infants and their families from prenatal and intensive care through the transition home and to community. *Newborn and Infant Nursing Reviews*. 2016;4(16):255-7.
16. Hynan MT, Hall SL. Psychosocial program standards for NICU parents. *Journal of perinatology: official journal of the California Perinatal Association*. 2015;35 Suppl 1:S1-4.
17. Talmi A, Harmon RJ. Relationships between preterm infants and their parents. *Zero to Three*. 2003;24(2):13-20.
18. Weatherston D, Browne JV. What is Infant Mental Health and why is it important for high-risk infants and their families? *Newborn and Infant Nursing Reviews*. 2016.
19. Als H. Reading the premature infant. In: Goldson E, editor. *Nurturing the premature infant: developmental interventions in the neonatal intensive care nursery*. New York: Oxford University Press; 1999. p. 18-85.
20. Als H, Butler S, Kosta S, McNulty G. The Assessment of Preterm Infants' Behavior (APIB): furthering the understanding and measurement of neurodevelopmental competence in preterm and full-term infants. *Mental retardation and developmental disabilities research reviews*. 2005;11(1):94-102.
21. Als H, Duffy FH. The Behavior of the Premature Infant. In: Brazelton TB, Lester BM, editors. *New Approaches to Developmental Screening of Infants*. New York, NY: Elsevier Science Publishing Co., Inc.; 1983. p. 153-73.
22. Welch MG, Myers MM. *Advances in family-based interven-*

tions in the neonatal ICU. *Curr Opin Pediatr.* 2016;28(2):163-9.

23. Bergman NJ, Ludwig RJ, Westrup B, Welch MG. Nurture-science versus neuroscience: A case for rethinking perinatal mother-infant behaviors and relationship. *Birth Defects Res.* 2019;111(15):1110-27.
24. Porges SW, Davila MI, Lewis GF, Kolacz J, Okonmah-Obazee S, Hane AA, et al. Autonomic regulation of preterm infants is enhanced by Family Nurture Intervention. *Developmental psychobiology.* 2019;61(6):942-52.

**Disclosures:** No author has professional or financial relationships with any companies that are relevant to this study. There are no conflicts of interest or sources of funding to declare.

**NT**

Corresponding Author



Joy Browne, Ph.D., PCNS, IMH-E(IV)  
Clinical Professor of Pediatrics and Psychiatry  
University of Colorado School of Medicine  
Aurora, Colorado  
Telephone: 303-875-0585  
Email: [Joy.browne@childrenscolorado.org](mailto:Joy.browne@childrenscolorado.org)

## Respiratory Syncytial Virus

# Really Serious Virus

Here's what you need to watch for this RSV season

Coughing that gets worse and worse



Breathing that causes their ribcage to "cave-in"

Rapid breathing and wheezing



Bluish skin, lips, or fingertips

RSV can be deadly. If your baby has these symptoms, don't wait. Call your doctor and meet them at the hospital.



Thick yellow, green, or grey mucus



that clogs their nose and lungs, making it hard to breathe

Fever that is more than 101° Fahrenheit



which is especially dangerous for babies younger than 3 months



[www.nationalperinatal.org/rsv](http://www.nationalperinatal.org/rsv)



# SHARED DECISION-MAKING PROTECTS MOTHERS + INFANTS

DURING COVID-19

## KEEPING MOTHERS + INFANTS TOGETHER

Means balancing  
the risks of...

- **HORIZONTAL INFECTION**
- **SEPARATION AND TRAUMA**



## EVIDENCE

We encourage families and clinicians to remain diligent in learning **up-to-date evidence**.

## PARTNERSHIP

What is the best  
for this unique dyad?

### SHARED DECISION-MAKING

- S**EEK PARTICIPATION
- H**ELP EXPLORE OPTIONS
- A**SSESS PREFERENCES
- R**EACH A DECISION
- E**VALUATE THE DECISION



## TRAUMA-INFORMED

Both parents and providers  
are confronting significant...

- **FEAR**
- **GRIEF**
- **UNCERTAINTY**

## LONGITUDINAL DATA

We need to understand more about outcomes for mothers  
and infants exposed to COVID-19, with special attention to:

- **MENTAL HEALTH**
- **POSTPARTUM CARE DELIVERY**



NEW DATA EMERGE DAILY. NANN AND NPA ENCOURAGE PERINATAL CARE PROVIDERS TO ENGAGE IN CANDID CONVERSATIONS WITH PREGNANT PARENTS PRIOR TO DELIVERY REGARDING RISKS, BENEFITS, LIMITATIONS, AND REALISTIC EXPECTATIONS.

Partnering for patient-centered care  
when it matters most.

[nann.org](http://nann.org) [nationalperinatal.org](http://nationalperinatal.org)



National  
Association of  
Neonatal  
Nurses



National  
Perinatal  
Association

**COURSE ORGANIZERS:**

Rangasamy Ramanathan, MD – Course Director  
Section Chief, Neonatology  
HIH Health, Good Samaritan Hospital  
Professor of Pediatrics  
Division Chief, LAC+USC Medical Center  
Keck School of Medicine, University of Southern California

Shahab Noori, MD, MS CBTI, RDCS  
Professor of Pediatrics-Neonatology,  
Keck School of Medicine, University of Southern California

Yogen Singh, MD, MA (Cantab), DCH, FRCPC  
Professor of Pediatrics-Neonatology,  
Loma Linda University School of Medicine, California

Mahmood "Mac" Ebrahimi, RDCS  
Instructor of Clinical Pediatrics  
Keck School of Medicine, University of Southern California

**FACULTY:**

Ruben Acherman, MD  
Professor of Pediatrics, Cardiology  
University of Nevada, Las Vegas, Nevada

Tai-Wei Wu, MD  
Assistant Professor of Pediatrics  
Keck School of Medicine, University of Southern California

Jennifer Shepherd, MD  
Assistant Professor of Pediatrics  
Keck School of Medicine, University of Southern California

Merujan Uzunyan, MD  
Associate Professor of Clinical Pediatrics  
Keck School of Medicine, University of Southern California  
Director, Division of Cardiology, LAC+USC Medical Center

**Website for the course material and echo simulator:**

[www.neochosim.com](http://www.neochosim.com)



Registration fee is \$1000. For those in training the registration fee is \$700

**For program information please contact: Ms Reyna Mayoral Program Coordinator at [Mayoral@usc.edu](mailto:Mayoral@usc.edu) or call (323) 409-3406**

**Space is limited. Please register prior to July 15, 2023**

**Simulator Instructors**

Dr. Rangasamy Ramanathan,  
Dr. Mahmood Ebrahimi  
Dr. Shahab Noori  
Dr. Yogen Singh  
Dr. Jennifer Shepherd  
Dr. Karla Ortiz  
Dr. Victoria Hamilton  
Dr. Gabriella Larusso

Dr. Paul Arichai  
Dr. Ivonne Sierra-Strum  
Dr. Jane Huang  
Dr. Stacy Kim  
Dr. Megan Chang  
Dr. Maria Martes Gomez  
Dr. Jessica Yom  
Dr. Rutuja Kibe

**Recommended Book for the course:**

Practical Neonatal Echocardiography  
Mc Graw Hill, 2019

**FACULTY DISCLOSURE**

Current guidelines state that participants in continuing medical education activities should be aware of any affiliation or financial interest that could affect the speaker's presentation(s). Faculty members have completed conflict of interest declarations and those potential conflicts will be listed in the course syllabus.

**ACCREDITATION STATEMENT**

The Keck School of Medicine of the University of Southern California is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.

The Keck School of Medicine of the University of Southern California designates this educational activity for (to be determined) *AMA PRA Category 1 Credit(s)*<sup>™</sup>



**The 20<sup>th</sup> Annual Echo Course**

**Point of Care  
Echocardiography in the  
Neonate**

**August 15-18, 2023**

**PIH Health Good Samaritan Hospital  
Los Angeles, California**



**Neonatology Grand  
Round Series**

Earn accredited CEs while learning  
about advancements in neonatology!



CENTER FOR RESEARCH,  
EDUCATION, QUALITY  
AND SAFETY

L O M A L I N D A

LLPC

PUBLISHING COMPANY  
EST 2018

# NPA 2023 Conference Reflection

Chavis A. Patterson, Ph.D

The National Perinatal Association (NPA) is an interdisciplinary organization that strives to be a leading voice for perinatal care in the United States. Our diverse membership is comprised of healthcare providers, parents & caregivers, educators, and service providers, all driven by their desire to give voice to and support babies and families at risk across the country.

Members of the NPA write a regular peer-reviewed column in Neonatology Today.



***“We had an amazing collection of speakers who shared great insights about how perinatology can lead to equitable care, from public health to rare diseases.”***

On behalf of NPA and my conference co-chair, I thank everyone for attending and participating in this year's conference. We had an amazing collection of speakers who shared great insights about how perinatology can lead to equitable care, from public health to rare diseases.

We kicked off this year's conference on Tuesday, May 18th, with a pre-conference retreat for Psychologists from the National

Network of Neonatal Psychologists, whose mission is to optimize care for all infants and their families in NICU settings through direct family involvement, staff support, research, and education. LaTrice Dowtin, PhD, and Elizabeth Fischer, PhD, organized a great day to include a keynote presentation, a panel discussion, a self-care activity, and of course, time for networking.

***“We participated in activities that had us acknowledge the emotional strain our work can have on us”***

Jane Lee, MD, started the retreat with a keynote presentation, "From Guilt and Grief to Love and Acceptance." After lunch, the group split into subcommittees to report the progress of each committee. Group updates covered Social Equity and Justice, Training & Education, Creating Semi-Universal Training Materials, Advocacy, and Research. The group came back together to hear a panel of experts talk about "Meeting Family Mental Health Needs across the Spectrum of NICU Care with participants." Crystal Shiller, MD, Darryl Owens, MDiv, BCC, CT, CPLC, and Alison Stuebe, MD, were the invited speakers. Shannon Hanson, PhD, MPH, wrapped up the day with an engaging activity that focused on self-care. As a group, we participated in activities that had us acknowledge the emotional strain our work can have on us. We then shared ideas and resources on how to make sure we take care of ourselves.

On Wednesday, Day 2 of the conference, we opened the day with three plenaries speakers setting the stage for our conference theme. Erika Gabriela Cordova-Ramos, MD, shared her views on "Standard versus Enhanced Social Needs Screening and Referral to Resources in the NICU a Mixed Method Study." Hendrée E. Jones, PhD, followed with a talk about "UNC Horizons - A Comprehensive Model of Dyadic Care." Sobi, a Platinum-level sponsor, offered our lunchtime presentation. The topic discussed was "RSV and RSV-related Hospitalizations in Very Preterm Infants <29wGA". After lunch, Linda Franck, RN, PhD, FRCPC, H,

FAAN, explained "Rapid Whole Genome Sequencing in Neonatal and Pediatric Acute Care: Keys to Successful Implementation." Lara Liszka, OTD, OTR/L, NTMTC, then shared insights on Developmental Outcomes with her discussion, "What's Everybody Talking About?" Dr. Nastassia Harris, DNP, MSN, RNC-MNN, IBCLC spoke passionately about "Reshaping Black Maternal Health from the Community Up." We ended our second day with a thoughtful panel discussion moderated by Maggie Runyon, MSN, RNC-OB, CYT2000, with participants Denise Bolds, MSW, Adv. CD (DONA), CLC, CBE, Michelle Gabriel-Caldwell, PhD, CD, CBE, and Talsasha M. Sumling, LMT/CD/EBB Instructor inspired the audience to think about "The Imperative of Equitable, Accessible Childbirth Education."

***“We ended our second day with a thoughtful panel discussion... Instructor inspired the audience to think about “The Imperative of Equitable, Accessible Childbirth Education.””***

Thursday, Day 3, started with NPA's current president, Viveka Prakash-Zawisza, MD, MS, MBA, opening the conference by reflecting on "The Past, Present, and Future of NPA." Samantha Meltzer-Brody, MD, MPH, followed with a plenary highlighting "Innovative Approaches in Psychopharmacology and Delivery of Psychotherapy in the Treatment of Perinatal Mood Disorders." Monica Hsiung Wojcik, MD, MPH, continued the medical theme with a presentation entitled "Where the Genetic Code Meets the ZIP Code: Diagnostic Equity in Perinatal Rare Disease." Mary Kimmel, MD, ended the morning session with her thoughts about "Ensuring Mental Health for All: Finding Moments to Empower You and Empower Your Patients." AngelEye Health, one of our Platinum level sponsors, gave the lunch talk about how angel eye cameras at the NICU bedside help reduce anxiety in caregivers when they are away from the bedside. After

lunch, we showcased 20 posters in two 60-minute segments. Each author had 10 minutes to briefly overview their work and allow the audience to ask questions.

After a short break and to close out Day 3, Karen Sheffield-Abdullah, PhD, RN, CNM- brought the group back together with her thought-provoking discussion of "Perinatal Mental Health for Black People: Who's Talking and Who's Not."

---

***"We showcased 20 posters in two 60-minute segments. Each author had 10 minutes to briefly overview their work and allow the audience to ask questions."***

---

Our final conference day began with Jerry Ballas, MD, MPH, immediate past president announcing the poster awards. Deitre Epps, MS, Courtnie Carter, BA, CCHW, Maya Jackson were recognized with a Research Award for their poster, "Engaging a Lived Experience Advisory Group in the Evaluation of Maternal Telehealth Access Project during the COVID-19 Pandemic." Also recognized were Agustina Bertone, PhD, Sierra Kuzava, PhD, Karolina Grotkowski, PhD, and Catherine Mogil, PsyD. They received the Model of Care Award for their poster, "Trauma-Informed and Resilience-Promoting Care in the Perinatal Settings."

Vincent C. Smith, MD, MPH, followed Dr. Ballas to share his work on "The Importance of NICU Discharge Planning Guidelines and Standards." Emma Roth, JD, offered a moving discussion of "Pregnancy Criminalization in Post-Roe America." Erin Thatcher rounded out the fourth day of the conference with her discussion on "Long-Term Care for Medically-Complex Children: How to Advocate for and Support Paid Family Caregivers."

---

***"She presented the challenge of taking information that is shared in a conference, whether it be new information or programs that have been started to make a positive impact on patient's lives, and discussing ways in which each person in the room can change something to have a more positive impact in their service they provide to their patients at home"***

---

Patti Bridges, MSW, LCSW, and conference co-chair, closed this year's conference with a call to action. She discussed the powerful messages that had been shared throughout the week. She presented the challenge of taking information that is shared in a conference, whether it be new information or programs that have been started to make a positive impact on patient's lives, and discussing ways in which each person in the room can change something to have a more positive impact in their service they provide to their patients at home. She challenged the audience to stand up and share one or

two key messages that resonated with them at the conference. She then challenged each person to return these messages to their institution, apply them to their practice, share them with their workforce, and make a difference.

In addition to our attendees, we would also like to thank and acknowledge our sponsors, with whom none of this would have been possible. Our Platinum level sponsors AngelEye Health and Sobi, Inc., Gold level, sponsors Prolacta Bioscience and Sage Therapeutics, and Silver level sponsors Mallinckrodt Pharmaceuticals and Ultragenyx Pharmaceutical.

**Disclosures:** *There are no reported disclosures*

**NT**

*Corresponding Author*



*Chavis A. Patterson, Ph.D.  
Director of Psychosocial Services, Division of Neonatology  
Associate Professor of Clinical Psychology in Psychiatry,  
Department of Psychiatry, Perelman School of Medicine at the  
University of Pennsylvania  
Children's Hospital of Philadelphia  
Division of Neonatology, 2 Main, Room 2NW59A  
3401 Civic Center Boulevard  
Philadelphia, PA 19104  
Email: [PattersonC1@email.chop.edu](mailto:PattersonC1@email.chop.edu)*

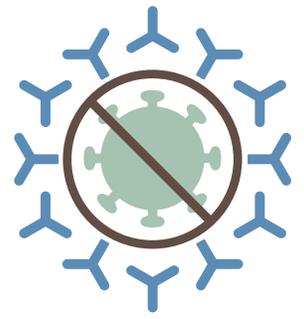
**Postpartum Revolution**

@ANGELINASPICER



Protecting your baby and family from

# Respiratory Viruses:



What parents need to know this RSV and flu season



Like COVID-19, RSV (Respiratory Syncytial Virus) and flu affect the lungs and can cause serious breathing problems for children and babies. Talk to your family about the risks.



Certain diagnoses can make children and babies more vulnerable for serious complications from respiratory viruses - including prematurity, chronic lung disease, and heart conditions.



You can limit the spread of viruses by wearing a mask, washing your hands with soap & water, using an alcohol-based hand sanitizer, and getting vaccinated.



The fewer germs your baby is exposed to, the less likely they are to get sick. Let people know you need their help to stay well. Limit visitors. Avoid crowds. Stay away from sick people.



Immunizations save lives. Stay up-to-date with your family's flu vaccinations and COVID-19 boosters. This helps our community stay safe by stopping the spread of deadly viruses.

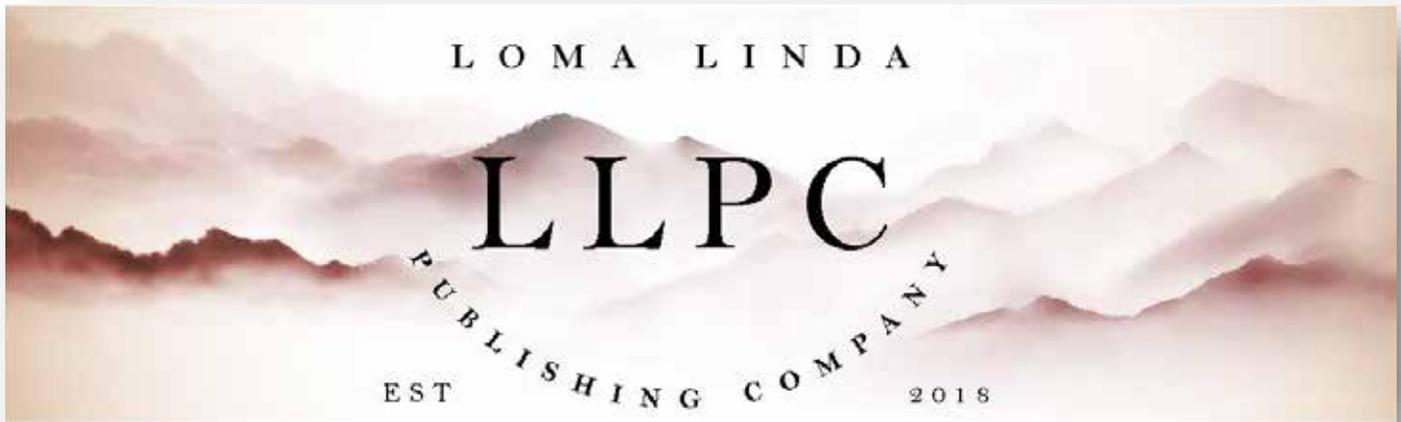


Babies older than 6 months can get a flu shot and COVID-19 vaccinations. There is no vaccine for RSV, but monthly antibody shots during RSV season can help protect them.



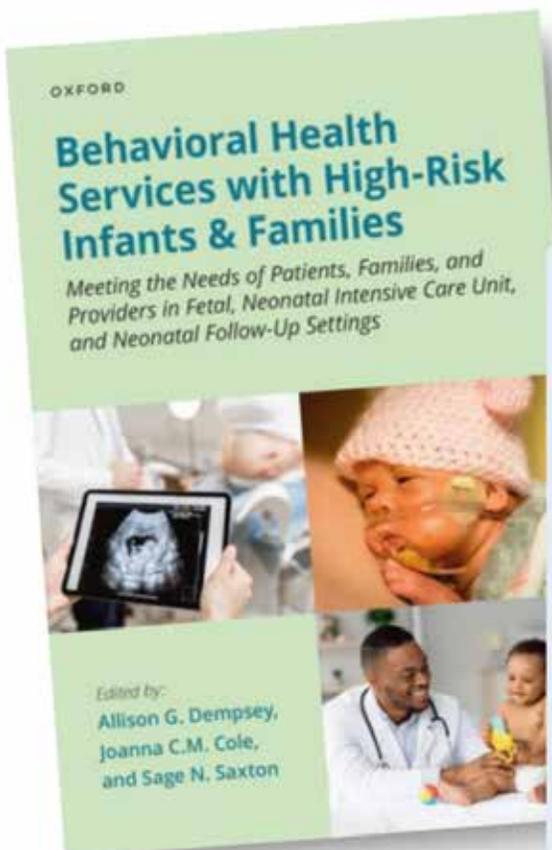
**WE CAN HELP PROTECT EACH OTHER.**





National Network  
of **NICU**  
Psychologists

Education, Resources, and  
Support for Perinatal Mental  
Health Professionals



We are pleased to announce  
the Publication of this  
**NEW** Essential Resource

## Behavioral Health Services with High-Risk Infants and Families

Meeting the Needs of Patients,  
Families, and Providers  
in Fetal, Neonatal Intensive Care Unit,  
and Neonatal Follow-Up Settings

Use discount code **ASPROMP8**  
and save **33%**  
online at [www.oup.com](http://www.oup.com)

**\$56.00**



[NATIONALPERINATAL.ORG/PSYCHOLOGISTS](http://NATIONALPERINATAL.ORG/PSYCHOLOGISTS)

# Lorestry: Parent-Led Child Development Monitoring Every Child Has A Story

Linda Craib, RN, MBA; Catherine J. Everett, MD, MBA; David Kovel, MSIS, CPHIMS; Bridget Gulotta, RN, MSN, MBA; Ashleigh Coltman, Harvard Class of 2024; and Alexa Garvin, MSc.



## Introduction

"Trust yourself, you know more than you think you do." - Dr. Benjamin Spock's advice to parents from *The Common Sense Book of Baby and Child Care* (1946)

***"In the past year in the United States, an estimated 4.7 million out of 7.2M children between the ages of 9 months and 35 months did not receive a recommended, parent-completed developmental screening"***

In the past year in the United States, an estimated 4.7 million out of 7.2M children between the ages of 9 months and 35 months did not receive a recommended, parent-completed developmental screening, according to the [2022 National Survey of Children's Health \(1\)](#).

***"[The AAP and CDC] reported that 18%-20% of young children have a developmental delay or disability, but only about 3% of children receive early intervention referrals and services before the age of 3 years."***

In March 2022, the American Academy of Pediatrics (AAP) and the Centers for Disease Control and Prevention (CDC) released an important paper, *Evidence-Informed Milestones for Devel-*

*opmental Surveillance Tools*, in the journal [Pediatrics \(2\)](#). They reported that 18%-20% of young children have a developmental delay or disability, but only about 3% of children receive early intervention referrals and services before the age of 3 years. Experts identified by the AAP established criteria for new CDC milestone checklists, including using milestones most children ( $\geq 75\%$ ) would be expected to achieve by a specific well-child visit and those easily observed in natural settings. The AAP and CDC recommended that improved developmental surveillance (monitoring) tools and screening processes may allow for more timely referrals of children. They stated:

*"Research in early identification has focused primarily on developmental screening, not surveillance (monitoring). Improvements in surveillance tools and processes could help to identify concerns and support clinical judgment regarding developmental screening to allow more timely referral to early intervention services and additional evaluation."*

Parents are keen observers of their newborns and children. Research shows that caregivers are reliable reporters about their [child's development \(3\)](#), and their ability to provide a longitudinal and detailed health history is important to any health encounter for shared understanding and decision-making.

Our approach to early childhood needs the tender and thoughtful attention that all babies deserve. We do not allocate enough of our finite time, skills, and financial resources to children and fail to process and design health systems. In the U.S., we are mired in a 1960s model of care while parenting and the world have changed. This paper outlines some of the complexities and considerations we have observed, how Alea Diagnostics has designed the foundation of Lorestry as one possible solution, and how we hope to partner with others.

***"We do not allocate enough of our finite time, skills, and financial resources to children and fail to process and design health systems. In the U.S., we are mired in a 1960s model of care while parenting and the world have changed."***

## Child Development Concerns in the U.S. - A History:

In 1962, workforce/war-force readiness was questioned by President Kennedy when 49.8% of men drafted under the selective service program did not meet basic skill requirements for work. The report, [One-Third of a Nation \(4\)](#) (the title a nod to the second inaugural address of President Franklin D. Roosevelt, Janu-

ary 20, 1937, and his reference to poverty) found that one-third of the men had conditions that had they been addressed during poverty-ridden childhoods, could have made a difference in the men's long-term health and their ability to work.

The findings of this report, published on June 1, 1964, led to subsequent changes in the Social Security Amendments of 1967 ([P.L. 90-248 \(5\)](#)) and then later establishment of the Early and Periodic Screening, Diagnostic, and Treatment ([EPSDT \(6\)](#)) program. This comprehensive and preventive child health program, designed in part by the AAP as part of the Healthy Children initiative, supports and implements early referrals of developmental and other childhood conditions. EPSDT ensures that children and adolescents receive appropriate preventive, dental, mental health, developmental, and specialty services. Although EPSDT was initially designed for the Medicaid population, private payers follow the recommended well-baby/well-child schedule of visits to monitor early child health and development. Twelve visits are recommended by the AAP between birth and age 3. Unfortunately, the promise of EPSDT, described in 1967, has not come to pass.

---

***“It is estimated that 30-50% of children (7) in the United States miss well-baby/well-child visits with social drivers/determinants of health (SDoH) as contributing factors (i.e., lack of transportation, inability to take time off from work, not understanding the value).”***

---

It is estimated that [30-50% of children \(7\)](#) in the United States miss well-baby/well-child visits with social drivers/determinants of health (SDoH) as contributing factors (i.e., lack of transportation, inability to take time off from work, not understanding the value). Race, language, and zip code/neighborhood predict high-risk preterm Infant Follow Up Program (IFUP) [participation \(8\)](#). Understanding social drivers of health across multiple points in time is all the more critical to achieving screening and referral goals. Even when well-baby/well-child visits occur under the best circumstances, they are months and sometimes years apart by fundamental design.

In March 2023, the CDC updated the latest autism prevalence figure to [1:36 \(9\)](#) children, an increase of 18% since the start of the pandemic. The CDC states that early detection "decreased dramatically" starting in 2020. We have not lacked public awareness campaigns about the importance of early developmental screening and referrals. Decade after decade, the statistics, recommendations, and reminders have been published. Notably, as recently as 2012, the [AAP reported \(10\)](#) that nearly half of all pediatricians were not using standardized developmental screening tools for children who actually made it to a visit, perhaps due to the added cost and time required to complete them.

*“Early identification and treatment of developmental disabilities that cause school-related problems is of considerable importance to practicing pediatricians. The motivation for*

*early identification programs is: (1) to identify the barriers to children's participation in the educational process, (2) to assist these children and their families in finding medical, educational, or other appropriate services, and (3) to overcome or mitigate the adverse effects of the disability.” AAP Committee on Children With Disabilities. [Pediatrics \(1986\) 78 \(3\): 526–528 \(11\)](#).*

*“Early Intervention Programs offer remediation and enhancement of development for children at biologic or environmental risk. Pediatricians should be alert to screen, identify, and assess children who may be helped by Early Intervention Programs. The primary care pediatrician should work with children who have these problems, help coordinate care, and serve as an advocate for the child and family.” AAP Committee on Children With Disabilities. [Pediatrics \(1994\) 93 \(5\): 863–865 \(12\)](#).*

---

***“Approximately 15% to 18% of children in the United States have developmental or behavioral disabilities. An additional 7% to 10% experience substantive school failure and dropout before completing high school. Overall, one in four children has serious psychosocial problems.”***

---

*“Approximately 15% to 18% of children in the United States have developmental or behavioral disabilities. An additional 7% to 10% experience substantive school failure and dropout before completing high school. Overall, one in four children has serious psychosocial problems. To ensure that these children are detected early and their difficulties addressed, the American Academy of Pediatrics' Committee on Children with Disabilities recommends that pediatricians use validated screening tools at each health supervision visit.” AAP, [Pediatrics in Review \(2000\) 21 \(8\): 272–280 \(13\)](#).*

*“With nearly half of pediatricians still not using standardized screening tools, primary care clinicians should know that the periodic use of general developmental and social-emotional screening tools has been proven to identify promptly two to six times more children (age 0–5 years) with suspected delays than a clinician's unstructured surveillance alone.” AAP, [Pediatrics in Review \(2012\) 33 \(10\): 448–458 \(14\)](#).*

### **Development Concerns - Present Day:**

The CDC reports that most children later diagnosed with autism have concerns about their development documented in their Electronic Health Records by three years of age. The [lag time between the parent's first concern and first developmental evaluation \(15\)](#), which averages 2-3 years (longer for children of color), contributes to poor outcomes. Parents have diligently reported concerns about their child's development for years, only to be told a "wait and see" approach is in the child's best interest. It is not.

Societal interest in child development and child health outcomes is not unique to the United States. Through her Royal Foundation,

the Princess of Wales has called the [Early Years \(16\)](#) and the new #ShapingUs campaign for future generations her "life's work." Her approach has been bold and comprehensive, with a desire to understand the root cause of child health outcomes, including social and environmental drivers of health. National [research studies \(17\)](#) have been completed by the foundation about [public perceptions \(18\)](#) and understanding of the early years. Educational programs are already in play for the next generation of parents. The [SEEN Oxford Programme \(19\)](#) (Secondary Education around Early Neurodevelopment), developed by [Kindred Squared \(20\)](#), provides secondary schools with lesson plans designed for students aged 11-14 years, a generation of parents still to come.

---

***“Parents have diligently reported concerns about their child's development for years, only to be told a "wait and see" approach is in the child's best interest. It is not.”***

---

In 2021, LEGO announced the [Build a World of Play \(21\)](#) global challenge with a stunning commitment of grants worth 900 million Danish Kroner (over \$130M) to organizations dedicated to giving children the best start in life. Lorestry, in partnership with the National Head Start Association, was one of 627 eligible applicants considered for the prize.

The AAP has launched a Screening Technical Assistance & Resource Center ([STAR Center \(22\)](#)) to improve the "health, wellness, and development of children through practice and system-based interventions to increase rates of early childhood screening, counseling, referral, and follow-up for developmental milestones, perinatal depression, and social determinants of health." The AAP is working toward a new system of care. Details are not yet described.

---

***“Many [screening] tools have been in use for decades, but few, if any, seem poised for an increasingly diverse and data-driven world, and none agree on naming conventions for data observations or coding that could support interoperability and information sharing in the best interests of children.”***

---

As part of this new screening awareness and support effort, the AAP now provides a [screening tool finder \(23\)](#) complete with provider costs but "does not approve nor endorse any specific tool for screening purposes." Many tools have been in use for decades, but few, if any, seem poised for an increasingly diverse and data-driven world, and none agree on naming conventions for data observations or coding that could support interoperability and information sharing in the best interests of children. Social and environmental screeners are listed as stand-alone, but these

crucial tools and findings must be considered in context, not as separate issues.

A [new edition \(24\)](#) of Ages and Stages, a common developmental screener four decades in the making, is currently being revised (for release in 2025) to reflect more diversity by "using a new normative sample that reflects the current U.S. population." It is unclear which population is inclusive in the current version or how diversity is being defined for the future. Diversity and inclusion are critical considerations for understanding child development since the population of children is rapidly changing.

#### **Child Populations: Disability and Diversity:**

The ACE Kids Act of 2019, called [the policy win of the decade \(25\)](#), is legislation to address the needs of children with medical complexity ([CMC \(26\)](#)). According to the Children's Hospital Association, this population of children is increasing at about 5% per year, exceeding the growth rate of the child population as a whole. Although children with medical complexity represent <1% of children in the U.S., they account for more than one-third of children's healthcare costs. An AAP [clinical report \(27\)](#) expands the definition of children with medical complexity as those with medical and/or behavioral conditions that impact two or more body systems, have high utilization rates and needs for healthcare services, and/or with technological assistance or dependence. Many of these children have a history of admission to a Neonatal Intensive Care Unit (NICU).

