

NEONATOLOGY TODAY

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



Volume 18 / Issue 10 October 2023

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ISSN: 1932-7137 (Online), 1932-7129 (Print)
All editions of the Journal and associated manuscripts are available on-line:
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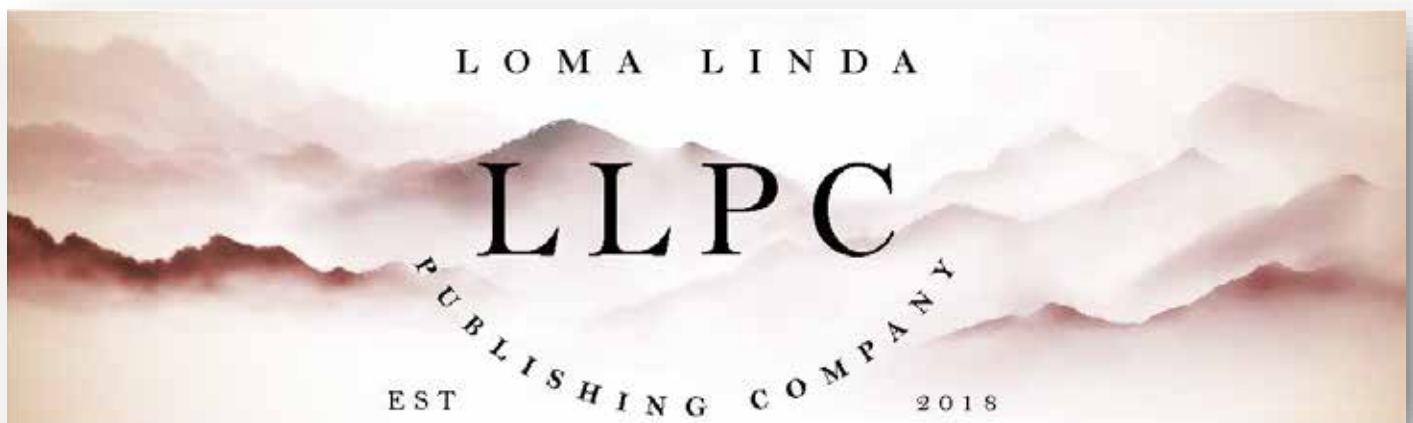
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A New Milestone in the NICU: New Growth References for Preterm Infants

Fu-Sheng Chou, MD, PhD, Reese H. Clark, MD

Historical view of growth reference in preterm infants

In 1977, The American Academy of Pediatrics Committee on Nutrition published a statement asking for “a prompt postnatal resumption of growth to a rate approximating intrauterine growth because this is believed to provide the best possible condition for subsequent normal development.” (1) At that time, at least two growth reference charts have been published. (2,3) These “intrauterine” growth charts were developed by taking measurements at the time of birth from infants born across a range of gestational ages. The measurements were typically grouped by the completed week of gestation (e.g., measurements from infants born between 24 weeks 0 days and 24 weeks 6 days were grouped together). Within each group, the measurement values at each predefined corresponding percentile (e.g., the 3rd, 10th, 50th, 90th, and 97th percentiles) can be calculated and plotted, with the x-axis being the gestational age in weeks and the y-axis being the birth measurement values for the percentiles. The measurement values that belong to the same percentile across gestational age were connected to form a curve for each percentile.

“In 1977, The American Academy of Pediatrics Committee on Nutrition published a statement asking for ‘a prompt postnatal resumption of growth to a rate approximating intrauterine growth because this is believed to provide the best possible condition for subsequent normal development.’”

Under the assumption of a skewed normal distribution of the measurement values (4–6), a power transformation proposed by Box and Cox can be applied to render the distribution of the measurement values normal. (7) The distribution of the measurement values at each completed gestational week can be summarized by three parameters—the Box-Cox power *Lambda* (L), the mean *Mu* (M), and the coefficient of variation *Sigma* (S). All three parameters—the L, M, and S—can then be plotted separately against the completed gestational age in weeks. Using the method of penalized maximum likelihood, the L, M, and S curves can be individually smoothed, and as a result, the percentile lines become smooth curves. (6)

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*“The distribution of the measurement values at each completed gestational week can be summarized by three parameters—the Box-Cox power *Lambda* (L), the mean *Mu* (M), and the coefficient of variation *Sigma* (S). All three parameters—the L, M, and S—can then be plotted separately against the completed gestational age in weeks.”*

The LMS method is the foundation of the Fenton growth charts for preterm infants. (8,9) The revised 2013 Fenton growth charts were based on a meta-analysis of six growth chart projects from Germany, the USA, Canada, Australia, the UK, and Italy. (9) Notably, while all six studies were used to generate the weight curves, only two studies (USA and Italy) were used for the length and head circumference curves. The developers of the revised Fenton growth charts connected the percentile curves to the 2006 World Health Organization Child Growth Standards at 50 weeks of gestation by extending the cubic splines between 36 and 50 weeks.

Issues with intrauterine growth charts

There are several significant issues associated with growth references developed using birth measurements:

- (1) The growth curves aim to represent intrauterine growth indirectly by measuring “fetal growth at the time of birth.” Consequently, infants affected by severe placental insufficiency, leading to growth restriction and being small for gestational age, may be overrepresented in the cohort due to the medical necessity of delivery to ensure maternal and fetal well-being. (10)
- (2) Specific to the 2013 Fenton growth charts, mathematically connecting the intrauterine growth curves (with data from 23 to 40 weeks gestation) to the WHO Child Growth Standards (11) (with data from birth to 24 months for the longitudinal component) may be problematic. While done with the intent to extend the growth reference to 50 weeks PMA, it may distort the data reference for values between 36 weeks and 50 weeks. As a result, no data supports the accuracy of these mathematically-derived, smoothed curves between 36 and 50 weeks of gestation. These curves tend to exhibit a bias towards the right, causing an underestimation of infants classified as large for gestational age (>90th percentile) and an overestimation of those classified as small for gestational age (<10th percentile).
- (3) Intrauterine growth occurs under low oxygen tension and within a confined intrauterine environment. This contrasts with postnatal growth, which occurs in the isolette in ambient air or at higher oxygen levels if an increased oxygen fraction is blended into the respiratory support modality.

“There are several significant issues associated with growth references developed using birth measurements: (1) The growth curves aim to represent intrauterine growth indirectly by measuring ‘fetal growth at the time of birth.’ (2)... mathematically connecting the intrauterine growth curves (with data from 23 to 40 weeks gestation) to the WHO Child Growth Standards (with data from birth to 24 months for the longitudinal component) may be problematic. (3) Intrauterine growth occurs under low oxygen tension and within a confined intrauterine environment.”

Postnatal growth charts are available now for clinical use and research.

We have developed a new set of gender- and gestational age-specific growth references for preterm infants, suitable for clinical use and growth/nutrition research. We will now refer to it as **Chou’s NICU postnatal growth charts for preterm infants**. The project began to compare postnatal growth under modern nutritional practices to intrauterine growth, utilizing real-world

data from the Pediatrix Clinical Data Warehouse. We employed a sophisticated multi-level longitudinal analysis to derive growth estimates in a piece-wise fashion, with Dr. Hung-Wen (Henry) Yeh overseeing the model development process at Children’s Mercy Research Institute.

The findings of this project were recently published in Nature Communications, revealing differences between postnatal and intrauterine growth, as well as a common pattern of postnatal growth across different gestational age groups. (12) Specifically, the postnatal growth pattern can be divided into three phases of weight gain, identified by calculating weight gain velocity in gram/kg/day and gram/day. These three phases of weight growth coincide with the three-interval modeling approach that the late Dr. Richard A. Ehrenkranz of Yale University School of Medicine adopted in his 1999 publication in *Pediatrics* on longitudinal growth of hospitalized very low birth weight infants. (13) Although the growth rate values may differ, the consistency in growth patterns between these two studies conducted a quarter-century apart suggests that the pattern does exist and that postnatal growth of preterm infants follows an alternative trajectory compared to their fetal counterparts.

“We have developed a new set of gender- and gestational age-specific growth references for preterm infants, suitable for clinical use and growth/nutrition research.”

To make the modeled postnatal growth trajectory curves accessible to the public, we created a series of web applications using R and the Shiny package. Anyone can sign up for an account to fully utilize the web application’s functionality.



Figure 1. Screenshot of the *nicugrowth.app* web application portal. The “Simplified Version” link will take the users to abbreviated versions of the web applications for weight, length, and head circumference, allowing measurement data entry, plotting, and trajectory percentile calculation. The Register link will take the users to the Registration page for account sign-up. The “Full Version” link will take the users to the Sign-In page of the full-version web application, which allows data storage and retrieval and other enhanced functions, including recommendations on the timing of transitioning to the WHO Child Growth Standards, as well as z-score/percentile data and plot export.

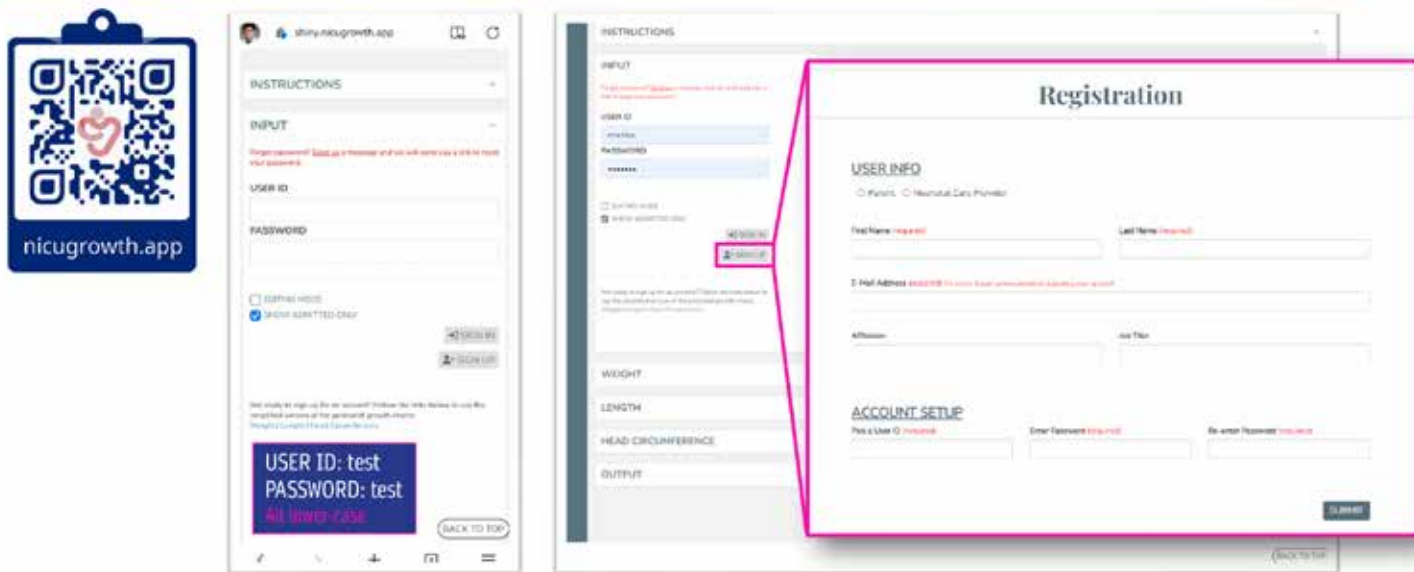


Figure 2. Full-version web application. The full-version web application can be accessed using the listed URL or the QR code. The full-version web application is optimized for viewing on mobile devices. The users may use the demo account (username/password:test) to trial the web application. The links to the Registration webpage and the simplified version of the weight, length, and head circumference web applications are available on the Sign-In page.

To access it, please visit <https://nicugrowth.app> (Figure 1) or use the QR code for direct access to the full-version website (Figure 2). The nicugrowth.app website serves as the portal for web applications. The Media page includes an introductory video and video clips to demonstrate web application use. The web applications have been optimized for mobile devices. These growth charts are suitable for infants born between 22 ½ and 34 3/7 weeks' gestation.

“Since these new growth charts were developed using rigorous statistical tools and consider individual variations in birth size and growth rate, we believe this tool will simplify the interpretation of preterm infants’ growth. It will make guiding nutrition delivery and necessary interventions to support adequate growth more intuitive.”

Since these new growth charts were developed using rigorous statistical tools and consider individual variations in birth size and growth rate, we believe this tool will simplify the interpretation of preterm infants’ growth. It will make guiding nutrition delivery and necessary interventions to support adequate growth more intuitive.

Furthermore, all or a subset of the growth measurements for each infant can now be automatically summarized into a percentile number using the postnatal growth charts—a *trajectory*

percentile. This convenience allows for an easy transition to the WHO Child Growth Standards with a matching percentile (think of the summarized trajectory percentile as the birth percentile). Additionally, when an infant recovers from a significant illness and is ready for nutritional support, clinicians can use the pre-illness trajectory percentile from a subset of measurements taken before the illness to guide post-illness nutrition administration, facilitating genuine “catch-up” growth.

Lastly, even though it remains an ongoing endeavor, we anticipate that we can now accurately redefine postnatal growth failure by enabling peer-to-peer comparisons of growth with this new reference, allowing us to determine whether an infant is deviating from the percentile line.

Summary

Postnatal growth of preterm infants diverges from intrauterine growth following preterm birth. Tracking postnatal growth using user-friendly tools like **Chou’s NICU postnatal growth charts for preterm infants** is intuitive and can easily complement the limitations of intrauterine growth charts in clinical settings. Feel free to contact us if you intend to integrate this growth reference tool into your electronic healthcare records.

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Acknowledgment: We would like to acknowledge Dr. Mitchell Goldstein for his help in establishing the collaboration that led to this paper.

Conflict of Interest: The author has no conflicts of interest relevant to this article to disclose.

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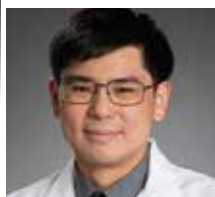
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Role of Glucose-6-Phosphate Dehydrogenase (G6PD) Deficiency and Altered Redox Status in Racial Disparities of Neonatal Outcomes: An Innocent Bystander or Unaccused Accomplice?

Ramesh Vidavalur, MD, MBA

“Glucose-6-phosphate dehydrogenase (G6PD) deficiency is the most prevalent inherited enzymopathy worldwide, with the highest population prevalence in sub-Saharan Africa and Southeast Asia and the lowest in the Americas (1).”

Introduction:

Glucose-6-phosphate dehydrogenase (G6PD) deficiency is the most prevalent inherited enzymopathy worldwide, with the highest population prevalence in sub-Saharan Africa and Southeast Asia and the lowest in the Americas (1). G6PD is a crucial rate-limiting regulatory enzyme in the hexose monophosphate shunt pathway, which clears free radicals and safeguards cellular structures against oxidant-induced damage, thereby maintaining a balanced redox status (2). It is essential for the equilibrium of the glutathione system, NADP oxidase system, and nitric oxide synthase (3) (Figure 1). This X-linked genetic disorder is mapped to the chromosome Xq28 region and encompasses over 140 described mutations, primarily point mutations (4). With more than 400 biochemical variants, this enzyme deficiency can manifest as neonatal jaundice, the hemolytic crisis resulting from medication exposure and infections, and chronic hemolytic anemia (5). The diverse biochemical variants and point mutations predispose affected individuals to exhibit various clinical manifestations.

Recent gene network analysis has revealed that G6PD-associated genes are involved in various cellular signaling mechanisms, and impaired regulation of these genes has been implicated in

cancers, autoimmune diseases, and disorders associated with oxidative stress (6). In order to mitigate the clinical consequences of G6PD deficiency, some countries with higher prevalence rates have implemented universal newborn screening along with provider and parental education about this disorder. The primary objective of this commentary is to emphasize the connection between G6PD deficiency, prematurity, and racial disparities in perinatal outcomes.

“Absent or reduced G6PD enzyme activity can accelerate oxidant-induced hemolysis in term and preterm newborns, thereby increasing the risk of hazardous levels of hyperbilirubinemia and neurotoxicity.”

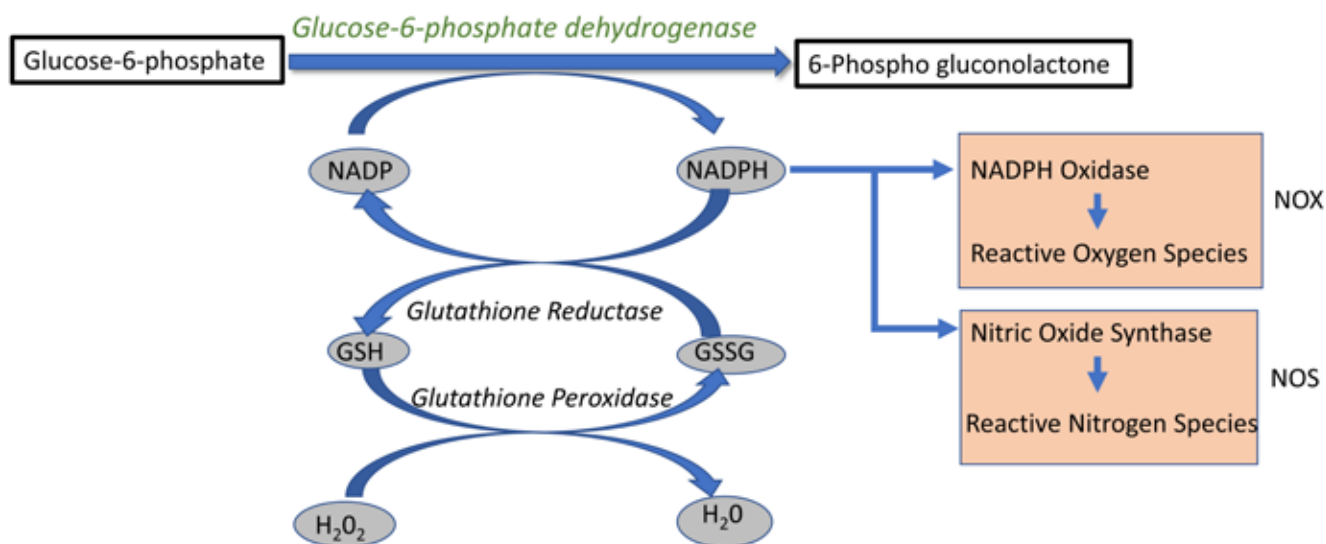
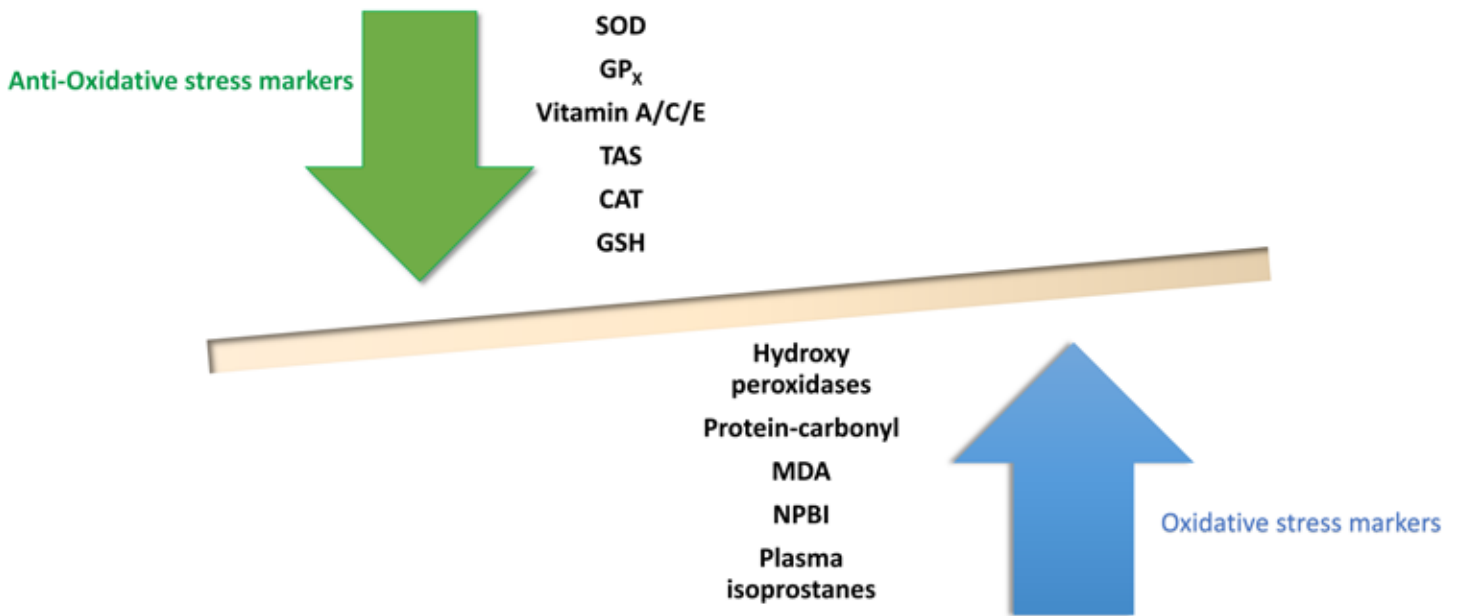


Figure 1: Interaction of G6PD with Glutathione, NOX, and NOS systems.



SOD-Super oxide dismutase; GP_x-Glutathione peroxidase; TAS-Total antioxidant status; CAT-catalase

Figure 2: Oxidative and Antioxidant stress markers in preterm infants at birth.

G6PD Deficiency and Hyperbilirubinemia:

Absent or reduced G6PD enzyme activity can accelerate oxidant-induced hemolysis in term and preterm newborns, thereby increasing the risk of hazardous levels of hyperbilirubinemia and neurotoxicity. Two large population studies conducted in the United States military revealed an overall G6PD deficiency prevalence of 2.2% (7). Disproportionately higher prevalence was observed among African Americans in both studies (overall prevalence: 9.5%; 11.2% in males and 5.6% in females). Based on 2018 US census data (8), out of 3.8 million annual births, 552,029 were non-Hispanic black infants, and 1.9 million were White Americans. Considering the population prevalence data from the aforementioned studies, approximately 52,445 non-Hispanic black infants are born with G6PD deficiency annually.

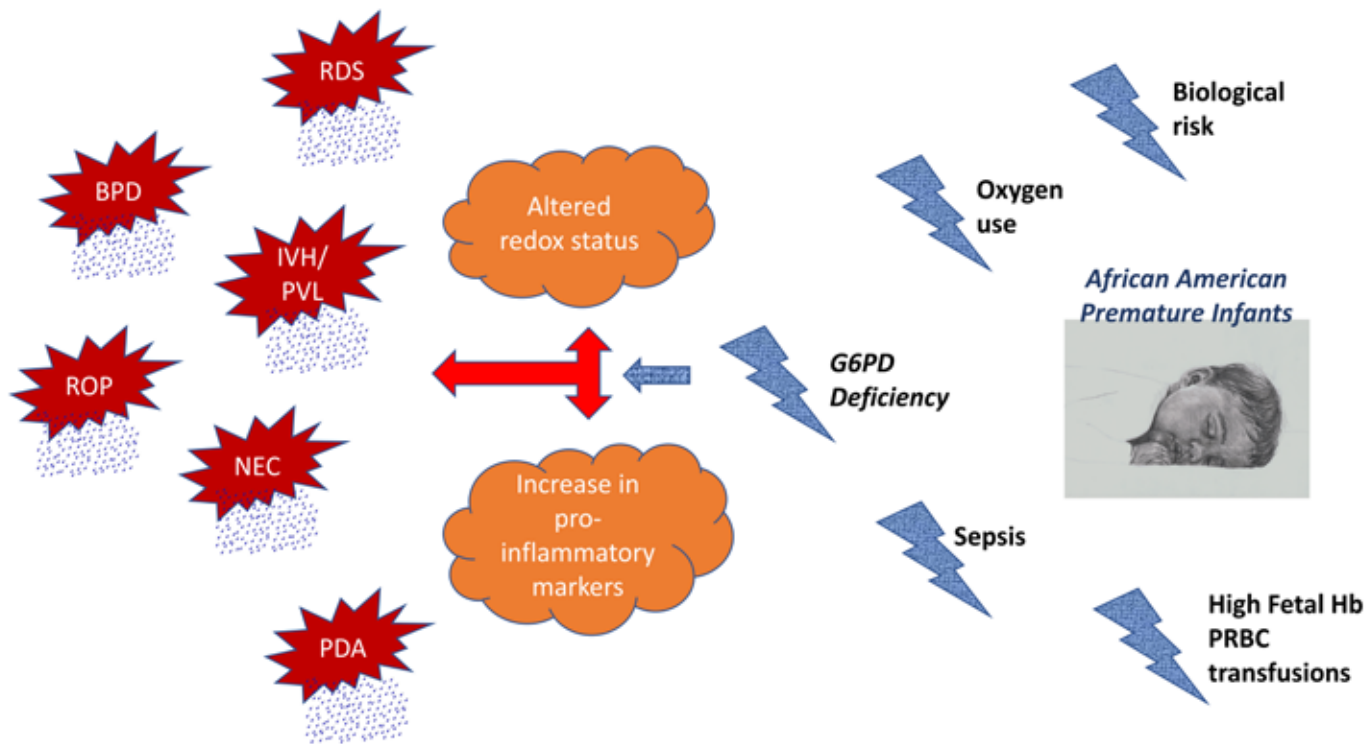
“Mounting evidence (17,30) suggests that small preterm infants have significantly lower catalase and GSH:NADPH ratios than late preterm and term infants. The compounding effect of G6PD deficiency on already weakened antioxidant defense mechanisms can theoretically cause cumulative end-organ damage in preterm infants. Future in vitro and in vivo research could shed light on this area.”

Data from the Kernicterus Registry indicate that 1 in 5 cases of kernicterus involved G6PD deficiency, which was believed to contribute to at least 2/3 of these cases among African American infants (9). Another population study conducted in California confirmed a four-fold increase (0.013% vs. 0.003%) in the rate of hazardous hyperbilirubinemia (bilirubin > 30mg/dl) among African American infants compared to White infants (10). Applying these rates to 2018-linked US birth population data (11), at least 72 African American and 58 White infants are expected to develop bilirubin levels > 30mg/dl. While studies conducted in Cleveland and Chicago (12,13) confirmed the prevalence and short-term outcomes of G6PD deficiency among the newborn population, there is a lack of data elucidating prematurity-related perinatal outcomes comparing normal and G6PD-deficient preterm newborns.

G6PD Deficiency, Prematurity, and Oxidative Injury:

G6PD enzyme is present in vital organs throughout the body, with the highest concentrations found in red blood cells, lungs, heart, and smooth muscles. It plays a key role in clearing and recycling free radicals, thereby maintaining cell redox equilibrium. Free radicals are highly reactive and unstable molecules that can cause extensive damage to cellular components. The generation of free radicals is a well-regulated process during cellular respiration, aided by three main intracellular antioxidant defenses: glutathione (GSH), catalase (CAT), and superoxide dismutase (SOD) systems. Nicotinamide adenine dinucleotide phosphate (NADPH) is critical for the detoxification of reactive free radicals by maintaining GSH in its reduced form, and G6PD plays a vital role in the regeneration cycle of NADPH (14). The allosteric binding site for NADPH is offered by catalase (CAT), and CAT activity is dependent on the amount of NADPH (15). Thus, NADPH is key in strengthening all organs' G6PD-related cellular antioxidant systems.

Despite significant technological advances and care practice improvements, preterm birth remains a major contributor to infant



BPD-Bronchopulmonary dysplasia; RDS-Respiratory distress syndrome; NEC-Necrotizing enterocolitis; PDA-Patent ductus arteriosus; ROP-Retinopathy of prematurity; PVL- Periventricular leukomalacia; IVH-Intraventricular hemorrhage

Figure 3: G6PD deficiency and perinatal morbidities.

mortality and morbidity. Multiple human studies have demonstrated that premature infants have higher oxidative stress markers and lower antioxidant defenses at birth (16,17) (Figure 2). Many of these markers are directly associated with the NADPH system. However, there is a lack of data regarding the detrimental effects of reduced enzyme activity in asymptomatic extremely preterm infants.