---

***“Although children with medical complexity represent <1% of children in the U.S., they account for more than one-third of children's healthcare costs.”***

---

Improving care and managing costs for this population are important goals of the ACE Kids Act. The law requires states to report quality measures tailored to ACE Kids-eligible children. The Children's Hospital Association made [recommendations \(28\)](#) for quality measures to the Centers for Medicare & Medicaid Services (CMS), including mental and developmental health screening.

Models predicting pediatric clinician shortages and geographic maldistribution have recently raised concerns regarding pediatric access to care in the immediate and long-term future. In 2021, the [AAP reported \(29\)](#) that almost 50% of children's hospitals reported vacancies in developmental and behavioral pediatrics and adolescent and child psychiatry, and >30% reported vacancies in child neurology and genetics. In 2022, the National Academies of Sciences, Engineering, and Medicine convened [The Pediatric Subspecialty Workforce and Its Impact on Child Health and Well-Being \(30\)](#) to address these concerning pediatric workforce trends.

With an average of one developmental-behavioral pediatrician in the U.S. for every 100,000 children and other [subspecialty shortages in pediatrics \(31\)](#), we will need new solutions, better triage, and [care coordination \(32\)](#) across the children's health ecosystem sooner than we can train a new generation of pediatric subspecialists to care for an increasingly complex population of children.

## **Loresy Data Observations and Storytelling by Parents:**

Alea Diagnostics (Alea) is committed to engaging parents as health historians and storytellers. By supporting how parents tell their child's development story through their observations and data, a primary goal is improved communication, partnership, and relationship building with care and early education teams. [Loresy \(33\)](#) was created during the Covid-19 pandemic as a solution for parents and children separated from care teams and support. The product meets the 2022 AAP/CDC call to action for surveillance tools and processes identifying concerns and supporting conversations regarding developmental progression and screening.

---

***“Designed as the world's most beautiful baby book, Lorestry is a private, ad-free, consumer-facing product used to collect and collate parent-reported observations (PRO) in the natural home environment.”***

---

Designed as the world's most beautiful baby book, Lorestry is a private, ad-free, consumer-facing product used to collect and collate parent-reported observations (PRO) in the natural home environment. Social and environmental drivers of health can be added (e.g., concerns about transportation, finances, and housing security), along with information about child health conditions that may impact developmental expectations and course (e.g., prematurity, diagnosed congenital conditions, results of newborn genetic screenings).

The product has two distinct elements: an app for efficiently collecting observations onto a digital storyline and into time-stamped lists; and detailed companion reports generated from parent or caregiver entries.

---

***“Social and environmental drivers of health can be added (e.g., concerns about transportation, finances, and housing security), along with information about child health conditions that may impact developmental expectations and course (e.g., prematurity, diagnosed congenital conditions, results of newborn genetic screenings).”***

---

## **Brand and Design Considerations:**

Loresy was designed with many attributes considered central to brand identity and design. Trust, privacy, inclusivity, and alignment to best practices for [Humane Technology \(34\)](#) served as guiding principles. Respect for the user's time to always give back

useful and meaningful information to a parent helped inform the design process and product development roadmap.

"Loresy" (a portmanteau combining the words "Lore" and "Story") is used for the collection and collation of child observations, including developmental milestones, firsts, favorites, images, feelings/emotions, and language acquisition. These observations generate a digital timeline story of a child's life and experiences through the eyes of a parent or primary caregiver.

---

***“Loresy is used for the collection and collation of child observations, including developmental milestones, firsts, favorites, images, feelings/emotions, and language acquisition. These observations generate a digital timeline story of a child's life and experiences through the eyes of a parent or primary caregiver.”***

---

Allegory and symbols associated with family storytelling and lore became a driver for art direction, illustration, features, and functionality (e.g., timelines, relationships, the North Star, lullabies, word clouds, and family trees). The Lorestry logo "L" includes a tree trunk for family stories in the vertical axis of the design, while the turning page of a storybook completes the horizontal axis. The North Star constantly reminds us that we are all on a journey through time and that Lorestry supports navigation.

Loresy blue, the brand's primary color, was selected for accessibility. As many as 10% of boys have some form of colorblindness, but the Lorestry blue color can be seen in a shade of blue by anyone unless they have monochromacy (complete color blindness, which occurs in <0.0001% of the population).

---

***“[The app] is not intended to replace a healthcare encounter or interfere with the important relationship between a trusted pediatrician or other health provider or between a parent and their child's teacher or early interventionist.”***

---

The application does not screen or diagnose conditions or give medical advice. It is not intended to replace a healthcare encounter or interfere with the important relationship between a trusted pediatrician or other health provider or between a parent and their child's teacher or early interventionist. Purposes include structured and unstructured data gathering and private record-keeping, raising awareness of resources available to a parent (such as federally funded early intervention programs that exist as part of federal ["Child Find" programs \(35\)](#)), and using personal observations for communication and advocacy on behalf of a child and/

or a family.

### **Lorestry Features & Functionality:**

Lorestry features and functionalities were selected to support a beautiful, simple, and magical story created for the user's (and child's) enjoyment, including elements that would also be of interest or importance to a primary care provider or an early childhood educator. Parents can access options for the storyline through each child's storyboard. (Up to 8 children can be added to an account starting during pregnancy and through age 6).

---

*“Lorestry features and functionalities were selected to support a beautiful, simple, and magical story created for the user's (and child's) enjoyment, including elements that would also be of interest or importance to a primary care provider or an early childhood educator.”*

---

**Baby/Child profile:** When creating an individual story, each child's home page can include one of 32 animals and birds representing every continent across the globe in one of 6 colors (helping to keep the stories of multiples in order and distinct). Relationships between the account holder and children, and the children to each other, represent the diversity of families in the 21st century (biological, foster, and adoptive family members, stepparents/siblings, surrogates, and donors are included). A child's optional health history includes items such as languages, ancestry, hospital of birth, results of newborn screenings, health conditions, and special education and related services. Data can be entered in real-time or entered retrospectively.

**Social and Environmental Drivers (SDoH/EDoH):** A comprehensive list of social and environmental drivers of health can be collected with Lorestry and populates the baby development report.

**Timeline:** The timeline includes a daily image and observations of baby/child feelings and celebratory events such as firsts, favorites, and milestone acquisition. Entries to the timeline can be supplemented with media such as images, short videos, and diary notes. The timeline can include family history and lore before a child's birth, intergenerational stories, and messages from an elder to a young child for future enjoyment.

**Feelings:** Emotional regulation starts at birth. A simple question can provide profound insights. "How is your baby feeling today?" Feelings, shown as leaves, populate the timeline, lists, and reports while simultaneously populating color into baby-feeling trees. This health data visualization provides a parent with a quick-look overview of general health and well-being with the goal of improved health data literacy.

**Baby Word Clouds:** Lorestry word clouds, starting with coos, cries, and behaviors, capture language acquisition

and progression. Over 1000 words, mapped to a leading baby word bank (including receptive language, expressive language, and gestural language), creates a personal speech and language data repository.

**Milestones:** Mapped to the updated AAP/CDC 2022 milestones, Lorestry flags when a parent has not entered a positive confirmation of an expected milestone. Parents can include developmental and health concerns and are encouraged to connect with their care provider. Access to [birth-3 resources \(public and private\) has been mapped by Lorestry to every state \(36\)](#) and U.S. territory for self-referrals. (N.B. - There is no agreement across disciplines about newborn and child milestone acquisition benchmarks. Notably, the new AAP/CDC milestones generated some important debate in 2022. Lorestry uses the AAP/CDC milestones and benchmarks as just one part of a more complex set of observations supporting how parents and others monitor development as part of a collective effort. We believe that data collected by parents and caregivers with Lorestry will support improved understanding for everyone in time.)

**Firsts and Favorites:** Over 100 firsts are available for one-time entry onto the timeline while favorite people, places, and things change, as preferences do, over time. All add to the timeline and can include supplementary media.

**Comfort:** A simple 5-question tracker that scores comfort (expression, tension, leg movements, ability to calm down, and crying) is included. Supplement with temperature and media is available.

**Measures:** During pregnancy, the measures from ultrasound can be entered. Height, weight, head circumference, and temperature can all be added continuously.

**Specialty Trackers:** Heart rate, skin color, skin warmth; respiratory rate and effort, O<sub>2</sub> and O<sub>2</sub> saturation; appetite level, nausea and vomiting, level of activity, and hydration status are all included.

**Lists and Reports:** Nearly all data entries populate useful time-stamp lists. A paid version of Lorestry includes unlimited monthly baby reports for 1 to 72 months for all children on an account. Reports can be updated at any time and sent as a PDF, in whole or in part, to show time-stamped observations.

**Lullabies:** Lorestry lullabies were commissioned from two composers to ensure that every baby with a Lorestry account has the gift of music. Both compositions have essential life stories of their own. [Mothú \(37\)](#) and [Sontse \(38\)](#) are available in-app and on the Lorestry website.

### **Privacy, Security, and Humane Data Entry:**

An essential feature of Lorestry is the offer of privacy and control. Lorestry is private by design, and sharing identifiable information requires parent engagement and activation. A future feature may include a mechanism for auto-sharing observations with a trusted provider or education team on a schedule, but sharing will always require parental approval and control. Alea is not a healthcare provider or covered entity but has been designed for alignment with the best practices of HIPAA and the GDPR. The Lorestry terms of use, privacy notice, and cookies policy reflect a grow-

ing expectation by users of technology that their data should be treated with respect for privacy. Data sharing by the company, if any, is statistical and requires a strict data use agreement modeled after the [Nationwide Data Use Agreement \(39\)](#) of the Agency for Healthcare Research and Quality (AHRQ). The company does not sell individually identifiable data to advertisers, ad brokers, or marketing companies.

---

***“Alea Diagnostics is not a healthcare provider or covered entity but has been designed for alignment with the best practices of HIPAA and the GDPR. The Lorestry terms of use, privacy notice, and cookies policy reflect a growing expectation by users of technology that their data should be treated with respect for privacy.”***

---

Within the construct of Humane Technology, Lorestry is not designed to create anxiety about data entry. For most children, collecting information should be a purely celebratory and a joyful event for life storytelling. Too often, baby-tracker apps are creating a sense of urgency when none should exist. Encouraging extensive daily use and data monitoring to an ICU level of precision is concerning. If anything should be tracked daily, we encourage simple data entry about how the baby/child is feeling (joyful, happy, content, sad, upset, anxious, or not feeling well). Lorestry creates extraordinary value if parents monitor observations about feelings and check milestones each month - an activity that takes limited time. For parents who feel compelled to enter extensive information about their child, the observations Lorestry elicits generate a joyful storyline, a timeline of memories, lists, and a meaningful and robust report.

---

***“For most children, collecting information should be a purely celebratory and a joyful event for life storytelling. Too often, baby-tracker apps are creating a sense of urgency when none should exist.”***

---

#### **The Fourth Trimester:**

Lorestry will include a special group of observations for the first 30-60-90 days for an upcoming release. This 4th Trimester feature will include observations related to successful transitions to home: feeding and hydration; home kangaroo care; tummy time; comfort; follow-up appointments; back-to-sleep positioning reinforcement; changes in skin color, temperature or breathing patterns; mother-baby feelings as a dyad; and a "when to call" checklist that includes elements from the CDC's new [Hear Her \(40\)](#) campaign.

Videos for babies with special needs can be added to an account before discharge.

The ability to structure information in an [S-BAR \(41\)](#) (Situation, Background, Assessment, Recommendation) format, long used for important communication between providers, introduces and models a structure parents can use for clear and succinct communication efforts for their child and is already understood by providers. Lorestry will include this format in future content designed for parents, including the replacement of "recommendation" with "request," as suggested by one of the world's leading quality and safety physician leaders, when considering [S-BAR for family to provider \(42\)](#) communication.

#### **Other Use Cases:**

The Lorestry platform and product are flexible, with unlimited use cases. Content can be created for the app unique to an organization (e.g., discharge teaching and videos, state newborn screening education) or a specific condition (e.g., rare and ultra-rare conditions, autism, dyslexia).

---

***“Many states will not provide early intervention services unless a child has fallen more than two standard deviations (S.D.) behind same-age peers in one or more developmental domains. Falling behind 95% of peers during rapid growth and without additional support to catch up may set a child up for lifelong struggles with learning, confidence, inclusion, and relationships.”***

---

For families pursuing early intervention services for a child under the Individuals with Disabilities Education Act (IDEA), concerning barriers to access exist. Many states will not provide early intervention services unless a child has fallen more than two standard deviations (S.D.) behind same-age peers in one or more developmental domains. Falling behind 95% of peers during rapid growth and without additional support to catch up may set a child up for lifelong struggles with learning, confidence, inclusion, and relationships. Empowering parents with a tool to advocate for access to services from the state or private payers is critical. To empower parents with data supports them as their child's most ardent champion and loyal protector.

For eligible newborns and children receiving services under an Individual Family Services Plan (IFSP) or an Individualized Education Plan (IEP) due to recognized developmental disabilities or delays, or learning differences, Lorestry can track progress toward goals and objectives. Using Lorestry to help parents monitor success with the early intervention team supports parent engagement as mandated by the IDEA. By engaging families in real-time as partners, teams can test new approaches and adjust programming quickly to avoid costly interventions that may not work for a child.

# Lorestry®

## Child Development Monitoring

- Engage parents as partners and historians
- Educate about the importance of development monitoring (surveillance). A new recommendation of the CDC and the AAP as published in [Pediatrics, March 2022](#).

*"Research in early identification has focused primarily on developmental screening, not surveillance (monitoring). Improvements in surveillance tools and processes could help to identify concerns and support clinical judgment regarding developmental screening to allow more timely referral to early intervention services and additional evaluation."*

- 4 easy to use education modules about child development monitoring, with short HIPAA-compliant surveys to measure understanding
- Use Lorestry for internal quality improvement initiatives to understand care experiences, care coordination, parental needs (pediatric rare disease), and Social Determinants of Health
- HIPAA compliant custom surveys to meet your needs

*Alea Diagnostics, Inc. / Lorestry® copyright 2023, All rights reserved.*

# Lorestry®

## Child Development Monitoring

### Learning Needs, Education Modules, and HIPAA Compliant Learning Surveys

- Learning needs / readiness assessment (JC Standard PC 6.10)
- Module 1: What is Development Monitoring?
- Module 2: Free Features of Lorestry
- Module 3: Baby Reports Feature
- Module 4: Early Intervention & Baby Advocacy

### HIPAA compliant surveys\* available

- Social Determinants of Health
- HCAHPS Pediatric Inpatient
- Parental Needs Scale for Rare Disease (PNSRD)
- Family Experiences with Care Coordination (FECC)
- Custom survey

*\*All surveys require parent opt-in for data sharing and the [Alea Diagnostics Data Use Agreement](#). Data is for internal use only. Alea Diagnostics is not a CMS approved HCAHPS vendor for reporting purposes.*



*Alea Diagnostics, Inc. / Lorestry® copyright 2023, All rights reserved.*

## A Category Creator:

Lorestry is the world's first consumer-facing product mapped to [SNOMED CT \(43\)](#). Beyond the beauty and utility of the digital timeline and baby reports, parents who use Lorestry generate a globally interoperable personal health history on a longitudinal timeline in real-time. SNOMED CT is a systematically organized computer-processable collection of terms used in clinical documentation and reporting and is considered the world's most comprehensive clinical terminology library. SNOMED CT also maps to ICD-10. Recognized by the National Library of Medicine and 80 nations, parents will have the ability to share readable information, without geographic boundaries, in the pursuit of care, to facilitate and participate in research, to provide patient/parent-reported outcomes ([PRO \(44\)](#)) and experiences, and even to support the social good.

This new product category helps parents who are increasingly expected to remember, collect, and collate their observations about their child, manage and coordinate their child's care, and achieve detailed longitudinal record-keeping. Armed with a self-created data asset under personal control, and observations mapped to the global language of healthcare, Lorestry is an important new source of empowerment and a tool for child advocacy.

## Our Desire for Partnership:

Every child has an important story to tell, and we intend to ensure those stories are heard. Collaboration is vital to humankind and to advancing our shared aspirations to improve the human condition. We continuously seek partners as passionate as we are about helping newborns and children, who can see the value for everyone when children thrive in the early years and beyond.

---

***“Armed with a self-created data asset under personal control, and observations mapped to the global language of healthcare, Lorestry is an important new source of empowerment and a tool for child advocacy.”***

---

Helping parents tell their child's story to those who need to hear it is our North Star. If Lorestry resonates with you, time is wasted until we work together. Please join us on our journey.

Lorestry is a free download from the [App Store](#) with plans for Android release later this year. Baby reports, a paid feature, are available directly to consumers and through hospitals, NICUs, educators, leading employers, and children's health advocates and organizations at a significant discount.

## References:

1. Child and Adolescent Health Measurement Initiative. 2020-2021 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administra-

tion (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved 03/22/2023 from [www.childhealthdata.org](http://www.childhealthdata.org).

2. Zubler JM, Wiggins LD, Macias MM, et al. Evidence-Informed Milestones for Developmental Surveillance Tools. *Pediatrics*. 2022;149(3):e2021052138 <https://doi.org/10.1542/peds.2021-052138>
3. Lauren E. Miller, Kayla A. Perkins, Yael G. Dai, Deborah A. Fein, Comparison of parent report and direct assessment of child skills in toddlers, *Research in Autism Spectrum Disorders*, Volumes 41–42, 2017, Pages 57-65, ISSN 1750-9467, <https://doi.org/10.1016/j.rasd.2017.08.002>.
4. One -Third Of A Nation, A Report On Young Men Found Unqualified For Military Service. President's Task Force On Manpower Conservation (June 1, 1964). <https://files.eric.ed.gov/fulltext/ED021045.pdf>
5. [https://www.ssa.gov/OP\\_Home/comp2/F090-248.html](https://www.ssa.gov/OP_Home/comp2/F090-248.html)
6. <https://mchb.hrsa.gov/programs-impact/early-periodic-screening-diagnosis-treatment>
7. Wolf ER, O'Neil J, Pecsok J, Etz RS, Opel DJ, Wasserman R, Krist AH. Caregiver and Clinician Perspectives on Missed Well-Child Visits. *Ann Fam Med*. 2020 Jan;18(1):30-34. doi: 10.1370/afm.2466.
8. Fraiman, Y.S., Stewart, J.E. & Litt, J.S. Race, language, and neighborhood predict high-risk preterm Infant Follow Up Program participation. *J Perinatol* 42, 217–222 (2022). <https://doi.org/10.1038/s41372-021-01188-2>
9. National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention. [https://www.cdc.gov/ncbddd/autism/pdf/Key\\_Findings\\_508.pdf](https://www.cdc.gov/ncbddd/autism/pdf/Key_Findings_508.pdf), March 23, 2023.
10. Marks KP, LaRosa AC. Understanding developmental-behavioral screening measures. *Pediatr Rev*. 2012 Oct;33(10):448-57; quiz 457-8. doi: 10.1542/pir.33-10-448. PMID: 23027599.
11. *Pediatrics* (1986) 78 (3): 526–528. <https://doi.org/10.1542/peds.78.3.526>
12. *Pediatrics* (1994) 93 (5): 863–865. <https://doi.org/10.1542/peds.93.5.863>
13. Glascoe FP. Early detection of developmental and behavioral problems. *Pediatr Rev*. 2000 Aug;21(8):272-9; quiz 280. doi: 10.1542/pir.21-8-272. PMID: 10922024.
14. Marks KP, LaRosa AC. Understanding developmental-behavioral screening measures. *Pediatr Rev*. 2012 Oct;33(10):448-57; quiz 457-8. doi: 10.1542/pir.33-10-448. PMID: 23027599.
15. <https://www.cdc.gov/ncbddd/autism/addm-community-report/delay-to-accessing-services.html>
16. <https://royalfoundation.com/early-childhood/>
17. <https://centreforearlychildhood.org/research/>

18. Ipsos MORI | State of the Nation: Understanding Public Attitudes to the Early Years (November 2020) [https://royalfoundation.com/wp-content/uploads/2020/11/Ipsos-MORI-SON-report\\_FINAL\\_V2.4.pdf](https://royalfoundation.com/wp-content/uploads/2020/11/Ipsos-MORI-SON-report_FINAL_V2.4.pdf)
19. <https://kindredquared.org.uk/wp-content/uploads/2022/05/SEEN-Report-2021.pdf>
20. <https://kindredquared.org.uk/>
21. <https://learningthroughplay.com/build-a-world-of-play/the-challenge>
22. <https://www.aap.org/en/patient-care/screening-technical-assistance-and-resource-center/>
23. <https://www.aap.org/en/patient-care/screening-technical-assistance-and-resource-center/screening-tool-finder/>
24. <https://agesandstages.com/faqs-about-asq-4/>
25. <https://storymaps.arcgis.com/stories/d6fd4c8d71f443b0a-800b7e8cd5adb75>
26. <https://www.aap.org/en/patient-care/children-with-medical-complexity/>
27. Pediatrics (2016) 138 (6): e20163021. <https://doi.org/10.1542/peds.2016-3021>
28. [https://www.childrenshospitals.org/-/media/files/public-policy/children\\_with\\_medical\\_complexity/letters/2020/ace\\_kids\\_quality\\_recommendation\\_to\\_cms\\_110220.pdf](https://www.childrenshospitals.org/-/media/files/public-policy/children_with_medical_complexity/letters/2020/ace_kids_quality_recommendation_to_cms_110220.pdf)
29. Pediatrics (2021) 147 (6): e2020013292. <https://doi.org/10.1542/peds.2020-013292>
30. <https://www.nationalacademies.org/our-work/the-pediatric-subspecialty-workforce-and-its-impact-on-child-health-and-well-being>
31. <https://www.abp.org/dashboards/pediatric-subspecialty-us-state-and-county-maps>
32. Pediatrics (2014) 133 (5): e1451–e1460. <https://doi.org/10.1542/peds.2014-0318>
33. <https://lorestry.com/>
34. <https://www.humanetech.com/>
35. U.S. Department of Education. Individuals with Disabilities Education Act. Sec. 300.111 Child find
36. <https://lorestry.com/parent-self-referral-sites>
37. <https://lorestry.com/mothu> - copyright Alea Diagnostics, Inc. All rights reserved.
38. <https://lorestry.com/sontse> - copyright Alea Diagnostics, Inc. All rights reserved.
39. <https://hcup-us.ahrq.gov/team/NationwideDUA.jsp>
40. <https://www.cdc.gov/hearher/>
41. Müller M, Jürgens J, Redaelli M, Klingberg K, Hautz WE, Stock S. Impact of the communication and patient hand-off tool SBAR on patient safety: a systematic review. *BMJ Open*. 2018 Aug 23;8(8):e022202. doi: 10.1136/bmjopen-2018-022202. PMID: 30139905; PMCID: PMC6112409.
42. [https://www.safetyleaders.org/wp-content/uploads/2022/01/Denham\\_SBAR-for-Patients2008JPatSaf4138-48LTR.pdf](https://www.safetyleaders.org/wp-content/uploads/2022/01/Denham_SBAR-for-Patients2008JPatSaf4138-48LTR.pdf)
43. <https://www.snomed.org/value-of-snomedct>
44. <https://mmshub.cms.gov/sites/default/files/Patient-Reported-Outcome-Measures.pdf>

*Disclosures: All contributors to this white paper are shareholders in Alea Diagnostics Inc., a privately held company. The authors have no other conflicts of interest relevant to this article to disclose.*

**NT**

*Corresponding Author*



*Linda Craib, RN, MBA  
 Founder & CEO  
 Lorestry® by Alea Diagnostics*



*Catherine J. Everett, MD, MBA*



*Ashleigh Coltman,  
Harvard Class of 2024  
Cambridge, MA*



*David Kovel, MSIS, CPHIMS;*



*Alexa Garvin, MSc.*

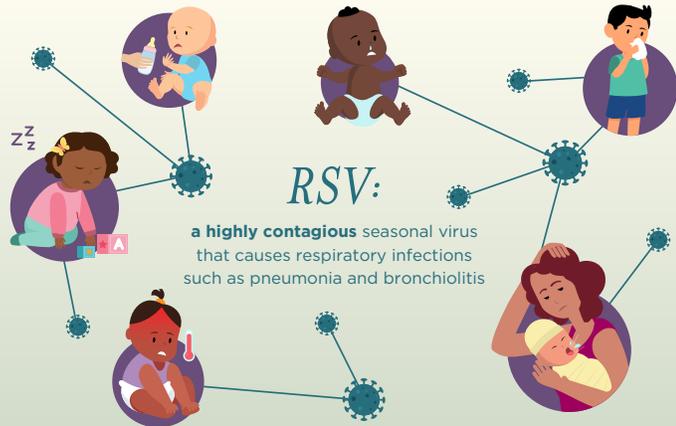


*Bridget Gulotta, RN, MSN, MBA*



# Respiratory Syncytial Virus

DID YOU KNOW?



## Infants under age 1



RSV is the leading cause of hospitalization



16x more likely to get RSV than the flu



## Kids under age 5 experience



500,000 emergency room visits for RSV each year



57,000 hospitalizations for RSV each year

**NCFIH** National Coalition for Infant Health  
Protecting Access for Premature Infants through Age Two

LEARN MORE >

# The Gap Baby: An RSV Story



# Postpartum Revolution

@ANGELINASPICER



Readers can also follow

**NEONATOLOGY TODAY**

via our Twitter Feed

@NEOTODAY

# 99nicu

Readers can also follow  
**NEONATOLOGY TODAY**  
via our Twitter Feed  
**@NEOTODAY**

READ

NPA's statement: **BLACK LIVES MATTER**



MedEd On The Go® presents  
3 Accredited Education Programs in Short-Form Video Format  
Available for CME/CNE Credits

## The Role of Nutrition & Exclusive Human Milk for Very Low Birth Weight Infants



Preventing  
Bronchopulmonary  
Dysplasia

1.75 credit hours

WATCH NOW



[www.MedEdOTG.com/video/program/599](http://www.MedEdOTG.com/video/program/599)

Preventing  
Neonatal  
Sepsis

0.5 credit hours

WATCH NOW



[www.MedEdOTG.com/video/program/609](http://www.MedEdOTG.com/video/program/609)

Preventing  
Retinopathy  
of Prematurity

1.0 credit hour

WATCH NOW



[www.MedEdOTG.com/video/program/608](http://www.MedEdOTG.com/video/program/608)



**Stephen E. Welty, MD**

Clinical Professor of Pediatrics  
University of Washington  
School of Medicine  
Seattle, WA



**Dan L. Stewart, MD**

Professor of Pediatrics & International Pediatrics  
University of Louisville School of Medicine  
Co-Director of NICU & ECMO  
Norton Children's Hospital  
Louisville, KY



**Jonathan R. Swanson, MD, MSc**

Associate Professor of Pediatrics  
University of Virginia  
Children's Hospital  
Charlottesville, VA

# FCC TASKFORCE

# NEWSLETTER

Malathi Balasundaram, MD

## FCC Core Team

### Co-Chairs

Malathi Balasundaram, MD  
Colby Day, MD  
Keira Sorrells

### Program Manager

Caroline Toney-Noland, MSc



Want to strengthen  
FCC in your NICU?  
Click this [link](#) or scan  
the QR code to join  
the FCC Taskforce

## Newsletter Committee

### Chair

Vargabi Ghei, MD, MSHS

### Members

Robert White, MD  
Malathi Balasundaram, MD  
Colby Day, MD  
Daphna Barbeau, MD  
Caroline Toney-Noland, MSc  
Keira Sorrells

### Graphic Design

Kavya Wazhi

## Mission Statement

The Family Centered Care (FCC) Taskforce aims to educate, create guidelines, and facilitate unit-based interventions related to FCC in the Neonatal Intensive Care Unit.

## New Website!

Be sure to visit our new website, [fcctaskforce.org](http://fcctaskforce.org), to view all past and upcoming webinars as well as shared resources.



Follow us on twitter: [@FCCTaskforce](https://twitter.com/FCCTaskforce)

Contact us:  
[familycenteredcaretaskforce@gmail.com](mailto:familycenteredcaretaskforce@gmail.com)

## In this Issue

- Gravens Conference: Lessons Learned
- Webinar Review
- Recommendations of the Quarter

# PARENT INSIGHTS

---

We were able to support seven small group leaders (SGL) to attend the Gravens Conference to build momentum and facilitate shared learning among FCC Taskforce small groups. The Gravens Conference offers a unique opportunity to connect with other family-centered initiatives around the world and hear how both community organizations and hospitals are improving the NICU environment. Below are thoughts from our SGLs on their takeaways and lessons learned from the conference:

- “Give parents a voice and make it be heard!”
- “Give **agency** to parents in their child’s care.”
- “Providing the highest level of care is helping parents **connect emotionally** with their babies; **bonding is brain-building.**”
- “Babies don’t need anything more than they need their parents.”
- “If parent is at bedside, infant shouldn’t be in bed.”
- “Ensure parental **mental and emotional resources** are being provided and supported.”
- “Facilitate understanding and empathy from caregivers to parents who are **showing up to play the most difficult role in the hospital** and showing up while experiencing immense stress and trauma.”
- “One of the key takeaways was a reaffirmation of the value and importance of family engagement in **decision-making processes** in the NICU. Involving families in the decision-making process has a positive impact on the well-being of the babies, their families, and on staff and the culture of care delivery in the NICU.”
- “Another significant lesson was the importance of **ongoing education and training for healthcare providers** in the NICU. Continuous education and training help healthcare providers engage with families and incorporate their perspectives into innovative, family-centered care plans. There is also a need for ongoing quality improvement initiatives in the NICU with a focus on involving families in the process to ensure that their needs and experiences are **taken into consideration.**”

---

# PARENT INSIGHTS

---

- “Family Centered Care is not optional or a 'nice thing to do'. It is not too difficult or time consuming. Family Centered Care is about **being human to another human**- it is relating to a family who is suffering and rallying around them to **mitigate that suffering.**” -Keira Sorrells, Founder and Executive Director of NICU Parent Network
- “THIS ISN'T SCIENCE FOR US, THIS IS **LOVE!**” -Kimberly Novod Founder and Executive Director of Saul's Light
- “WE AREN'T SHOWING UP TO WORK. **WE'RE SHOWING UP TO TRAUMA!**” -Mia Malcolm PharmD, mother of 24 weeker
- The people with the most difficult job in the NICU, are the parents.”  
-Michelle Wrench, CPQCC Family Advisory Council Chair
- “The only person who outranks everyone else on the team, is the baby.”  
-Eric Rideout MD Neonatologist, Intermountain Healthcare St. George UT



*Above: Some of the FCC Taskforce Executive Council Family Partners at the Gravens Conference; Right: Dr. Malathi Balasundaram presenting about the Taskforce*



---

# WEBINAR REVIEW

---

In our March 2023 FCC Taskforce Webinar, Dr. Vincent Smith and Kristin Love reviewed the inception of the most recent National Perinatal Association Discharge Guidelines and Dr. Malathi Balasundaram spoke about a quality improvement project at El Camino Health that sought to increase family satisfaction with discharge planning. **The recording and slides are available [here](#)**; thanks for Dr. Vargarbi Ghei for reviewing the content.

## Discharge Guidelines

Dr. Smith reviewed the evolution of the discharge guidelines, describing the efforts of various experts and organizations that worked over the course of years to go through several drafts of the guidelines to ensure they include the most up to date evidence. The final guidelines aim to maximize discharge readiness for caregivers. The process of achieving this goal is outlined in the guideline and includes: recommendations for tailoring discharge education, improving the discharge summary, conducting a family and home and needs assessment and most importantly successfully executing the transition and coordination of care. Notably, for many families, Dr. Smith noted this is an area of weakness. To improve transition of care, NICU teams should aim to ensure that NICU families have a medical home after discharge. This would include contact with primary care providers as the infant nears discharge, contacting the family after discharge, assessing parental mental health, and providing community resources as appropriate. Here at [NICU to Home](#), companion website to the guidelines, units can find free resources to help with discharge planning.



---

# WEBINAR REVIEW

---

## **Increasing Parent Satisfaction with Discharge Planning ([article](#))**

The main goal of the project was to increase discharge related patient satisfaction scores on the Press-Ganey survey from 47 to 70%. The main interventions included creating an e-book with standardized discharge educational content and a corresponding paper discharge teaching checklist completed by nurses. The e-book was later incorporated into the electronic health record (MyChart) allowing parents to check-off items on the Discharge Education Checklist. Ultimately, the Discharge Education Checklist was integrated into the EHR to be started upon admission. Lastly, the group started making follow-up phone calls to families after discharge to assess families' views of the discharge preparation process. The interventions proved impactful as the unit was successful in improving the patient satisfaction with discharge preparation from 47 to 70%. Dr. Balasundaram's work at El Camino NICU shows how starting the discharge process early (at admission) and leveraging technology as a discharge tool can help families feel more prepared for discharge.



## ***Recommendations of the Quarter:***

Looking for a NICU Family Leader for your FCC council? Reach out to those who don't look like you to ensure the full breadth of your NICU population is represented. And don't forget about full term NICU families! Aim for a variety of lived experiences.

Have you tried incorporating nature into your units? This can be achieved through windows and natural light, bringing nature indoors, or even including images of nature in your decor. Nature brings a calming effect to healing spaces.

When families leave the NICU, their lifelong journey with a medically fragile/complex child in many ways is just beginning. Intentionally seek out and build relationships with key community partners (beyond the follow-up clinic) that can provide emotional and practical support the families will need for years to come.

Remember, the day an infant passes away is a day few families have planned and none are truly prepared for. It is a day that can not be redone. Does your unit have a comprehensive bereavement program or a community bereavement partner to assist and support families on that day and in the weeks and months that follow?

Connecting with families comes second nature to some and for others, it requires additional training and education. [Myperinatalnetwork.org](http://Myperinatalnetwork.org) has a full menu of online CE courses focused specifically on equipping you to support the psychosocial needs of maternity care and NICU families. You don't have to do this alone, there are resources and people to support YOU too!

Corresponding Author



Malathi Balasundaram, MD  
Clinical Associate Professor  
Stanford School of Medicine  
FCC Committee Chair  
El Camino Hospital  
Mountain View, CA, United States




**Neonatology Grand Round Series**  
Earn accredited CEs while learning about advancements in neonatology!



CENTER FOR RESEARCH, EDUCATION, QUALITY AND SAFETY

**newly validated**

**Caring for Babies and their Families: Providing Psychosocial Support to NICU Parents**  
7- Module Online Course in NICU Staff Education



National Perinatal Association and NICU Parent Network  
mynicunetwork.org

**COVID-19**

**National Network of NICU Psychologists FREE for our NICU COMMUNITY**

- Helping Children and Families Cope
- Bonding with Your Baby
- Caregivers Need Care Too



Download at [www.nationalperinatal.org/psychologists](http://www.nationalperinatal.org/psychologists)

**The National Urea Cycle Disorders Foundation**



The NUCDF is a non-profit organization dedicated to the identification, treatment and cure of urea cycle disorders. NUCDF is a nationally-recognized resource of information and education for families and healthcare professionals.

[www.nucdf.org](http://www.nucdf.org) | Phone: (626) 578-0833

# Practical Data Analytics for Innovation in Medicine:

Building Real Predictive and Prescriptive Models in Personalized Healthcare and Medical Research Using AI, ML, and Related Technologies

**Second Edition**

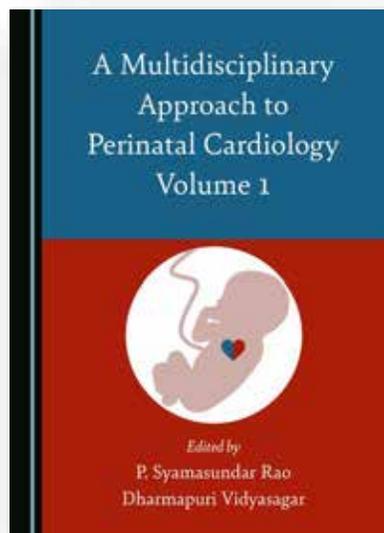
**Gary D. Miner, Linda A. Miner,  
Scott Burk, Mitchell Goldstein,  
Robert Nisbet, Nephi Walton,  
Thomas Hill**



# A Multidisciplinary Approach to Perinatal Cardiology

## Volume 1

*Edited by P. Syamasundar Rao and Dharmapuri Vidyasagar*



### Hardback

#### ISBN-13:

978-1-5275-6722-1

#### ISBN-10:

1-5275-6722-2

#### Date of Publication:

24/04/2021

#### Pages / Size:

794 / A5

#### Price:

£99.99

---

## Book Description

Recent developments in diagnostic and therapeutic aspects of cardiac and neonatal issues have advanced the care of the newborn. To achieve excellence in cardiac care, however, close interaction and collaboration of the pediatric cardiologists with neonatologists, pediatricians, general/family practitioners (who care for children), anesthesiologists, cardiac surgeons, pediatric cardiac intensivists, and other subspecialty pediatricians is mandatory. This book provides the reader with up-to-date evidence-based information in three major areas of neonatology and prenatal and neonatal cardiology. First, it provides an overview of advances in the disciplines of neonatology, prenatal and neonatal cardiology, and neonatal cardiac surgery in making early diagnosis and offering treatment options. Secondly, it presents a multidisciplinary approach to managing infants with congenital heart defects. Finally, it provides evidence-based therapeutic approaches to successfully treat the fetus and the newborn with important neonatal issues and congenital cardiac lesions. This first volume specifically explores issues related to perinatal circulation, the fetus, ethics, changes in oxygen saturations at birth, and pulse oximetry screening, diagnosis, and management.

---

## About the Editors

**Dr P. Syamasundar Rao**, MD, DCH, FAAP, FACC, FSCAI, is Professor of Pediatrics and Medicine and Emeritus Chief of Pediatric Cardiology at the University of Texas-Houston Medical School. He received his medical degree from Andhra Medical College, India, and subsequently received post-graduate training both in India and the USA before joining the faculty at the Medical College of Georgia, USA, in 1972. He has also served as Chairman of Pediatrics at King Faisal Specialist Hospital and Research Center, Saudi Arabia, and Professor and Director of the Division of Pediatric Cardiology at the University of Wisconsin and St. Louis University, USA. He has authored 400 papers, 16 books and 150 book chapters, and is a recipient of numerous honors and awards.

**Dr Dharmapuri Vidyasagar**, MD, MSc, FAAP, FCCM, PhD (Hon), is currently Professor Emeritus in Pediatrics at the University of Illinois, Chicago, where he served as Professor of Pediatrics for four decades. He is a graduate of Osmania Medical College, India. He has published over 250 papers and authored several books with a focus on prematurity, neonatal pulmonary diseases and neonatal ventilation. His goal is to reduce neonatal mortality in the USA and around the world, and he has received multiple awards and honors including the Ellis Island Award.

---

*A Multidisciplinary Approach to Perinatal Cardiology Volume 1* is available now in Hardback from the Cambridge Scholars [website](#), where you can also access a free [30-page sample](#).



# Online L&D Staff Education Program

**Caring for Pregnant Patients & Their Families:**  
Providing Psychosocial Support During  
Pregnancy, Labor and Delivery

[WWW.MYPERINATALNETWORK.ORG](http://WWW.MYPERINATALNETWORK.ORG)



Continuing education credits provided by



# About the Program

- **WHO SHOULD TAKE THE PROGRAM?** This program is designed for both office and hospital staff in all disciplines that interact with pregnant patients and their families. A key focus is recognizing risk factors for perinatal mood and anxiety disorders, and mitigating their impact through provision of trauma-informed care.
- **WHY TAKE THE PROGRAM?** Families will benefit when staff have improved skills, through enhanced parental resilience and better mental health, and improved parent-baby bonding leading to better developmental outcomes for babies. Benefits to staff include improved skills in communicating with patients; improved teamwork, engagement and staff morale; reduced burnout, and reduced staff turnover.
- **HOW DOES THE PROGRAM ACHIEVE ITS GOALS?** Program content is representative of best practices, engaging and story-driven, resource-rich, and developed by a unique interprofessional collaboration of obstetric and neonatal professionals and patients. The program presents practical tips and an abundance of clinical information that together provide solutions to the emotional needs of expectant and new parents.
- **HOW WAS THE PROGRAM DEVELOPED?** This program was developed through collaboration among three organizations: a multidisciplinary group of professionals from the National Perinatal Association and Patient + Family Care, and parents from the NICU Parent Network. The six courses represent the different stages of pregnancy (antepartum, intrapartum, postpartum), as well as perinatal mood and anxiety disorders, communication techniques, and staff support.

## Program Objectives

- Describe principles of trauma-informed care as standards underlying all communication during provision of maternity care in both inpatient and outpatient settings.
- Identify risk factors, signs, and symptoms of perinatal mood and anxiety disorders; describe treatment options.
- Define ways to support pregnant patients with high-risk conditions during the antepartum period.
- Describe obstetric violence, including ways that providers may contribute to a patient's experience of maternity care as being traumatic; equally describe ways providers can mitigate obstetric trauma.
- Describe the importance of providing psychosocial support to women and their families in times of pregnancy loss and fetal and infant death.
- Define the Fourth Trimester, and identify the key areas for providing psychosocial support to women during the postpartum period.
- Identify signs and symptoms of burnout as well as their ill effects, and describe both individual and systemic methods for reducing burnout in maternity care staff.

Continuing education credits will be provided for physicians, clinic and bedside nurses, social workers, psychologists, and licensed marriage and family therapists. CEUs will be provided by Perinatal Advisory Council: Leadership, Advocacy, and Consultation.

# PROGRAM CONTENT



## COMMUNICATION SKILLS CEUs offered: 1

Learn principles of trauma-informed care, use of universal precautions, how to support LGBTQ patients, obtaining informed consent, engaging in joint decision-making, delivering bad news, dealing with challenging patients.

Faculty: Amina White, MD, MA, Clinical Associate Professor, Department of OB/Gyn, University of North Carolina, Chapel Hill, NC; Sue Hall, MD, MSW, FAAP, St. John's Regional Medical Center, Oxnard, CA; Karen Saxer, CNM, MSN, University of North Carolina Maternal-Fetal Medicine, UNC Women's Hospital, Chapel Hill, NC; Tracy Pella, Co-Founder & President, Connected Forever, Tecumseh, NE.



## PERINATAL MOOD AND ANXIETY DISORDERS CEUs offered: 1

Identify risk factors for and differential diagnosis of PMADs (perinatal mood and anxiety disorders), particularly perinatal depression and/or anxiety and posttraumatic stress syndrome. Learn the adverse effects of maternal depression on infant and child development, and the importance of screening for and treating PMADs.

Faculty: Linda Baker, PsyD, psychologist at Unstuck Therapy, LLC, Denver, CO; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Angela Davids, Founder of Keep 'Em Cookin', Baltimore, MD; Brittany Boet, Founder of Bryce's NICU Project, San Antonio, TX.



## PROVIDING ANTEPARTUM SUPPORT CEUs offered: 1

Identify psychosocial challenges facing high risk OB patients, and define how to provide support for them, whether they are inpatient or outpatient. Recognize when palliative care is a reasonable option to present to pregnant patients and their families.

Faculty: Amina White, MD, MA, Clinical Associate Professor, Department of OB/Gyn, University of North Carolina, Chapel Hill, NC; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Angela Davids, Founder of Keep 'Em Cookin', Baltimore, MD; Erin Thatcher, BA, Founder and Executive Director of The PPRM Foundation, Denver, CO.



## PROVIDING INTRAPARTUM SUPPORT CEUs offered: 1

Describe how to manage patient expectations for labor and delivery including pain management; identify examples of obstetric violence, including identification of provider factors that may increase patients' experience of trauma; learn how to mitigate patients' trauma, and how to provide support during the process of labor and delivery.

Faculty: Sara Detlefs, MD, Fellow in Maternal-Fetal Medicine, Baylor College of Medicine, Houston, TX; Jerry Ballas, MD, MPH, Associate Clinical Professor, UCSD Health System, Maternal-Fetal Medicine, Department of Obstetrics, Gynecology and Reproductive Sciences, University of California at San Diego, San Diego, CA; MaryLou Martin, MSN, RNC-NIC, CKC, Women's and Children's Services Nurse Educator, McLeod Regional Medical Center, McLeod, SC; Claire Hartman, RN, IBCLC, Labor & Delivery, University of North Carolina Hospital, Chapel Hill, NC; Crystal Duffy, Author of Twin To Twin (from High Risk Pregnancy to Happy Family), and NICU Parent Advisor, Houston, TX; Erin Thatcher, Founder and Executive Director of The PPRM Foundation, Denver, CO.



## PROVIDING POSTPARTUM SUPPORT CEUs offered: 1

Define the 4th Trimester and the importance of follow-up especially for high risk and minority patients, learn to recognize risk factors for traumatic birth experience and how to discuss patients' experiences postpartum; describe the application of trauma-informed care during this period, including support for patients who are breastfeeding and those whose babies don't get to go home with them.

Faculty: Amanda Brown, CNM, University of North Carolina Hospital, Chapel Hill, NC; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Crystal Duffy, Author of Twin To Twin (from High Risk Pregnancy to Happy Family), and NICU Parent Advisor, Houston, TX.



## SUPPORTING STAFF AS THEY SUPPORT FAMILIES CEUs offered: 1

Define burnout and compassion fatigue; identify the risks of secondary traumatic stress syndrome to obstetric staff; describe adverse impacts of bullying among staff; identify the importance of both work-life balance and staff support.

Faculty: Cheryl Milford, EdS, Consulting NICU and Developmental Psychologist, Director of Development, National Perinatal Association, Huntington Beach, CA; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Erin Thatcher, BA, Founder and Executive Director, The PPRM Foundation, Denver, CO

---

## Cost

- RNs: \$10/CEU; \$60 for the full program
- Physicians, licensed clinical social workers (LCSWs), licensed marriage and family therapists (LMFTs): \$35/CEU; \$210 for the full program
- Although PACLAC cannot award CEs for certified nurse midwives, they can submit certificates to their own professional organization to request credit. \$35/CEU; \$210 for the full program

Contact [help@myperinatalnetwork.org](mailto:help@myperinatalnetwork.org) to learn more.

# Faculty

**Linda Baker, PsyD**

Psychologist at Unstuck Therapy, LLC, Denver, CO.

**Jerasimos (Jerry) Ballas, MD, MPH**

Associate Clinical Professor, UCSD Health System, Maternal-Fetal Medicine, Department of Obstetrics, Gynecology and Reproductive Sciences, University of California at San Diego, San Diego, CA.

**Amanda Brown, CNM, MSN, MPH**

University of North Carolina-Chapel Hill Hospitals, Chapel Hill, NC.

**Sara Detlefs, MD**

Fellow in Maternal-Fetal Medicine, Baylor College of Medicine, Houston, TX.

**Sue L. Hall, MD, MSW, FAAP**

Neonatologist, Ventura, CA.

**Claire Hartman, RN, IBCLC**

Labor & Delivery, University of North Carolina Hospital, Chapel Hill, NC.

**MaryLou Martin, MSN, RNC-NIC, CKC**

Women's and Children's Services Nurse Educator, McLeod Regional Medical Center, McLeod, SC.

**Cheryl Milford, EdS.**

Former NICU and Developmental psychologist, in memoriam.

**Karen Saxer, CNM, MSN**

University of North Carolina Maternal-Fetal Medicine, UNC Women's Hospital, Chapel Hill, NC.

**Amina White, MD, MA**

Clinical Associate Professor, Department of Obstetrics and Gynecology, University of North Carolina, Chapel Hill, NC.

**Parent/Patient Contributors:****Brittany Boet**

Founder, Bryce's NICU Project, San Antonio, TX.

**Angela Davids**

Founder, Keep 'Em Cookin', Baltimore, MD.

**Crystal Duffy**

Author of Twin To Twin (from High Risk Pregnancy to Happy Family), and NICU Parent Advisor, Houston, TX.

**Tracy Pella, MA**

Co-Founder and President, Connected Forever, Tecumseh, NE.

**Erin Thatcher, BA**

Founder and Executive Director, The PPROM Foundation, Denver, CO.

## CANCELLATIONS AND REFUNDS

**For Individual Subscribers:**

- If you elect to take only one course, there will be no cancellations or refunds after you have started the course.
- If you elect to take more than one course and pay in advance, there will be no cancellations or refunds after payment has been made unless a written request is sent to [help@myperinatalnetwork.com](mailto:help@myperinatalnetwork.com) and individually approved.

**For Institutional Subscribers:**

- After we are in possession of a signed contract by an authorized agent of the hospital and the program fees have been paid, a 50% refund of the amount paid will be given if we are in receipt of a written request to cancel at least 14 (fourteen) days prior to the scheduled start date for your hospital's online program.
- Refunds will not be given for staff members who neglect to start the program. Also, no refunds for those who start the program, but do not complete all 6 courses within the time frame allotted.

For Physicians: This activity has been planned and implemented in accordance with the Institute for Medical Quality and the California Medical Association's CME Accreditation Standards (IMQ/CMA) through the Joint Provisership of the Perinatal Advisory Council: Leadership, Advocacy and Consultation (PAC/LAC) and the National Perinatal Association. PAC/LAC is accredited by the Institute for Medical Quality/California Medical Association (IMQ/CMA) to provide continuing education for physicians. PAC/LAC takes responsibility for the content, quality and scientific integrity of this CME activity. PAC/LAC designates this activity for a maximum of 6 *AMA PRA Category 1 Credit(s)™*. Physicians should only claim credit commensurate with the extent of their participation in the activity. This credit may also be applied to the *CMA Certification in Continuing Medical Education*.

For Nurses: The Perinatal Advisory Council: Leadership, Advocacy and Consultation (PAC/LAC) is an approved provider by the California Board of Registered Nursing Provider CEP 5862. When taken as a whole, this program is approved for 7 contact hours of continuing education credit.

For CAMFT: Perinatal Advisory Council: Leadership, Advocacy, and Consultation (PAC/LAC) is approved by the California Association of Marriage and Family Therapists to sponsor continuing education for LMFTs and LCSWs. CE Provider #128542. PAC/LAC maintains responsibility for the program and its content. Program meets the qualifications for 6 hours of continuing education credit for LMFTs and LCSWs as required by the California Board of Behavioral Sciences. You can reach us at [help@myperinatalnetwork.org](mailto:help@myperinatalnetwork.org).

Follow us online at [@MyNICUNetwork](https://www.instagram.com/MyNICUNetwork)

[www.myperinatalnetwork.org](http://www.myperinatalnetwork.org) Phone: 805-372-1730



# SHARED DECISION-MAKING PROTECTS MOTHERS + INFANTS

DURING COVID-19

## KEEPING MOTHERS + INFANTS TOGETHER

Means balancing  
the risks of...

- **HORIZONTAL INFECTION**
- **SEPARATION AND TRAUMA**



## EVIDENCE

We encourage families and clinicians to remain diligent in learning **up-to-date** evidence.



## PARTNERSHIP

What is the best  
for this unique dyad?

### SHARED DECISION-MAKING

- S**EEK PARTICIPATION
- H**ELP EXPLORE OPTIONS
- A**SSESS PREFERENCES
- R**EACH A DECISION
- E**VALUATE THE DECISION



## TRAUMA-INFORMED

Both parents and providers  
are confronting significant...

- **FEAR**
- **GRIEF**
- **UNCERTAINTY**

## LONGITUDINAL DATA

We need to understand more about outcomes for mothers  
and infants exposed to COVID-19, with special attention to:

- **MENTAL HEALTH**
- **POSTPARTUM CARE DELIVERY**



NEW DATA EMERGE DAILY. NANN AND NPA ENCOURAGE PERINATAL CARE PROVIDERS TO ENGAGE IN CANDID CONVERSATIONS WITH PREGNANT PARENTS PRIOR TO DELIVERY REGARDING RISKS, BENEFITS, LIMITATIONS, AND REALISTIC EXPECTATIONS.

Partnering for patient-centered care  
when it matters most.

[nann.org](http://nann.org) [nationalperinatal.org](http://nationalperinatal.org)



National  
Association of  
Neonatal  
Nurses



National  
Perinatal  
Association

# Coping with COVID-19



A viral pandemic

A racial pandemic within a viral pandemic



Will mental illness be the next inevitable pandemic?

[WWW.MYNICUNETWORK.ORG](http://WWW.MYNICUNETWORK.ORG)



# Latest Data Show Maternal Mortality Continues to Spike

Josie Cooper

The Alliance for Patient Access, founded in 2006, is a national network of physicians dedicated to ensuring patient access to approved therapies and appropriate clinical care. AfPA accomplishes this mission by recruiting, training and mobilizing policy-minded physicians to be effective advocates for patient access. AfPA is organized as a non-profit 501(c)(4) corporation and headed by an independent board of directors. Its physician leadership is supported by policy advocacy management and public affairs consultants.

In 2012, AfPA established the Institute for Patient Access, a related 501(c)(3) non-profit corporation. The Institute for Patient Access is a physician-led policy research organization dedicated to maintaining the primacy of the physician-patient relationship in the provision of quality health care. In furtherance of its mission, IfPA produces educational materials and programming designed to promote informed discussion about patient access to approved therapies and appropriate clinical care.

Visit [allianceforpatientaccess.org](http://allianceforpatientaccess.org) and [instituteforpatientaccess.org](http://instituteforpatientaccess.org) to learn more about each organization.



## Latest Data Show Maternal Mortality Continues to Spike

Among high-income countries, the United States remains the most [dangerous place](#) for women to become mothers, especially women of color. (1)

***“Among high-income countries, the United States remains the most dangerous place for women to become mothers, especially women of color. (1)”***

This disgraceful distinction was established pre-pandemic, but the [latest data](#) show COVID-19 helped drive an egregious 40% increase in maternal deaths during 2021. (2) Maternal mortality is defined as the death of a woman while pregnant or within 42 days post-pregnancy.

## The Worst Death Rate in Six Decades

The national maternal mortality rate jumped to 32.9 deaths per 100,000 live births in 2021 – up from 23.8 in 2020. That is the highest rate in more than 60 years and a sobering reflection of the vulnerability of pregnant women.

***“The rates among Black women are particularly alarming. Maternal deaths among this cohort occurred 2.6 times the rate of non-Hispanic white women: a startling 69.9 deaths per 100,000 births.”***

The rates among Black women are particularly alarming. Maternal deaths among this cohort occurred 2.6 times the rate of non-Hispanic white women: a startling 69.9 deaths per 100,000 births. Disparities have long plagued the country's health system, but these differences are “of terrifying proportions.”

Across racial and ethnic groups, older women, particularly those over 40, are at increased risk of death. Income, in contrast, is not as consistent of a predictor. A California-based [study](#) found wealthy Black mothers and babies were twice as likely to die as white mothers and babies of comparable financial status. (3)

## Targeted Interventions

Despite the horrible figures, officials report that upward of 80% of pregnancy-related deaths are [preventable](#). (4)

The leading underlying causes were mental health conditions, including deaths from suicide and overdose, excessive bleeding, and cardiac and coronary conditions. Infection, blood clots, and cardiomyopathy, a heart muscle disease, were also high contributors.

***“Overcoming the maternal mortality crisis will require ongoing commitment from all levels of leadership, targeted interventions, and expanded access to care.”***

Overcoming the maternal mortality crisis will require ongoing commitment from all levels of leadership, targeted interventions, and expanded access to care.

## A Bounce Back?

Even though [preliminary data](#) from 2022 show maternal mortality rates might be trending down toward pre-pandemic levels, those rates were terrible, too. (5)

America has much work to do to become a leader instead of a laggard in maternal health care, but it is a struggle the nation cannot afford to lose.

**References:**

1. [Gunja MZ, Gumas ED, Williams RD II. The U.S. Maternal Mortality Crisis Continues to Worsen: An International Comparison \[Internet\]. New York: Commonwealth Fund; 2022 Dec 1 \[cited 2023 Apr 5\]. Available from: <https://www.commonwealthfund.org/blog/2022/us-maternal-mortality-crisis-continues-worsen-international-comparison>](https://www.commonwealthfund.org/blog/2022/us-maternal-mortality-crisis-continues-worsen-international-comparison)
2. [National Center for Health Statistics. Maternal Mortality Rates in the United States, 2021 \[Internet\]. Atlanta \(GA\): Centers for Disease Control and Prevention; \[updated 2021; cited 2023 Apr 5\]. Available from: <https://www.cdc.gov/nchs/data/hestat/maternal-mortality/2021/maternal-mortality-rates-2021.htm>](https://www.cdc.gov/nchs/data/hestat/maternal-mortality/2021/maternal-mortality-rates-2021.htm)
3. [Miller CC, Kliff S, Buchanan L. Childbirth Is Deadlier for Black Families Even When They're Rich, Expansive Study Finds \[Internet\]. New York: The New York Times; 2023 Feb 12 \[cited 2023 Apr 5\]. Available from: <https://www.nytimes.com/interactive/2023/02/12/upshot/child-maternal-mortality-rich-poor.html>](https://www.nytimes.com/interactive/2023/02/12/upshot/child-maternal-mortality-rich-poor.html)
4. [Centers for Disease Control and Prevention. Four in 5 pregnancy-related deaths in the U.S. are preventable \[Internet\]. Atlanta \(GA\): Centers for Disease Control and Prevention; 2022 Sep 19 \[cited 2023 Apr 5\]. Available from: <https://www.cdc.gov/media/releases/2022/p0919-pregnancy-related-deaths.html>](https://www.cdc.gov/media/releases/2022/p0919-pregnancy-related-deaths.html)
5. [Stobbe M. U.S. pregnancy deaths dropped in 2022, after Covid spike \[Internet\]. New York: NBC News; 2023 Mar 16 \[cited 2023 Apr 5\]. Available from: <https://www.nbc-news.com/health/womens-health/us-pregnancy-deaths-dropped-2022-covid-spike-rcna75243>](https://www.nbc-news.com/health/womens-health/us-pregnancy-deaths-dropped-2022-covid-spike-rcna75243)

*Josie Cooper is executive director of the Alliance for Patient Access. This article was also published at [healthpolicytoday.org](https://healthpolicytoday.org).*

**NT**

*Corresponding Author*



*Josie Cooper,  
Executive Director,  
Alliance for Patient Access.  
2020 K Street NW, Suite 505  
Washington, DC 20006  
Email: [jcooper@allianceforpatientaccess.org](mailto:jcooper@allianceforpatientaccess.org)*

**New subscribers are always welcome!**

**NEONATOLOGY TODAY**

**To sign up for a free monthly subscription,  
just click on this box to go directly to our  
subscription page**



**99nicu**

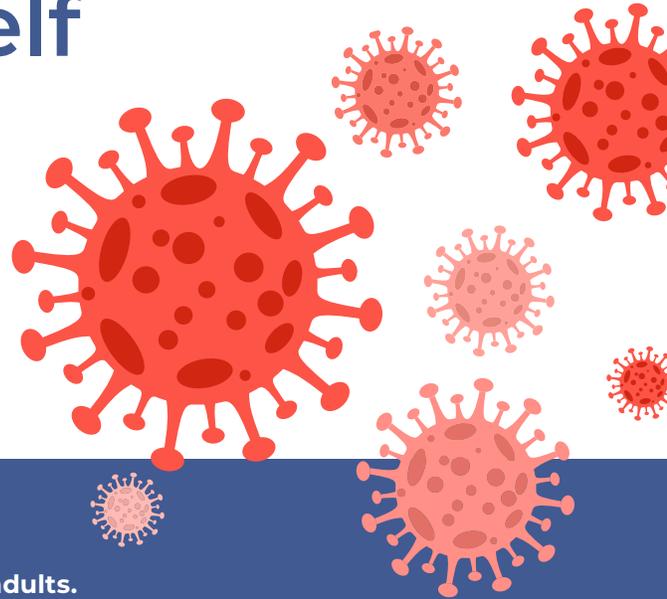
Sign up for free membership at 99nicu, the Internet community for professionals in neonatal medicine. Discussion Forums, Image Library, Virtual NICU, and more..."

[www.99nicu.org](http://www.99nicu.org)

# Immunizing Yourself Against COVID-19

## COVID-19 vaccines have been shown to:

- ✓ Lessen the severity of symptoms<sup>1</sup>
- ✓ Reduce disease transmission<sup>3</sup>
- ✓ Reduce risk of mortality<sup>2</sup>
- ✓ Make communities healthier and safer<sup>4</sup>



## Understanding the Options

COVID-19 vaccines are available for children, adolescents and adults. There are 3 types to choose from.



### mRNA VACCINES

New to market, but research has been ongoing since the 1990s.



### PROTEIN SUBUNIT VACCINES

Used for three decades against the flu, whooping cough and hepatitis B.



### VECTOR VACCINES

Used for decades against chickenpox, malaria and tuberculosis.

#### HOW THEY WORK:

Instruct cells to make COVID-like proteins that trigger the immune system to fight the virus.

Deliver harmless versions of the COVID protein that train the immune system to fight the virus.

Use a modified virus, such as a common cold, to teach the body to fight off COVID.

COVID vaccines are recommended for everyone ages 6 months and older, and boosters for everyone ages 5 years and older, if eligible.<sup>5</sup>



## Safe and Sound

COVID vaccines have been:



### Thoroughly tested

through multi-phase trials with tens of thousands of participants<sup>6</sup>



### Proven safe and effective

for adults as well as children<sup>7</sup>



### Vetted and approved by

the US FDA and EMA and endorsed by the WHO<sup>8-10</sup>

## Get Your Job

Vaccines are available at your:



Doctor's office



Neighborhood pharmacy



Community health center

1. <https://www.mayoclinic.org/diseases-conditions/coronavirus/symptoms-causes/syc-20479963>  
2. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8782520/>  
3. <https://www.nejm.org/doi/full/10.1056/nejmc2107717>  
4. <https://royalsocietypublishing.org/doi/full/10.1098/rsif.2020.0683>  
5. <https://www.cdc.gov/vaccines/covid-19/clinical-considerations/interim-considerations-us.html>  
6. <https://doh.wa.gov/emergencies/covid-19/vaccine-information/safety-and-effectiveness>

7. <https://doh.wa.gov/emergencies/covid-19/vaccine-information/safety-and-effectiveness>  
8. <https://www.fda.gov/emergency-preparedness-and-response/coronavirus-disease-2019-covid-19/covid-19-vaccines>  
9. <https://www.ema.europa.eu/en/human-regulatory/overview/public-health-threats/coronavirus-disease-2019-treatments-vaccines/vaccines-covid-19/covid-19-vaccines-authorised>  
10. [http://www.bccdc.ca/Health-Info-Site/Documents/COVID-19\\_vaccine/WHO-EUA-qualified-covid-vaccines.pdf](http://www.bccdc.ca/Health-Info-Site/Documents/COVID-19_vaccine/WHO-EUA-qualified-covid-vaccines.pdf)



# Save the Date!

## May 25, 2023

26<sup>th</sup> Annual Conference  
Quality of Life for Families XXVI

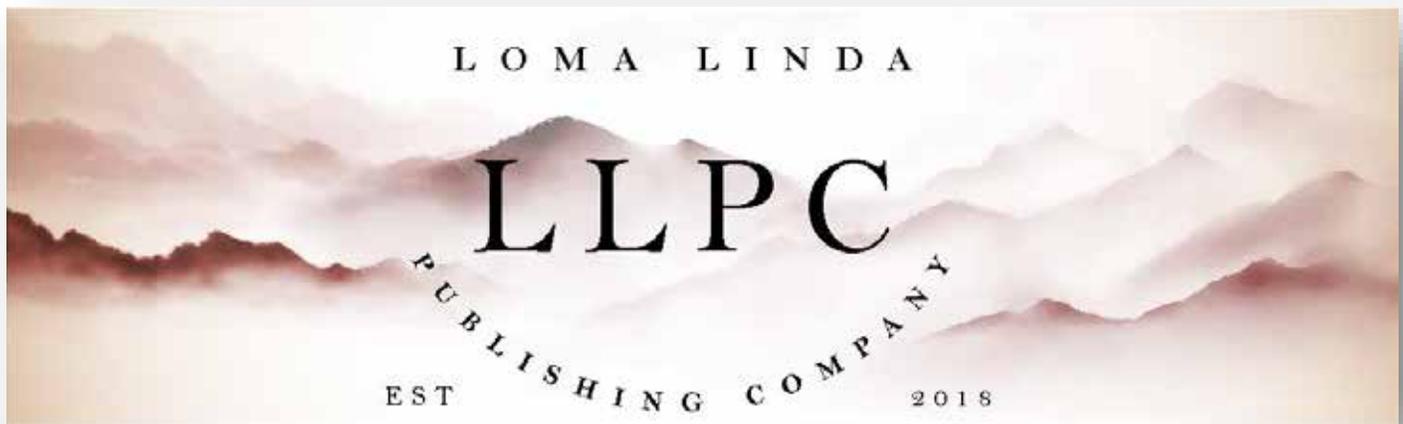


Keynote Speaker: **Dr. Diana Ramos**  
California Surgeon General

Where: [Hilton Los Angeles North/Glendale](#)  
[100 West Glenoaks Blvd,](#)  
[Glendale, CA 91202](#)



You can attend In-Person or Hybrid



The only worldwide monthly publication exclusively serving Pediatric and Adult Cardiologists that focus on Congenital/ Structural Heart Disease (CHD), and Cardiothoracic Surgeons.