“Given the multitude of etiological factors influencing retinopathy of prematurity (ROP), the impact of G6PD deficiency on immature retinal vasculature remains unknown.”

G6PD Deficiency, Race, and Perinatal Outcomes:

Numerous studies have shown significant racial differences in prematurity-related perinatal outcomes, including respiratory distress syndrome (RDS), bronchopulmonary dysplasia (BPD), intraventricular hemorrhage (IVH), necrotizing enterocolitis (NEC), and retinopathy of prematurity (ROP), even after controlling for care practices, maternal risk factors, and quality of care (18-23). Recent population studies conducted in Wisconsin and California revealed that prematurity and race pose a significant risk to gestational age-adjusted infant mortality and morbidity in black infants compared to white infants, even when receiving advanced equitable neonatal care in the United States, after accounting for potential confounders such as birth weight, sex, maternal characteristics, and social factors (24,25).

to all these morbidities, a few case reports have associated it with neonatal sepsis and necrotizing enterocolitis (26,27). Two human studies demonstrated a negative correlation between G6PD activity and gestational age in G6PD-normal infants with similar GSH levels at baseline, and G6PD activity did not interfere with diagnosing G6PD deficiency (28,29). Given the heterogeneity of effects generated by pentose pathway byproducts in G6PD deficiency, predicting the ultimate effects on specific organs and tissues is challenging. Mounting evidence (17,30) suggests that small preterm infants have significantly lower catalase and GSH:NADPH ratios than late preterm and term infants. The compounding effect of G6PD deficiency on already weakened antioxidant defense mechanisms can theoretically cause cumulative end-organ damage in preterm infants. Future in vitro and in vivo research could shed light on this area.

Another prospective study in adult diabetic patients revealed a six-fold higher incidence of proliferative diabetic retinopathy in G6PD-deficient diabetic adults than those without this deficiency (18). Given the multitude of etiological factors influencing retinopathy of prematurity (ROP), the impact of G6PD deficiency on immature retinal vasculature remains unknown. Similarly, new bronchopulmonary dysplasia (BPD) is characterized by arrested alveolar and vascular development due to altered cytokine exposure and signaling pathways (30). Interestingly, similar cytokine and gene profiles have been implicated in the pathophysiology of G6PD deficiency (6). A community population study confirmed significantly lower plasma glutathione levels in African Americans, even after adjusting for traditional cardiovascular disease risk factors and inflammation (31). However, further studies are needed to understand the relative contribution and attributable risk of G6PD deficiency to higher oxidative stress in the black population. After adjusting for relevant covariates, another recent perinatal study in placentas from preterm births confirmed significantly greater chronic inflammatory changes in African American mothers. Whether these chronic inflammatory markers and underlying

biological mechanisms influence postnatal transition through oxidative stress and impact preterm morbidities remains unknown.

“Given the interconnected pathways associated with higher oxidative stress in premature infants, studying the relative contribution of quantitative G6PD enzyme activity and its correlation with perinatal morbidities is prudent (29-35) (Figure 3). Specifically, understanding the influence of altered redox status and unregulated free radical activity, with different phenotypes and genotypes, on the outcomes among vulnerable African American preterm infants should be a priority in future neonatal research.”

Although various intrinsic and extrinsic factors can influence prematurity-related morbidities, questions remain regarding the plausible biological contribution of suboptimal G6PD enzyme activity to these outcomes. Given the interconnected pathways associated with higher oxidative stress in premature infants, studying the relative contribution of quantitative G6PD enzyme activity and its correlation with perinatal morbidities is prudent (29-35) (Figure 3). Specifically, understanding the influence of altered redox status and unregulated free radical activity, with different phenotypes and genotypes, on the outcomes among vulnerable African American preterm infants should be a priority in future neonatal research.

Conclusion:

Approximately 10% of births nationwide are preterm, and G6PD deficiency affects at least 50,000-60,000 newborns annually in the United States. The influence of altered redox status from G6PD deficiency on immature respiratory, digestive, immune, and cardiovascular systems in preterm infants is unknown. The combination of a high prevalence of G6PD deficiency in African Americans, poor social determinants of health, higher morbidities, and oxidative injury may create a perfect storm leading to underestimated poor outcomes. Postnatal adaptation resulting from altered oxidative stress in these infants may further influence the onset of chronic diseases such as hypertension and metabolic syndrome in adulthood. Therefore, understanding G6PD deficiency, prematurity, and their interrelationships with underlying immature cellular and organ systems can provide critical insights.

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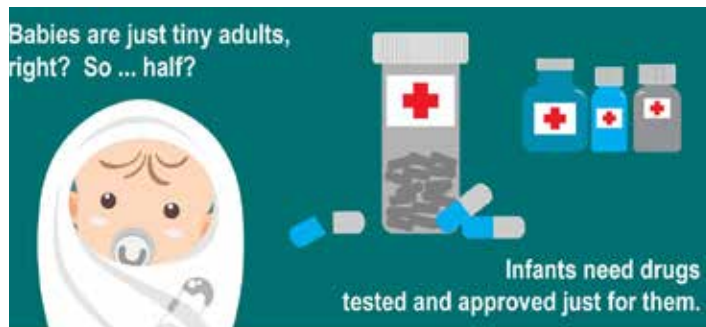
Conflict of Interest: The author has no conflicts of interest relevant to this article to disclose.

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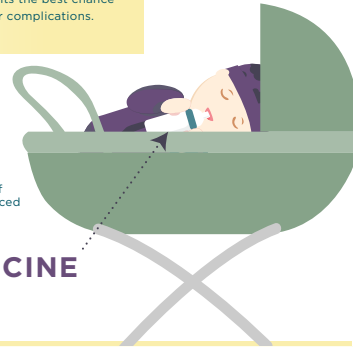
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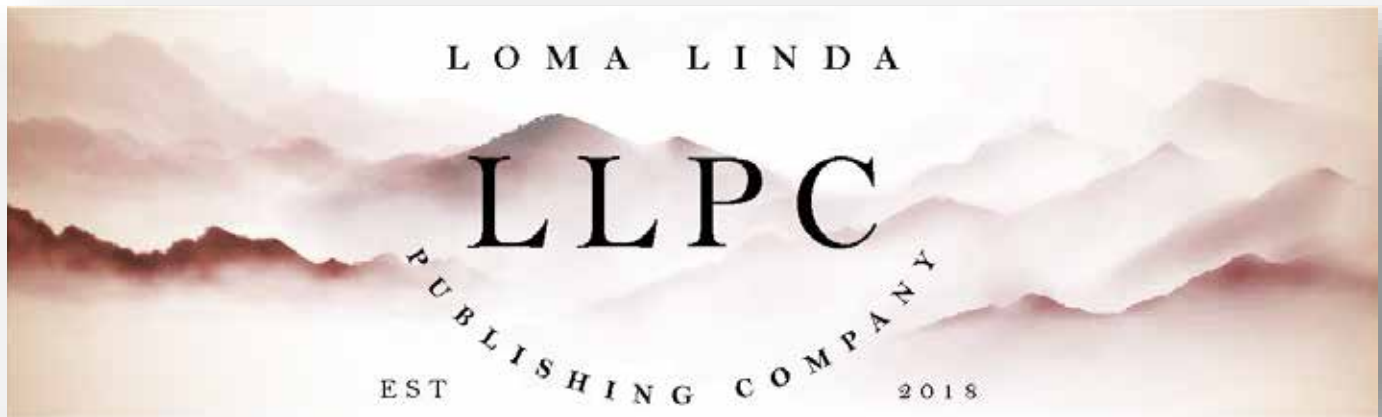
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Ethical Issues with Placebo Use In Neonatal Research

Shabih Manzar, MD, MPH

Summary:

While we cannot deny the benefits and evidence generated by placebo-controlled trials in neonatal research, using any painful procedure or agent with potential side effects should be viewed critically. The neonate has the right to personal respect. All ethical and moral principles should be followed when performing research on neonates.

“While we cannot deny the benefits and evidence generated by placebo-controlled trials in neonatal research, using any painful procedure or agent with potential side effects should be viewed critically.”

A placebo is an inactive substance that looks like the drug or treatment being tested. In research, a placebo is used as a control when studying the effect of certain drugs or treatments. Intramuscular (IM) injection of a placebo into neonates causes pain, and there have been concerns about its use in randomized controlled trials (RCT). A recent article discussed this issue and concluded that placebo injections are neither necessary nor ethically acceptable in neonatal research (1). Examples of unnecessary IM placebo include IM saline injection in 30 control babies while studying the safety of stannosporfin in neonatal jaundice (2). Firstly, the drug is new; secondly, the drug is not a life-saving drug; third, there are better alternatives available to treat neonatal jaundice.

In another study (3), premature neonates received a placebo intravenously every 48 hours for six doses, followed by sham injections three times a week until postmenstrual age (PMA) of 32 weeks (6-7 days), so a preterm infant born at 22 weeks would have received approximately thirty subcutaneous injections (3 per week times ten weeks, 32-week PMA). How could we justify the magnitude of this injustice? In addition to the pain associated with these subcutaneous sham injections, there is a potential risk of infection related to breaching the skin integrity, which is colonized with bacteria. The other example is using saline IM injection of 484 infants while studying the effect of the RSV vaccine (4).

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IM injections hurt, which is an adverse event. So, how can we justify using an IM placebo during RCT in neonates? A placebo's perceived or potential benefits are irrelevant to the study subject. This defeats the fundamental ethical principle of beneficence.

When we look at oral placebo use in neonates, we also see a problem. The choice of a suitable placebo substance is essential. In a recent paper, the investigators used a high sugar-containing oral solution in the control group of neonates with neonatal opiate withdrawal syndrome (NOWS) (5). They used a simple syrup USP (Humco, Sucrose 85% weight per volume; Purified Water; Citric Acid; 0.1% Methylparaben or equivalent). The authors aimed to look at the effect of a drug (ondansetron) in reducing the severity of NOWS symptoms, judged by a score (Finnegan score). This score has 21 components, many of which would be affected by oral sucrose administration. For example: crying, tremors, sucking and feeding, and stools. Sucrose is an active substance used as a non-pharmacological agent during minor painful procedures in neonates. Why shouldn't they use water? This is an example of a breach of the second ethical principle, non-maleficence.

“When we look at oral placebo use in neonates, we also see a problem. The choice of a suitable placebo substance is essential.”

The third crucial ethical principle in research is autonomy. Neonates are incapable of consenting to any intervention. Parents, as surrogates, make all the decisions and are mostly unaware/or told of the pain associated with placebo injections. The fourth principle is also breached during the placebo. Using a painful procedure (IM injection) for research purposes is performed; it is an act of unduly burden imposed, which is injustice.

“Axelin and Salanterä reviewed multiple studies and found that in 75% of the studies, the infants suffered pain during the research with a placebo, and 25% of the journals did not have ethical guidelines for submitted manuscripts.”

Axelin and Salanterä (6) reviewed multiple studies and found that in 75% of the studies, the infants suffered pain during the research with a placebo, and 25% of the journals did not have ethical guidelines for submitted manuscripts. Fleischman (7) looked at the ethical issues in neonatal research involving human subjects and described specific categories of permissible research based on levels of risk. The first category is no greater than minimal; the second is a prospect of direct benefit; and the third is a minor

increase over minimal. A painful placebo or placebo with potential side effects is beyond these criteria.

“Fleischman looked at the ethical issues in neonatal research involving human subjects and described specific categories of permissible research based on levels of risk. The first category is no greater than minimal; the second is a prospect of direct benefit; and the third is a minor increase over minimal. A painful placebo or placebo with potential side effects is beyond these criteria.”

We cannot deny the benefits and evidence generated by RCT in neonatal research. DeMauro et al. (8) stated that RCTs are needed to improve neonatal care, identify better care practices, uncover useless or harmful therapies, reveal new knowledge gaps, and improve outcomes. However, using any painful procedure or agent with potential side effects should be viewed critically. The neonate has the right to personal respect. All ethical principles should be followed when performing research on neonates.

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Author contribution: Dr. Manzar conceptualized and wrote the draft.

Funding and financial support: None

Conflict of interest: None

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Ethics and Wellness Column: Defamation, Slander, and Libel in Medical Practice: Building a Culture of Trust and Accountability

T. Allen Merritt, MD, MHA, Mitchell Goldstein, MD, MBA

Abstract:

This manuscript delves into the critical concepts of defamation, slander, and libel and their relevance within medical practice and interpersonal relationships in healthcare. Emphasizing the profound impact of "To Err is Human," (1) this paper argues for designing systems that prioritize patient safety while fostering a blame-free culture. By examining the role of ethical codes of professional organizations in shaping physicians' conduct towards their peers and other healthcare professionals, the manuscript explores how personal ethics can impact career advancement and overall trust within the medical community. Apologies are addressed as a starting point for rebuilding trust, but progress lies in reducing and preventing errors rather than engaging in futile criticism and peer denigration.

"By examining the role of ethical codes of professional organizations in shaping physicians' conduct towards their peers and other healthcare professionals, the manuscript explores how personal ethics can impact career advancement and overall trust within the medical community. Apologies are addressed as a starting point for rebuilding trust, but progress lies in reducing and preventing errors rather than engaging in futile criticism and peer denigration."

Introduction:

Defamation, slander, and libel are legal terms encompassing false statements or representations that harm an individual's reputation. In the medical realm, such actions can have severe consequences, affecting professional relationships and compromising patient care. This manuscript aims to shed light on the significance of these issues in healthcare settings, emphasizing the need for a proactive approach to building a culture of trust and accountability.

Defining Defamation, Slander, and Libel:

Distinguishing between Defamation, Slander, and Libel is fundamental to understanding the legal and ethical implications of making false statements about an individual that can tarnish their

reputation. (2) In medical practice, where trust and credibility are paramount, grasping the nuances of these terms becomes exceptionally crucial.

In its broadest sense, defamation encompasses making false statements that can harm an individual's reputation. Within this overarching definition, two key subcategories emerge: slander and libel. These subcategories help us differentiate between the mode of communication and the permanence of the medium used to convey the damaging statements.

Slander pertains to defamatory statements that are spoken or orally communicated. When someone makes false claims about another person verbally, and these statements have the potential to harm their reputation, it qualifies as slander. In a medical context, slander might involve making unsubstantiated allegations about a healthcare professional's competence or ethics during a conversation, a meeting, or a verbal exchange. Such statements can lead to not only a decline in the reputation of the individual targeted but also affect their professional relationships and potentially result in legal consequences.

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On the other hand, libel specifically relates to defamatory statements made in writing or through other permanent forms of communication, such as emails, printed publications, or social media posts. These written or recorded statements are considered libel because they are enduring and can be preserved or shared widely. In medical practice, libel might encompass instances where false information about a healthcare provider's qualifications or behavior is published online or disseminated in written documents. The lasting nature of libelous statements makes them especially damaging, as they can be referenced and perpetuated over time, compounding the harm to the individual's reputation.

Recognizing these distinctions between defamation, slander, and libel is essential for several reasons in healthcare. Firstly, healthcare professionals must protect their reputations, as their credibility and integrity directly impact their ability to provide effective patient care. Secondly, understanding these distinctions helps individuals and organizations address the potential impact of harmful rumors and misinformation in a more informed manner.

In a world where information travels rapidly through various chan-

nels, the consequences of slander and libel can be far-reaching and damage the targeted individual's reputation and the trust and confidence that patients and colleagues have in the healthcare system. Therefore, promoting a culture of integrity, accountability, and ethical communication is pivotal in maintaining patients' trust and confidence, upholding healthcare practitioners' professionalism, and ensuring high-quality medical care.

“Therefore, promoting a culture of integrity, accountability, and ethical communication is pivotal in maintaining patients' trust and confidence, upholding healthcare practitioners' professionalism, and ensuring high-quality medical care.”

The Relevance of Defamation in Medical Practice:

Trust is a foundational element in healthcare that binds patients and medical professionals together. Patients rely on the expertise and integrity of their healthcare providers to make life-altering decisions about their well-being. Defamation can undermine this trust, leading to fractured interpersonal relationships and a decline in the quality of patient care. Also, false accusations against healthcare practitioners can damage reputations and potential legal repercussions. Therefore, medical professionals must be vigilant about their words and actions, fostering an environment where open communication and constructive feedback are encouraged.

“Medicine involves complex decision-making, and errors may occur despite the best intentions and efforts. Recognizing that blaming individuals for errors rarely resolves the root cause of mistakes is crucial. Instead, a systemic approach to patient safety should be adopted, emphasizing checks and rechecks to prevent errors and improve healthcare delivery.”

Emphasizing “To Err is Human”:

Lucian Leape's book “Making Healthcare Safe: The Story of the Patient Safety Movement” highlights the inevitability of human error in any profession, including medicine. Medicine involves complex decision-making, and errors may occur despite the best intentions and efforts. Recognizing that blaming individuals for er-

rors rarely resolves the root cause of mistakes is crucial. Instead, a systemic approach to patient safety should be adopted, emphasizing checks and rechecks to prevent errors and improve healthcare delivery. (3) This requires shifting from a culture of blame to learning from mistakes and collectively working toward improvement.

“These ethical guidelines ensure that practitioners adhere to high professionalism and patient care standards. However, the changing landscape of medicine, with its increasing demands and pressures, raises the question of whether these ethical standards are being upheld or if expediency and self-advancement have taken precedence over ethical considerations.”

The Role of Ethical Codes and Professional Organizations:

This section explores how the Code of Ethics, as set forth by the American Medical Association (AMA) and other professional bodies, shapes the behavior and attitudes of physicians and healthcare professionals. These ethical guidelines ensure that practitioners adhere to high professionalism and patient care standards. However, the changing landscape of medicine, with its increasing demands and pressures, raises the question of whether these ethical standards are being upheld or if expediency and self-advancement have taken precedence over ethical considerations. The medical community must reflect on these values and recommit to upholding integrity, respect, accountability, and trust. (4)

Cultivating a Culture of Trust and Accountability:

Building a culture of trust and accountability requires a collective effort from all healthcare team members. This includes physicians, nurses, technicians, administrators, and support staff. Open communication channels are essential, where concerns can be raised without fear of retribution. Fostering a blame-free environment also encourages healthcare professionals to report errors and near-misses, providing valuable data for improving safety protocols and preventing future mistakes. Apologies, when sincere, can serve as a starting point for repairing relationships, but they should be accompanied by concrete actions to prevent future errors and foster a culture of continuous improvement.

Implementing Systems for Error Reduction:

While it is acknowledged that eliminating human error within the healthcare system may not be entirely attainable, it is essential to recognize the extensive array of strategies and measures that healthcare organizations have diligently adopted. These measures aim to reduce the incidence of errors and mitigate the po-

tential or actual harm that may befall patients. In their pursuit of enhancing patient safety, healthcare institutions have employed multifaceted approaches.

“While it is acknowledged that eliminating human error within the healthcare system may not be entirely attainable, it is essential to recognize the extensive array of strategies and measures that healthcare organizations have diligently adopted. These measures aim to reduce the incidence of errors and mitigate the potential or actual harm that may befall patients.”

One of the fundamental strategies that healthcare organizations have embraced is the standardization of procedures. Standardizing protocols and processes ensures that healthcare professionals consistently follow established, evidence-based guidelines. This approach helps minimize the likelihood of errors and promotes a more systematic and streamlined approach to patient care. Additionally, checklists have become invaluable tools in healthcare settings, as reminders for critical tasks and reducing the risk of overlooking essential steps in patient treatment or surgery.

Enhancing communication and teamwork among healthcare professionals is another cornerstone in improving patient safety. Effective communication and collaboration are essential to ensuring that vital information is shared among team members, reducing the likelihood of misunderstandings and errors. This collaborative approach is particularly significant in situations requiring coordinated efforts, such as surgeries and emergency medical interventions.

“Investing in training and education for all healthcare professionals is also critical to mitigating errors. Continuous education and skill development keep healthcare workers up-to-date with the latest advancements and enhance their ability to make informed decisions in high-stress situations.”

Investing in training and education for all healthcare professionals is also critical to mitigating errors. Continuous education and skill development keep healthcare workers up-to-date with the latest advancements and enhance their ability to make informed decisions in high-stress situations. The more prepared healthcare professionals are, the more likely they are to provide safe and ef-

fective patient care.

Moreover, technology and data-driven decision-making have emerged as powerful tools in the quest for improved patient safety. Integrating technology, such as electronic health records and decision support systems, has significantly enhanced the accuracy and efficiency of healthcare processes. (5) These innovations provide healthcare providers access to critical patient information and clinical guidelines, facilitating well-informed decisions and reducing the likelihood of errors.

A noteworthy advancement in the healthcare field is the implementation of procedural “time-outs” and identifying team roles. These measures have made substantial progress in minimizing errors, especially in surgical settings. Time-outs allow the surgical team to pause and verify critical information, such as the patient’s identity, the procedure to be performed, and any allergies or special considerations. Simultaneously, clearly defined team roles ensure that each member understands their responsibilities, reducing the risk of miscommunication and errors.

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Despite these commendable efforts, specific patient safety concerns persist. In-hospital falls, medication errors, and documentation mistakes are areas of heightened concern. These issues necessitate ongoing attention and innovation to enhance patient safety further and reduce the occurrence of adverse events.

Regrettably, professional integrity, safety, and trust in the healthcare industry have faced challenges due to the persistence of a “blame game” culture employed by some individuals. In pursuing personal career interests, these individuals often blame their colleagues for errors or incidents. This approach erodes trust and teamwork, hindering the progress of patient safety initiatives. Healthcare organizations must promote a culture of transparency, accountability, and continuous improvement to counteract this damaging trend and prioritize the well-being of their patients above all else.

Conclusion:

In summary, it is essential to acknowledge that defamation, slander, and libel have far-reaching implications within medical practice, significantly influencing patient care and professional relationships. To effectively address these issues, healthcare systems should adopt a culture that refrains from assigning blame and

instead emphasizes proactive measures for enhancing patient safety and healthcare practitioners' well-being.

“The healthcare environment can evolve into supportive and trust-based by upholding ethical standards and strongly emphasizing accountability. Such a transformation ultimately proves advantageous for both patients and healthcare professionals.”

The healthcare environment can evolve into supportive and trust-based by upholding ethical standards and strongly emphasizing accountability. Such a transformation ultimately proves advantageous for both patients and healthcare professionals. By recognizing that “To Err is Human” and by working collaboratively to prevent errors not only in the context of patient care but also in interactions with peers and fellow medical professionals, physicians and other healthcare providers can continue on their journey toward delivering the highest quality of care while maintaining the principles of integrity and professionalism.

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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

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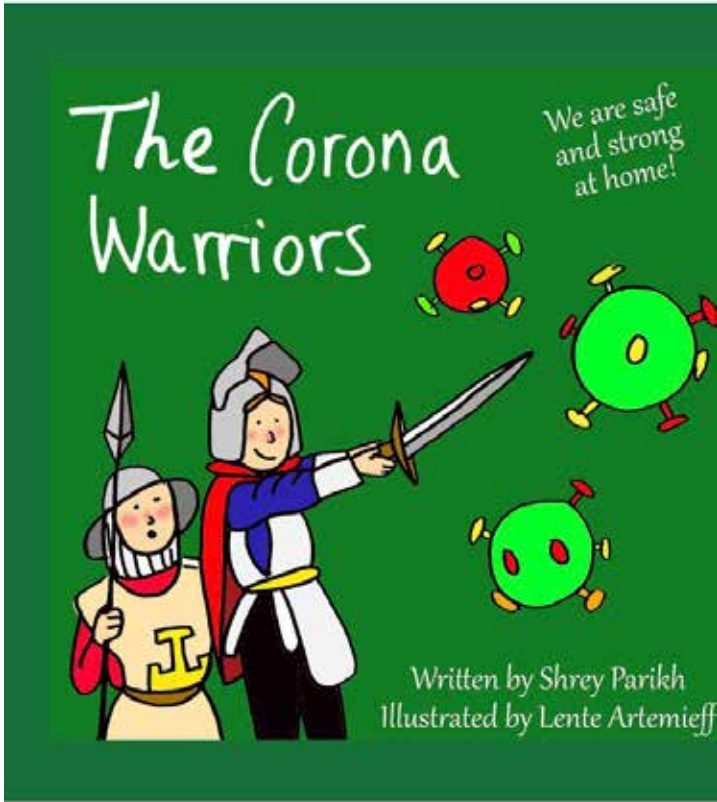


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Keeping Your Baby Safe

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.
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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.
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Letters to the Editor

Letter to Editor: "Gravens By Design: Six Weeks that Changed the Preterm Infant Brain: Insights from the Family Nurture Intervention (FNI) Randomized Control Trials"

Dear Editor:

It is with great pleasure that I write to discuss "Gravens By Design: Six Weeks that Changed the Preterm Infant Brain: Insights from the Family Nurture Intervention (FNI) Randomized Control Trials" Welch, M; Ledwig, R; Hane, A; Myers, M; (Gravens By Design: Six Weeks that Changed the Preterm Infant Brain: Insights from the Family Nurture Intervention (FNI) Randomized Control Trials, Neonatology Today. May 2023;217-226)

"In this article, the authors discuss randomized controlled studies they conducted from 2008 to 2020 that support adding Family Nurture Intervention (FNI) to standard care in the neonatal intensive care unit (NICU). Traditional care in the NICU includes skin-to-skin contact, odor exchange, firm, sustained touch, eye contact, and oral communication."

In this article, the authors discuss randomized controlled studies they conducted from 2008 to 2020 that support adding Family Nurture Intervention (FNI) to standard care in the neonatal intensive care unit (NICU). Traditional care in the NICU includes skin-to-skin contact, odor exchange, firm, sustained touch, eye contact, and oral communication. FNI uses these sensorineural modalities and emphasizes 'emotional expression' between mother and child. Overall, it was found that mother and child had better relational and physiologic health. I find it essential that emotional connection should be prioritized during this extremely plastic time in neonatal cognitive development. FNI significantly improved neurobehavioral functioning, autonomic health, and development in neonates. These early moments of development are crucial because "Brain maturation spans prenatal and early postnatal (infancy) periods, and the sculpting of many important brain circuits continues to adulthood" (1). Ultimately, the foundation set by FNI can lead to positive development into adulthood.

FNI also showed improvement in depressive symptoms in mothers. Pregnancy and childbirth can already be difficult and emotional for mothers. Some "research suggests that depression is one of the most common complications of the prenatal and postpartum periods" (2). It is even more complicated when mothers are separated from their babies, and their only interaction with their infants

is through an incubator. Mothers often blame themselves and suffer from extreme guilt.

"Some "research suggests that depression is one of the most common complications of the prenatal and postpartum periods"(2). It is even more complicated when mothers are separated from their babies, and their only interaction with their infants is through an incubator."

Furthermore, interacting with their babies in this setting leaves them feeling disconnected from their babies. Postpartum depression is already so likely for mothers, with "prevalence [ranging] from 8.5 percent to 11.0 percent at different times during pregnancy and from 6.5 percent to 12.9 percent at different times during the first year postpartum" (2), let alone if you add these extra barriers. The most impactful part of the article was how the authors acknowledged that these feelings of guilt exist and encouraged mothers to heal these wounds with their infants because "prenatal or postpartum periods are not times for nonpsychiatric clinicians to ignore depression" (2). I think it was beautiful that they mentioned one of the ways mothers could emotionally connect with their babies was to apologize to the baby for the suffering and separation they are going through. This often allowed others to cry with their babies, which can be a deep and powerful emotional bonding experience. While mothers may assume that they can only show their babies happiness and positivity, this shows mothers that they can even show real, raw, and sometimes even sad emotions to their babies and still aid their development. This takes tremendous pressure off mothers to be perfect caregivers. Instead, mothers can heal emotionally just by being vulnerable and honest with their infants during this time. I believe that FNI's focus on the mother and child dyad and their emotional connection can make extraordinary differences in the field of neonatology by improving the long-term physiological and physical development of the neonates and mental health of mothers.