**Subscribe Electronically**  
Free on the Home Page

[www.CongenitalCardiologyToday.com](http://www.CongenitalCardiologyToday.com)

# Keeping Your Baby Safe

during the COVID-19 pandemic

## How to protect your little one from germs and viruses

Even though there are some things we don't know about COVID-19 yet, there are many more things that we do know. We know that there are proven protective measures that we can take to stay healthy.

### Here's what you can do...

#### Wash Your Hands

- This is the single, most important thing you can do to stop the spread of viruses.
- Use soap.
- Wash for more than 20 seconds.
- Use alcohol-based sanitizers.



#### Limit Contact with Others

- Stay home when you can.
- Stay 6 feet apart when out.
- Wear a face mask when out.
- Change your clothes when you get home.
- Tell others what you're doing to stay safe.



#### Provide Protective Immunity

- Hold baby skin-to-skin.
- Give them your breast milk.
- Stay current with your family's immunizations.



#### Take Care of Yourself

- Stay connected with your family and friends.
- Sleep when you can.
- Drink more water and eat healthy foods.
- Seek mental health support.



**Immunizations** Vaccinations save lives. Protecting your baby from flu and pertussis lowers their risks for complications from coronavirus.



**WARNING**

#### Never Put a Mask on Your Baby

- Because babies have smaller airways, a mask makes it hard for them to breathe.
- Masks pose a risk of strangulation and suffocation.
- A baby can't remove their mask if they're suffocating.



#### If you are positive for COVID-19

- Wash with soap and water and put on fresh clothes before holding or feeding your baby.
- Wear a mask to help stop the virus from spreading.
- Watch out for symptoms like fever, confusion, or trouble breathing.
- Ask for help caring for your baby and yourself while you recover.



We can help protect each other.

[Learn more](#)

[www.nationalperinatal.org/COVID-19](http://www.nationalperinatal.org/COVID-19)



## The Gap Baby: An RSV Story



A collaborative of professional, clinical, community health, and family support organizations improving the lives of premature infants and their families through education and advocacy.



### The National Coalition for Infant Health advocates for:

- **Access to an exclusive human milk diet** for premature infants
- **Increased emotional support resources** for parents and caregivers suffering from PTSD/PPD
- **Access to RSV preventive treatment** for all premature infants as indicated on the FDA label
- **Clear, science-based nutrition guidelines** for pregnant and breastfeeding mothers
- **Safe, accurate medical devices** and products designed for the special needs of NICU patients

[www.infanthealth.org](http://www.infanthealth.org)

# “Empowering Pediatric Patients Worldwide”

Sabina Schmidt Goldstein-Becerra



**Get involved today and Join the iCAN Parent Council!**

***“iCAN, or the International Children's Advisory Network, is committed to providing numerous opportunities for the pediatric community to come together and hear from the most crucial stakeholders in healthcare: the patients.”***

iCAN, or the International Children's Advisory Network, is committed to providing numerous opportunities for the pediatric community to come together and hear from the most crucial stakeholders in healthcare: the patients. Our organization is dedicated to empowering all pediatric patients worldwide by facilitating their active participation in innovation, research, and medicine. Whether you are a patient, family member, healthcare professional, or supporter of the cause, we welcome you to visit our website at [www.iCAN.health](http://www.iCAN.health) to learn more about our mission, various programs, and initiatives. Join us in the effort to ensure that every child's voice is heard and their unique experiences are taken into account to improve healthcare outcomes for all pediatric patients.

iCAN is a global organization committed to bringing together various organizations and stakeholders to empower pediatric patients worldwide. iCAN is proud to collaborate with several renowned organizations like Pfizer, Jumohealth, labcorp, Pediatric Trials Network, Advances in Therapeutics and Technology,

**SAVE THE DATE!**

**July 10 - 14**

**The iCAN Annual Advocacy and Research Summit, presented by Jumo Health, will take place in San Diego, California.**

Georgia Institute of Technology, Everlylife Foundation for Rare Diseases, and Global Center for Medical Innovation, among others, for our various programs. These partnerships play a vital role in helping us achieve our goal of ensuring that every patient has a voice in medicine, research, and innovation. In addition to these partnerships, iCAN also works closely with the International Society for Pediatric Innovation (iSPI), our sister organization, to make our annual summit possible.

***“One of the primary objectives of this summit is to provide our youth members with a platform to network with some of the leading healthcare professionals and learn from one another's unique experiences as children living with chronic and/or rare diseases.”***

Our upcoming 2023 Summit presented by Jumo Health promises to be an exciting event, and we are still searching for sponsors and donations to help make it even more impactful. One of the primary objectives of this summit is to provide our youth members with a platform to network with some of the leading healthcare professionals and learn from one another's unique experiences as children living with chronic and/or rare diseases. The summit also creates an opportunity for direct interaction between the scientific community and young patients and their families, thereby educating them on the importance and relevance of the pediatric patient's perspective in medicine, research, and innovation.

We have some exciting news to share with you! Our iCAN San Diego Chapter was tasked with designing the official t-shirts for the 2023 Summit. We would like to extend our sincere thank you to all the participants who submitted their designs for the competition. The creativity and quality of the designs we received were creative and exceptional, making it very challenging to select the finalists from such a talented pool of individuals. However, after receiving an overwhelming amount of incredibly unique designs, we are thrilled to announce and showcase the three exceptional finalists:

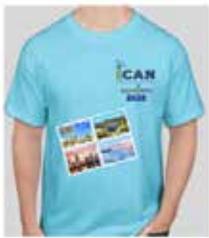


**Help Support a Child  
\$1,000**

**Help Our Youth Share Their Story**

**Did you know that iCAN has a  
Young Adult Professionals Program?**

- Hannah Eghtedari's design (left) comprises bold graphic designs that depict San Diego's landscapes
- Holden Schroeder's design (middle) integrates the skyline of San Diego
- Isaac Hardy's design (right) incorporates a sleek and stylish aesthetic that incorporates the location of the summit, The University of California San Diego



It is with great excitement that we announce the winner of the iCAN San Diego Chapter's official t-shirt design competition for the 2023 Summit!

May we have a drumroll, please?

Our winner is...Holden Schroeder (middle design)!

Congratulations on your outstanding design that brilliantly captures the theme of the 2023 summit with the essence of San Diego. Your captivating design will be featured on the official summit t-shirts that will be worn by all attendees, providing an excellent opportunity to showcase your talent to a global audience. We appreciate all your hard work and dedication, and we simply cannot wait to see your design come to life. Once again, congratulations to Holden, and a special thank you to all those who submitted entries and made this competition a resounding success!

***“Register now to be a part of an unforgettable experience at the 2023 iCAN Summit in San Diego, where you will have the chance to wear Holden’s winning t-shirt design and learn from pediatric patients, caregivers, and pediatric healthcare experts.*”**

So why wait? Register now to be a part of an unforgettable experience at the 2023 iCAN Summit in San Diego, where you will have the chance to wear Holden’s winning t-shirt design and learn from pediatric patients, caregivers, and pediatric healthcare experts. We are so excited to have you join us, and we cannot wait to see you there!

For more information or to register please visit

[www.icanresearch.org/summit](http://www.icanresearch.org/summit)

**Become a sponsor and provide an iCAN youth member with the opportunity to attend the 2023 Summit!**



Chicago KIDS Advisory Board, iCAN Summit 2022, France

Every year, the iCAN Summit draws youth chapter members from all corners of the world, and this is made possible through the sponsorship(s) of iCAN. This year, we aim to uphold this tradition and bring together an even larger group of youth chapter members to participate in this summer event.

Our mission is to provide a platform for young people to share their valuable voices, insights, and perspectives at the iCAN Summit, and to network with leading healthcare professionals. We believe that this experience can inspire, educate, and empower our future leaders in the field of pediatric healthcare.

We invite you to join us in our goal and consider sponsoring a child to attend the 2023 iCAN Summit. Together, we can undoubtedly create a meaningful impact and advance the cause of pediatric healthcare advocacy and innovation.

**Learn How to Support iCAN Youth:**  
<https://www.icanresearch.org/donate>

In observance of Stress Awareness Month, we had the honor of hosting two distinguished speakers, Aaron Blacker and Joshua Wayne, on our Ask the Experts (ATE) segment on April 15th. The focus of their discussion was on the importance of having access to mental health care and the correlation between stress levels and the increasing use of technology.

We host our ATE segment every month, featuring different topics and experts from the field of healthcare, technology, and innovation. Our upcoming session is just around the corner, May 20th at 10:00 AM EST, and we encourage you to register for it by visiting our website at

<https://www.icanresearch.org/events-1/ask-the-experts-may-2023/form>.

We invite all to join us for these informative sessions. To keep up with the latest ATE topics and dates, please follow our Instagram account, @icanresearch.

At iCAN, we believe that it's important to provide a platform for experts to share their knowledge and insights. If you are an expert in pediatric healthcare (innovation, medicine, or technology) and would like to speak at one of our ATE sessions, please reach out to us at [abbyclark@icanresearch.org](mailto:abbyclark@icanresearch.org) for more information.

Don't miss out on the opportunity to learn from and engage with top healthcare experts. Register now for our upcoming ATE session, and we look forward to having you join us!

#### **iCAN at The Pediatric Trials Network (PTN) Meeting:**

In Washington DC, representatives from iCAN had the opportunity to participate in the PTN session, where they were able to delve into a number of different controversies surrounding pediatric clinical trials. The session aimed to provide a platform for researchers, clinicians, and other stakeholders to engage in a rapid-fire debate on critical issues affecting pediatric clinical trials today. Through this meeting, the iCAN representatives were able to gain deep insights into the latest developments in the field, as well as network and connect with other professionals who share a common interest in advancing pediatric healthcare. Overall, iCAN's participation in the PTN session gave an excellent opportunity to stay abreast of current advancements and trends in pediatric research, which can help inform our future advocacy and awareness initiatives as a non-profit organization.

#### **iCAN SPOTLIGHT:**

Rhiannon Perry is an inspirational young adult whose impact on the Pediatric Trial Network (PTN) session in Washington DC was nothing short of remarkable. Perry, who holds the position of "2022 iCAN Young Adult Professional Chair," has a deep interest in the debates surrounding the controversial topics across pediatric medicine, research, and innovation. Her firsthand experiences as a patient and a clinical trial participant has given her a clear understanding of the ongoing challenges faced by patients and subsequently their families. Perry is highly dedicated to advocating for the pediatric patient community and making a significant difference in the pediatric field.

Perry's dedication to advocating for patients and their families is evident in her academic pursuits in the fields of Psychology and Criminology. These areas of study offer insights for healthcare professionals, including a better understanding of child behavior, development, and trauma. Because of this, healthcare providers can provide more effective care and treatment for pediatric patients, taking into account the unique needs of each child and their family. Overall, Perry's academic interests demonstrate her commitment to improving the care and well-being of children and their families in healthcare settings. Moreover, she is currently working as a patient ambassador with Hope For Henry, a patient health advocacy organization, in addition to her academic pursuits. Perry is highly involved in all aspects of iCAN and serves as both a member of the patient advisory council and the young adult professional chair.

During the PTN session, Perry worked with Dr. Rachel Greenberg, an Associate Professor of Pediatrics in the Division of Neonatal-Perinatal Medicine and the Program Director of Duke Neonatal-Perinatal Medicine Fellowship. Dr. Greenberg was very impressed with Perry's contributions to the event- she believed that Perry's participation was crucial to the success of the session. Perry's firsthand experience as a patient and clinical trial participant provided invaluable insights that could help to advance the field of pediatric clinical trials.

Perry's contributions to the PTN session were an inspiration to all other attendees. Her tenacity to advocate for patients and her firsthand experience are a true testament to her passion for bettering the healthcare system, especially in pediatric clinical trials. Perry's impact on the PTN session highlights something very important: involving patients- the recipients themselves- in the decision-making process when it comes to clinical trials. Her voice was important in providing a patient-centered perspective that shapes the future of pediatric clinical trials. Overall, Perry's contributions to the PTN session were vitally important, and her dedication to advocating for pediatric patients will continue to make a significant and positive impact in the field of pediatric medicine.

**Disclosures:** *There are no reported disclosures*

**NT**

*Corresponding Author*



*Sabina Schmidt Goldstein-Becerra*

Website: [www.icanresearch.org](http://www.icanresearch.org)

Phone: (+1) 818-256-7120

Email: [sabina.goldstein@icanresearch.org](mailto:sabina.goldstein@icanresearch.org)

**Readers can also follow**  
**NEONATOLOGY TODAY**  
**via our Twitter Feed**  
**@NEOTODAY**



# 2023 iCAN SUMMIT

to be held July 10-14th in Southern California



Join Us In-Person for 2023  
**Kids - Make Your Summer Count!**

- Travel to California
- Share your expert voice
- Shape the future of clinical research
- Support new pediatric innovation
- Learn about careers in healthcare
  - Engage with global leaders
- Meet friends from around the world
- Make a positive impact in healthcare



[www.iCANResearch.org](http://www.iCANResearch.org)

Registration opens March 1st, 2023

iCAN is not responsible or liable for any and all travel arrangements (including but not limited to flights, trains, cars, transport of any kind, accommodations, meals, reservations or other rental/vacation services acquired) by/for participants for any reason. iCAN is not responsible for any attendee medical needs. iCAN advises attendees to purchase travel insurance for the iCAN Summit.



# SHARED DECISION-MAKING PROTECTS MOTHERS + INFANTS DURING COVID-19

## KEEPING MOTHERS + INFANTS TOGETHER

Means balancing...



## EVIDENCE

We encourage families and clinicians to remain diligent in learning **up-to-date evidence**.

## PARTNERSHIP

SHARED DECISION-MAKING

What is the best for this unique dyad?

- S**EEL PARTICIPATION
- H**ELP EXPLORE OPTIONS
- A**SSESS PREFERENCES
- R**EACH A DECISION
- E**VALUATE THE DECISION



## TRAUMA-INFORMED

Both parents and providers are confronting significant...

- **FEAR**
- **GRIEF**
- **UNCERTAINTY**

## LONGITUDINAL DATA

We need to understand more about outcomes for mothers and infants exposed to COVID-19, with special attention to:

- **MENTAL HEALTH**
- **POSTPARTUM CARE DELIVERY**



NEW DATA EMERGE DAILY. NANN AND NPA ENCOURAGE PERINATAL CARE PROVIDERS TO ENGAGE IN CANDID CONVERSATIONS WITH PREGNANT PARENTS PRIOR TO DELIVERY REGARDING RISKS, BENEFITS, LIMITATIONS, AND REALISTIC EXPECTATIONS.

Partnering for patient-centered care when it matters most.



National Association of Neonatal Nurses

nann.org



nationalperinatal.org

# Your Pregnancy and Substance Use

4 Things you can do to improve your health and lower your risk for complications



## Get Prenatal Care

Start early. Go to all your visits. Empower yourself with information so you can make smart decisions. Build relationships with providers who understand Substance Use Disorders (SUDs) and know how to help. Partner with them to reach your goals. But remember, you do not need to be abstinent from substance use to get care. Go now.

## Reduce Your Use

There are simple things you can do to limit the harm substances might do.

- Use fewer substances
- Use smaller amounts
- Use less often
- Learn how to use safer



Reducing or quitting smoking is a good place to start. Set your goals, then ask for help. One of the best things you can do is to stop using alcohol. We know that even small amounts are risky. And when combined with benzos and opioids, alcohol can kill.

## Use Medications for Opioid Use Disorder (MOUD) if you are opioid dependent

Methadone and Buprenorphine (Subutex® or Suboxone®) are the "Standard of Care" during pregnancy because they:

- Eliminate the risks of illicit use
- Reduce your risk for relapse
- Can be a positive step towards recovery



## Take Good Care of Yourself

You deserve a healthy pregnancy & childbirth.

- Eat healthy and take your prenatal vitamins
- Find the right balance of rest and exercise
- Surround yourself with people who care



## Your Health Matters



Academy of Perinatal Harm Reduction

www.perinatalharmreduction.org



www.nationalperinatal.org

*Education.  
Anytime, Anywhere.*

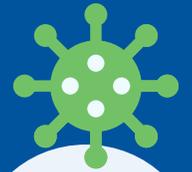
*Academy of Neonatal Care*



**The Academy of Neonatal Care serves to educate Respiratory Therapists, Nurses, and Doctors in current and best practices in Neonatal ICU care. We prepare RT's new to NICU to fully function as a bedside NICU RT. Our goal is to enrich NICU care at all levels. Beginner to Advanced Practice, there is something for you at:**

**[www.AcademyofNeonatalCare.org](http://www.AcademyofNeonatalCare.org)**

# Keeping Your Baby Safe from respiratory infections



RSV  
COVID-19  
colds  
flu

## How to protect your little ones from germs and viruses

This year is an especially dangerous cold and flu season - especially for vulnerable infants and children. Fortunately, there are proven protective measures that we can take to stay healthy.

### Here's what you can do...

#### Wash Your Hands

- This is the single, most important thing you can do to stop the spread of viruses.
- Use soap.
- Wash for more than 20 seconds.
- Use alcohol-based sanitizers.



#### Limit Contact with Others

- Stay home when you can.
- Stay 6 feet apart when out.
- Wear a face mask when out.
- Change your clothes when you get home.
- Tell others what you're doing to stay safe.



#### Provide Protective Immunity

- Hold your baby skin-to-skin.
- Give them your breast milk.
- Stay current with your family's immunizations.



#### Take Care of Yourself

- Stay connected with your family and friends.
- Drink more water and eat healthy foods.
- Seek mental health support.
- Sleep when you can.



#### Get Immunized

Vaccinations save lives. Protecting your baby from COVID-19, flu and pertussis lowers their risks for complications from respiratory infections.



WARNING

#### Never Put a Mask on Your Baby

- Because babies have smaller airways, a mask makes it hard for them to breathe.
- Masks pose a risk of strangulation and suffocation.
- A baby can't remove their mask if they're suffocating.



#### If you feel sick or are positive for COVID-19

- Wash with soap and water and put on fresh clothes before holding or feeding your baby.
- Wear a mask to help stop the virus from spreading.
- Watch out for symptoms like fever, confusion, or trouble breathing.
- Ask for help caring for your baby and yourself while you recover.



We can help protect each other.  
[www.nationalperinatal.org/rsv](http://www.nationalperinatal.org/rsv)



# PROTECT YOUR FAMILY FROM RESPIRATORY VIRUSES

flu coronavirus

pertussis RSV



**WASH YOUR HANDS** often with soap and warm water.

**GET VACCINATED** for flu and pertussis. Ask about protective injections for RSV.



**COVER COUGHS AND SNEEZES.** Sneeze and cough into your elbow.

**USE AN ALCOHOL-BASED HAND SANITIZER.**



**STAY AWAY FROM SICK PEOPLE** Avoid crowds. Protect vulnerable babies and children.

[www.nationalperinatal.org](http://www.nationalperinatal.org)

National Perinatal Association

## FREE RESOURCES FOR YOUR NICU

# Coping During COVID-19



Targeted interventions to improve the mental health of parents, infants, families, and providers

## BONDING WITH YOUR BABY



## HELPING CHILDREN AND FAMILIES COPE

## CAREGIVERS NEED CARE TOO



National Network of NICU Psychologists

[nationalperinatal.org/psychologists](http://nationalperinatal.org/psychologists)

# Respiratory Syncytial Virus:

## How you can advocate for babies this RSV season

Track national data and trends at the CDC's website [www.cdc.gov/rsv](http://www.cdc.gov/rsv)



Identify babies at greatest risk



including those with CLD, BPD, CF, and heart conditions

Teach families how to protect



their babies from respiratory infections

Advocate for insurance coverage for palivizumab prophylaxis so more babies can be protected \*



Use your best clinical judgement



when prescribing RSV prophylaxis

Tell insurers what families need



and provide the supporting evidence



\*See the NPA's evidence-based guidelines at [www.nationalperinatal.org/rsv](http://www.nationalperinatal.org/rsv)

## Survey Says: RSV

RESPIRATORY SYNCYTIAL VIRUS, or RSV, is a dangerous virus that can lead to:

- Hospitalization
- Lifelong health complications
- Death

for infants and young children



ACCORDING TO A NATIONAL SURVEY, Specialty Health Care Providers say:

- 80% They treat RSV as a priority, "often" or "always" evaluating their patients
- 77% RSV is the "most serious and dangerous" illness for children under four
- 77% Barriers to access and denials from insurance companies limit patients' ability to get preventive RSV treatment



But Parents are Unprepared.

- 18% Only 18% know "a lot" about RSV
- 22% Only 22% consider themselves "very well" prepared to prevent RSV



RSV EDUCATION & AWARENESS CAN HELP

After parents learned more about RSV, they were:

- 65% "More concerned" about their child contracting the disease
- 67% Likely to ask their doctor about RSV



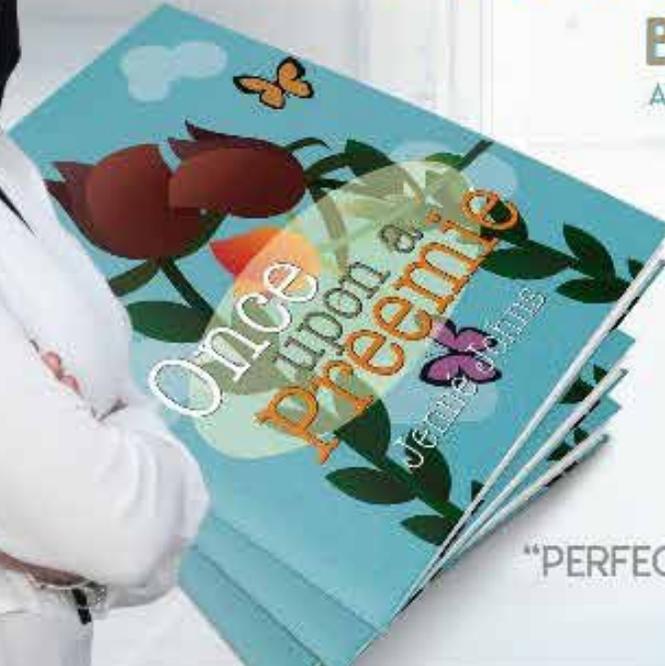
NCJIH National Coalition for Infant Health  
Preventing RSV in Preterm Infants through Age Five

Learn More about RSV at [www.infanthealth.org/rsv](http://www.infanthealth.org/rsv)

# PREEMIE BOOK ON SALE

## ONCE UPON A PREEMIE

BY JENNÉ JOHNS  
AUTHOR | SPEAKER | ADVOCATE



“ONE OF A KIND”  
“PERFECT FOR PREEMIE FAMILIES”  
“ENCOURAGING”

@ONCEUPONAPREEMIE    @ONCEAPREEMIE    EMAIL: HI@ONCEUPONAPREEMIE

ONCE UPON A PREEMIE IS A BEAUTIFUL NEW WAY TO LOOK AT THE LIFE OF A PREEMIE BABY. IT EXPLORES THE PARENT AND CHILD NEONATAL INTENSIVE CARE UNIT (NICU) JOURNEY IN A UNIQUE AND UPLIFTING WAY.

### SPEAKING ENGAGEMENTS

- PREEMIE PARENT ALLIANCE SUMMIT
- NATIONAL ASSOCIATION OF PERINATAL SOCIAL WORKERS
- CONGRESSIONAL BLACK CAUCUS ANNUAL LEGISLATIVE CONFERENCE
- NATIONAL MEDICAL ASSOCIATION ANNUAL CONFERENCE
- HUDSON VALLEY PERINATAL PUBLIC HEALTH CONFERENCE
- MATERNITY CARE COALITION ADVOCACY DAY

### MEDIA APPEARANCES



AVAILABLE FOR \$12.99 ON AMAZON OR ONCEUPONAPREEMIE.COM

# Still a Premie?

Some preemies are born months early, at extremely low birthweights. They fight for each breath and face nearly insurmountable health obstacles.

But that's not every preemie's story.

## Born between 34 and 36 weeks' gestation?

**STILL A PREMIE**

Just like preemies born much earlier, these "late preterm" infants can face:



And their parents, like all parents of preemies, are at risk for postpartum depression and PTSD.



## Born preterm at a "normal" weight?

**STILL A PREMIE**

Though these babies look healthy, they can still have complications and require NICU care.

But because some health plans determine coverage based on a preemie's weight, families of babies that weigh more may face access barriers and unmanageable medical bills.

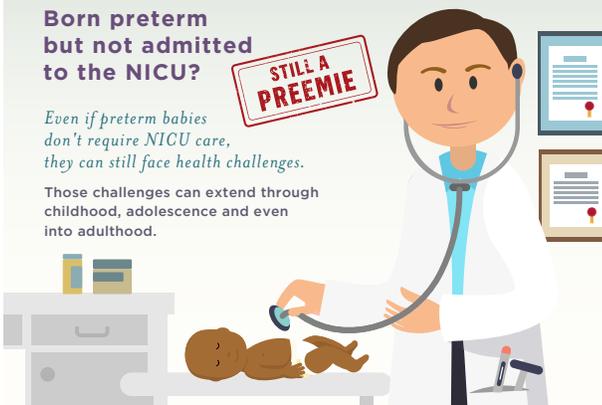


## Born preterm but not admitted to the NICU?

**STILL A PREMIE**

Even if preterm babies don't require NICU care, they can still face health challenges.

Those challenges can extend through childhood, adolescence and even into adulthood.



### Some Premies

- Will spend weeks in the hospital
- Will have lifelong health problems
- Are disadvantaged from birth

### All Premies

- Face health risks
- Deserve appropriate health coverage
- Need access to proper health care

**NCJFH** National Coalition for Infant Health  
Protecting Access for Premature Infants through Age Two  
[www.infanthealth.org](http://www.infanthealth.org)

## OPIOIDS and NAS

When reporting on mothers, babies, and substance use

# LANGUAGE MATTERS



### I am not an addict.

I was exposed to substances in utero. I am not addicted. Addiction is a set of behaviors associated with having a Substance Use Disorder (SUD).



### I was exposed to opioids.

While I was in the womb my mother and I shared a blood supply. I was exposed to the medications and substances she used. I may have become physiologically dependent on some of those substances.



### NAS is a temporary and treatable condition.

There are evidence-based pharmacological and non-pharmacological treatments for Neonatal Abstinence Syndrome.



### My mother may have a SUD.

She might be receiving Medication-Assisted Treatment (MAT). My NAS may be a side effect of her appropriate medical care. It is not evidence of abuse or mistreatment.

### My potential is limitless.

I am so much more than my NAS diagnosis. My drug exposure will not determine my long-term outcomes. But how you treat me will. When you invest in my family's health and wellbeing by supporting Medicaid and Early Childhood Education you can expect that I will do as well as any of my peers!



Learn more about Neonatal Abstinence Syndrome at [www.nationalperinatal.org](http://www.nationalperinatal.org)





# Nurses: parents trust you.

You can help reduce the risk of Sudden Infant Death Syndrome (SIDS), the leading cause of death among infants between 1 month and 1 year of age. Take our **free continuing education (CE) activity** to stay up to date on the latest safe infant sleep recommendations. Approved for 1.5 contact hours.

Learn more about the free online activity at <https://nichd.nih.gov/SafeSleepCE>.

The CE activity explains safe infant sleep recommendations from the American Academy of Pediatrics and is approved by the Maryland Nurses Association, an accredited approver of the American Nurses Credentialing Center's Commission on Accreditation.



Eunice Kennedy Shriver National Institute  
of Child Health and Human Development



Compiled and Reviewed by Saba Saleem, BS, OMS 4

## Children's Hospital of Philadelphia, Princeton Researchers Identify Novel Genetic Disorder

NEWS PROVIDED BY

[Children's Hospital of Philadelphia](#)

April 26, 2023

Researchers from Children's Hospital of Philadelphia (CHOP) and Princeton University have discovered a novel genetic disorder associated with neurodevelopmental differences. The discovery identified the disorder in 21 families from all over the world. The findings were published today in *Science Advances*.

The as-yet unnamed disorder is the result of a series of rare variants in the MAP4K4 gene, which is involved in many signaling pathways, including the RAS pathway that normal cell growth, and is being investigated as a druggable target for multiple disorders.

The researchers had documented several patients with craniofacial and neurodevelopmental issues that indicated a then-unknown genetic cause. They put out an international call for patients who seemed to fit these specific criteria. Ultimately, they were able to identify patients from 36 countries to determine whether there was a genetic variant linking them to their clinical issues.

"We were able to connect with patients from all over the world who had overlapping symptoms, and eventually we were able to pinpoint the overlapping genes that helped us identify the variants causing these issues," said co-senior author Elizabeth Bhoj, MD, PhD, an attending physician in the Division of Human Genetics at CHOP.

At CHOP, research scientist Dong Li, PhD, identified variants that had not been linked to a particular disorder in families in which multiple patients exhibited the same symptoms. Once those variants of interest had been identified, researchers created a zebrafish model to confirm that these variants were indeed responsible for the symptoms among these patients.

"The zebrafish is an excellent model for testing identified variants



for their potential pathogenicity," said co-senior author Rebecca Burdine, PhD, a professor of molecular biology at Princeton University. "Given the accessible early development of the zebrafish, we were able to assess MAP4K4 variants quantitatively and rapidly in a living embryo. The approach is a powerful one we plan to continue to use to assess variants of unknown function for potential disease genes."

The researchers showed that decreasing activity of MAP4K4 causes developmental defects in zebrafish, which is what is observed in these patients. Additionally, MAP4K4 activity can restrain signaling in the RAS pathway during embryonic stages, which is why these symptoms were being observed in children. However, overactive RAS activity can lead to cancer, which is why any therapeutic interventions targeting MAP4K4 need to be finely tuned to strike a balance between treating one disorder while also making sure not to increase the risk of cancer.

Since this is a newly discovered genetic variant that causes disease in certain patients, researchers would like to know if it is implicated in more general disease.

"With a new discovery like this, it's possible we may have missed how these variants influence other diseases," Bhoj said.

This study was supported by the National Institute of Child and Human Development grants K23HD088742 and R01HD105868, the National Center for Advancing Translational Sciences grant R21TR002770, the National Institute of Mental Health grant R01MH106826, the National Institutes of Health grants R01HD055651-11 and U01HG006487-05, and a Duke/UNC CTSA Consortium Collaborative Translational Research Grant DUR41703-UL1TR002553.