"While mothers may assume that they can only show their babies happiness and positivity, this shows mothers that they can even show real, raw, and sometimes even sad emotions to their babies and still aid their development. This takes tremendous pressure off mothers to be perfect caregivers. Instead, mothers can heal emotionally just by being vulnerable and honest with their infants during this time."

While reading the article, I questioned whether this emotional connection is only developmentally beneficial for neonates when it comes from the mom or is emotional care in general. While the mother and child dyad was the focus of this article, I would find it interesting to apply the FNI technique with fathers. Distress, worry, guilt, and depression can also be seen in fathers of preterm infants. Studies have found that “although mothers experienced significantly more postpartum blues (PPB) symptoms than did fathers... fathers showed PPB symptoms earlier than mothers (peak on day 1 for fathers vs. days 3 - 4 for mothers)”(3). This can be because “Unlike the mother who experiences the child growing inside her, it is often only at childbirth that the baby becomes real to the father...studies have shown that many fathers report lacking information and may feel unheard, frustrated, and even excluded at the maternity ward”(4). Encouraging fathers to channel their emotional side with their infants could help improve fathers’ emotional distress, leading to a closer father and baby dyad and a deepened family dynamic overall. For those infants who do not have a mother or father present, it would be interesting to find the effectiveness of FNI with caregivers.

“Encouraging fathers to channel their emotional side with their infants could help improve fathers’ emotional distress, leading to a closer father and baby dyad and a deepened family dynamic overall. For those infants who do not have a mother or father present, it would be interesting to find the effectiveness of FNI with caregivers.”

Thank you to the authors Welch, M; Ledwig, R, Hane, A, Myers, M for completing such dedicated research and exploring the importance of fostering the mother and child dyad emotional relationship. It was a pleasure reading this thought-provoking article. I hope FNI can be implemented in more NICUs to help neonates and their families.

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Best Regards,

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Dear Dr. to be Mirhosseini

The editor wishes to convey gratitude for the reader’s thorough and insightful response to the article, delving into the profound implications of Family Nurture Intervention (FNI) within the neonatal intensive care unit (NICU). The reader’s commentary underscores the significance of emotional connectivity during the initial stages of neonatal development and explores the various research dimensions that warrant more extensive examination.

“The editor wishes to convey gratitude for the reader’s thorough and insightful response to the article, delving into the profound implications of Family Nurture Intervention (FNI) within the neonatal intensive care unit (NICU). The reader’s commentary underscores the significance of emotional connectivity during the initial stages of neonatal development and explores the various research dimensions that warrant more extensive examination.”

In the editor’s estimation, the research conducted by the authors accentuates the importance of prioritizing emotional bonds between parents and their neonates during this particularly vulnerable period. The reader’s discernment regarding the potential advantages of FNI in enhancing neurobehavioral functionality, autonomic health, and overall neonatal development aligns with the article’s central tenets. The editor is heartened by the reader’s recognition of the prospective, enduring benefits that FNI can bestow by establishing a robust groundwork for lifelong well-being.

Furthermore, the reader’s recommendation to contemplate extending FNI techniques to include fathers and other caregivers is a commendable and worthwhile point of discussion. As astutely noted, fathers, too, grapple with emotional challenges when their infants are placed in the NICU, and the cultivation of a more intimate father-infant relationship, coupled with improved familial dynamics, could yield far-reaching positive outcomes. Furthermore, examining the potential efficacy of FNI when applied to various

caregivers in instances where parents may be absent is a novel and captivating avenue for further investigation. The diversification of the application of FNI to encompass a broader spectrum of caregivers has the potential to induce a meaningful transformation within neonatal care and familial support.

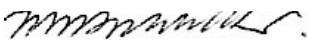
“Furthermore, examining the potential efficacy of FNI when applied to various caregivers in instances where parents may be absent is a novel and captivating avenue for further investigation. The diversification of the application of FNI to encompass a broader spectrum of caregivers has the potential to induce a meaningful transformation within neonatal care and familial support.”

The editor shares the reader’s optimism concerning the increased implementation of FNI within NICUs throughout the healthcare system, with a shared commitment to enhancing the well-being of neonates and their families. The research executed by Welch, Ledwig, Hane, Myers, and their peers is regarded as a noteworthy and invaluable contribution to neonatology, for it underscores the critical significance of nurturing emotional bonds during this pivotal phase.

“To conclude, the editor acknowledges the reader’s sagacious insights and analytical acumen as a testament to their profound engagement with the subject matter. The editor encourages continued dialogue and the pursuit of further research endeavors to realize the full potential of FNI and similar interventions.”

To conclude, the editor acknowledges the reader’s sagacious insights and analytical acumen as a testament to their profound engagement with the subject matter. The editor encourages continued dialogue and the pursuit of further research endeavors to realize the full potential of FNI and similar interventions. The reader’s considerate response substantially enriches the ongoing discourse on neonatal care and familial well-being.

Sincerely,



Mitchell Goldstein, MD, MBA, CML

Editor in Chief

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

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Please address your response in the form of a letter. For further formatting questions and submissions, please contact Mitchell Goldstein, MD at LomaLindaPublishingCompany@gmail.com.

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Erratum (Neonatology Today September, 2023)

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

Corrections can be sent directly to LomaLindaPublishingCompany@gmail.com. The most recent edition of Neonatology Today including any previously identified erratum may be downloaded from www.neonatologytoday.net.

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Cardiology Corner: A Prenatal Diagnosis of Transposition of the Great Arteries

Gil Wernovsky MD, FAAP, FACC; Benjamin Hopkins BS (Discussant)

“In this series, I plan on emphasizing case studies and important points for front-line providers and neonatologists regarding complex cardiovascular physiology, particularly in neonates with structurally abnormal hearts.”

In this series, I plan on emphasizing case studies and important points for front-line providers and neonatologists regarding complex cardiovascular physiology, particularly in neonates with structurally abnormal hearts.

I want to discuss a recent case involving a full-term baby with a prenatal diagnosis of transposition of the great arteries with an intact ventricular septum (TGA/IVS). The baby was delivered by spontaneous vaginal delivery at term and was transferred to a level 4 NICU in good condition, weighing 3.3 kg, with APGARs of eight and nine, and was a very vigorous baby with no distress. The pulse oximeter recordings in the right arm and right leg were in the high 70s. A prostaglandin infusion was started at 0.05 mcg/kg/min; umbilical venous and arterial catheters were placed. The baby was electively intubated for a balloon atrial septostomy at the bedside within the first 24 hours of age, which proceeded uneventfully. Oxygen saturations rose to the high 80's, in an FIO₂ of 0.4.

A discussion was then had between the staff neonatologist and the consulting cardiologist about the saturation goals. I am always hesitant to answer that question in a dogmatic fashion, as it may result in overtreatment or undertreatment of the underlying pathophysiology in certain situations. Picking a “goal” saturation may oversimplify the unique anatomy and physiology of the particular baby in front of you, and does not take into account the unknowns of the transitional circulation. The question is better framed in the context of not what the saturations “*should*” be, but if they are not as expected, what contributes to the changes in arterial oxygen saturation in *this particular baby* with *this particular disease*? This is particularly important in understanding the implications of a saturation of 70 versus a saturation of 90. Another essential aspect to remember is that you must always state where in the body saturation is being measured in TGA: is it measured in the right hand proximal to the ductus, or is the saturation measured in the foot distal to the ductus?

Transient elevations in the pulmonary vascular resistance in babies with TGA and an open ductus will result in a post-ductal saturation higher than the preductal saturation: so-called “reverse differential cyanosis.” From a management perspective, a small difference is of no clinical importance, and management of TGA in any circumstance should be

based on the pre-ductal saturation – the blood that supplies the brain and the coronary arteries.

I need to emphasize that each one of these babies with TGA is different in “how the blood goes around,” TGA being less predictable than, for example, truncus arteriosus, total anomalous venous return, or hypoplastic left heart syndrome as inter-circulatory mixing is more variable and in TGA than the other three examples. Secondly, the impact of more routine NICU interventions (volume, supplemental oxygen, mechanical ventilation), as well as the transitional circulation and labile pulmonary vascular resistance, change oxygen delivery considerably more than in babies with other forms of CHD and certainly compared to babies with structurally normal hearts.

“It is important to remember what contributes to the peripheral arterial oxygen saturation in babies with TGA. The only way oxygenated blood gets from the pulmonary veins to the ascending aorta is through an atrial septal defect (ASD), which may be the most crucial part of the discussion of this baby.”

Differential Diagnosis of Unacceptable Hypoxemia in a Baby with TGA:

It is important to remember what contributes to the peripheral arterial oxygen saturation in babies with TGA. **The only way oxygenated blood gets from the pulmonary veins to the ascending aorta is through an atrial septal defect (ASD)**, which may be the most crucial part of the discussion of this baby. Therefore, in this patient, the upper body oxygen saturation is primarily related to the amount of left atrial return, which is the total pulmonary blood flow. If the saturation is in the 90 range, there is considerable blood flow from the left to the right atrium (RA). If one is dealing with a saturation of 75 percent, there is less blood flow going from the LA to the RA to the ascending aorta.

There are three reasons why there might be decreased LA return going to the right atrium, with resultant unacceptable hypoxemia:

1. Less pulmonary blood flow due to a small patent ductus arteriosus
2. Less shunting of blood from the LA to the RA due to a small intra-atrial communication
3. Less pulmonary blood flow due to elevated or labile pulmonary vascular resistance

Note that the top 2 of these 3 are “cardiac” causes rather than more common pulmonary vascular causes found in most babies in the NICU.

I have seen situations where the prostaglandin at a usual dose has less effect than expected. I have also seen hypoxemic babies where the prostaglandin is correctly ordered, but the infusion is disconnected at the hub and delivered into the bed. I have seen situations where the vascular access is extravascular, and the baby is not receiving prostaglandin. If you are caring for a baby whose circulation is “PGE dependent,” the very first thing to check is that the PGE is being delivered in the right place and at the correct dose.

The second thing to assess is if the ASD is adequate in size. If the PDA and atrial septal defect are acceptable, then a baby’s oxygen saturation is going to be, in general, 75 to 85 percent in the upper body. If a baby is saturating in the very high range for TGA, say, 88 to 92, that tells you that there is significant pulmonary blood flow, which gives a fair amount of pulmonary venous return and, therefore, LA to RA shunting. However, one must be mindful in a patient with a PDA that if saturations are high (high pulmonary blood flow), frequent assessment of adequate systemic blood flow is very important. As in babies with a structurally normal heart, high flow from the aorta to the pulmonary artery through a PDA puts systemic flow at risk, particularly to the coronaries, brain, and gut.

Back to this Case:

The challenge for the team in this particular baby was on the first post-operative night when the saturations in the right arm were very labile - between 78 to 92. The team correctly diagnosed labile pulmonary vascular resistance physiology and started up to 80 percent supplemental oxygen. The saturations then remained in the low 90 range. About 6 hours later, saturations fell into the mid-80s and inhaled nitric oxide was instituted. The baby became tachycardic and hypotensive and developed an elevated serum lactate. Volume infusions were given, and an epinephrine infusion was begun.

“One of the things I tell my trainees frequently is, ‘Don’t fall in love with your first diagnosis.’”

One of the things I tell my trainees frequently is, “Don’t fall in love with your first diagnosis.” The first diagnosis, correctly, was labile pulmonary vascular resistance. However, this then resolved and resulted in quite a bit of pulmonary blood flow and intra-atrial shunting with saturations in the 90s. Nonetheless, an additional vasodilator was added to the oxygen, and a significant “systemic steal” occurred into the pulmonary arteries, with resultant low systemic blood flow. The presence of an open ductus and pulmonary vasodilators may have deleterious effects on systemic blood flow. Another important point for all of us in the ICU: if a baby is not responding to the therapies as expected, check your underlying assumptions.

The final point I would like to emphasize is the difference between oxygen saturation in the blood and oxygen delivery to the tissues. Higher oxygen saturations may not be “better” oxygen saturations (although I frequently hear colleagues refer to them as “better”) if the systemic blood flow delivering that oxygen is compromised.

In summary, this baby had TGA and an excellent septostomy with

an initially labile transitional circulation. The oxygen saturations in the 70s were considered problematic and required treatment. In retrospect, the appropriate management after the septostomy became problematic over the ensuing hours when the pulmonary vascular resistance fell and remained low. Fortunately for the baby, with the removal of the pulmonary vasodilators (supplemental oxygen and nitric oxide), there was a prompt improvement in the blood pressure, systemic oxygen delivery, and the lactate normalized. The baby was then scheduled for an arterial switch, which went well and was uneventful.

“Four Takeaway Points:

- 1. An ASD is the only reliable way to get oxygenated blood from the pulmonary veins to the aorta.***
 - 2. Instead of asking what the saturation “should” be, the bedside staff should understand all the factors that determine the oxygen saturation and why they might change over time.***
 - 3. The combination of a PDA and any type of pulmonary vasodilator – including supplemental oxygen - must be monitored exceptionally cautiously. (This is important for babies with structurally normal hearts as well)***
 - 4. Lastly, blue is better than gray.”***
-

Four Takeaway Points:

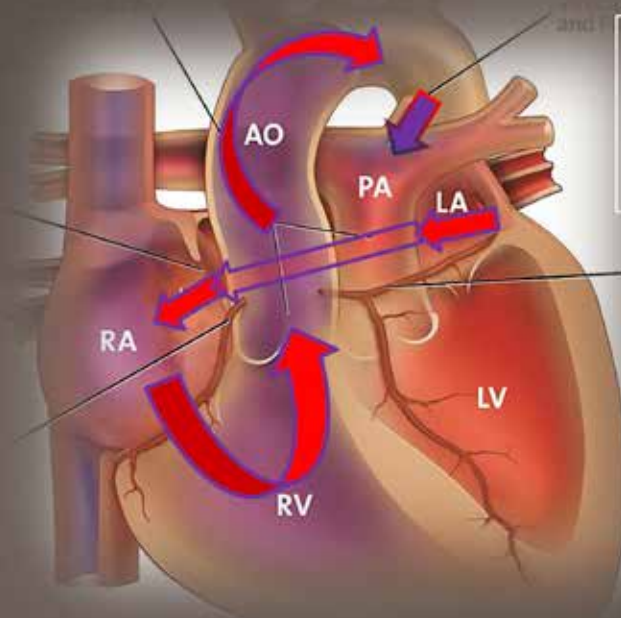
1. An ASD is the only reliable way to get oxygenated blood from the pulmonary veins to the aorta
2. Instead of asking what the saturation “should” be, the bedside staff should understand all the factors that determine the oxygen saturation and why they might change over time.
3. The combination of a PDA and any type of pulmonary vasodilator – including supplemental oxygen - must be monitored exceptionally cautiously. (This is important for babies with structurally normal hearts as well)
4. Lastly, blue is better than gray.

Disclosure: The authors have no conflicts of interests to disclose.

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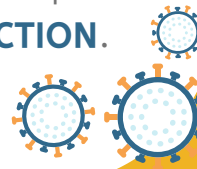
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Should Infants Be Separated from Mothers with COVID-19?

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.



BASED ON THE ARTICLE:

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

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Fellows Column: Case Report: Intraoperative Identification of PDA During Surgical Ligation

Tushara Govind, OSM3, Suha Godil, OSM3, Amal Shafi, OSM3

Background:

The ductus arteriosus is a vascular structure that connects the proximal descending aorta to the pulmonary artery. In fetal circulation, approximately 65% of cardiac output is from the right ventricle, and a patent ductus arteriosus (PDA) allows this right ventricular output to be diverted from its path into pulmonary circulation into the descending aorta. After birth, increased oxygen tension and systemic vascular resistance will cause a reversal from the fetal right-to-left flow to a neonatal left-to-right shunt (1, 2). It typically closes spontaneously after birth, but its persistence beyond a few weeks of life is abnormal.

“After birth, increased oxygen tension and systemic vascular resistance will cause a reversal from the fetal right-to-left flow to a neonatal left-to-right shunt (1, 2). It typically closes spontaneously after birth, but its persistence beyond a few weeks of life is abnormal.”

In extremely premature infants, closure of the ductus arteriosus can be significantly delayed, and a PDA is associated with increased morbidity and mortality (2,3). The hemodynamic impact of the PDA largely depends on the magnitude of shunting and the size of the cardiac vessels. Left-to-right shunting increases pulmonary flow and fluid volume, resulting in increased work of breathing and pulmonary edema. Increased flow to the left heart causes compensation by the left atrium and ventricle, leading to tachycardia, increased myocardial oxygen demand, and potential subendocardial ischemia (2). Closure of the PDA can be achieved pharmacologically with COX inhibitors, including Indomethacin and Ibuprofen, and surgically via catheter-based procedures or surgical ligation (4,5).

Patients with hemodynamically significant PDAs (hsPDA) demonstrate significant differences between pre and post-ductal perfusion indexes (PI). Echocardiography is the gold standard for diagnosing a PDA and a hemodynamically significant degree of shunt, particularly in extremely premature neonates (3). Saturation probes placed on the patient's right hand obtain a pre-ductal reading, and on either foot to obtain post-ductal readings. As such, studies have shown the effectiveness of using PI as a bedside measurement to identify PDA in premature infants and assess the post-operative success of PDA ligation (6). Following successful ligation of hsPDAs, significant increases in oxygen saturation occur (7).

Case presentation:

HPI:

A 615g male infant was born at 23 weeks and 6 days of gestational age by emergency cesarean section. Upon delivery, the infant was limp, apneic, and pulseless, with Apgar scores of 0, 3, 3, 5, and 7 at 1, 5, 10, 15, and 20 minutes, respectively. The infant was intubated, given PPO2 with 100% oxygen, and continued via an endotracheal tube. Epinephrine was administered via an endotracheal tube with continued cardiac compression. An umbilical vein catheter was then placed, and the patient was given epinephrine with NS bolus, after which the heart rate improved to greater than 100 bpm. Upon admission to the NICU, the patient was placed on a high-frequency jet ventilator, and UAC/UVC lines were placed.

“An initial echocardiogram performed on day 5 of life showed a large PDA with a left-to-right flow and a small mid-septal interatrial communication with a left-to-right flow. Subsequent echos demonstrated increased left to right shunting, with repeat echos showing an increasing left atrium to aortic root diameter over 15 days.”

NICU Course:

The infant continued to experience hypoxemia, need for mechanical ventilation, and hemodynamic instability during his time in the NICU. An initial echocardiogram performed on day 5 of life showed a large PDA with a left-to-right flow and a small mid-septal interatrial communication with a left-to-right flow. Subsequent echos demonstrated increased left to right shunting, with repeat echos showing an increasing left atrium to aortic root diameter over 15 days. These ratios were measured at 1.2, 1.43, 1.5, and finally 1.6 3 days prior to surgical ligation. The standard of care within the Queen of the Valley Hospital NICU is to perform PDA ligation in symptomatic infants under 1000g whose PDAs do not spontaneously close. Given the evidence that the PDA persisted, the decision to proceed with the surgical ligation was made. However, the surgery was delayed by eight days due to candidal tracheitis, for which cardiology and infectious disease recommended one week of treatment before surgery.

An echo performed four days prior to the PDA ligation, at which time the neonate was 20 days old, showed moderate PDA with a left to right flow (with peak gradient 10mmHg), LA/Aorta ratio of 1.6, moderate mid septal interatrial communication with a left to right flow, and mild tricuspid valve regurgitation (with peak TR jet at 42mmHg). Using these results, we proceeded with surgery.

Surgery

The patient was 970g and 24 days old at the time of surgery. A lateral thoracotomy with PDA ligation via titanium clips was performed (8). The patient was placed with right lateral decubitus and

left arm abducted, left chest prepped and draped. Pre-ductal and post-ductal monitors were placed on the patient's right hand and left foot. The incision was made on the posterolateral left chest below and parallel to the inferior scapula, entering the superior border of the third rib. After spreading through the musculature, the rib spreader was used to access the thoracic cavity. The left lung was retracted to expose the descending aorta, after which the pleura and fascia were dissected to reveal the PDA. The vagus nerve was also identified, and care was taken to avoid injury to the structure. There were no other visualized vessels in the field of vision, and a comparison was made to distinguish the aorta from the presumed PDA, noting that the walls of the aorta were thicker and whiter than the PDA. However, the PDA was large, approximately equal in visual diameter to the aorta, and longer, extending further into the cardiac region than expected.

“There were no other visualized vessels in the field of vision, and a comparison was made to distinguish the aorta from the presumed PDA, noting that the walls of the aorta were thicker and whiter than the PDA. However, the PDA was large, approximately equal in visual diameter to the aorta, and longer, extending further into the cardiac region than expected.”

After visualizing the descending aorta, vagus nerve, and suspected PDA, vascular forceps, utilized as the test clamp, were placed on the PDA. Additionally, the pre and post-ductal monitoring was changed to the Masimo saturation monitor (Masimo rainbow SET), allowing for the display of aortic flow waveform, oxygen saturation level, and PI (perfusion index). Post-ductal oxygen saturation marginally increased (to approximately 94-96%), but after a few seconds, pre-ductal and post-ductal oxygen saturation (to mid-80%) and PI (perfusion index) decreased quickly. Of note, the decrease in pre-ductal and post-ductal PI was proportional, with a constant pre-ductal to post-ductal PI ratio of 2:1. There was also no significant increase in blood pressure. Due to the unexpected decrease in vital signs, test clamping was repeated several times, each with the same changes seen. Although the oxygen saturation and PI acutely increased and decreased when the PDA was clamped, the aortic wave flow stayed constant. This was one indication that flow through the aorta was not compromised while clamping the presumed PDA.

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Due to the abnormal changes in vital signs throughout the test clamping, the decision was made to perform an echocardiogram intraoperatively. Once the echo technician arrived, she followed sterile protocol and attempted to identify the PDA. However, she could not do so due to an artifact secondary to the mechanical ventilation. Therefore, focus was shifted to the vasculature, and the ascending and descending aorta were visualized. Doppler was used to confirm flow throughout the aorta, first without the test clamp placed and then with the test clamp. While clamping the presumed PDA, there was sufficient flow through the aorta at both time points. Therefore, with clear, strong flow visualized through the entirety of the aorta, despite the transitory decrease in O₂ saturation and PI, the team concurred that the clamped vessel was the PDA. The procedure proceeded with ligation via two titanium clips placed distally on the aortic end of the ductus to occlude its entire width. Hemostasis was ensured, and a left chest tube was placed. The chest was closed, the muscles were approximated, and the skin was closed. Ultimately, the procedure lasted approximately 3 hours, with the patient requiring fluid administration once.

“While clamping the presumed PDA, there was sufficient flow through the aorta at both time points. Therefore, with clear, strong flow visualized through the entirety of the aorta, despite the transitory decrease in O₂ saturation and PI, the team concurred that the clamped vessel was the PDA.”

Post-operative Management:

The neonate experienced an adrenal crisis post-op day 1, requiring hydrocortisone and volume resuscitation. He also was placed on dopamine for two days to improve blood pressure and urine output, after which he was weaned off. He also experienced edema and hyperkalemia 1-day post-op, for which he received Lasix. Complications included “cath” toes of the first and second digits of the left foot on post-op day 1, which were improved after applying hot compresses to the inguinal region. Renal doppler was consequently performed and unremarkable. The chest tube was removed post-op day four without complications. Blood pressure continued improving through the post-operative period, and the patient was weaned off hydrocortisone.

Discussion:

This case highlights complications and atypical changes that may occur during surgical PDA ligation, with an innovative approach via intraoperative echocardiogram to confirm the identity of the PDA. The appearance of the PDA will vary greatly between neonates, and in this case, given the large size and length and unexpected changes in pre- and post-ductal oxygen monitoring, confirmation was required. Few case reports have reported such changes in vital signs (7, 8), although they are possible outcomes in a PDA ligation procedure. This case provides an example of the abnormalities that can occur during the procedure and a solution to resolve doubt regarding the identity of the ductus arteriosus.

The decision to perform the surgical ligation over alternative treat-

ment methods was clinical and institutional. The standard of care of the NICU at Queen of the Valley Hospital is to perform surgical PDA ligation, rather than medical treatment or other surgical methodologies, in infants under 1000g whose PDAs do not spontaneously close due to concerns for necrotizing enterocolitis (NEC) and intestinal underperfusion. The center has an extraordinarily low rate of spontaneous intestinal perforations and NEC with this standard of care. In this case, our patient was born at 615g with a persistent PDA visualized with serial echocardiograms in the 24 days of life. Indomethacin is typically used as a conservative treatment option for smaller PDAs. Device occlusion (catheter closure) is often not considered an alternative treatment due to the technical challenges of treating small infants under 1 kg and may have been difficult in our patient with aberrant anatomy (9).

“Device occlusion (catheter closure) is often not considered an alternative treatment due to the technical challenges of treating small infants under 1 kg and may have been difficult in our patient with aberrant anatomy (9).”

Classically, the expectation during PDA ligation is for post-ductal oxygen saturation and PI to acutely increase and remain high following placement of the test clamp and removal of the left-to-right shunt (7). This expectation was not met during the procedure, casting doubt about whether the vessel identified was the PDA or another vessel, such as the aorta. This abnormality can be explained by the physiological changes that occur with removing the left-to-right shunt provided by the PDA. Acutely, closure of the shunt can cause increased perfusion through the descending aorta, causing an acute, slight increase in PI and oxygen saturation; however, as the heart receives increased systemic volume, cardiac work, and systemic vascular resistance increase. This can cause PI to decrease, as there is no longer a low-resistance conduit for flow.

Moreover, this patient had a patent PDA for 24 days, so there was an element of heart failure, which would result in post-ligation changes of hypotension rather than hypertension. Of note, there are very few case reports detailing changes monitored during surgical ligation, as we have done in this report. Even further, there are none that detail problems encountered in the identification of the PDA.

“Of note, there are very few case reports detailing changes monitored during surgical ligation, as we have done in this report. Even further, there are none that detail problems encountered in the identification of the PDA.”

The use of echocardiograms during surgical ligation is a novel approach. Echocardiograms are used as the gold standard for the diagnosis of PDAs and the identification of hemodynamic signifi-

cance. However, they are not used for intraoperative confirmation of PDA identity or flow strength through the vasculature as the test clamp is placed. During this procedure, we could not only identify flow through the ascending and descending aorta, but also measure the flow rate with the echocardiogram. According to the echo, numerical measurements were not recorded in real time but were verbally noted to improve after test clamping. Additionally, although we could not identify the PDA due to mechanical ventilator placement, monitoring changes made to the PDA itself before and after test clamping is also a possible use for the intraoperative echo.

Although not routinely seen, an acute post-ductal oxygenation increase followed by a decrease in both pre- and post-ductal oxygen levels is a possible outcome of ligation. To prevent future intraoperative uncertainty, increased reporting of intraoperative, pre- and post-operative changes in oxygenation monitoring and blood pressure can provide a more comprehensive timeline for surgical PDA ligations. Additionally, the innovative approach of using echocardiogram intraoperatively serves as a solution in cases where uncertainty in identifying the PDA does occur. Intraoperative echocardiography provides real-time information regarding the PDA and cardiac flow. This identifies the PDA and can also provide measurements for the strength of circulation, which may inform practitioners of the risk for future hemodynamic complications. PI changes that correlate with echocardiographic findings may be useful in avoiding the need for interoperative echocardiography.

“While clamping the presumed PDA, there was sufficient flow through the aorta at both time points. Therefore, with clear, strong flow visualized through the entirety of the aorta, despite the transitory decrease in O2 saturation and PI, the team concurred that the clamped vessel was the PDA.”

This report has multiple weaknesses. We describe only one case; no conclusion can be drawn from these findings. A full echocardiogram was not obtained during surgery, as the primary focus was confirming PDA identification. The use of echocardiography also increased the total duration of the surgery significantly, and the consequences of increased operating time must be weighed against its benefits in future use.

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Disclosure: The authors have no conflicts of interests to disclose.