Patterson et al, "Abrogation of MAP4K4 protein function causes congenital anomalies in humans and zebrafish." *Sci Adv*. Online April 26, 2023. DOI: 10.1126/sciadv.ade0631.

Contact: Ben Leach, The Children's Hospital of Philadelphia, 267-426-2857 or leachb@email.chop.edu

SOURCE CHOP NEWS

## The National Urea Cycle Disorders Foundation



The NUCDF is a non-profit organization dedicated to the identification, treatment and cure of urea cycle disorders. NUCDF is a nationally-recognized resource of information and education for families and healthcare professionals.

[www.nucdf.org](http://www.nucdf.org) | Phone: (626) 578-0833

## Eat, Sleep, Console Approach or Usual Care for Neonatal Opioid Withdrawal

NEWS PROVIDED BY

[New England Journal of Medicine](#)

April 30, 2023

Leslie W. Young, M.D., Songthip T. Ounpraseuth, Ph.D., Stephanie L. Merhar, M.D., Zhuopei Hu, M.S., Alan E. Simon, M.D., Andrew A. Bremer, M.D., Ph.D., Jeannette Y. Lee, Ph.D., Abhik Das, Ph.D., Margaret M. Crawford, B.S., Rachel G. Greenberg, M.D., P.Brian Smith, M.D., Brenda B. Poindexter, M.D., et al.

ABSTRACT

BACKGROUND

Although clinicians have traditionally used the Finnegan Neonatal Abstinence Scoring Tool to assess the severity of neonatal opioid withdrawal, a newer function-based approach — the Eat, Sleep, Console care approach — is increasing in use. Whether the new approach can safely reduce the time until infants are medically ready for discharge when it is applied broadly across diverse sites is unknown.

METHODS

In this cluster-randomized, controlled trial at 26 U.S. hospitals, we enrolled infants with neonatal opioid withdrawal syndrome who had been born at 36 weeks' gestation or more. At a randomly assigned time, hospitals transitioned from usual care that used the Finnegan tool to the Eat, Sleep, Console approach. During a 3-month transition period, staff members at each hospital were trained to use the new approach. The primary outcome was the time from birth until medical readiness for discharge as defined by the trial. Composite safety outcomes that were assessed during the first 3 months of postnatal age included in-hospital safety, unscheduled health care visits, and nonaccidental trauma or death.

RESULTS

A total of 1305 infants were enrolled. In an intention-to-treat analysis that included 837 infants who met the trial definition for medical readiness for discharge, the number of days from birth until readiness for hospital discharge was 8.2 in the Eat, Sleep, Console group and 14.9 in the usual-care group (adjusted mean difference, 6.7 days; 95% confidence interval [CI], 4.7 to 8.8), for a rate ratio of 0.55 (95% CI, 0.46 to 0.65;  $P < 0.001$ ). The incidence of adverse outcomes was similar in the two groups.

CONCLUSIONS

As compared with usual care, use of the Eat, Sleep, Console care approach significantly decreased the number of days until infants with neonatal opioid withdrawal syndrome were medically ready for discharge, without increasing specified adverse outcomes.

SOURCE NEJM

NT

Supporting NICU Staff so they can support families



Providing online education that is...

- Story-Driven
- Trauma-Informed
- Evidence-Based

 National  
Perinatal  
Association

 NPN  
NICU PARENT NETWORK

The preeminent provider of compelling perinatal education on psychosocial support created through interprofessional collaboration

[www.mynicunetwork.org](http://www.mynicunetwork.org)

---

# Association of Hospital Adoption of Probiotics With Outcomes Among Neonates With Very Low Birth Weight

---

NEWS PROVIDED BY

[JAMA Pediatrics](#)

May 12, 2023

Leila Agha, PhD; Douglas Staiger, PhD; Christopher Brown, BA; et al

## KEY POINTS

**Question** Did probiotic use change in US neonatal intensive care units (NICUs) between 2012 and 2019, and is use of probiotics associated with improved health outcomes in neonates with very low birth weight (VLBW)?

**Findings** In this cohort study of 307 905 neonates with VLBW in 807 NICUs from 2012 to 2019, 17% of NICUs had adopted routine use of probiotics by 2019. Incidence of necrotizing enterocolitis declined by 18% at adopting NICUs vs nonadopting NICUs, and probiotic adoption was not associated with significant changes in mortality or sepsis.

**Meaning** In this study, probiotic use increased in US NICUs, and probiotic use was associated with a decline in necrotizing enterocolitis but not with sepsis or mortality rates.

## ABSTRACT

**Importance** For neonates with very low birth weight (VLBW), randomized clinical trials (RCTs) indicate that probiotic treatment decreases the risk of necrotizing enterocolitis (NEC), with smaller decreases in the risk of sepsis and death. There is little evidence on the rate of probiotic adoption in US neonatal intensive care units (NICUs) and whether the benefits seen in trials have materialized in practice.

**Objective** To estimate changes in probiotic

use among neonates with VLBW and to test whether neonates with VLBW treated at NICUs adopting routine probiotic use experience better outcomes compared with neonates treated at nonadopting NICUs.

**Design, Setting, and Participants** This cohort study used Vermont Oxford Network data on neonates with VLBW in US NICUs from January 1, 2012, to December 31, 2019. Data were analyzed from January 2022 through February 2023.

**Exposure** Probiotics adoption vs non-adoption. Adopting NICUs were defined as those that currently or previously treated at least 20% of neonates with VLBW with probiotics.

**Main Outcomes** The primary outcomes were rates of NEC, in-hospital mortality, and sepsis, defined as bacterial or fungal infection occurring after day 3 from birth. A difference-in-differences analysis compared changes in VLBW infant outcomes between adopting and nonadopting NICUs before and after hospital-level adoption of probiotics. Additional analyses used the proportion of neonates treated with probiotics in each neonate's birth NICU and year.

**Results** The analysis included 307 905 neonates with VLBW (mean [SD] gestational age, 28.4 [2.9] weeks; 50.0% male) at 807 US hospitals. The rate of probiotic treatment of neonates with VLBW rose from 1572 of 38 296 neonates (4.1%) in 2012 to 4788 of 37 910 (12.6%) in 2019. Only 123 of 745 NICUs (16.5%) adopted probiotics by 2019, with 4591 of 6017 neonates with VLBW (76.3%) receiving probiotics in 2019 at adopting NICUs. Incidence of NEC declined by 18% at adopting NICUs (odds ratio [OR], 0.82; 95% CI, 0.70-0.95; P=.10) compared with nonadopting NICUs. Probiotic adoption was not associated with a significant reduction in sepsis (OR, 1.11; 95% CI, 0.98-1.25; P=.09) or mortality (OR, 0.93; 95% CI, 0.80-1.08; P=.33).

**Conclusion and Relevance** In this cohort study, adoption of routine use of probiotics increased slowly in US NICUs and was associated with lower NEC risk but not with sepsis or mortality among neonates with VLBW. The findings for probiotic adoption and NEC, sepsis, and mortality were smaller than would have been predicted by the totality of RCT evidence but are consistent with a meta-analysis restricted to

studies at low risk of bias.

SOURCE JAMA PEDIATRICS

NT

---

# FDA advisers agree maternal RSV vaccine protects infants, but are divided on its safety

---

Some have concerns about premature births after vaccination against respiratory syncytial virus

News Provided By

[Science](#)

May 19, 2023

By Meredith Wadman

A committee of advisers to the U.S. Food and Drug Administration (FDA) yesterday voted unanimously that a vaccine from Pfizer, given as an injection during pregnancy, is efficacious at protecting infants from severe respiratory syncytial virus (RSV) disease during the first 6 months of life. If approved by the agency, the vaccine would be a major advance against a disease that is the leading cause of hospitalization of U.S. infants. But troubled by side effect data from Pfizer's trials and by another big drugmaker's abandonment of a similar vaccine given during pregnancy, the panel split on the question of the vaccine's safety, with multiple members concerned that it may increase the rate of premature births.

GlaxoSmithKline (GSK) last year stopped a late-stage clinical trial of its RSV vaccine in pregnant people over an elevated risk of premature birth and associated neonatal deaths in the babies

**NEONATOLOGY TODAY** is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)

born prematurely. In the GSK trial, premature birth was 38% more likely in the vaccinated pregnancies than in the placebo group. And there were hints of excess premature births as well in Pfizer's data presented to the panel yesterday. The FDA advisers expressed frustration that the company's final phase 3 trial wasn't large enough to know whether the increased rate in the vaccinated group compared with the placebo group—5.7% versus 4.7%—was a real effect as the difference wasn't statically significant.

FDA will need to consider the split vote in deciding whether to license the vaccine, called RSVpreF and which the company has branded Abrysvo for use in pregnant people. The agency's decision is due in August.

RSV is the leading cause of lower respiratory tract infections in babies worldwide, killing an estimated 13,000 infants younger than 7 months old every year in hospitals globally. It takes a major toll in preschoolers' early years as well, killing an estimated 101,000 children before they reach age 5. In the United States, it hospitalizes 2% to 3% of infants annually, mostly between 0 and 5 months of age. Hundreds don't survive. The virus also spurs about 500,000 emergency department visits in the U.S. annually.

Given this toll, the clear protection offered by Pfizer's vaccine was enthusiastically welcomed by the advisory committee. "This is good news for kids and moms everywhere in the [U.S.]," said David Kim, a physician with the U.S. Department of Health and Human Services.

But the premature birth concern loomed large over the meeting, as babies born before the standard 37 weeks of gestation are also at significantly higher risk of death and disability, from both RSV and generally, which could counter any benefits of the vaccine.

Pfizer's late-stage clinical trial enrolled more than 7300 pregnant people in 18 countries and documented 201 premature deaths in the vaccinated group versus 169 in the placebo group.

Those data were enough to sway four of 14 panelists to vote no on the question of whether Pfizer's data were adequate to say that the vaccine is safe. "Patterns don't lie. And there is a pattern here," said Hana El Sahly, a vaccinologist at Baylor College of Medicine who chairs the Vaccines and Related Biological Products Advisory Committee (VRBPAC) that voted yesterday and was among the four dissenters on safety. She noted that in Pfizer's smaller, phase 2B trial, there was also a higher rate of premature births in the vaccinated people than in those who received placebo.

Others on the committee said the benefit offered by the vaccine outweighed their concerns about risk. "Over 90% of these children are going to get RSV and I have seen the harm that that does," said Jay Portnoy, a professor of pediatrics at Children's Mercy Hospital in Kansas City, Missouri, who voted yes on safety. "If I compare the very small risk of earlier birth with the almost certain risk of getting RSV and a very high risk of ending up in the hospital, I have to, on balance, say the risk is much greater if we don't give the vaccine than if we do."

The Pfizer vaccine contains labmade versions of an RSV surface protein, F, that fuses with host cells, enabling the virus to invade them. Pfizer took the vaccine forward after foundational work by scientists at the U.S. National Institutes of Health who developed a method to lock the shape-shifting protein in its pre-fusion conformation, which elicits a vigorous immune response.

The big clinical trial that supported Pfizer's application, the results of which were published in *The New England Journal of Medicine* last month, tested the vaccine in 3682 people between 24 weeks and 36 weeks of pregnancy. Another 3676 people at the same stages of pregnancy received a placebo. The vaccine is meant to produce F-blocking antibodies in the adult, who would pass them, via the placenta, to the fetus during the later stages of pregnancy. Protective maternal antibodies acquired this way persist in the baby during its initial months of

life before its immune system is mature enough to produce its own protective antibodies.

The vaccine was 69.4% efficacious in protecting the young infants through 6 months of age against severe lower respiratory tract infections. For infants up through 3 months old, whose infection rates are highest, the efficacy was 81.8%. The vaccine was also 51.3% efficacious in preventing less severe infections that still required medical care. But because the lower bound of the confidence interval around this figure fell below FDA's required 20%, it didn't meet the agency's efficacy standard for preventing less severe disease.

Those data nonetheless "suggest that there was meaningful clinical efficacy out to 6 months," William Gruber, Pfizer's senior vice president of clinical research and development for vaccines, told the committee.

The safety question, however, occupied much of the meeting. Yugenia Hong-Nguyen, an FDA medical officer who presented to the committee, said the rate of premature births in the vaccine group, although 1% higher than the placebo group, was "not statistically significant and lower than background incidence rates in the general population." In the U.S. population at large, about 10% of women deliver prematurely.

But Paul Offit, a vaccinologist at the Children's Hospital of Philadelphia and member of VRBPAC, cited GSK's halting the pregnancy trial of its vaccine because of premature births as cause for concern. "[The GSK] vaccine was almost identical to this vaccine," Offit said. That GSK halted its vaccine plans over premature births "is going to hang over this program. It [needs] to be addressed."

FDA officials would not comment on the GSK program at a meeting devoted to the Pfizer vaccine. Gruber argued that the two shots were not identical, differing, for instance, in the means used to lock the protein in its pre-fusion conformation and in the substances they were





Perinatal Advisory Council:  
Leadership, Advocacy and Consultation

## CONTINUING MEDICAL EDUCATION

The Continuing Education Department at PAC/LAC is pleased to consider requests to be a joint provider of your CME activity. PAC/LAC is actively involved in direct and joint-providership of multiple continuing education activities and programs and works with our partners to ensure the highest standards of content and design. PAC/LAC is the recipient of the 2018 Cultural & Linguistic Competency Award. This award recognizes a CME provider that exemplifies the goal of integrating cultural and linguistic competency into overall program and individual activities and/or a physician who provides leadership, mentorship, vision, and commitment to reducing health care disparities

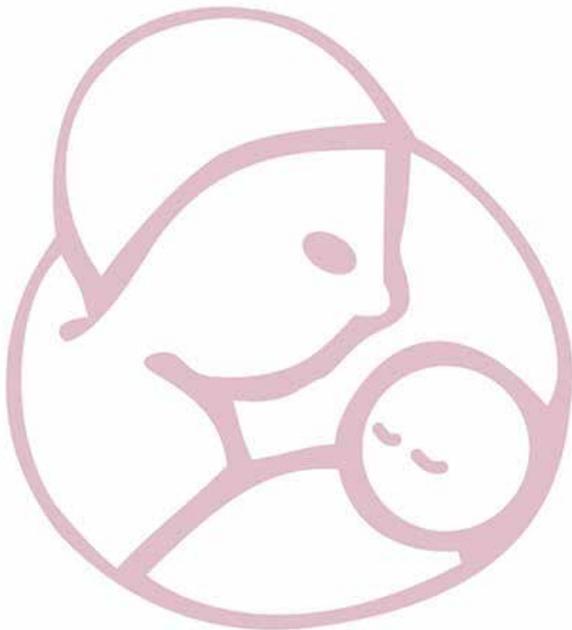
PAC/LAC is an accredited provider of continuing education by Accreditation Council for Continuing Medical Education / Institute for Medical Quality, the California Board of Registered Nursing, the California Association of Marriage and Family Therapists, the National Commission for Health Education Credentialing, and the American Association for Respiratory Care.

To inquire about Continuing Education Joint-Providership opportunities for your event please visit our website and complete the online request form.

PAC/LAC offers continuing education for:

- Continuing Medical Education (CME)
- California Registered Nurses (CEU)
- Licensed Clinical Social Workers (LCSW)
- Licensed Marriage and Family Therapists (LMFT)
- Licensed Professional Clinical Counselors (LPCC)
- Licensed Educational Psychologists (LEP)
- Certified Health Education Specialists (CHES)
- Continuing Respiratory Care Education (CRCE)

[www.paclac.org](http://www.paclac.org)



**PAC/LAC's core values** for improving maternal and child health have remained constant for over 30 years – a promise to lead, advocate and consult with others.

### **Leadership**

Providing guidance to healthcare professionals, hospitals and healthcare systems, stimulating higher levels of excellence and improving outcomes for mothers and babies.

### **Advocacy**

Providing a voice for healthcare professionals and healthcare systems to improve public policy and state legislation on issues that impact the maternal, child and adolescent population.

### **Consultation**

Providing and promoting dialogue among healthcare professionals with the expectation of shared excellence in the systems that care for women and children.

**NEONATOLOGY TODAY** is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)

mixed with for administration. He also stressed that the prematurity differential stemmed almost completely from participants in South Africa, where the prematurity rate was 8.3% in vaccine recipients and 4% in placebo recipients. The difference was not present in data from the U.S. or other high-income countries. Pfizer also stressed that most of the pre-term births everywhere occurred after 33 weeks of pregnancy.

Offit, who voted no on the vaccine safety question, was skeptical that the differences in the GSK and Pfizer vaccines were enough to put them in separate categories when it comes to the risk of premature births. "I was not reassured" by either FDA or the company's responses, he commented before the advisers began voting. "[GSK] abandoned that program and those decisions are never made lightly."

Key to keeping the vaccine on the market if FDA licenses it will be a follow-up safety study Pfizer plans to run—and which FDA said it expects Pfizer to conduct. Sarah MacDonald, a Pfizer epidemiologist who is leading the planned postmarketing study, said the company will use multiple commercial insurance claims databases and data from Medicaid to follow safety endpoints, including the percentages of premature births, babies born with low birth weight, and babies otherwise born small for their gestational age.

That didn't mollify some committee members, including Holly Janes, a biostatistician at the Fred Hutchinson Cancer Center. "I'm highly concerned about the ability to tease this out with postmarketing surveillance data given the mul-

iple different databases that need to be linked both for the mother and for the infant," said Janes, who also voted no on the safety question.

Other committee members were concerned because a study of Pfizer's RSV vaccine in nonpregnant people showed that the shot, when administered at the same time as the tetanus, diphtheria, and pertussis vaccine, reduced Tdap's potency against pertussis, or whooping cough. Tdap is routinely given later in pregnancy to lower the risk of pertussis in very young babies. But others on the committee argued that potential problem would primarily be a logistical one, and that physicians would develop schedules to administer the two vaccines at different times during prenatal visits.

Yoko Allen, a senior program manager and policy analyst with the nonprofit Black Women's Health Imperative who spoke during the public comment session of the meeting, noted that disease and death from RSV disproportionately affect Black infants in the U.S., as they account for 26% of infant RSV deaths. (Black babies have accounted for just 15% of U.S. births in recent years.) Her group, which advocates for the health and wellness of Black women and girls, would like to see clinical trial recruitment rates "that reflect the rate of infant RSV mortality," Allen said. In the current trial, only 10% of the U.S. participants were Black whereas 83% were white. Trials reflecting the populations most impacted "would help increase future treatment study participation and support from Black and brown community stakeholders," she said.

Both the Pfizer and GSK vaccines have also been tested in clinical trials of older adults, who are vulnerable to severe RSV disease. The GSK vaccine was licensed by FDA earlier this month for adults 60 and older; an approval for the Pfizer vaccine in older adults is expected before the end of this month.

Currently, treatment for RSV infection

is supportive only, except for high-risk infants who qualify to receive monthly injections of a monoclonal antibody, palivizumab. Another such antibody, nirsevimab, may be approved by FDA later this year. It is a single, long-acting injection for which AstraZeneca is seeking approval for use in all infants.

SOURCE SCIENCE

NT

---

## 'Step-Down' Approach to Baby Formula Shows Benefit for Milk Allergy

---

After 1 year with extensively hydrolyzed formula, 48% of babies developed immune tolerance

News Provided By

[MedPage Today](#)

April 26, 2023

By Elizabeth Short

Switching infants with IgE-mediated cow's milk allergy (CMA) from an amino acid-based baby formula to an extensively hydrolyzed casein (EHCF) product supplemented with a probiotic was feasible and led to higher rates of immune tolerance acquisition, a small randomized trial from Italy showed.

In the single-center, double-blind study of 59 infants without CMA symptoms after at least 4 weeks on an amino acid-based formula, the 1-year rate of immune tolerance acquisition to cow's milk proteins was 48% (95% CI 29-67) for kids switched to EHCF plus *Lactobacillus rhamnosus* GG (LGG), as compared with 3% (95% CI 0.1-17) for those kept on their original formula, reported Roberto Berni Canani, MD, PhD, of the University of Naples in Italy, and col-

New subscribers are always welcome!

NEONATOLOGY TODAY

To sign up for a free monthly subscription, just click on this box to go directly to our subscription page



CONGENITAL  
CARDIOLOGY  
TODAY

The only worldwide monthly publication exclusively serving Pediatric and Adult Cardiologists that focus on Congenital/Structural Heart Disease (CHD), and Cardiothoracic Surgeons.



Subscribe Electronically  
Free on the Home Page

[www.CongenitalCardiologyToday.com](http://www.CongenitalCardiologyToday.com)

leagues.

Body growth patterns during the 1-year study were similar regardless of the baby formula used, the researchers detailed in *Allergy*.

While amino acid-based formula can be the first-line strategy in severe CMA cases, "when a full resolution of symptoms is achieved, the step-down approach with EHCF+LGG could promote faster acquisition of immune tolerance," Berni Canani's group concluded.

Amino acid-based formula "is considered the safest dietary strategy for severe CMA children, but it is also the most expensive," they noted. Furthermore, "preclinical and clinical data suggest that this formula is unable to promote tolerogenic effects, substantially due to the absence of peptides," while prior evidence has suggested that EHCF+LGG "could promote the acquisition of immune tolerance."

The results of the SDACMA (Step-Down Approach for Cow's Milk Allergy) study confirm that "EHCF+LGG has a greater potential in reducing disease duration" compared with an amino acid-based formula, Berni Canani and coauthors wrote. "These data are relevant considering the most recent evidence suggesting that the

natural history of CMA has changed over time, with slower rates of resolution and a higher proportion of children with disease persisting into school age and older."

CMA is one of the most common forms of food allergy, with one recent study opens in a new tab or window estimating that nearly 5% of the U.S. population have the allergy. Babies unable to receive breast milk must receive specialized formulas -- often EHCF as a first-line approach, or an amino acid-based formula for severe forms of CMA or in those with multiple food allergies -- leading to high costs for families if the disease persists.

Strict exclusion criteria were used in the SDACMA trial, and infants with multiple food allergies, eosinophilic gastrointestinal disorders, and CMA-induced anaphylaxis could not enroll. During a double-blind placebo-controlled food challenge, 98% (95% CI 91-99) showed tolerance to the hydrolyzed formula on their first exposure, a far higher rate than in past series, the researchers noted, perhaps due to the trial design among other factors.

Fifteen adverse events, none serious, were recorded during the study (acute gastroenteritis, respiratory infections, and febrile illness/viral infections), though none

were classified as related to the formulas.

A total of 60 infants under 6 months old with CMA were included in the study, which was conducted at a single center in Italy from 2018 to 2020. All kids (about 5 months old on average, 56% boys, two-thirds with a familial risk for allergies) were on a cow's milk protein elimination diet and had been on an amino acid-based formula for at least 4 weeks prior to the start of the trial.

Following skin-prick tests, they were randomized 1:1 to either stay on the amino acid-based formula (n=30) or switch to EHCF+LGG (Nutramigen LGG; n=29). Nursing staff, the researchers, and families of the patient were blinded to which formula was provided.

While all the infants had positive skin-prick test results for raw milk, 58% were positive for casein, 71% for beta-lactoglobulin, and 81% were positive for alpha-lactalbumin. At the time of allergy onset, 71% of infants were experiencing gastrointestinal symptoms, 73% had cutaneous symptoms, and 12% had respiratory symptoms.

For the double-blind placebo-controlled food challenge, patients were given seven doses of formula -- either EHCF+LGG or the amino acid-based formula they were



Do you know  
enough about  
**PMADs**  
Perinatal Mood and  
Anxiety Disorders  
to make a  
difference?

Join  NPA

[nationalperinatal.org/mental\\_health](http://nationalperinatal.org/mental_health)

already on as placebo. Doses started at 3 mg and increased up to 3,000 mg at intervals of 20 minutes, and patients were observed for 2 hours after the last dose for reactions.

If infants showed no symptoms in the first full day, parents were advised to administer a single dose of formula every day at home for 7 days and instructed to introduce no new foods. "In addition, an emergency treatment plan and prescriptions for emergency medications were provided to the parents," the researchers noted.

If infants were able to tolerate the 7-day initial testing, they were then randomly assigned to either continue the amino acid-based formula or switch to EHCF+LGG for the full study duration, with follow-up visits conducted at 6 and 12 months.

Limitations to the study include that the findings cannot be generalized to children with non-IgE-mediated CMA or those tolerating baked milk, along with other CMA patients excluded from enrollment.

#### Disclosures

Berni Canani reported relationships with Biocodex, Chr. Hansen, Danone, DBV, Humana, Kraft Heinz, iHealth, Mead Johnson Nutrition, Nestlé, Novalac, and Sanofi. No other disclosures were reported.

#### Primary Source

Nocerino R, et al "The step-down approach in children with cow's milk allergy: results of a randomized controlled trial" *Allergy* 2023; DOI: 10.1111/all.15750.

#### SOURCE MEDPAGE TODAY

**NT**

## Efficacy of a Vibrating Crib Mattress to Reduce Pharmacologic Treatment in Opioid-Exposed Newborns A

## Randomized Clinical Trial

#### NEWS PROVIDED BY

JAMA Pediatrics

May 15, 2023

Elisabeth Bloch-Salisbury, PhD<sup>1,2</sup>; James D. Wilson, PhD<sup>1</sup>; Nicolas Rodriguez, BS<sup>2</sup>; et al

#### KEY POINTS

**Question** Is stochastic vibrotactile stimulation (SVS) via a crib mattress an effective intervention for reducing pharmacologic treatment in newborns with prenatal opioid exposure (POE)?

**Findings** In this randomized clinical trial, analysis of 181 newborns with POE revealed SVS duration was associated with a significantly reduced risk of pharmacologic treatment. Among infants who completed pharmacotherapy within 3 weeks, those receiving SVS completed treatment in 3.18 fewer days and received 1.76 mg/kg less morphine than infants treated as usual.

**Meaning** The findings of this study suggest that SVS may serve as a complementary nonpharmacologic intervention for treating infants with POE; less pharmacotherapy has implications for reduced hospitalization and costs.

#### ABSTRACT

**Importance** Pharmacologic agents are often used to treat newborns with prenatal opioid exposure (POE) despite known adverse effects on neurodevelopment. Alternative nonpharmacological interventions are needed.

**Objective** To examine efficacy of a vibrating crib mattress for treating newborns with POE.

**Design, Setting, and Participants** In this dual-site randomized clinical trial, 208 term newborns with POE, enrolled from March

9, 2017, to March 10, 2020, were studied at their bedside throughout hospitalization.

**Interventions** Half the cohort received treatment as usual (TAU) and half received standard care plus low-level stochastic (random) vibrotactile stimulation (SVS) using a uniquely constructed crib mattress with a 3-hour on-off cycle. Study initiated in the newborn unit where newborns were randomized to TAU or SVS within 48 hours of birth. All infants whose symptoms met clinical criteria for pharmacologic treatment received morphine in the neonatal intensive care unit per standard care.

**Main Outcomes and Measures** The a priori primary outcomes analyzed were pharmacotherapy (administration of morphine treatment [AMT], first-line medication at both study sites [number of infants treated], and cumulative morphine dose) and hospital length of stay. Intention-to-treat analysis was conducted.

**Results** Analyses were performed on 181 newborns who completed hospitalization at the study sites (mean [SD] gestational age, 39.0 [1.2] weeks; mean [SD] birth weight, 3076 [489] g; 100 [55.2%] were female). Of the 181 analyzed infants, 121 (66.9%) were discharged without medication and 60 (33.1%) were transferred to the NICU for morphine treatment (31 [51.7%] TAU and 29 [48.3%] SVS). Treatment rate was not significantly different in the 2 groups: 35.6% (31 of 87 infants who received TAU) and 30.9% (29 of 94 infants who received SVS) ( $P = .60$ ). Adjusting for site, sex, birth weight, opioid exposure, and feed type, infant duration on the vibrating mattress in the newborn unit was associated with reduction in AMT (adjusted odds ratio, 0.88 hours per day; 95% CI, 0.81-0.93 hours per day). This translated to a 50% relative reduction in AMT for infants who received SVS on average 6 hours per day. Among 32 infants transferred to the neonatal intensive care unit for morphine treatment who completed treatment within 3 weeks, those assigned to SVS finished treatment nearly twice as fast (hazard ratio, 1.96; 95% CI, 1.01-3.81), resulting in 3.18 fewer treatment days (95% CI, -0.47 to -0.04

**NEONATOLOGY TODAY** is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)

days) and receiving a mean 1.76 mg/kg less morphine (95% CI, -3.02 to -0.50 mg/kg) than the TAU cohort. No effects of condition were observed among infants treated for more than 3 weeks (n=28).

**Conclusions and Relevance** The findings of this clinical trial suggest that SVS may serve as a complementary nonpharmacologic intervention for newborns with POE. Reducing pharmacotherapy with SVS has implications for reduced hospitalization stays and costs, and possibly improved infant outcomes given the known adverse effects of morphine on neurodevelopment.

SOURCE JAMA PEDIATRICS

NT

---

## FDA Approves New Treatment for Pneumonia Caused by Certain Difficult-to-Treat Bacteria

---

For Immediate Release:

May 23, 2023

Today, the U.S. Food and Drug Administration approved Xacduro (sulbactam for injection; durlobactam for injection), a new treatment for hospital-acquired bacterial pneumonia (HABP) and ventilator-associated bacterial pneumonia (VABP) caused by susceptible strains of bacteria called *Acinetobacter baumannii-calcoaceticus* complex, for patients 18 years of age and older.

According to the World Health Organization, *Acinetobacter* species top the list of critical bacterial pathogens that pose the greatest threat to human health, highlighting the high level of need for additional treatment options amid growing global resistance to antimicrobial medicines.

“The FDA is dedicated to supporting the development of safe and effective treat-

ment options for infections caused by difficult-to-treat bacteria like *Acinetobacter baumannii-calcoaceticus* complex,” said Peter Kim, M.D., M.S., director of the Division of Anti-Infectives in the FDA’s Center for Drug Evaluation and Research. “Today’s approval helps address a high unmet medical need by providing an additional treatment option for some of the sickest patients in our nation’s hospitals.”

*Acinetobacter baumannii-calcoaceticus* complex (henceforth referred to as *A. baumannii*) includes four species of bacteria in the *Acinetobacter* family. These bacteria can cause infections in various parts of the body, occurring most frequently in health-care settings and predominantly causing pneumonia. *A. baumannii* can become highly resistant to multiple antibacterial drugs and current treatment options for drug-resistant *A. baumannii* are limited.

Xacduro consists of sulbactam, a drug structurally related to penicillin, and durlobactam. Sulbactam kills *A. baumannii* whereas durlobactam protects sulbactam from being degraded by enzymes that may be produced by *A. baumannii*. Xacduro is administered by intravenous infusion.

Xacduro’s efficacy was established in a multicenter, active-controlled, open-label (investigator-unblinded, assessor-blinded), non-inferiority clinical trial in 177 hospitalized adults with pneumonia caused by carbapenem-resistant *A. baumannii*. Patients received either Xacduro or colistin (a comparator antibiotic) for up to 14 days. Both treatment arms also received an additional antibiotic, imipenem/cilastatin, as background therapy for potential HABP/VABP pathogens other than *Acinetobacter baumannii-calcoaceticus* complex. The primary measure of efficacy was mortality from all causes within 28 days of treatment in patients with a confirmed infection with carbapenem-resistant *A. baumannii*. Of those who received Xacduro, 19% (12 of 63 patients) died, compared to 32% (20 of 62 patients) who received colistin; this demonstrated that Xacduro was noninferior to colistin.

The most common adverse reaction with Xacduro was liver function test abnormalities. Xacduro comes with certain warnings and precautions, such as hypersensitivity reactions and *Clostridioides*, *difficile*-associated diarrhea.

Patients should not receive Xacduro if they have a history of known severe hypersensitivity to components of Xacduro,

sulbactam or other beta-lactam antibacterial drugs.

The FDA granted Xacduro Fast Track, Qualified Infectious Disease Product and Priority Review designations for this application.

The FDA granted the approval of Xacduro to Entasis Therapeutics.

Related Information

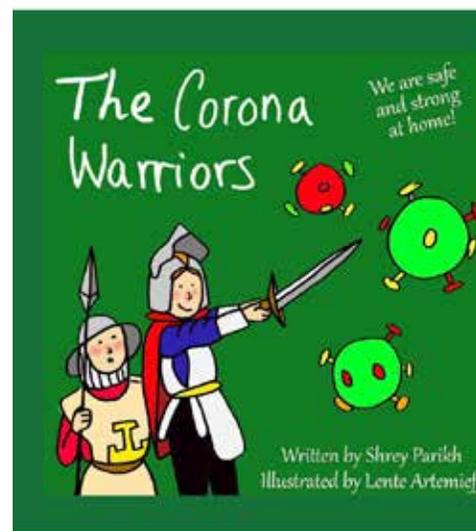
Antimicrobial Resistance Information from FDA

CDC: *Acinetobacter* in Healthcare Settings

###

The FDA, an agency within the U.S. Department of Health and Human Services, protects the public health by assuring the safety, effectiveness, and security of human and veterinary drugs, vaccines and other biological products for human use, and medical devices. The agency also is responsible for the safety and security of our nation’s food supply, cosmetics, dietary supplements, products that give off electronic radiation, and for regulating tobacco products.

NT





“Even in the middle of taking this course, I could see myself changing the way that I spoke to parents. After taking this course, I am much better at emotionally supporting our NICU families.”

COURSE PARTICIPANT

Learn How Now

validated online NICU staff education

[WWW.MYNICUNETWORK.ORG](http://WWW.MYNICUNETWORK.ORG)

My NICU Network  
My Perinatal Network



National Perinatal  
Association



NICU Parent  
Network

**NEONATOLOGY TODAY** is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)



“Even in the middle of taking this course, I could see myself changing the way that I spoke to parents. After taking this course, I am much better at emotionally supporting our NICU families.”

COURSE PARTICIPANT

Learn How Now

validated online NICU staff education

[WWW.MYNICUNETWORK.ORG](http://WWW.MYNICUNETWORK.ORG)

My NICU Network  
My Perinatal Network



National Perinatal  
Association



NICU Parent  
Network

**NEONATOLOGY TODAY** is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)



# 8th World Congress of Pediatric Cardiology and Cardiac Surgery

WASHINGTON D.C.

In 2023, for the first time ever, the World Congress of Pediatric Cardiology and Cardiac Surgery will be held in the continental United States of America. The 2023 WCPCCS promises to be the most comprehensive, up-to-date and technologically advanced meeting ever designed for Pediatric and Congenital Heart Disease.



AUGUST 27 – SEPTEMBER 1, 2023

## SUBSPECIALTY TRACKS

- Cardiac Surgery • Ambulatory Cardiology •
- Cardiac Catheterization • Multimodal Imaging •
- Cardiovascular Nursing • Rheumatic Heart Disease •
- Fetal Cardiology • Adult Congenital Heart Disease •
- Cardiovascular Disease in the Neonate •
- Basic and Translational Science • Neurodevelopment •
- Heart Failure and Transplantation • Echocardiography •
- Administration & Leadership • Cardiac Anesthesia •
- Pulmonary Hypertension • Global Cardiac Health •
- Electrophysiology • Quality Improvement •
- Special Sessions for Trainees and Junior Faculty •
- Big Data, New Technology & Artificial Intelligence •
- Cardiac Intensive Care Advocacy • Cardiopulmonary Bypass, ECMO & Mechanical Circulatory Support •

Please subscribe to our mailing list and visit the website for the latest information on abstract submission, registration, lodging and more details to help you prepare for #WCPCSS2023

Join our mailing list at  
[WCPCCS2023.org](https://www.wcpcss2023.org)

Connect and learn  
#WCPCCS2023



Abstract Submission is Now Open

newly  
validated

## Caring for Babies and their Families: Providing Psychosocial Support to NICU Parents

7- Module Online Course in NICU Staff Education



National Perinatal Association  
and NICU Parent Network  
[myNICUnetwork.org](https://myNICUnetwork.org)

L O M A L I N D A

LLPC

PUBLISHING COMPANY

EST

2018

# Genetics Corner: Noonan Syndrome and Central Conducting Lymphatic Anomaly: Trametinib Treatment for Chronic Chylothorax Following Cardiovascular Surgery

Robin D. Clark, MD

***“A genetics consultation was requested for a 6 1/2-month-old male infant hospitalized for respiratory distress shortly after surgical repair of his perimembranous VSD (Dacron patch repair), supraaortic pulmonic stenosis (Doty patch repair), open pulmonary valvuloplasty, PDA ligation, and primary PFO repair.”***

## Case Summary:

A genetics consultation was requested for a 6 1/2-month-old male infant hospitalized for respiratory distress shortly after surgical repair of his perimembranous VSD (Dacron patch repair), supraaortic pulmonic stenosis (Doty patch repair), open pulmonary valvuloplasty, PDA ligation, and primary PFO repair.

The parents noted the onset of respiratory distress ten days after his cardiac surgery and four days after his hospital discharge. A chest radiograph showed pleural effusions, and an echocardiogram demonstrated a small pericardial effusion. His respiratory distress worsened despite outpatient treatment with Lasix, Aldactone, and propranolol. He was admitted for intravenous diuretics. A chest tube drained chylous fluid. His chylothorax was refractory to left thoracic duct embolization by interventional radiology, performed one month after his cardiac surgery. The Scout lymphangiogram before the procedure demonstrated unremarkable iliac nodal chain, multiple lumbar lymphatic ducts, and cisterna chyli at L1-2 level. The passage of lipiodol continued to the venolymphatic confluence. The thoracic duct was patent and coursed approximately at the L1 level from right to left. The leak was demonstrated at the T 3-4 level. MRI lymphangiogram almost two weeks later showed postprocedural changes after thoracic duct embolization: diversion of lymphatic drainage to prominent right intercostal and perihilar lymphatic vessels with contrast noted in the right pleural fluid. Forty-five days after cardiac surgery, his echo-

cardiogram demonstrated no pericardial effusion, but there was a "double-chambered right ventricle with moderate to severe mid cavity dynamic obstruction,  $\sim V_{max}$  4 m/s [and] right pulmonary artery was moderately hypoplastic."

The baby had gained weight slowly since birth, and his development was delayed; both problems had been attributed to his cardiac anomalies. He was smiling and reaching out for objects but could not roll over at six months of age. His growth parameters and BMI at 7.5 months of age were below the normal range based on WHO data: 4 %ile (Z= -1.79) for length, <1 %ile (Z= -2.55) weight, <1 %ile (Z= -2.64) head circumference, 2 %ile (Z= -2.04) BMI.

The mother had hypothyroidism but denied teratogenic exposures or complications during pregnancy. The baby was born by induced vaginal delivery at a community hospital for suspected large size for gestational age. His birth weight was 6 lbs 13 oz. A cardiac murmur was noted at birth, and an echocardiogram revealed supraaortic pulmonic stenosis with a dysplastic pulmonary valve (4 leaflets), PDA, PFO, and VSD. He went home with his mother, followed by a pediatric cardiologist as an outpatient.

Parents, who are both of Mexican ancestry, denied consanguinity. They have a healthy 6-year-old daughter. The mother is 21 years of age and healthy. The father, age 24, has a history of vasculitis, ascites, Kikuchi syndrome (lymphadenopathy, recurrent ascites), and SLE. He had several lymph nodes removed as a child. He had dyslexia and did poorly in school. No relatives are similarly affected by congenital heart defects.

***“The mother is 21 years of age and healthy. The father, age 24, has a history of vasculitis, ascites, Kikuchi syndrome (lymphadenopathy, recurrent ascites), and SLE. He had several lymph nodes removed as a child. He had dyslexia and did poorly in school. No relatives are similarly affected by congenital heart defects.”***

**NEONATOLOGY TODAY is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.**

**Please submit your manuscript to: [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)**



Figure 1. 7-month-old Infant with Noonan syndrome and chylothorax resembles his father, who has a history of lymphatic problems in childhood.

The physical exam was significant for dysmorphic, somewhat coarse facial features: scalp hair was normal, not curly or coarse, broad square forehead, deep set eyes, down-slanting palpebral fissures, bulbous nasal tip. The neck was not webbed. Palmar creases were not deep. There was mild pedal edema. There was no organomegaly, nor were there any papillomata or other skin lesions. The patient and his father resembled each other. (Figure 1).

Noonan syndrome (NS) was suspected clinically. The diagnosis of NS was confirmed at 7 ½ months of age when a RAS-opathy gene panel revealed a pathogenic variant in PTPN11: (NM\_002834.4), chr12(GRCh37):g.112888165G>A, c.181G>A, p.Asp61Asn (p.D61N). Parental testing was recommended. The parents expressed concern that the father is similarly affected with NS, but they deferred his testing because he has no medical insurance.

Treatment with trametinib (0.025 mg/kg/day by NG), a MEK inhibitor, was initiated two months after his cardiac surgery with the expectation that clinical benefits could be evident within 2-4 weeks. After 15 days of trametinib therapy, the double-chambered right ventricular gradient had improved (peak velocity ~2.6 m/s), but his chest tube output remained high (400 mL/d). After four weeks of trametinib therapy, his right chest tube output was modestly reduced to ~330 mL/day. He remains hospitalized, and his treatment is ongoing.

#### Assessment:

Noonan syndrome (NS; OMIM #163950) is a genetic disorder, usually an autosomal dominant trait, causing a spectrum of cardiac defects (in 50-80%), facial dysmorphism, short stature, and frequent lymphatic derangements. The most common cardiac anomalies in

NS are pulmonic stenosis and hypertrophic cardiomyopathy. The facial features can be subtle but recognized by a broad forehead and down-slanting palpebral fissures. Clotting factors are often abnormal. A webbed neck, which is sometimes present, is evidence of aberrant fetal lymphatic function.

---

***“Noonan syndrome (NS; OMIM #163950) is a genetic disorder, usually an autosomal dominant trait, causing a spectrum of cardiac defects (in 50-80%), facial dysmorphism, short stature, and frequent lymphatic derangements.”***

---

NS is caused by heterozygous pathogenic gain-of-function variants in various genes in the RAS/Mitogen-Activated-Protein (MAP) kinase pathway, of which PTPN11 is the most prevalent (1).

NS is a prototypical RAS-opathy caused by activation of this gene pathway.

Central conducting lymphatic anomaly (CCLA) is caused by disruption of central lymphatic flow that causes leakage or dilation of central lymphatic channels. The most common genetic cause of CCLA is a RAS-opathies, and it also occurs in chromosome disorders, especially Trisomy 21 and 22q11.2 deletion syndrome and Mendelian lymphatic dysplasias. Each produces its distinct lymphatic phenotype (2). The prevalence of lymphatic anomalies in NS throughout the lifetime is 37% (3,4). In this case, the family history of Kikuchi syndrome in the patient's father is intriguing and may be better described as a central conducting lymphatic anomaly. The father may eventually be shown to have NS, as he has a strikingly similar appearance to his son.

---

***“Because cardiovascular surgery stimulates cell division, it would likely further activate the MAP kinase pathway in a child with Noonan syndrome whose disease process has already resulted in activating this pathway. Therefore a child with NS could be expected to have more complications after cardiac surgery than an unaffected child.”***

---

The word Mitogen, which figures in the name of the MAP kinase pathway, is a clue to how this pathway is activated. Mitogens stimulate mitosis or cell division, as do inflammation, ischemia, trauma, and surgery, especially surgery that causes vascular injury. Because

cardiovascular surgery stimulates cell division, it would likely further activate the MAP kinase pathway in a child with Noonan syndrome whose disease process has already resulted in activating this pathway. Therefore a child with NS could be expected to have more complications after cardiac surgery than an unaffected child. Indeed this is the case. NS is associated with a longer hospital stay (by 4.5 days), more significant cost (\$54K), and increased mortality following cardiac surgery. To the point, patients with NS are 90% more likely to experience chylothorax (5).

---

***“If NS were diagnosed in all affected individuals prior to cardiac surgery, complications could be anticipated, and appropriate treatment could be offered without delay.”***

---

Although inhibitors of the RAS/MAP kinase pathway, such as trametinib, have been effectively utilized to treat chylothorax in NS (6-10), there may be a role for prophylactic treatment prior to surgery as more targeted and better-tolerated drugs become available to inhibit this pathway. A necessary first step is a timely diagnosis to achieve the promise of precision medicine and improve outcomes based on the specific nature of the disease. If NS were diagnosed in all affected individuals prior to cardiac surgery, complications could be anticipated, and appropriate treatment could be offered without delay. To that end, I suggest that genetic testing for RAS-opathies in infants with suggestive features of NS, pulmonic stenosis, pulmonary valve dysplasia, or hypertrophic cardiomyopathy would improve outcomes for these patients if performed as a routine test at the time of the cardiac diagnosis and prior to surgery.

#### **Practical applications:**

1. Recognize the typical dysmorphic features and common cardiac anomalies, especially pulmonary valvular dysplasia and/or stenosis and hypertrophic cardiomyopathy associated with Noonan syndrome (NS).
2. Appreciate that lymphatic abnormalities are common in individuals with NS. Consider NS in infants with cardiac anomalies and those with lymphedema, chylothorax, or ascites.
3. Recognize the benefit of establishing the diagnosis of NS early in life, especially before surgery. Incorporate testing for NS with a RAS-opathy gene panel when the clinical features or family history suggests the disorder.
4. Recognize NS as an autosomal dominant trait with variable expression within a family. Examine parents for signs of NS whenever it is suspected in the newborn.
5. Please recognize that the gain-of-function gene variants that cause NS activate the RAS-MAP kinase pathway, as does surgery. This may explain, in part, why infants with NS have more complications and longer hospital stays after surgery. They are also more likely to develop chylothorax after surgery but even without surgery.

- Anticipate common complications in individuals with NS, such as abnormal clotting factors and lymphatic disorders.
- Appreciate that drugs that inhibit the RAS-MAP kinase pathway may be of therapeutic benefit for the cardiac and lymphatic complications associated with Noonan syndrome.
- Dori Y, Smith C, Pinto E, Snyder K, March ME, Hakonarson H, Belasco J. Severe Lymphatic Disorder Resolved With MEK Inhibition in a Patient With Noonan Syndrome and SOS1 Mutation. *Pediatrics*. 2020 Dec;146(6):e20200167. doi: 10.1542/peds.2020-0167. PMID: 33219052.

#### References

- Roberts AE. Noonan Syndrome. 2001 Nov 15 [updated 2022 Feb 17]. In: Adam MP, Mirzaa GM, Pagon RA, Wallace SE, Bean LJH, Gripp KW, Amemiya A, editors. *GeneReviews*® [Internet]. Seattle (WA): University of Washington, Seattle; 1993–2023. PMID: 20301303.
- Liu M, Smith CL, Biko DM, Li D, Pinto E, O'Connor N, Skraban C, Zackai EH, Hakonarson H, Dori Y, Sheppard SE. Genetics etiologies and genotype phenotype correlations in a cohort of individuals with central conducting lymphatic anomaly. *Eur J Hum Genet*. 2022 Sep;30(9):1022-1028. doi: 10.1038/s41431-022-01123-9. Epub 2022 May 24. Erratum in: *Eur J Hum Genet*. 2022 Jun 3;: PMID: 35606495; PMCID: PMC9436962.
- Swarts JW, Kleimeier LER, Leenders EKSM, Rinne T, Klein WM, Draaisma JMT. Lymphatic anomalies during lifetime in patients with Noonan syndrome: Retrospective cohort study. *Am J Med Genet A*. 2022 Nov;188(11):3242-3261. doi: 10.1002/ajmg.a.62955. Epub 2022 Aug 18. PMID: 35979676; PMCID: PMC9804719.
- Sleutjes J, Kleimeier L, Leenders E, Klein W, Draaisma J. Lymphatic Abnormalities in Noonan Syndrome Spectrum Disorders: A Systematic Review. *Mol Syndromol*. 2022 Feb;13(1):1-11. doi: 10.1159/000517605. Epub 2021 Sep 10. PMID: 35221870; PMCID: PMC8832235.
- Kriz C, Flores S, Villarreal EG, Bronicki RA, Loomba RS. Impact of Noonan Syndrome on admissions for pediatric cardiac surgery. *Minerva Pediatr (Torino)*. 2022 Aug;74(4):461-467. doi: 10.23736/S2724-5276.19.05461-6. Epub 2019 Jun 28. PMID: 31264394.
- Gordon K, Moore M, Van Zanten M, Pearce J, Itkin M, Madden B, Ratnam L, Mortimer PS, Nagaraja R, Mansour S. Case Report: Progressive central conducting lymphatic abnormalities in the RASopathies. Two case reports, including successful treatment by MEK inhibition. *Front Genet*. 2022 Sep 27;13:1001105. doi: 10.3389/fgene.2022.1001105. PMID: 36238151; PMCID: PMC9550924.
- Nakano TA, Rankin AW, Annam A, Kulungowski AM, McCallen LM, Hill LR, Chatfield KC. Trametinib for Refractory Chylous Effusions and Systemic Complications in Children with Noonan Syndrome. *J Pediatr*. 2022 Sep;248:81-88.e1. doi: 10.1016/j.jpeds.2022.05.030. Epub 2022 May 20. PMID: 35605646.

**Disclosures:** There are no reported disclosures

**NT**

#### Corresponding Author



Robin Clark, MD  
 Professor, Pediatrics  
 Loma Linda University School of Medicine  
 Division of Genetics  
 Department of Pediatrics  
 Email: [rclark@llu.edu](mailto:rclark@llu.edu)

Readers can also follow

**NEONATOLOGY TODAY**

via our Twitter Feed

**@NEOTODAY**

**Neonatology Grand Round Series**  
 Earn accredited CE while learning about pressing neonatology topics!

**pediatrix**  
 CENTER FOR RESEARCH, EDUCATION, QUALITY AND SAFETY



Did you know that  
**PMAD**  
 related suicides  
 account for

**20%**

of Postpartum  
 Maternal Deaths?

Join  **NPA**

[nationalperinatal.org/mental\\_health](http://nationalperinatal.org/mental_health)

**Support the  
 Open Letter**



**Breastfeeding  
 Innovations  
 Team**

## Why Pregnant and Nursing Women Need Clear Guidance on **THE NET BENEFITS OF EATING FISH**

**2 to 3** servings per  
 week of properly cooked  
 fish can provide health  
 benefits for pregnant  
 women and babies alike:



Iron



Omega 3 fatty acids



Earlier Milestones  
 for Babies



shrimp

salmon

pollock

tilapia

cod

catfish

canned light tuna

But **mixed messages** from the media and regulatory agencies cause pregnant women to sacrifice those benefits by eating less fish than recommended.

**GET THE FACTS  
 ON FISH CONSUMPTION  
 FOR PREGNANT  
 WOMEN, INFANTS,  
 AND NURSING MOMS.**

**NCfIH** National Coalition  
 for Infant Health  
Protecting Access for Premature Infants through Age Two

**LEARN MORE** ▶



# 40th Advances in Neonatal and Pediatric Cardiorespiratory Care

This conference is unique because it focuses on physiology based patient care

*Attend in person or virtually*

**January 31-  
February 2, 2024**

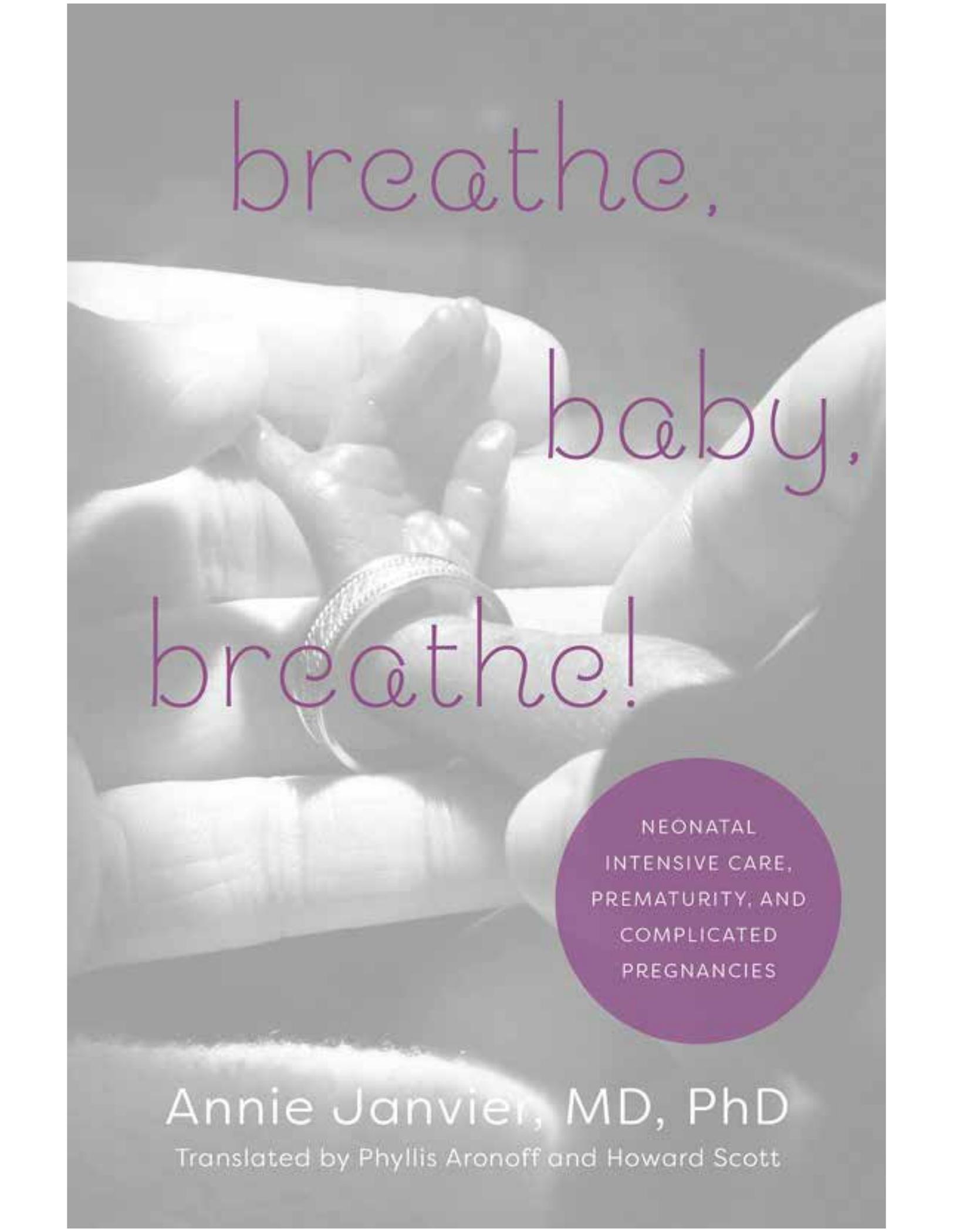
**Location:  
Hilton Hotel  
Glendale, CA**



## Confirmed Guest Speakers

- Frank Ing
- Donald Null
- Colleen Kraft
- Shahab Noori
- Amy B. Hair
- Rangasamy Ram
- Mitch Goldstein
- Kathi Salley Randall
- Valerie Y-L Chock
- Cynthia L. Blanco
- Amy Yeh
- Jennifer Shepard
- Yogen Singh

**Hands-on Practice Sessions for FECHO/LUS/aEEG**



breathe,

baby,

breathe!

NEONATAL  
INTENSIVE CARE,  
PREMATURITY, AND  
COMPLICATED  
PREGNANCIES

Annie Janvier, MD, PhD

Translated by Phyllis Aronoff and Howard Scott

# American Medical Association Survey Finds Nearly One in Three Physicians Have Been Sued During Their Careers

Jonathan M. Fanaroff, MD, JD

Nearly one in three physicians have been sued for medical malpractice throughout their careers, although the risk varies based on several factors, including specialty, gender, and age. This was one of the main findings of a report analyzing data from the American Medical Association (AMA) 2016-2022 Benchmark Survey published earlier this month. The report "Medical Liability Claim Frequency Among U.S. Physicians" was authored by Jose R. Guardado, a senior economist for the AMA. The survey, which looks at many issues besides liability, is a nationally representative sample of clinical physicians (> 20 hours of patient care per week) who have finished their residency. It is important to note that the liability questions focused on whether the physician had been sued, not the lawsuit's outcome, or whether the lawsuit had any merit.

***"The longer a physician has been practicing, the greater the malpractice risk. Approximately half (47%) of physicians age 55 and older had faced at least one lawsuit compared to less than ten percent (9.5%) for younger physicians under age forty."***

Not surprisingly, age has a significant impact on the risk of having ever been sued. The longer a physician has been practicing, the greater the malpractice risk. Approximately half (47%) of physicians age 55 and older had faced at least one lawsuit compared to less than ten percent (9.5%) for younger physicians under age forty. Overall in 2022, 31.2 percent of physicians had been sued during their professional careers. This rate is a decline from 34 percent in 2016, although the impact of the COVID-19 pandemic is unclear.

***"Indeed, 76.2% of OB/GYNs over 55 have been sued, compared to 27.7% of Pediatricians. Neonatologists are, however, at higher risk of being sued than many Pediatricians."***

Women are less likely to have been sued than men. This finding was also reported in the American Academy of Pediatrics (AAP) Periodic Survey of Fellows. Many factors, such as age and choice of specialty, may help explain the gender differential, but even after adjusting for known relevant factors in the AMA survey, women

were 7.2% less likely than men to face a malpractice lawsuit.

Not surprisingly, the greatest contribution to liability risk is the choice of specialty. The specialties with the highest risk of being sued are Obstetrician-Gynecologists (OB/GYN) and General Surgeons. Indeed, 76.2% of OB/GYNs over 55 have been sued, compared to 27.7% of Pediatricians. Neonatologists are, however, at higher risk of being sued than many Pediatricians. This trend was seen in the AAP survey, which found that hospital-based subspecialties such as neonatology were associated with higher malpractice claim risk than outpatient-based specialties. Second, many birth injury lawsuits allege negligence against obstetric care during labor, neonatal resuscitation, and post-delivery care.

***"Second, many birth injury lawsuits allege negligence against obstetric care during labor, neonatal resuscitation, and post-delivery care."***

The AMA report is available at the link below. While this column often focuses on the impact of individual court decisions, periodic surveys can provide a big-picture overview of malpractice risk factors and trends over time.

#### References:

1. Guardado, JR. American Medical Association Policy Research Perspectives: Medical Liability Claim Frequency Among U.S. Physicians. Available at <https://www.ama-assn.org/system/files/policy-research-perspective-medical-liability-claim-frequency.pdf>
2. Bondi SA, Tang SS, Altman RL, et al. Trends in Pediatric Malpractice Claims 1987–2015: Results From the Periodic Survey of Fellows. *Pediatrics*. 2020;145(4):e20190711

NT

Corresponding Author



Jonathan Fanaroff, MD, JD, FAAP  
Professor of Pediatrics  
Case Western Reserve University School of Medicine  
Director, Rainbow Center for Pediatric Ethics  
Rainbow Babies & Children's Hospital  
Cleveland, Ohio  
Email: [jmf20@case.edu](mailto:jmf20@case.edu)



To every NICU nurse who has cared for these precious babies we say.....  
"Thank you."

Did you know that premature and low birth weight babies have a 4x greater risk for SIDS?

At First Candle we're educating parents, grandparents and caregivers about safer sleep to make sure all babies reach their first birthday. Learn more at [firstcandle.org](http://firstcandle.org)

"Even in the middle of taking this course, I could see myself changing the way that I spoke to parents. After taking this course, I am much better at emotionally supporting our NICU families."

COURSE PARTICIPANT

Learn How Now

validated online NICU staff education

[WWW.MYNICUNETWORK.ORG](http://WWW.MYNICUNETWORK.ORG)

My NICU Network  
My Perinatal Network





**VACCINES**

**PREVENTIVE MONOCLONAL ANTIBODIES**

Teach the body to create antibodies that fight off a specific disease.

Introduce antibodies that are ready to ward off disease in the body.

By introducing an inactive piece of a disease or proteins that look like the disease, they trigger an immune response, training the body to create antibodies that defeat the disease.

Instead of teaching the body to create antibodies and defenses, they provide antibodies that are readily available.

**Both support the immune system's defenses.**

Many vaccines are readily and easily available.

The technology behind vaccines has been around for decades.

Preventive monoclonal antibodies can provide protection for diseases where there isn't an existing vaccine or there isn't an existing vaccine for certain patient groups.

**Both protect against disease and provide a public health benefit by decreasing the burden of disease.**

Polio  
Measles  
COVID-19  
And more

RSV  
COVID-19

**Both can provide tailored protection from a variety of diseases.**

Yes

Yes

**Both vaccines and preventive monoclonal antibodies undergo extensive testing for safety and efficacy.**

# Vaccines and Preventive Monoclonal Antibodies

## WHAT'S THE DIFFERENCE?

### The Importance of Immunization

Vaccines and preventive monoclonal antibodies are two different types of immunization. While they function differently, they both serve the same purpose: protecting people from serious illnesses and diseases.

### Different Technology, Same Protective Value



<https://www.who.int/news-room/feature-stories/detail/how-do-vaccines-work#:~:text=Vaccines%20contain%20weakened%20or%20inactive,rather%20than%20the%20antigen%20itself.>

[https://static1.squarespace.com/static/5523bf7e4b0111e668e6/v/62445af1d0134140f1954206/1648686910465/NCIH\\_Monoclonal+Antibodies+Inclusion+in+the+VFC+Program\\_Position+Paper\\_Mar+2022.pdf](https://static1.squarespace.com/static/5523bf7e4b0111e668e6/v/62445af1d0134140f1954206/1648686910465/NCIH_Monoclonal+Antibodies+Inclusion+in+the+VFC+Program_Position+Paper_Mar+2022.pdf)

**READ** NPA's statement: **BLACK LIVES MATTER**

LOMA LINDA  
**LLPC**  
PUBLISHING COMPANY  
EST 2018

# The Indirect Impact of RSV

Susan Hepworth, Suzanne Staebler, DNP, APRN, NNP-BC, FAANP, FAAN, Mitchell Goldstein, MD, MBA, CML

## OVERVIEW

### RSV impacts not only infants and young children, but also entire families.

The National Coalition for Infant Health and the Alliance for Patient Access sought to examine the multifaceted burden that RSV places on families and to identify potential policy solutions.

Two surveys were conducted, one of parents who had at least one child contract RSV and one of health care providers who treat infants and children with RSV.

Both surveys were conducted with YouGov, a global public opinion and data company. Parents and providers were recruited from a pool of pre-selected respondents to ensure they met the survey's requirements. Participants received an honorarium.



## RSV PARENT SURVEY

340 parents who had at least 1 child sick with RSV



67% of parents said their child was hospitalized for RSV

## RSV HEALTH CARE PROVIDER SURVEY

175 health care providers across various pediatric and neonatal subspecialties



67% worked in an outpatient facility  
33% worked in a hospital

## RESULTS



### FINANCIAL BURDEN

**More than 2/3** of parents said the costs of RSV posed a financial burden or financial crisis.

**7%** of parents said they were fired as a result of caring for their child with RSV.

**32%** of parents reported losing potential income while their child had RSV.



### EMOTIONAL BURDEN

**68%** of parents said watching their child suffer affected their mental health.

**69%** of parents felt guilty that they could not do more to prevent their child's RSV.

When parents found out there was no treatment for RSV, only supportive care:

- 48% felt angry
- 46% felt helpless



### SOCIAL BURDEN

**43%** of parents had never heard of RSV before finding out their child was sick.

**54%** of parents had to rely on family and friends for sibling care, transportation and other responsibilities.

**42%** of parents said they struggled to care for their other children when one faced RSV.

## RESULTS



### PARENT EDUCATION & AWARENESS

**86%** of providers said they include RSV education as part of routine care.

**99%** of providers agreed that parents need more information about RSV.



### TREATMENT CHALLENGES

**Nearly 1/3** of providers have been reluctant to test for RSV because no treatment exists.

**48%** of providers said it was difficult to decide whether to send an infant or child with RSV to the emergency room.

**92%** agreed that if an immunization were available, it should be added to the Vaccines for Children program's list of pediatric vaccines.