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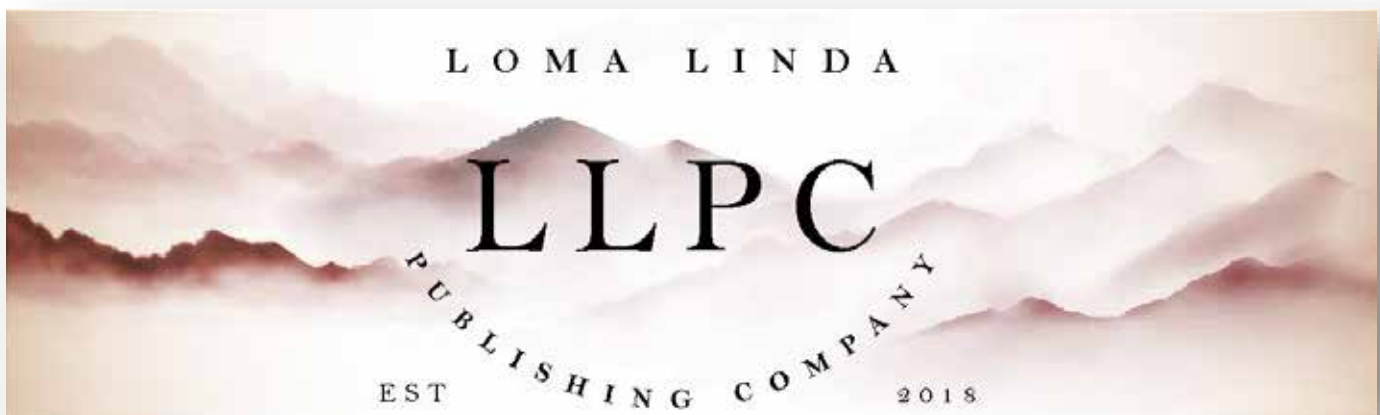
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High-Reliability Organizing (HRO) for Disasters: Lessons Learned

Daved van Stralen, MD, FAAP; Sean D. McKay, Element Rescue, LLC; Thomas A. Mercer, RAdm, USN (Retired)

Abstract:

This abstract summarizes critical insights from the manuscript, focusing on lessons learned in neonatal disaster response. The manuscript emphasizes the multifaceted challenges in such scenarios, including environmental issues, clinical care considerations, staffing concerns, communication difficulties, simulation needs, government agency collaboration, and comprehensive planning. Adopting a broader perspective and collaborating with experts from various fields to enhance neonatal disaster preparedness is highlighted. The structured process of lessons learned is emphasized, especially the analysis of observed data, the formulation of corrective actions and recommendations, and the integrating of diverse perspectives and expertise. Ultimately, the goal is to reduce potential failures and improve the survivability of neonates during disasters.

Introduction:

We have reviewed published accounts of disasters that led to Neonatologists evacuating neonates from the NICU or sheltering in place (1-3). The disasters formed three groups: an abrupt change, a rapid approach, and a sustained presence. The reactions of NICU staff were to rapidly protect and move the neonates, consider the dynamically changing safety between evacuation and sheltering, and continual improvisation to preserve life.

“We have reviewed published accounts of disasters that led to Neonatologists evacuating neonates from the NICU or sheltering in place (1-3). The disasters formed three groups: an abrupt change, a rapid approach, and a sustained presence. The reactions of NICU staff were to rapidly protect and move the neonates, consider the dynamically changing safety between evacuation and sheltering, and continual improvisation to preserve life.”

The Lessons Learned that the respective authors and our review identified were shared across all experiences. The authors expressed the more typical lessons learned as suggestions from their experience rather than an investigation expanding their experience into other scientific domains or using outside Subject Matter Experts.

They missed lessons embedded in their vibrant descriptions of their intense experiences. They accepted improvisation as the expected response rather than close adherence to rules or reliance

on distant authorities. This was the material we teased out of their experience and presented it with little interpretation of the experience and more interpretation as examples of the natural feel of High-Reliability Organizing (HRO).

It is a testament to the care and evacuation of over 235 infants with prolonged care lasting hours to days that only two infants died. Neonatology would be well-served to exploit the ingenuity and dedication demonstrated by this Neonatology community for answers about preparing to shelter and evacuate.

Lessons Learned programs are continually at risk for “conceptual arrest” – the Lesson Learned that is a concept, an abstraction, something that has not, and cannot, be contextualized. A disaster creates abrupt gaps between what we thought we could do and what we must do, with the urgent need to engage the situation. Lessons Learned convert these experiences into more effective organizational performance and improved personnel capabilities. In these volatile and uncertain environments, failure is an option.

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A disaster is an *environmental* disruption of medical care, a *victim generator* that disrupts the *ability to treat* multiple patients. The government’s response is to bring in an infrastructure for managing the disaster to increase survivability and return the community to routine operations. The medical response most often relies on the pre-disaster healthcare infrastructure, continuation of medical care, and the goal of *reducing mortality* by treating factors that cause death (4).

The Lesson Learned provides realistic, actionable recommendations that cause an organization to improve from the knowledge acquired after an adverse experience. It reduces or eliminates potential failures and mishaps or reinforces a positive result. Analytical processes discover what happened and why it happened. By identifying the root causes and remedial or corrective actions, experiences are transformed into best practices and lessons. Expert consultation from subject matter experts (SME) helps the organization understand the collected data to create informed recommendations (5).

The US military has a history of active learning from successes and failures from at least WWII. They have structured this learning as “Lessons Learned,” a formal approach to collect lessons for organizational improvement: an issue is identified as a potential problem, observation and experience of the conditions, then propose recommendations (5). How civilian organizations carry out a Lessons Learned program will differ from the military Lessons Learned system.

The military operates under a single chain of command with appropriate commands that can take ownership of particular issues.

Though the lessons collected are mainly at the tactical level, the internal structure of the military facilitates absorbing observations from the field. The US Army does not consider a lesson to be “learned” until it is implemented and the problem is solved (6).

Healthcare organizations work with other organizations, regulatory agencies, various funding sources, and diverse professional organizations, resulting in multiple chains of command. Civilian organizations do not have the internal structure to absorb Lessons Learned. No single group or agency has the authority to address problems and solutions identified through Lessons Learned (6). Nevertheless, we can use the structure of military Lessons Learned to develop effective healthcare programs.

A Lessons Learned program does not evaluate, inspect, or review incidents. Lessons Learned derive from thoroughly discussing the observations and experiences, highlighting lessons, and then making recommendations within participants’ expertise. Avoid opinions and do not write truisms that are known to be true at all times. “Be generic when it comes to sources but specific when it comes to issues.” (5).

The Lesson Learned must connect to measurable change in behavior. The organization must take deliberate corrective actions from the lessons learned to enhance performance (5). Lessons Learned can prepare the organization for the next disaster or improve routine operations in a manner that supports operations during the next disaster.

“A Lessons Learned program does not evaluate, inspect, or review incidents. Lessons Learned derive from thoroughly discussing the observations and experiences, highlighting lessons, and then making recommendations within participants’ expertise.”

A lesson is knowledge gained by observation or experience, often an adverse experience, that changes behaviors in individuals or organizations. Experiences can be positive (a best practice) or negative (a mishap or failure). For negative experiences, the lessons can be how to avoid the incident, but possibly more useful are lessons for correction and recovery. If an incident happened once, it can happen again; if it happens again, it can happen worse. Teaching correction and recovery are seminal to High-Reliability *Organizing* as the verb (compared to the noun form of HRO, High-Reliability *Organization*).

Lessons come from action, either success or failure, by acting. Action makes the results visible. Karl Weick described failure as not acting, which is not visible and too readily becomes organizational knowledge (7). Social pressure not to act is a hallmark of the ecology of fear, an environment where fear of the threat causes more harm than the threat itself (8). Fear drives failure to act. Hence, fear and “not acting” become a source of organizational knowledge. Error is frequently considered a threat rather than a source of a Lesson Learned (9). Evaluations and investigations of error, the procedure itself is not a Lesson Learned. Error investigations too easily create blame or attribution and an environment that blocks information flow from those who have information to those who need it (5).

In our review of the Neonatology disaster responses (1-3), we find

rapid engagement of a problem that abruptly appears. No descriptions or evidence that fear drove inaction. There was also no evidence that fear impaired effective action. These disaster experiences generated material for effective Lessons Learned that can inform disaster plans for NICUs. However, reviewing the Lessons Learned described in the articles reveals observations without analysis. Specific corrections or improvements accompanied no identified actions. Likewise, there were no descriptions of operational methods that should be reproduced.

We identified common problems the operators encountered. The time course of events, as direction and velocity, had material influences on decisions and actions independent of the nature of the disaster. While the disaster environment was influenced by the type of disaster and the season, the common influences were ambient temperature and air quality. Effectively maintaining effective clinical care came from the attitudes and improvisations of bedside staff rather than support from hospital administration or government agencies.

The Lessons Learned

Operational Lessons Learned were from the environment, clinical care, staffing, and evacuation. Logistics Lessons Learned included communication, simulations, government agencies, and planning.

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Environment

Environmental problems are not isolated but are embedded into each other – damaged structures, toxic air, and cold temperatures. Moving the neonate from a hazardous environment often necessitated entering the same environment but with added transport hazards and fewer protections. This is the conundrum of evacuation before the disaster –moving a neonate from a safe environment through a less safe transport environment when there is no surety of evacuation.

Air quality was the focus of wildland fire Lessons Learned (2). If healthcare providers are seriously affected within the hospital, consider the effect of air quality on the babies in the well-baby nursery and NICU. Also, consider that evacuation will expose neonates to smokey conditions, possibly for over an hour. Evacuation plans should include fire hazards, exposure to debris, and poor air quality (10). Despite ‘air scrubbers’ in place, air quality within the hospitals was poor, with soot and debris (10, 11). Healthcare pro-

viders within the hospital were affected, and some experienced bronchospasm (11).

“Environmental problems are not isolated but are embedded into each other – damaged structures, toxic air, and cold temperatures. Moving the neonate from a hazardous environment often necessitated entering the same environment but with added transport hazards and fewer protections.”

Ambient temperatures for neonatal thermoneutral temperatures, around 90° F. (3), would be considered warm for adults, particularly when humid. Neonates can develop hypothermia when directly exposed to such temperatures or from radiant heat loss to a cloudless sky. Neonates did develop hypothermia in humid “warm” weather with temperatures down to 73° F / 23° C (12-16) and when exposed to colder winter temperatures (17). It is a testament to the healthcare providers that only one adverse event, a death due to hypothermia, occurred. (1)

Thermoregulation was the focus of hurricane Lessons Learned (3). Several NICUs placed neonates in the incubator for warmth and better proximity for nursing care (14, 18). Solutions utilized included using polyethylene bags, chemically activated warming or perineum pads, and skin-to-skin contact using kangaroo mother care if possible (14, 16, 18, 19). Also, better charting and education on the thermoregulation of preterm infants during disaster management is needed (14).

Clinical Care

Treat all expectant mothers and infants as neonates. That is, treat the maternity nursery as a NICU. Consider recovery rooms or similar units as a temporary emergency buffer (20).

Staffing

Identify methods to mobilize additional staffing (11). Prepare a script for on-duty staff to explain the crisis, reasons for the recall, and their responsibilities (10, 11). Concerned about their families and homes, staff may need certain information before returning to work (11).

Give staff guidance on when and where to report for duty and clarify their role and responsibility during the disaster (10). Keep everyone informed promptly. A stressful and intense situation with contradictory information from leaders becomes a significant problem and source of confusion. “The realization that knowledge is power against panic” (21).

An internal alarm system for clinical and facility administrators can facilitate the rapid recruitment of sufficient staff (20). A crisis management system can identify who has authority and what instructions can be issued (20). Calmness, open-mindedness, tolerance, and improvisation are valuable traits (22).

Incorporate the NICU social worker into the disaster response rather than a social worker from an unfamiliar unit. The social worker, trusted and familiar to families, assists staff during the crisis (21).

Hospital administrations can assist staff in developing family evacuation plans, alleviating some of their worry (21). To return to, or stay at, work can create untenable tension between their duty to protect patients and their duty to protect their families (11).

Staff as Victims

A person becomes drained after 24-48 hours of uninterrupted professional experience with disruption and loss (21, 23). The disaster experienced personally by staff compounds the fatigue.

“An internal alarm system for clinical and facility administrators can facilitate the rapid recruitment of sufficient staff (20). A crisis management system can identify who has authority and what instructions can be issued (20). Calmness, open-mindedness, tolerance, and improvisation are valuable traits (22).”

Healthcare providers and hospital workers may have young children, teenagers, or disabled dependents at home. To stay at the hospital could endanger their family members. Staff may also need to remain at home or return home (11). PICU staff at Loma Linda University Children’s Hospital, supported by colleagues and hospital administration, returned to their homes and children during the Panorama Fire (CA) on November 24, 1980.

Under even mild stress, we lose our prefrontal cortex abilities (24). Adolescents are the most susceptible. Their loss of PFC function is more significant, yet unrecognized, as they revert to an earlier childhood state. Adults commonly revert to the mental state of middle adolescence.

Staff may be losing their homes or a loved one during the disaster (23). Travel during a disaster can become deadly. One nurse, evacuating with her family during a wildland fire, was caught in the fire. Her daughter died, and another daughter suffered severe burns (11). Returning to duty immediately after the Northridge Earthquake, an LAPD officer died as he drove his motorcycle off a sheared-off freeway (25).

Evacuation

Develop a central authority or system to facilitate mass transfers of neonates (26). Inefficiencies and communication disconnections interfered with the development of evacuation plans and evacuation preparation (10, 21). Identify methods to mobilize additional staffing, develop transportation options, and identify receiving hospitals (11).

The JSNHD disaster communication team facilitated a network with remote NICUs. The online directory and communication tools included internet phone text messages facilitating contact with outlying NICUs (17). Not having a program like this was identified as a significant deficit during an abrupt disaster (20). Such a system would benefit larger hospitals for internal communication, where communication during an internal disaster became problematic (27).

Develop a NICU-specific evacuation policy with procedures, have

a quick triage method, and create easy-to-use checklists and supply lists (21). Improvisation for transport triage is effective. One NICU created its system for evacuation priority, relying on its knowledge of the infants.