### MISCONCEPTIONS

**A majority of providers (60%)** explained that around 50% or more of the babies they see hospitalized for RSV were born healthy, despite many people thinking severe RSV only impacts premature infants or those with preexisting conditions.

## CONCLUSION

### Both surveys highlighted that the burden of RSV extends well beyond its physical symptoms.

The virus may lead to:

- **Long-lasting health challenges** for babies and young children
- **Financial, social and emotional burdens** for families
- **Frustration for providers**, who lack a cure or viable preventive interventions

This burden is not experienced by the few. Most infants and children contract RSV by the time they are two, and challenges that accompany RSV may impact anyone who has been affected.

Moving forward, the many burdens of RSV demonstrate the need for:

- **More RSV education**
- **Research and innovation** for preventive interventions
- **Access to prevention and treatment** for all babies and children

The challenges caused by RSV can reach far and wide, and its indirect impacts often leave families struggling.

## Safety in the NICU

Susan Hepworth, Mitchell Goldstein, MD, MBA, CML



*The National Coalition for Infant Health is a collaborative of more than 200 professional, clinical, community health, and family support organizations focused on improving the lives of premature infants through age two and their families. NCfIH's mission is to promote lifelong clinical, health, education, and supportive services needed by premature infants and their families. NCfIH prioritizes safety of this vulnerable population and access to approved therapies.*

This past August, the coalition released *Safety in the NICU*. The video emphasizes the ways in which infants do not always receive the health care they need due to current policies and systemic issues, and demonstrates how these problems can start to be fixed.

The text from the video follows. Please feel free to share it with your networks.

Sometimes the healthcare system treats infants like they are tiny adults, and it's not just inaccurate—it can actually cause problems, especially when it comes to medications and medical devices used to treat infants in hospitals.

***“Infants need healthcare that’s tailored to their age, weight, and medical condition; but, that’s not always what they receive. Instead, they may be treated with devices and medications that were designed for adults, not for babies.”***

Caring for babies in the hospital often involves ventilators for breathing support, monitors to track vital signs and lung function, incubators to normalize babies' temperatures, and infusion pumps and tubing to deliver medication or nutrition. Accuracy and precision are critical, whether it's fragile infants fighting for their lives in the NICU, or older babies receiving care elsewhere in the hospital.

Infants need healthcare that's tailored to their age, weight, and medical condition; but, that's not always what they receive. Instead, they may be treated with devices and medications that were designed for adults, not for babies. That can lead to errors, such as unintentional medication overdoses, dangerously high

## Infants Are Not “Tiny Adults”



NCfIH National Coalition  
for Infant Health  
Protecting Access for Premature Infants through Age Two



# SAFETY = Devices & Medications Specifically Developed For Infants

**NCfIH** National Coalition  
for Infant Health  
Protecting Access for Premature Infants through Age Two

oxygen levels, and variable blood sugar levels. These errors can lead to further illness, injury, or even death.

*Disclosures: The authors have no disclosures*

***“Infants deserve protection and the safest possible health care. That requires policies that promote the development of drugs and devices for infants under 2, and hospital systems that implement the use of these drugs and devices.”***

Infants deserve protection and the safest possible health care. That requires policies that promote the development of drugs and devices for infants under 2, and hospital systems that implement the use of these drugs and devices. With more tools designed specifically for tiny patients, more babies can receive the best hospital care.

#### References:

1. National Coalition for Infant Health; Available from: <https://www.infanthealth.org/prematurity>

**NT**

#### **National Coalition for Infant Health Values (SANE)**

**Safety.** Premature infants are born vulnerable. Products, treatments and related public policies should prioritize these fragile infants' safety.

**Access.** Budget-driven health care policies should not preclude premature infants' access to preventative or necessary therapies.

**Nutrition.** Proper nutrition and full access to health care keep premature infants healthy after discharge from the NICU.

**Equality.** Prematurity and related vulnerabilities disproportionately impact minority and economically disadvantaged families. Restrictions on care and treatment should not worsen inherent disparities.

**NEONATOLOGY TODAY** is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)



Susan Hepworth  
 Director  
 National Coalition for Infant Health  
 2020 K Street NW  
 Suite 505  
 Washington, DC 20006  
 Email: [info@infanthealth.org](mailto:info@infanthealth.org)



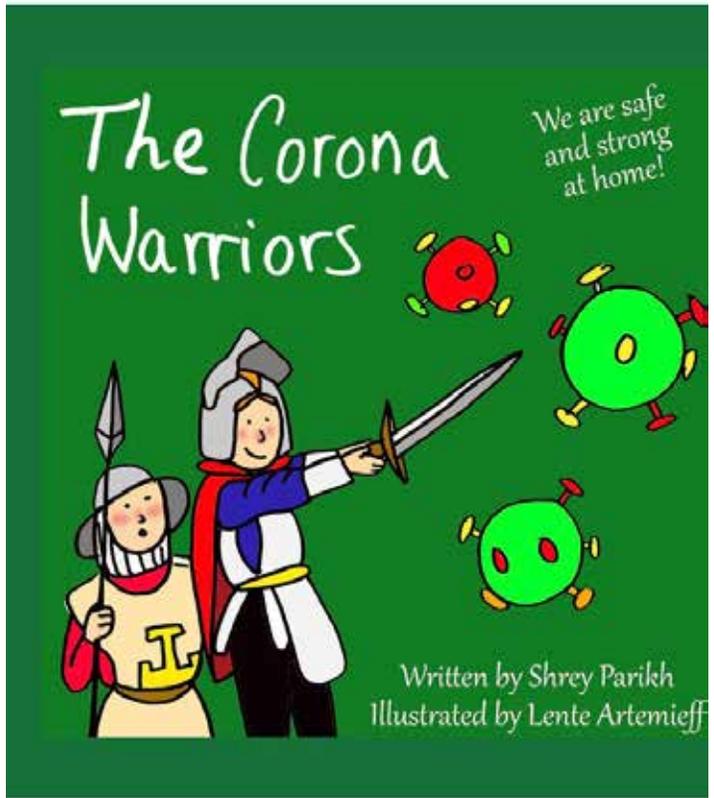
Mitchell Goldstein, MD, MBA, CML  
 Professor of Pediatrics  
 Loma Linda University School of Medicine  
 Division of Neonatology  
 Department of Pediatrics  
 Email: [mgoldstein@llu.edu](mailto:mgoldstein@llu.edu)



Readers can also follow  
**NEONATOLOGY TODAY**  
 via our Twitter Feed  
 @NEOTODAY



New subscribers are always welcome!  
**NEONATOLOGY TODAY**  
 To sign up for a free monthly subscription,  
 just click on this box to go directly to our  
 subscription page



# Save the Date! May 25, 2023

26<sup>th</sup> Annual Conference  
Quality of Life for Families XXVI

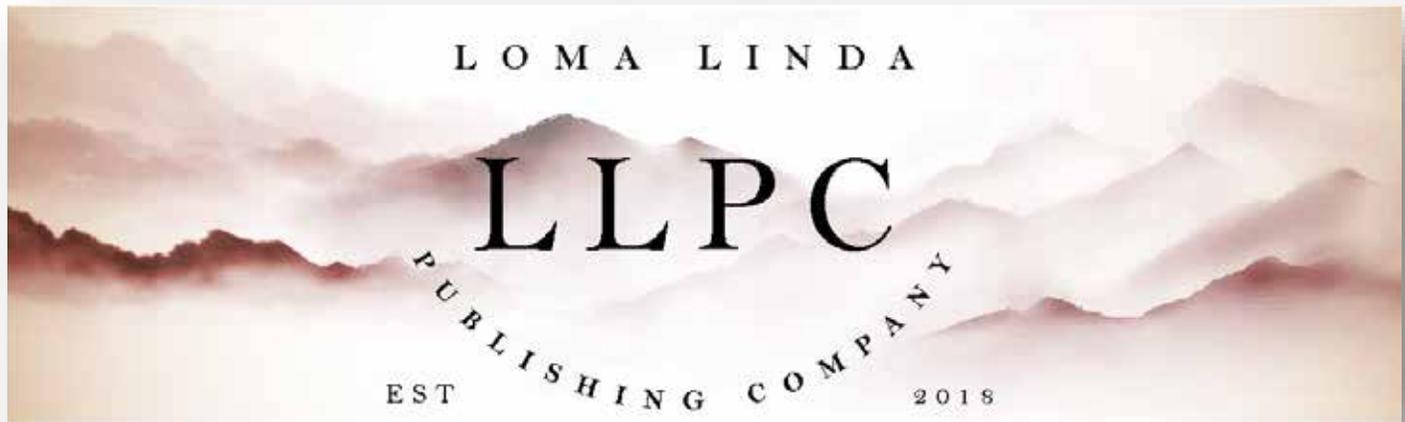


Keynote Speaker: **Dr. Diana Ramos**  
California Surgeon General

Where: [Hilton Los Angeles North/Glendale](#)  
[100 West Glenoaks Blvd,](#)  
[Glendale, CA 91202](#)



You can attend In-Person or Hybrid



## Neonatology Grand Round Series

Earn accredited CE while learning about pressing neonatology topics!



CENTER FOR RESEARCH,  
EDUCATION, QUALITY  
AND SAFETY

# The Signs & Symptoms of RSV

## RESPIRATORY SYNCYTIAL VIRUS

### *Know the Signs & Symptoms of RSV*



Cough



Runny Nose



Struggling to Breathe  
*(breastbone sinks inward when breathing)*



Difficulty Eating



Lethargy



Wheezing

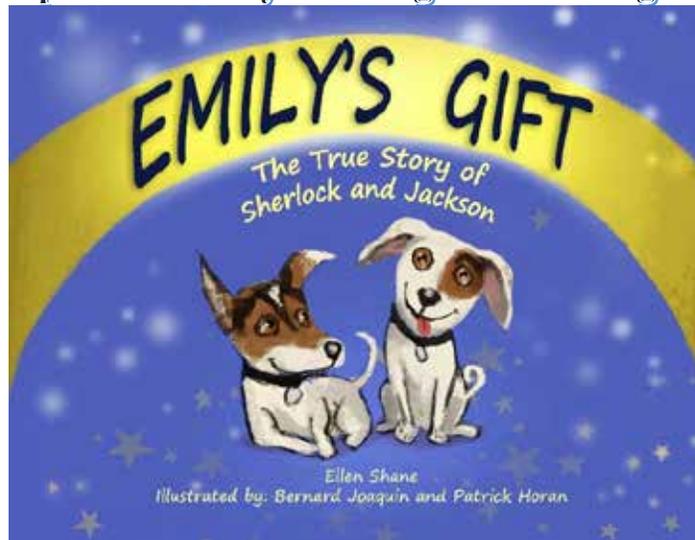
## RESPIRATORY SYNCYTIAL VIRUS

is a highly contagious seasonal virus that can lead to hospitalization for some babies and young children.

*Know the Signs.*



**“Emily’s Gift” can be purchased by clicking on the image of the cover below.**



Purchases of this engaging **true story** provide disadvantaged middle school students, risking academic failure, the opportunity to attain their best personal and academic potential.

Purchasing options include a limited quantity of signed and numbered books specifically to support the SEA Program, an ebook, soft and hardcover versions, and the option to donate one or more books to support organizations supporting young children.

**You can provide both reading entertainment for younger children, and make a difference in the lives of the disadvantaged middle schoolers we support.**

Sales support our nonprofit charity's SEA Program. You can make a difference for these children!

[Emily's Gift-Click Here to Buy](#)

[Direct SEA Support-Click Here](#)



*The Emily Shane Foundation is a 501(c)3 nonprofit charity. Our flagship SEA (Successful Educational Achievement) Program is a unique educational initiative that provides essential mentoring/tutoring to disadvantaged middle school children across Los Angeles and Ventura counties. All proceeds fund the SEA Program, which make a difference in the lives of the students we serve.*

For more information, please visit [emilyshane.org](http://emilyshane.org).

# The Premie Parent's SURVIVAL GUIDE to the NICU

By

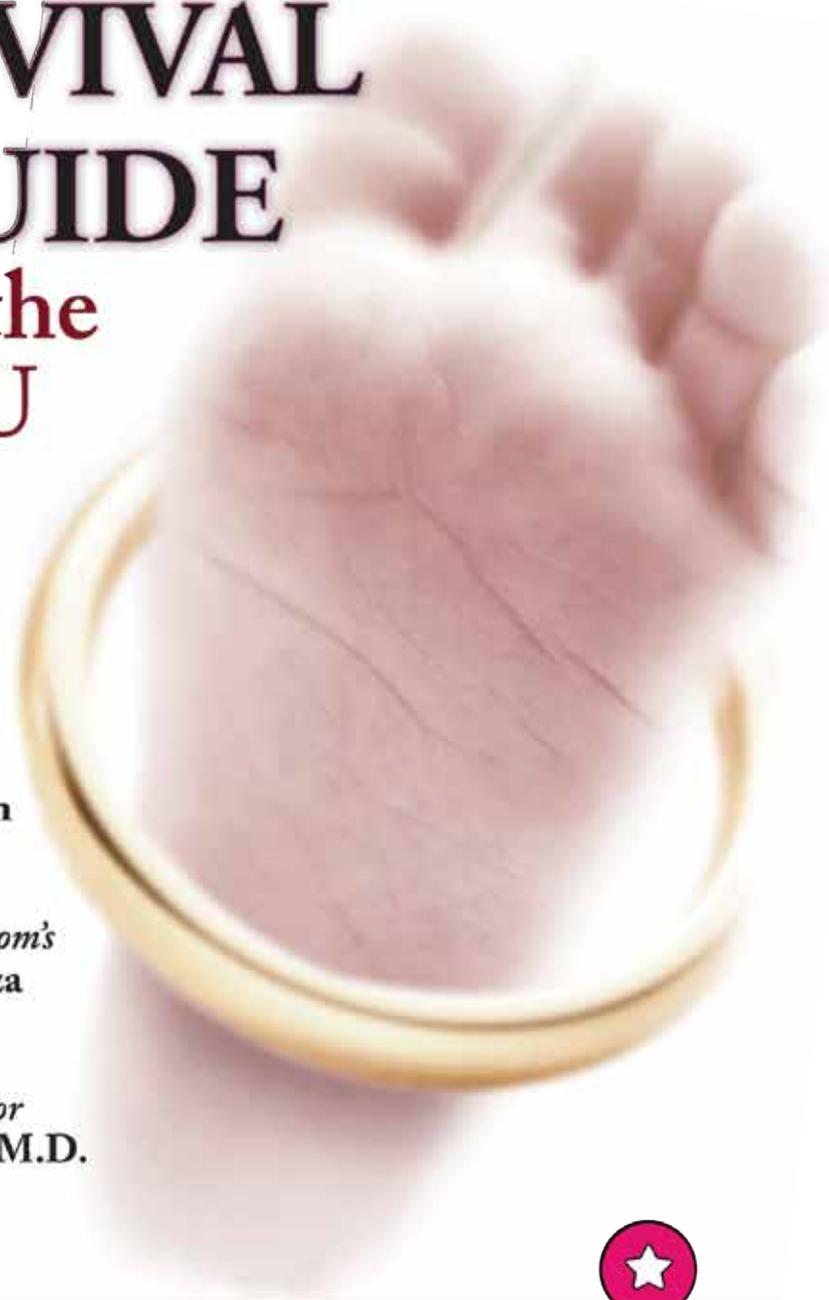
*little man's*  
Nicole Conn

&

*PremieWorld.com's*  
Deb Discenza

with

*Medical Editor*  
Alan R. Spitzer, M.D.



HOW TO  
MAINTAIN YOUR SANITY  
& CREATE A NEW NORMAL

second edition

# National Perinatal Association PERINATAL SUBSTANCE USE

[nationalperinatal.org/position](http://nationalperinatal.org/position)  
[www.nationalperinatal.org/Substance\\_Use](http://www.nationalperinatal.org/Substance_Use)



We know  
that there are  
barriers that  
keep pregnant  
people from  
accessing care.  
We believe  
that perinatal  
providers  
have a duty to  
help remove  
those barriers.

Educate. Advocate. Integrate.



CONGENITAL  
CARDIOLOGY  
TODAY

The only worldwide monthly publication exclusively serving Pediatric and Adult Cardiologists that focus on Congenital/Structural Heart Disease (CHD), and Cardiothoracic Surgeons.



**Subscribe Electronically**  
Free on the Home Page

[www.CongenitalCardiologyToday.com](http://www.CongenitalCardiologyToday.com)

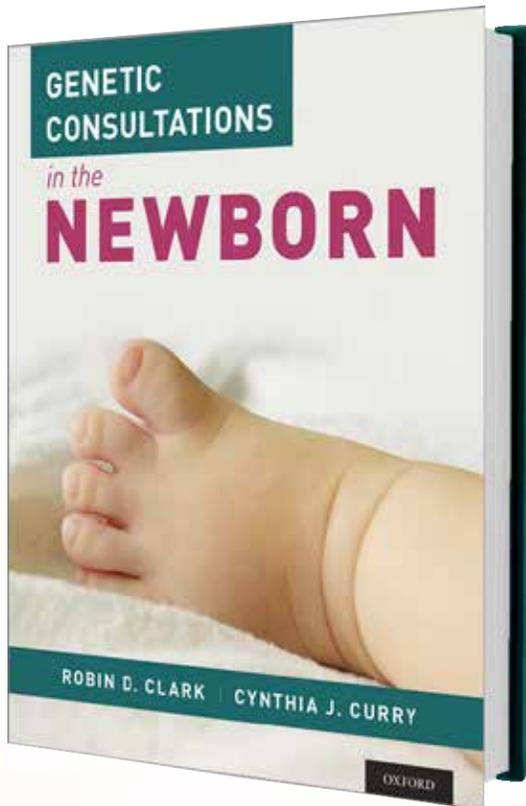


*“The definitive work in genetic evaluation of newborns”  
- Judith G. Hall*

## GENETIC CONSULTATIONS

# in the **NEWBORN**

\$99.95  
Hardcover



**Robin D. Clark | Cynthia J. Curry**

- A streamlined diagnostic manual for neonatologists, clinical geneticists, and pediatricians - any clinician who cares for newborns
- Organized by symptom and system, enriched with more than 250 photography and clinical pearls derived from authors' decades of clinical practice
- Includes “Syndromes You Should Know” appendix, distilling the most frequently encountered syndromes and chromosomal abnormalities in newborns
- OMIM numbers for each condition situate authors' practical guidance in the broader genetics literature, connecting readers to the most up-to-date references

Comprising of more than 60 chapters organized by system and symptom, *Genetic Consultations in the Newborn* facilitates fast, expert navigation from recognition to management in syndromes that manifest during the newborn period. Richly illustrated and packed with pearls of practical wisdom from the authors' decades of practice, it empowers readers to recognize the outward signs and symptoms crucial for an effective diagnosis.

Order now by [clicking here](#).

OXFORD

# Clinical Pearl: The Effects of Prenatal Exposure to Marijuana: Is Legalization in 21 States a Good Idea for the Fetus?

Joseph R Hageman, MD, Lolita Alkureishi, MD, Mitchell Goldstein, MD

***“Now that recreational marijuana (Cannabis sativa) and its active components are legal in 21 states and Washington D.C, many women take it in different forms prenatally and during pregnancy (1).”***

Now that recreational marijuana (*Cannabis sativa*) and its active components are legal in 21 states and Washington D.C, many women take it in different forms prenatally and during pregnancy (1). The perception is that now that it has been legalized, it is safe to consume, even during pregnancy (and beyond), and has been recommended for morning sickness (1). However, the American College of Obstetricians and Gynecologists (ACOG) has not recommended its use for any medicinal purposes prenatally, during pregnancy, or lactation (2).

***“Pregnant mothers who were documented to have used marijuana beginning in the first trimester only showed significantly less weight gain in their fetuses (1). If they continued to use throughout gestation, their fetuses had significant less weight gain and smaller head circumferences and a trend toward less growth in length as well (1)”***

There has been much discussion about the potential effects of marijuana on the placenta and the fetus (1,2). In a rat study, marijuana use during gestation has been found to compromise oxygen transfer and nutrition to the fetus, secondary to compromised development of fetal-placental circulation, which resulted in compromised fetal growth (1,3).

In a well-organized study by Dodge and colleagues, in comparing fetal growth of weight, length, and head circumference during pregnancy, pregnant mothers who were documented to have used marijuana beginning in the first trimester only showed significantly less weight gain in their fetuses (1). If they continued to use throughout gestation, their fetuses had

significantly less weight gain and smaller head circumferences and a trend toward less growth in length as well (1). These abnormalities in fetal growth, especially in head circumference, have been associated with abnormalities in neurodevelopment in other studies (1).

Further, what we know about marijuana during pregnancy reflects a large body of literature published before marijuana was legalized and available for controlled trials. Enhanced potency, drug delivery using vape pens, and the potentially deleterious effects of the vehicle for administration have not been evaluated sufficiently.

The situation following delivery can be problematic. Even where marijuana is legal, most states have laws restricting the furnishing of marijuana to those under 18. If a mother continues to use it following the baby's delivery, is breastfeeding a criminal act? In California, Health and Safety Code 11361 establish five to seven years behind bars as the penalty for furnishing or offering to furnish "any marijuana" to a minor. Offering to furnish can include nurses, physicians, hospital administrators, clinic workers, or any health provider that reassures a mom that it is okay to breastfeed while using (4).

***“These data strongly suggest that women who are trying to become pregnant and are pregnant should not use any form of recreational marijuana (1-3) as recommended by ACOG, even for the treatment of morning sickness (1-3).”***

These data strongly suggest that women who are trying to become pregnant and are pregnant should not use any form of recreational marijuana (1-3) as recommended by ACOG, even for the treatment of morning sickness (1-3). Further, after delivery, beyond further potential compromise in developmental outcomes, using marijuana may create an at-risk legal environment for those moms who choose to breastfeed as well as their providers.

## References:

1. Dodge P, Nadolski K, Kopkau H et al. The impact of timing of in utero marijuana exposure on fetal growth. *Frontiers in Pediatrics* DOI: 10.3389/fped.2023.1103749. Published 16 May 2023.
2. Marijuana use during pregnancy and lactation committee opinion No. 722. American College of obstetricians and gynecologists. *Obstet Gynecol* (2017) 130:e205-209. doi.

10.1097/ACOG.0000000000002354.

- Natalie BV, Agustin KN, Lee K, et al. Delta 9-tetrahydrocannabinol exposure during rat pregnancy leads to symmetrical fetal growth restriction and labyrinth-specific vascular defects in the placenta. *Sci Rep.* (2020) 10(1):544-548. doi.10.1038/s41598-019-57318-6.
- <https://law.justia.com/codes/california/2020/code-hsc/division-10/chapter-6/article-2/section-11361/>

*Disclosures: The authors have no disclosures*

**NT**



Lolita Alkureishi, MD  
Associate Professor of Pediatrics  
Assistant Director, Ambulatory Care Residency Program  
Director, Pediatric Clerkship  
University of Chicago  
Chicago, IL

*Corresponding Author*



Joseph R. Hageman, MD  
Senior Clinician Educator, Pritzker School of Medicine  
University of Chicago  
MC6060  
5841 S. Maryland Ave.  
Chicago, IL 60637  
Phone: 773-702-7794  
Fax: 773-732-0764  
Email: [jhageman@peds.bsd.uchicago.edu](mailto:jhageman@peds.bsd.uchicago.edu)

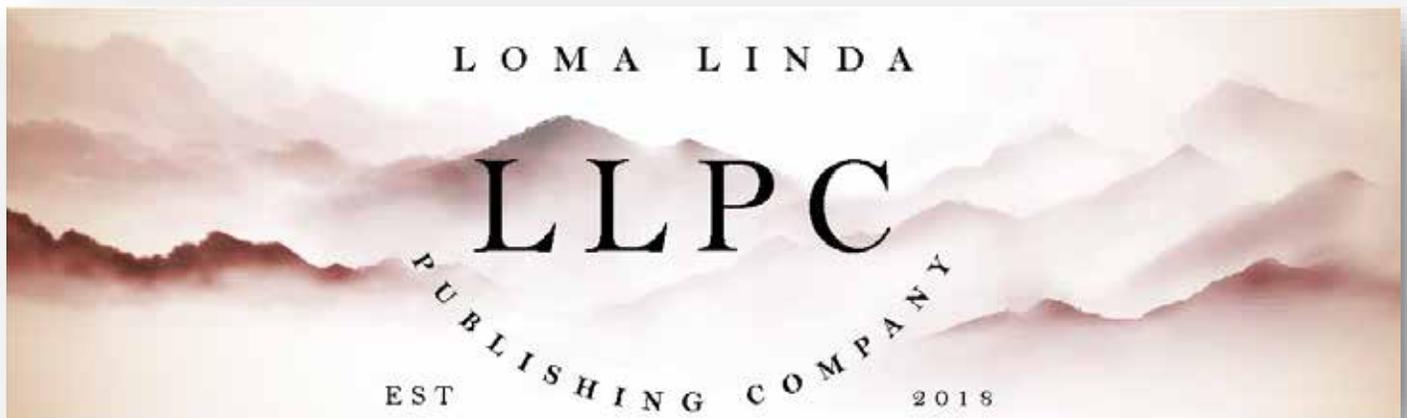


Mitchell Goldstein, MD, MBA, CML  
Professor of Pediatrics  
Loma Linda University School of Medicine  
Division of Neonatology  
Department of Pediatrics  
Email: [mgoldstein@llu.edu](mailto:mgoldstein@llu.edu)

# 99nicu

Sign up for free membership at 99nicu, the Internet community for professionals in neonatal medicine. Discussion Forums, Image Library, Virtual NICU, and more..."

[www.99nicu.org](http://www.99nicu.org)



New subscribers are always welcome!

## NEONATOLOGY TODAY

To sign up for free monthly subscription, just click on this box to go directly to our subscription page

Readers can also follow

## NEONATOLOGY TODAY

via our Twitter Feed

@NEOTODAY

MedEd On The Go® presents

3 Accredited Education Programs in Short-Form Video Format  
Available for CME/CNE Credits

# The Role of Nutrition & Exclusive Human Milk for Very Low Birth Weight Infants



### Preventing Bronchopulmonary Dysplasia

1.75 credit hours

WATCH NOW



[www.MedEdOTG.com/video/program/599](http://www.MedEdOTG.com/video/program/599)

### Preventing Neonatal Sepsis

0.5 credit hours

WATCH NOW



[www.MedEdOTG.com/video/program/609](http://www.MedEdOTG.com/video/program/609)

### Preventing Retinopathy of Prematurity

1.0 credit hour

WATCH NOW



[www.MedEdOTG.com/video/program/608](http://www.MedEdOTG.com/video/program/608)



**Stephen E. Welty, MD**

Clinical Professor of Pediatrics  
University of Washington  
School of Medicine  
Seattle, WA



**Dan L. Stewart, MD**

Professor of Pediatrics & International Pediatrics  
University of Louisville School of Medicine  
Co-Director of NICU & ECMO  
Norton Children's Hospital  
Louisville, KY



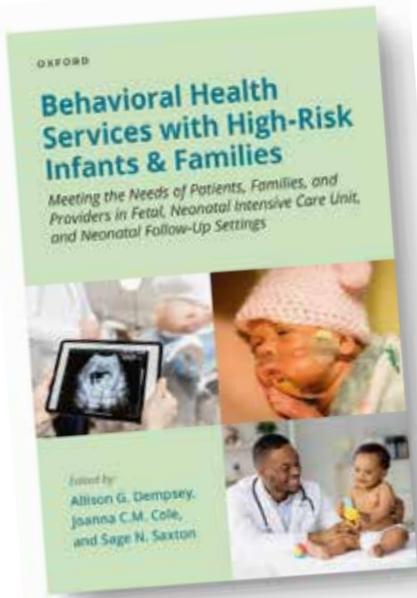
**Jonathan R. Swanson, MD, MSc**

Associate Professor of Pediatrics  
University of Virginia  
Children's Hospital  
Charlottesville, VA



# National Network of NICU Psychologists

Education, Resources, and Support for Perinatal Mental Health Professionals



Preorder

## Behavioral Health Services with High-Risk Infants and Families

Use discount code **ASPROMP8** and save **33%** online at [www.oup.com](http://www.oup.com)

**\$56.00**



### Free Resources

Empower families with the skills they need.

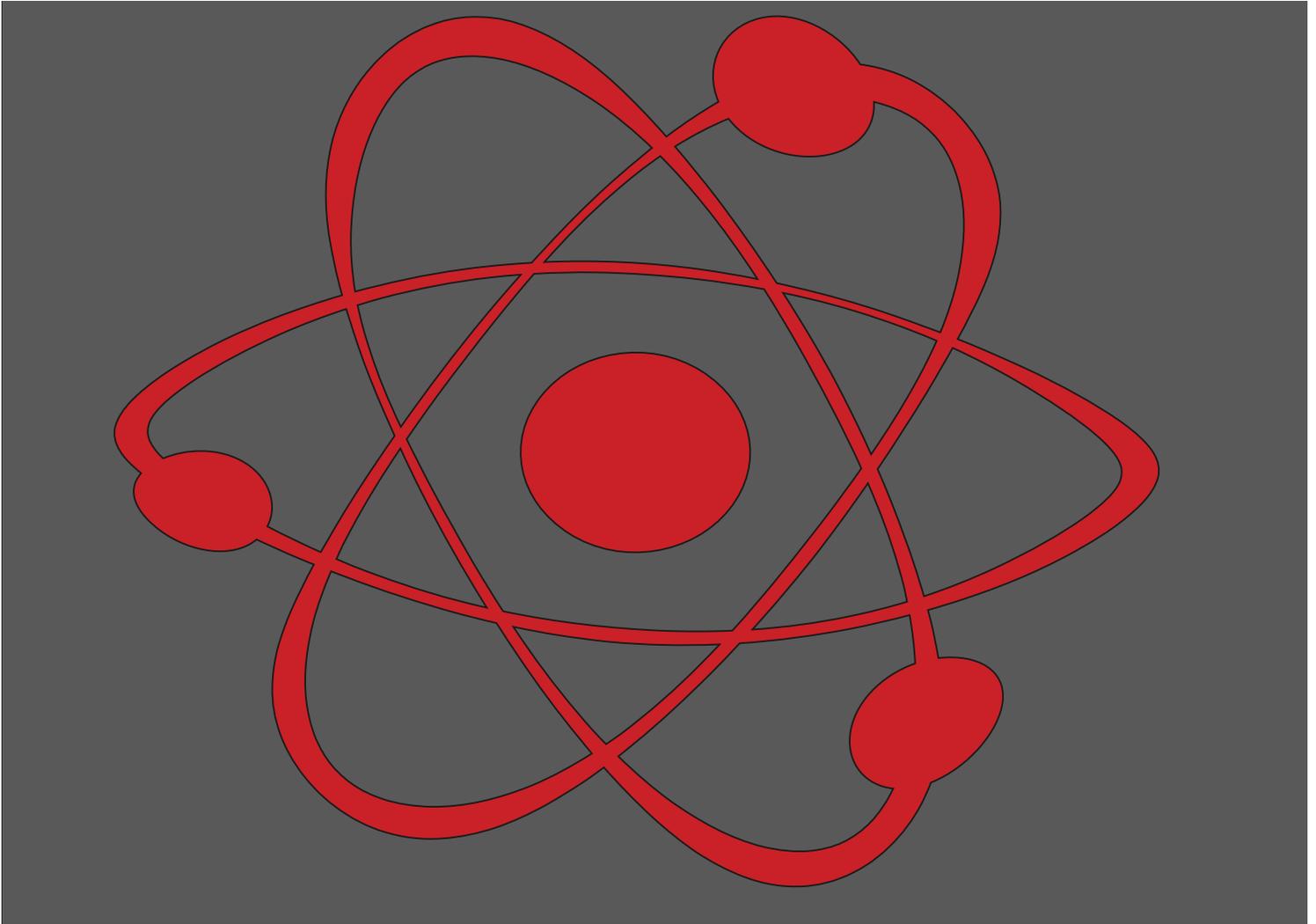
Download our perinatal Mental Health Plan worksheets.

Support NICU families and staff during COVID-19.

See resources created by the National Network of NICU Psychologists.



# Academic True Open Model (ATOM)



Loma Linda Publishing Company supports the Academic True Open Model (ATOM)

Journals listed support the following principles:

1. Free subscriptions (electronic or paper) to all.
2. Peer review of all submitted manuscripts
3. Timely review of manuscripts
4. Timely response to letters to the editor
5. Listing and correction of erratum
6. Appropriate disclosure of any related conflicts of interest in published manuscripts
7. No charge for submission of manuscripts
8. No charge for review of manuscripts
9. No charge for processing of artwork, color, layout, or length of manuscript
10. No charge for publication of manuscript in electronic or digital form.
11. A commitment to the ethical treatment of humans and animals in research.
12. Documentation of informed consent where indicated.

**NT**

Any journal that supports the ATOM principles can be listed here, along with their logo and a link back to their site, free of charge. Please contact Loma Linda Publishing Company at [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com) for additional details.



Neonatology Today, a publication of Loma Linda Publishing Company.  
© 2006-2020 by Neonatology Today  
Published monthly. All rights reserved.  
ISSN: 1932-7137 (Online), 1932-7129 (Print)

**Readers can also follow**

**NEONATOLOGY TODAY**

**via our Twitter Feed**

**@NEOTODAY**

Will your **PRETERM INFANT** need **EARLY INTERVENTION** services?

Preterm infants are:

**2x** more likely to have developmental delays

**5x** more likely to have learning challenges



**1 in 3** preterm infants will require support services at school



Early intervention can help preterm infants:



Enhance language and communication skills



Build more effective learning techniques



Process social and emotional situations



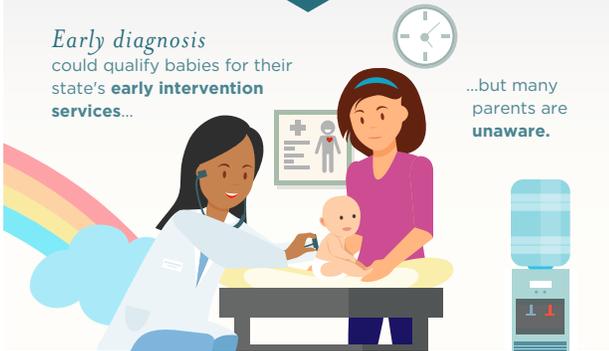
Address physical challenges



Prevent mild difficulties from developing into major problems

Early diagnosis could qualify babies for their state's **early intervention services**...

...but many parents are **unaware**.



**NICU staff, nurses, pediatricians and social workers should talk** with NICU families about the challenges their baby may face.

Awareness, referral & timely enrollment in early intervention programs can help **infants thrive** and grow.



**NCFIH** National Coalition for Infant Health  
Protecting Access for Premature Infants through Age Two  
[www.infanthealth.org](http://www.infanthealth.org)

Visit [CDC.gov](http://CDC.gov) to find contact information for your state's early intervention program.

Las nuevas mamás necesitan acceso a la detección y tratamiento para **LA DEPRESIÓN POSPARTO**



**1 DE CADA 7** MADRES AFRONTA LA DEPRESIÓN POSPARTO, experimentando



Sin embargo, sólo el **15%** recibe tratamiento!

LA DEPRESIÓN POSTPARTO **NO TRATADA PUEDE AFECTAR:**

El sueño, la alimentación y el comportamiento del bebé a medida que crece?



La salud de la madre

La capacidad para cuidar de un bebé y sus hermanos

PARA AYUDAR A LAS MADRES A ENFRENTAR LA DEPRESIÓN POSPARTO



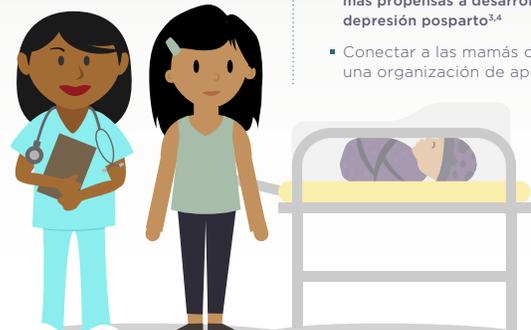
**LOS ENCARGADOS DE FORMULAR POLÍTICAS PUEDEN:**

- Financiar los esfuerzos de despistaje y diagnóstico
- Proteger el acceso al tratamiento



**LOS HOSPITALES PUEDEN:**

- Capacitar a los profesionales de la salud para proporcionar apoyo psicosocial a las familias... **Especialmente aquellas con bebés prematuros, que son 40% más propensas a desarrollar depresión postparto**<sup>3,4</sup>
- Conectar a las mamás con una organización de apoyo



**NCFIH** National Coalition for Infant Health  
Protecting Access for Premature Infants through Age Two  
[www.infanthealth.org](http://www.infanthealth.org)

<sup>1</sup> American Psychological Association. Accessed on: <http://www.apa.org/women/resources/reports/postpartum-depression.aspx>

<sup>2</sup> National Institute of Mental Health. Accessed on: <http://www.nimh.nih.gov/health/publications/postpartum-depression-facts/index.shtml>

<sup>3</sup> Journal of Perinatology (2015) 35, 529–536. doi:10.1097/JP.0000000000000147

<sup>4</sup> Prevalence and risk factors for postpartum depression among women with problem and low-birth-weight infants: a systematic review. Vigod SN, Villages L, Dennis CL. *PLoS One* 2010 Apr; 11(7):1540-50.

## Upcoming Medical Meetings

**Perinatal District 8 Conference**  
June 1-4, 2023  
San Diego, CA  
<https://district8sonpm.org/>

**8th World Congress of Pediatric  
Cardiology and Cardiac Surgery**  
August 27-September 1, 2023  
Washington, DC  
<http://wcpccs2023.org/>

**2023 AAP National Conference &  
Exhibition**  
October 20-24, 2023  
Washington, DC.  
<https://aapexperience.org>

**40<sup>th</sup> Advances in Neonatal and  
Pediatric Cardiorespiratory Care**  
January 31-February 2, 2024  
Hilton Los Angeles North/Glendale  
100 West Glenoaks Blvd.  
Glendale, CA 91202  
<https://paclac.org/advances-in-care-conference/>

**2024 Gravens Conference: The  
Power of Voice: Using Your Voice for  
Babies, Family, Staff and Beyond**  
March 6-9, 2024  
Sheraton Sand Key Resort  
Clearwater Beach, FL  
<https://paclac.org/https-paclac-org-gravens-conference/>

*For up to date Meeting  
Information, visit  
[NeonatologyToday.net](http://NeonatologyToday.net) and click  
on the events tab.*

## NEONATOLOGY TODAY

© 2023 by Neonatology Today  
ISSN: 1932-7137 (Online). ISSN: 1932-7129 (Print). Published monthly. All rights reserved.

### Publication

Mitchell Goldstein, MD  
Loma Linda Publishing Company  
11175 Campus Street  
Suite #11121  
Loma Linda, CA 92354  
[www.NeonatologyToday.net](http://www.NeonatologyToday.net)  
Tel: +1 (302) 313-9984  
[LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)

### Editorial and Subscription

Mitchell Goldstein, MD  
Neonatology Today  
11175 Campus Street  
Suite #11121  
Loma Linda, CA 92354

### Sponsorships and Recruitment Advertising

For information on sponsorships or recruitment advertising call Andrea Schwartz Goodman at: +1 (302) 313-9984 or send an email to [andrea.schwartzgoodman@neonatologytoday.net](mailto:andrea.schwartzgoodman@neonatologytoday.net)

### FREE Subscription

Neonatology Today is available free to qualified individuals worldwide interested in neonatology and perinatology. International editions are available in electronic PDF file only; North American edition available in print once a year in February. To receive your free qualified subscription please click [here](#).

### Submit a Manuscript:

On case studies, clinical and bench research, hospital news, meeting announcements, book reviews, and "state of the art" meta analysis.  
Please submit your manuscript to:  
[LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)  
We will respond promptly  
Twitter Account: [@NeoToday](https://twitter.com/NeoToday)



The only worldwide monthly publication exclusively serving Pediatric and Adult Cardiologists that focus on Congenital/Structural Heart Disease (CHD), and Cardiothoracic Surgeons.



**Subscribe Electronically**  
Free on the Home Page

[www.CongenitalCardiologyToday.com](http://www.CongenitalCardiologyToday.com)



**THE VOICES OF ALL PROFESSIONALS WHO WORK WITHIN THE ENVIRONMENT OF CARE FOR HIGH RISK NEWBORNS AND THEIR FAMILIES NEED TO BE HEARD.**

**WE WANT TO HEAR FROM PROFESSIONALS WHO REPRESENT A BROAD RANGE OF BACKGROUNDS, CULTURES, BELIEFS GENDER AND LIFESTYLE DIFFERENCES.**

**Please contribute to the Gravens Professional Diversity Fund!**

**Funds will provide support professionals from diverse backgrounds to attend the Gravens conference.**

**Send your tax deductible contribution to**

**Neonatology Today  
Division of Neonatology, Department of Pediatrics  
Loma Linda University Children's Hospital  
11175 Campus Street, CP 11121  
Loma Linda, CA 92354**

*Or PayPal*

**Save the Date!**

**January 31- February  
2<sup>nd</sup>, 2024**



**40<sup>th</sup> Advances in Neonatal  
and Pediatric  
Cardiorespiratory Care**

**You can attend In-Person or  
Virtual**



**Where: Hilton Los Angeles North/Glendale  
100 West Glenoaks Blvd,  
Glendale, CA 91202**

*Attractions Distances are displayed to the nearest 0.1 mile and kilometer.*

- Glendale Galleria - 1.7 km / 1.1 mi
- Americana at Brand - 2 km / 1.2 mi
- Griffith Park - 3.3 km / 2.1 mi
- Los Angeles Zoo - 5.3 km / 3.3 mi
- Walt Disney Studios - 7.9 km / 4.9 mi
- Nickelodeon Animation Studio - 7.9 km / 4.9 mi
- Warner Brothers Studio - 8.2 km / 5.1 mi
- Greek Theatre - 9.9 km / 6.1 mi
- Descanso Gardens - 9.9 km / 6.2 mi
- Hollywood Boulevard - 10.3 km / 6.4 mi
- Universal Studios Hollywood - 10.9 km / 6.8 mi
- Rose Bowl Stadium - 11.2 km / 7 mi
- Pasadena Convention Center - 11.6 km / 7.2 mi

***Other Attractions***

- Disneyland – 35 mi
- Santa Monica Pier -26 mi
- Venice Beach - 28 mi

**The nearest airports are:**

- Hollywood Burbank Airport (BUR) - 12.8 km / 8 mi
- Los Angeles Intl. (LAX) - 43.5 km / 27 mi
- Ontario International Airport- 45 mi
- Long Beach Airport- 35 mi

# Clinical Trial Center (Full-Time, Day Shift) - Research Coordinator

The Loma Linda University Health's Clinical Trial Center is actively seeking and recruiting top clinical research coordinator talent.

Our mission is to participate in Jesus Christ's ministry, bringing health, healing, and wholeness to humanity by creating a supportive faculty practice framework that allows Loma Linda University School of Medicine physicians and surgeons to educate, conduct research, and deliver quality health care with optimum efficiency, deploying a motivated and competent workforce trained in customer service and whole-person care principles and providing safe, seamless and satisfying health care encounters for patients while upholding the highest standards of fiscal integrity and clinical ethics. Our core values are compassion, integrity, humility, excellence, justice, teamwork, and wholeness.

Able to read, write and speak with professional quality; use computer and software programs necessary to the position, e.g., Word, Excel, PowerPoint, Access; operate/troubleshoot basic office equipment required for the position. Able to relate and communicate positively, effectively, and professionally with others; provide leadership; be assertive and consistent in enforcing policies; work calmly and respond courteously when under pressure; lead, supervise, teach, and collaborate; accept direction. Able to communicate effectively in English in person, in writing, and on the telephone; think critically; work independently; perform basic math and statistical functions; manage multiple assignments; compose written material; work well under pressure; problem solve; organize and prioritize workload; recall information with accuracy; pay close attention to detail. Must have documented successful research administration experience focused on managing clinical trials function. Able to distinguish colors as necessary; hear sufficiently for general conversation in person and on the telephone; identify and distinguish various sounds associated with the workplace; see adequately to read computer screens and written documents necessary to the position. Active California Registered Nurse (RN) licensure preferred. Valid Driver's License required at time of hire.

The Clinical Trial Center is actively involved in many multi-center global pediatric trials, which span different Phases of research to advance health care in children. Please reach out to Jaclyn Lopez at 909-558-5830 or [JANLopez@llu.edu](mailto:JANLopez@llu.edu) with further interest. We would love to discuss the exciting research coordinator opportunities at our Clinical Trials Center.

## Additional Information

- Organization: Loma Linda University Health Care
- Employee Status: Regular
- Schedule: Full-time
- Shift: Day Job
- Days of Week: Sunday, Monday, Tuesday, Wednesday, Thursday, Friday, Saturday



LOMA LINDA  
UNIVERSITY



# Loma Linda University Children's Hospital is hiring Neonatal Nurse Practitioners

**Children's Hospital, centrally located in Southern California, has earned Magnet Recognition as part of the American Nurses Credentialing Center's (ANCC) Program.**

We are looking for experienced or new graduate Neonatal Nurse Practitioners (NNPs) who are excited to join a cohesive team that practices in a collaborative, fast-paced, high-acuity setting.

- Full-time and part-time positions available
- Level IV, 84-bed Neonatal Intensive Care Unit (NICU)
- Regional referral center encompassing Tiny Baby unit, ECMO, Cardiac ICU, Neuro NICU and Surgical services
- Maternity services and delivery center
- 24/7 coverage by NNP team and Fellows
- Competitive employee benefit packages



**For more information, please contact:**

Karin Colunga, MSN, RN, PNP-BC  
*Director of Advanced Practice Nursing*  
kecolunga@llu.edu | 909-558-4486

\*Offering a **sign-on bonus** with relocation reimbursement for full-time, direct applicants who meet requirements.



LOMA LINDA  
UNIVERSITY  
CHILDREN'S  
HOSPITAL

**HEALING. HEALTHY. HAPPY.**  
*A Seventh-day Adventist Organization*

# NEONATOLOGY TODAY

News and Information for BC/BE Neonatologists and Perinatologists



**We Can Help  
You Recruit  
from 1,045  
NICUs in the  
USA & Canada**

## **Your Recruitment Advertising Includes:**

- Full color Recruitment Ad in the issue(s)
- Your recruitment listing in the e-mail blast for the issue(s) with a hot link
- 3-Step Special Recruitment Opportunity Website Section on three (3) areas of the website
- *We can create your recruitment ad at no extra charge!*

**For more information, contact:**

**Melissa LaMarca**

+1 (302) 313-9984 or

[Melissa.LaMarca@neonatologytoday.net](mailto:Melissa.LaMarca@neonatologytoday.net)

# NEONATOLOGY TODAY

Peer Reviewed Research, News and Information in Neonatal and Perinatal Medicine  
Loma Linda Publishing Company | c/o Mitchell Goldstein, MD | 11175 Campus St, Ste. 11121 | Loma Linda, CA 92354 |  
[LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)

© 2020 Neonatology Today | ISSN: 1932-7137 (digital). Published monthly. All rights reserved.

## Editorial Board



Mitchell Goldstein, MD - Editor-in-Chief  
[LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)  
[MGoldstein@llu.edu](mailto:MGoldstein@llu.edu)  
Professor of Pediatrics  
Loma Linda University School of Medicine  
Division of Neonatology, Department of Pediatrics  
Loma Linda University Children's Hospital



T. Allen Merritt, MD - Senior Associate Editor for Contributions & Reviews  
[AllenMerritt.md@gmail.com](mailto:AllenMerritt.md@gmail.com)  
Professor of Pediatrics  
Loma Linda University School of Medicine  
Division of Neonatology, Department of Pediatrics  
Loma Linda University Children's Hospital



Larry Tinsley, MD - Senior Managing Editor  
[LTinsley@llu.edu](mailto:LTinsley@llu.edu)  
Associate Professor of Pediatrics  
Division of Neonatology-Perinatal Medicine  
Loma Linda University Children's Hospital



Elba Fayard, MD - Interim Fellowship Editor  
[Efayard@llu.edu](mailto:Efayard@llu.edu)  
Professor of Pediatrics  
Division Chair  
Division of Neonatology-Perinatal Medicine  
Loma Linda University Children's Hospital



Munaf Kadri, MD - International Editor  
[MKadri@llu.edu](mailto:MKadri@llu.edu)  
Executive Board  
UMMA Clinic  
Los Angeles, CA  
Assistant Professor Loma Linda  
Loma Linda University Children's Hospital



Michael Narvey, MD - Canada Editor  
[MNarvey@exchange.hsc.mb.ca](mailto:MNarvey@exchange.hsc.mb.ca)  
Section Head of Neonatology  
Children's Hospital Research Institute of Manitoba



Joseph R. Hageman, MD - Clinical Pearls Editor  
[jhageman@peds.bsd.uchicago.edu](mailto:jhageman@peds.bsd.uchicago.edu)  
Senior Clinician Educator  
Pritzker School of Medicine  
University of Chicago



Clara H. Song, MD - Social Media Editor  
[clara.h.song@kp.org](mailto:clara.h.song@kp.org)  
Southern California Permanente Medical Group



Thomas A Clarke, MD - Western Europe Editor  
[tclarke347@gmail.com](mailto:tclarke347@gmail.com)  
Emeritus Consultant in Neonatology  
The Rotunda Hospital,  
Dublin, Ireland



Jan Mazela, MD - Central Europe Editor  
[janco@pol-med.com.pl](mailto:janco@pol-med.com.pl)  
Associate Professor  
Poznan University of Medical Sciences  
Poznan, Greater Poland District, Poland



Stefan Johansson, MD PhD - Scandinavian Editor  
[stefan.johansson@99nicu.org](mailto:stefan.johansson@99nicu.org)  
Consultant Neonatologist, Sachs' Childrens Hospital  
Associate Professor, Karolinska Institutet  
Stockholm, Sweden



Francesco Cardona, MD - European Editor at Large  
[francesco@99nicu.org](mailto:francesco@99nicu.org)  
Consultant, Medical University of Vienna  
Department of Paediatrics and Adolescent Medicine  
Vienna, Austria



Arun Pramanick, MD - India Editor  
[aprama@lsuhsc.edu](mailto:aprama@lsuhsc.edu)  
Professor, Pediatrics,  
Louisiana State University School of Medicine,  
Shreveport, LA



Melissa LaMarca  
Senior Editorial Project Director  
[Melissa.LaMarca@NeonatologyToday.net](mailto:Melissa.LaMarca@NeonatologyToday.net)  
Loma Linda, CA



Mita Shah, MD - Arts Editor  
[mitashah@llu.edu](mailto:mitashah@llu.edu)  
Neonatal Intensive Care Unit Medical Director  
Queen of the Valley Campus,  
Emanate Health  
West Covina, CA



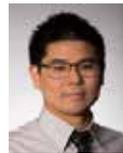
Giang Truong, MD - QI/QA Editor  
[GTruong@llu.edu](mailto:GTruong@llu.edu)  
Associate Professor of Pediatrics  
Division of Neonatology-Perinatal Medicine  
Loma Linda University Children's Hospital



Jerassimos Ballas, MD, MPH - Perinatology Editor  
[jballas@ucsd.edu](mailto:jballas@ucsd.edu)  
Associate Professor of Obstetrics and Gynecology  
University of California, San Diego



Maha Amr, MD - Academic Affairs Editor  
[maha.amr@neonatologytoday.net](mailto:maha.amr@neonatologytoday.net)  
 Assistant Professor of Pediatrics  
 Division of Neonatology, Department of Pediatrics  
 Loma Linda University Children's Hospital



Fu-Sheng Chou, MD, PhD - Senior Associate Editor,  
 Director, Digital Enterprise  
[FChou@llu.edu](mailto:FChou@llu.edu)  
 Assistant Professor of Pediatrics  
 Division of Neonatology, Department of Pediatrics  
 Loma Linda University Children's Hospital



Mikko Hallman MD, Ph.D. - Finnish Editor  
[mikko.hallman@oulu.fi](mailto:mikko.hallman@oulu.fi)  
 PEDEGO Research Unit, and MRC Oulu,  
 University of Oulu  
 Department of Children and Adolescents,  
 Oulu University Hospital, Oulu, Finland



Kimberly Hillyer, DNP, RN, LNC, NNP-BC - News Anchor  
[KHillyer@llu.edu](mailto:KHillyer@llu.edu)  
 Neonatal Nurse Practitioner/ Neonatal Intensive Care  
 Loma Linda University Health Advanced Practice  
 Services



Joy Browne, Ph.D., PCNS, IMH-E(IV) - FIFI-S Editor  
[Joy.browne@childrenscolorado.org](mailto:Joy.browne@childrenscolorado.org)  
 Clinical Professor of Pediatrics and Psychiatry  
 University of Colorado School of Medicine  
 Aurora, Colorado



Robert D. White, MD - Gravens Editor  
[Robert.White@pediatrix.com](mailto:Robert.White@pediatrix.com)  
 Director, Regional Newborn Program  
 Beacon Children's Hospital  
 615 N. Michigan St.  
 South Bend, IN 46601

Dilip R. Bhatt, MD - Kaiser Fontana, Fontana, CA  
 Barry D. Chandler, MD  
 Anthony C. Chang, MD - Children's Hospital of Orange County  
 K.K. Diwakar, MD - Malankara Orthodox Syrian Church Medical College  
 Willa H. Drummond, MD, MS (Informatics)  
 Philippe S. Friedlich, MD - Children's Hospital Los Angeles  
 Andrew Hopper, MD, Loma Linda University Children's Hospital  
 Lucky Jain, MD - Emory School of Medicine  
 Prakash Kabbur, MBBS, DCH (UK), MRCPCH (UK) - Kapiolani  
 Medical Center of Women & Children  
 Gail Levine, MD - Loma Linda University Children's Hospital  
 Lily Martorell, MD - Loma Linda University Children' Hospital  
 Patrick McNamara, MD - Sickkids, Toronto, ON  
 Rita Patel, NNP - Loma Linda University Children's Hospital  
 John W. Moore, MD - Rady Children's Hospital  
 Raylene Phillips, MD, Loma Linda University Children's Hospital  
 Michael A. Posencheg, MD - Children's Hospital of Philadelphia  
 DeWayne Pursley, MD, MPH - Boston Children's Hospital  
 Luis Rivera, MD - Loma Linda University Children's Hospital  
 Japmeet Sandhu, OMS IV - Western University of Health Sciences  
 P. Syamasundar Rao, MD - UT-Houston Medical School  
 Joseph Schulman, MD, MS - California Department of Health Care Services  
 Steven B. Spedale, MD, FAAP - Woman's Hospital  
 Alan R. Spitzer, MD  
 Cherry Uy, MD, FAAP - University of California, Irvine  
 Dharmapuri Vidysagar, MD - University of Illinois Chicago  
 Farha Vora, MD, Loma Linda University Children's Hospital  
 Leonard E. Weisman, MD - Texas Children's Hospital  
 Stephen Welty, MD - Seattle Children's Hospital  
 T.F. Yeh, MD - Cook County and Taipei Medical University

## PROTECT YOUR FAMILY FROM RESPIRATORY VIRUSES

flu

coronavirus

pertussis

RSV



### WASH YOUR HANDS

often with soap and warm water.

### GET VACCINATED

for flu and pertussis.  
 Ask about protective injections for RSV.



### COVER COUGHS AND SNEEZES.

Sneeze and cough into your elbow.

### USE AN ALCOHOL-BASED HAND SANITIZER.



### STAY AWAY FROM SICK PEOPLE

Avoid crowds.  
 Protect vulnerable babies and children.



[www.nationalperinatal.org](http://www.nationalperinatal.org)

 National  
Perinatal  
Association

## Neonatology Today's Policy on Animal and Human Research

Neonatology Today's policies ensure the protection and responsible use of animals and humans in all research articles under consideration. Authors are encouraged to follow the guidelines developed by the National Centre for the Replacement, Refinement & Reduction of Animals in Research (NC3R), International Committee of Medical Journal Editors, and the Guide for the Care and Use of Laboratory Animals and U.S. Public Health Service's Policy on Humane Care and Use of Laboratory Animals (PHS Policy). Authors are expected to demonstrate to their institutional review board or suitable proxy that ethical standards are met. If there is doubt whether research conducted was in accordance with ethical standards, then there must be verification that the institutional review body approved the uncertain aspects. Research not following these policies on participating animal and human subjects may be rejected. Researchers have a moral obligation towards the humane treatment of animals and ethical considerations for humans participating in research and are expected to consider their welfare when designing studies.

<https://www.nc3rs.org.uk/arrive-guidelines>

<http://www.icmje.org>

<https://olaw.nih.gov/policies-laws/phs-policy.htm>

NT

## Neonatology and the Arts

This section focuses on artistic work which is by those with an interest in Neonatology and Perinatology. The topics may be varied, but preference will be given to those works that focus on topics that are related to the fields of Neonatology, Pediatrics, and Perinatology. Contributions may include drawings, paintings, sketches, and other digital renderings. Photographs and video shorts may also be submitted. In order for the work to be considered, you must have the consent of any person whose photograph appears in the submission.

Works that have been published in another format are eligible for consideration as long as the contributor either owns the copyright or has secured copyright release prior to submission.

Logos and trademarks will usually not qualify for publication.

This month we continue to feature artistic works created by our readers on one the next to last page as well as photographs of birds on rear cover.. For this edition, we have a Sichuan Takin and a Lark both by Dr. Paula Whiteman.



Mita Shah, MD,  
Neonatal Intensive Care Medical Director  
Queen of the Valley Campus  
Emanate Health, West Covina, CA

NT

## Manuscript Submission: Instructions to Authors

1. Manuscripts are solicited by members of the Editorial Board or may be submitted by readers or other interested parties. Neonatology Today welcomes the submission of all academic manuscripts including randomized control trials, case reports, guidelines, best practice analysis, QI/QA, conference abstracts, and other important works. All content is subject to peer review.

2. All material should be emailed to: [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com) in a Microsoft Word, Open Office, or XML format for the textual material and separate files (tif, eps, jpg, gif, ai, psd, SVG, or pdf) for each figure. Preferred formats are ai, SVG, psd, or pdf. tif and jpg images with sufficient resolution so as not to have visible pixelation for the intended dimension. In general, if acceptable for publication, submissions will be published within 3 months.

3. There is no charge for submission, publication (regardless of number of graphics and charts), use of color, or length. Published content will be freely available after publication. There is no charge for your manuscript to be published. NT does maintain a copyright of your published manuscript.

4. The title page should contain a brief title and full names of all authors, their professional degrees, their institutional affiliations, and any conflict of interest relevant to the manuscript. The principal author should be identified as the first author. Contact information for the principal author including phone number, fax number, e-mail address, and mailing address should be included.

5. A brief biographical sketch (very short paragraph) of the principal author including current position and academic titles as well as fellowship status in professional societies should be included. A picture of the principal (corresponding) author and supporting authors should be submitted if available.

6. An abstract may be submitted.

7. The main text of the article should be written in formal style using correct English. The length may be up to 10,000 words. Abbreviations which are commonplace in neonatology or in the lay literature may be used.

8. References should be included in standard "NLM" format (APA 7<sup>th</sup> is no longer acceptable). Bibliography Software should be used to facilitate formatting and to ensure that the correct formatting and abbreviations are used for references.

9. Figures should be submitted separately as individual separate electronic files. Numbered figure captions should be included in the main file after the references. Captions should be brief.

10. Only manuscripts that have not been published previously will be considered for publication except under special circumstances. Prior publication must be disclosed on submission. Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.

11. NT recommends reading Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals from ICMJE prior to submission if there is any question regarding the appropriateness of a manuscript. NT follows Principles of Transparency and Best Practice in Scholarly Publishing (a joint statement by COPE, DOAJ, WAME, and OASPA). Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.

NT

**NEONATOLOGY TODAY is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.**

**Please submit your manuscript to: [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)**



# NICU BABY'S Bill of Rights

## 1- THE RIGHT TO ADVOCACY

My parents know me well. They are my voice and my best advocates. They need to be knowledgeable about my progress, medical records, and prognosis, so they celebrate my achievements and support me when things get challenging.

## 2- THE RIGHT TO MY PARENTS' CARE

In order to meet my unique needs, my parents need to learn about my developmental needs. Be patient with them and teach them well. Make sure hospital policies and protocols, including visiting hours and rounding, are as inclusive as possible.

## 3- THE RIGHT TO BOND WITH MY FAMILY

Bonding is crucial for my sleep and neuroprotection. Encourage my parents to practice skin-to-skin contact as soon as and as often as possible and to read, sing, and talk to me each time they visit.

## 4- THE RIGHT TO NEUROPROTECTIVE CARE

Protect me from things that startle, stress, or overwhelm me and my brain. Support things that calm me. Ensure I get as much sleep as possible. My brain is developing for the first time and faster than it ever will again. The way I am cared for today will help my brain when I grow up. Connect me with my parents for the best opportunities to help my brain develop.

## 5- THE RIGHT TO BE NOURISHED

Encourage my parents to feed me at the breast or by bottle, whichever way works for us both. Also, let my parents know that donor milk may be an option for me.

## 6- THE RIGHT TO PERSONHOOD

Address me by my name when possible, communicate with me before touching me, and if I or one of my siblings pass away while in the NICU, continue referring to us as multiples (twin/triplets/quads, and more). It is important to acknowledge our lives.

## 7- THE RIGHT TO CONFIDENT AND COMPETENT CARE GIVING

The NICU may be a traumatic place for my parents. Ensure that they receive tender loving care, information, education, and as many resources as possible to help educate them about my unique needs, development, diagnoses, and more.

## 8- THE RIGHT TO FAMILY-CENTERED CARE

Help me feel that I am a part of my own family. Teach my parents, grandparents, and siblings how to read my cues, how to care for me, and how to meet my needs. Encourage them to participate in or perform my daily care activities, such as bathing and diaper changes.

## 9- THE RIGHT TO HEALTHY AND SUPPORTED PARENTS

My parents may be experiencing a range of new and challenging emotions. Be patient, listen to them, and lend your support. Share information with my parents about resources such as peer-to-peer support programs, support groups, and counseling, which can help reduce PMAD, PPD, PTSD, anxiety and depression, and more.

## 10- THE RIGHT TO INCLUSION AND BELONGING

Celebrate my family's diversity and mine; including our religion, race, and culture. Ensure that my parents, grandparents, and siblings feel accepted and welcomed in the NICU, and respected and valued in all forms of engagement and communication.

Presented by:



NICU PARENT NETWORK

## NICU Parent Network

Visit [nicuparentnetwork.org](http://nicuparentnetwork.org) to identify national, state, and local NICU family support programs.

\* The information provided on the NICU Baby's Bill of Rights does not, and is not intended to, constitute legal or medical advice. Always consult with your NICU care team for all matters concerning the care of your baby.

copyright © 2020 NICU Parent Network



@drpaulawhiteman

*W*



@drpaulawhiteman