Envisage evacuation, emergency routes, and necessary actions you would take if the expected route becomes obstructed or dangerous (20). In an emergent evacuation, specialized ambulance transport teams would be used without accompanying neonatologists or nurses (21). Medicating patients prior to transfer reduces difficulties in equipment (11) and medication administration by EMS personnel.

“Develop a central authority or system to facilitate mass transfers of neonates (26). Inefficiencies and communication disconnections interfered with the development of evacuation plans and evacuation preparation (10, 21). Identify methods to mobilize additional staffing, develop transportation options, and identify receiving hospitals (11). ”

Urgent or emergency transportation exposes infants to kinetic activity and vibration, exposing them to the risk of compromised cerebral circulation or loss of a secure endotracheal tube or vascular access (17, 20). For sick infants on long-distance transportation, minimize the threat from transport using helicopters or neonatal ambulances (17).

Impaired patient handoff for the adult hospital resulted when patients were transported with minimal medical information. Nurses counteracted this problem by nurse-initiated RN-to-RN phone reports (10).

For internal evacuation of patients, bring care stock items and medication carts to the same unit (27).

Communication

Improve the communication structure and include physicians in hospital incident command meetings. Inefficiencies and communication disconnections interfered with the development of evacuation plans and evacuation preparation (10, 21). Develop an incident command communication workflow specific to the NICU that connects to the hospital incident command (21, 28).

Simulations

Conduct simulations for evacuation and/or transport. Prepare or think through general scenarios for a framework to operate in a disaster (21)—*hospital as a haven*. Residents arrived at the hospital with families and pets (10).

Government Agencies

Work with government agencies to correct “covert but serious risks in relying on the adult-based coordination system of transportation” (17). Neonatologists can present to government disaster agencies the unique way the danger of a disaster brings threats to the neonate, such as hypothermia, vibration, and toxic

air (17, 20, 27).

Work with public safety to develop a unified or unifiable command structure with public safety. Obtain the capability to communicate on a public safety radio frequency (27).

“Improve the communication structure and include physicians in hospital incident command meetings. Inefficiencies and communication disconnections interfered with the development of evacuation plans and evacuation preparation (10, 21).”

Planning

Food supplies in the NICU (22). From experience, it is recommended that each person should bring necessary food and supplies for three days separate from the hospital supply.

Created an organizational structure for NICU-specific disaster management (26):

- Evacuation and surge plans are incorporated into the preparedness plan.
- Coordinated with the New York City Pediatric Disaster Coalition.
- Explicitly detail our NICU Incident Command Structure, which includes the designation of our staff social worker as liaison to NICU families.
- NICU-specific evacuation equipment must be stocked in an easily accessible location.
- The disaster plan includes strategic placement of transport isolettes (ground floor)
- Evacuation and power outage checklists.
- Simulation center has a plan for neonates and vertical evacuation.

The listed Lessons Learned tended toward generalities with few concrete recommendations. No Lesson Learned went beyond the domain of Neonatology or contained information from Subject Matter Experts (SME). No Lessons Learned connected a problem described in the article with a solution that the Neonatologist can act upon. Our review identified consequential problems that may lead to more robust discussions for disaster education, training, and planning.

Problems Encountered

For healthcare, a disaster is an *environmental disruption* of medical care that disrupts the *ability to treat multiple patients*. This is a functional, ecological definition (29). Environmental problems are not isolated but are embedded into each other – damaged structure, toxic air, cold temperatures, moving from one problem places the neonate into another.

A disaster creates an adverse, austere environment. Whether remaining in the disaster environment or evacuating to a better location, healthcare providers will improvise. Evacuation has hazards unique to transportation, contributing to whether to transport neonates when the environment is stable or unstable and hazardous. Standards of care also differ. Stable circumstances constrain the choice of transport team and vehicle to a higher level with less

availability. More typical was transport when the environment had become hazardous, changing the standards of care to allow access to more vehicles. However, during the disaster, government agencies control transport resources and restrict the movement of vehicles, whether air or ground. This is the disaster infrastructure that was unfamiliar to hospital-based healthcare professionals.

“For healthcare, a disaster is an environmental disruption of medical care that disrupts the ability to treat multiple patients. This is a functional, ecological definition (29).”

Time Course

When the environment abruptly entered the NICU, evacuation became an action rather than a decision (1). Staff responded expeditiously to protect the neonate from cold while moving to a safer location. These are granular actions taken at the local level emerging from local capabilities and resources. In the published experiences, one neonate died from exposure to the environment.

- Staff may benefit from preparatory discussions regarding the movements of multiple neonates and safe zones at various distances from the NICU - Also, articulating what constitutes a safe zone for various circumstances: damaged windows, fire, smoke, etc.

A slower-approaching danger, such as wildland fire, creates a different dilemma between evacuating or sheltering (2) - Visibility from smoke impaired surface transport of neonates and air operations (10, 11, 21). Congestion from evacuating residents, fire burn over, and visibility impaired the use of roads (10, 11, 21). The Neonatologists made simultaneous plans to shelter and transport.

- Staff may benefit from preparatory discussions regarding road conditions and hazards, ‘weatherproofing’ neonates, and articulating dangers from smoke or flood.

After the disaster event passes, a different time course develops – the return of regular operations or formal evacuation out of the hospital. Evacuation times in this series were 4-12 hours at approximately 2-4 neonates per hour. One hospital had data for evacuation *before* a hurricane – 19 neonates in 18 hours, one neonate per hour. The need for specialized ambulance transport as a standard of care accounted for the longer evacuation time.

- Preparatory discussions about transportation constraints and modes of transportation available or unavailable due to the disaster or disaster management can better support improvised transportation. Neonatologists have used private vehicles, including the personal vehicles of physicians and canoes with a Chief Orthopedic Resident, followed by a fire engine. Neonatologists could become familiar with evacuation times *before* and *after* a disaster.

An additional time course occurred for evacuating several NICUs, with delays in days due to limited resources for evacuation. In one case, disaster managers’ lost’ the hospital, which was evacuated days after staff called a friend out of state who called the NICU evacuation dispatch center.

- Neonatologists can discuss food reserves and toiletries brought by staff for personal use should evacuation from the NICU be delayed for several days.

Environment

Disasters compromise the environment of the NICU and during transport. Neonates may become exposed to cold air, water and contamination, smoke, soot, and toxic gases—visibility from the smoke impaired staff recall, surface transport of patients, and air operations. Hospital ventilation systems could not maintain clean air (10, 11, 21), with some hospitals creating internal respiratory treatment stations (11).

- Preparatory discussions can focus on methods to maintain neonate body temperature and air filtering for the NICU. Hospital and NICU respiratory treatment stations will support staff and family members present during the disaster.

Communication

Communication is commonly brought up in discussions of disaster and a problem for a hospital operating during a structure fire (27). However, *no* NICU reported communication problems, either internal or external.

“After the disaster event passes, a different time course develops – the return of regular operations or formal evacuation out of the hospital.”

Internal command lines of authority and communication did not function well (26, 30). Hospital administration and NICU staff often lacked a clear communication structure. Medical directors and physicians were not included in hospital incident command meetings. In one instance, medical staff leadership decided on evacuation, while nursing leadership decided on shelter. The contradictory conclusions were communicated to their respective staff, creating confusion and exacerbating the tension of an intense situation (21). Furthermore, delegation of responsibilities was problematic. One participant said that if they could have changed one thing, it would be to have a clear command structure in the unit (1, 23).

- Preparatory discussions can bring Neonatologists into medical staff governance and hospital administration to make the neonates’ unique and specific needs visible.

Emergency communication was hampered when staff members were unfamiliar with portable radios, and the hospital had no shared frequency with public safety (27). Notification of family by the media sometimes occurs. If an internal disaster occurs, the family may not know about the problem until they see it on the news (27). For an area-wide disaster, the family may not realize the hospital was evacuated (31).

- Preparatory discussions can bring Neonatologists into the hospital communication system to keep families apprised of the status of the NICU during a disaster.

Transport communication for bed availability, acceptance of the referral, and transportation became a problem independent of the technology. One participant had to text an intermediary to communicate (23). Neonates might arrive at the referral NICU without a call from the evacuating NICU asking for permission or providing a warning. Internet and phone call issues did not help. The surge capacity of receiving NICUs was not predictable. It was fortunate that receiving NICUs could absorb the surge. When this was not practical, improvisations were the PICU, anesthesia recovery

rooms, and the ED (20, 32).

- Preparatory discussions can identify alternate neonatal admission sites within or with receiving hospitals.

“Communication is commonly brought up in discussions of disaster and a problem for a hospital operating during a structure fire (27). However, no NICU reported communication problems, either internal or external.”

Staffing

Increasing staff. Staff requested more information as they balanced work, the safety of their family, the threat to their home, and the ability to travel on the roads to the hospital. Some were trapped in their neighborhoods. Some staff were called home to help the family. Fire trapped one nurse evacuating her family, resulting in a fatality and severe burns (2).

Isolation from family and the expectations to care for premature babies in austere conditions became a severe problem. Staff felt less connected with hospital management during the prolonged isolation (33). Staff provided mutual assistance to each other and the families of patients (3, 14, 16, 18, 19, 22, 33).

Convergent volunteers and returning staff will overwhelm the physical space and the ability of healthcare providers to perform (27). This can occur in public safety incidents also (34). No NICU reported this as a problem.

Clinical Management

Parental contact suffered from power and cell tower outages. This also created distractions for staff working in the NICU concerned about their relatives (3).

Thermoregulation. Keeping babies warm during a tropical cyclone may seem counterintuitive, except thermoneutral temperatures for neonates are around 90° F. Several NICUs placed multiple neonates in the same incubator for warmth or to use the proximity for nursing care (14, 18). Solutions utilized included using polyethylene bags, chemically activated warming or perineum pads, and skin-to-skin contact using kangaroo mother care if possible (3, 14, 16, 18, 19). Neonates would benefit from better charting and education on thermoregulation of preterm infants during disaster management (14).

Supplies and Equipment

Hand disinfectant was a problem for all NICUs.

The availability of oxygen cylinders for one NICU during an earthquake was quickly solved when the infants shared a cylinder (17).

Supplies are damaged during an internal disaster. Evacuating patients internally without accompanying supplies creates shortages in the new unit. Referring to evacuations as transfers rather than an evacuation may trigger normal transfer behaviors and etiquette. Accustomed to moving the patient and not taking supplies from the originating unit, staff carry the same behavior into an evacuation.

Transportation

Neonatal transport with incubator support is not readily available through EMS (20, 27). One NICU used general ambulances to evacuate some of their neonates (17). Neonates are susceptible to environmental stressors such as vibration and cold and kinetic activity or vibration affecting cerebral circulation or the security of endotracheal tubes and vascular access (17, 20).

“Isolation from family and the expectations to care for premature babies in austere conditions became a severe problem. Staff felt less connected with hospital management during the prolonged isolation (33). Staff provided mutual assistance to each other and the families of patients (3, 14, 16, 18, 19, 22, 33).”

Equipment. It is not feasible to pack a bag at the moment for every patient (21).

Medical records. Some patients evacuated with incomplete records due to the limited preparation time (10).

Distance. For an internal evacuation, distance creates a problem because of the smaller response magnitude. That is, the time for transport to an adjacent building is nearly the same as driving to a hospital in the same city. We see this in the decision of whether to move neonates internally or seek receiving hospitals (20). For longer distances, driving three hours increases the risk of adverse events, including hypothermia in a neonate and death (17).

Time. Seeking receiving facilities and the medical handover of complex patients can occupy significant time for the Neonatologist. In some cases, internal evacuation reduced this load (20, 27). We can appreciate transport time in several ways – the actual transport, loss of bedside staff, and complete evacuation. Transport time within a hospital or to an adjacent building was often 40 minutes or more (20, 27). Internal, controlled evacuations occupy 3-7 people for each infant. The time away from bedside care is doubled for preparation and return to the NICU (20, 27). When evacuating infants out of the region, flight times of 40 minutes (32) or driving times of several hours (17) are to be expected.

Bed availability. Most receiving NICUs accepted 2-4 neonates, while a few could accommodate more. The acuity level of the infant affects bed availability. The placement of neonates receiving HFO, mechanical ventilation, and CPAP is a problem. One solution was to change the mode of respiratory support from HFO to conventional ventilation or decrease the classification for oxygen administration to ‘infant status’ (20).

- Preparatory discussions can identify methods to make neonates more accommodating for transfer, such as reducing the support level to create emergency early discharge criteria.

Adult standards.

The uncontrolled environment can rapidly change neonatal physiology. The environment then becomes an independent pathology, increasing neonatal mortality and reducing neonatal survivability. Unfortunately, triage systems in use during disasters derive from

adult pathology and physiology (17), creating a gap in understanding by disaster professionals for supporting the NICU.

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Government agencies.

Constrained use of helicopters and ambulances in two earthquake disasters demonstrate government control of transportation resources (32, 35). Government agencies generally coordinate activity and control out-of-area resource allocation during a disaster. Transportation vehicles are resources controlled by these agencies. Hospitals with a previous contract for transportation vehicles may be exempt from this control.

- Preparatory discussions can educate Neonatologists about the duties and responsibilities of disaster agencies and agencies at federal, state/provincial, county, and municipality levels of government.

In the experience of NICUs in different countries, government agencies do not reliably support NICUs during a disaster (17, 32). In several wildland fire disasters, Neonatologists contacted receiving NICUs, and administrators coordinated transportation for the neonates. They did not have government regional coordination (21). During recovery from a hurricane, contacting NICUs was local to pre-existing personal relationships.

- Preparatory discussions can develop relations between NICUs that may transfer or receive neonates during a large disaster.

Infrastructure of Disaster

A disaster brings together diverse infrastructures, but they are infrastructures of organizations and disciplines accustomed to collaborating. When viewed as relations, infrastructure builds a community. New for NICU sheltering or evacuation are the types of organizations and infrastructures they utilize. For example, air transport will be controlled by a central government agency, and FAA rules and procedures will become more visible.

More commonly identified as shared organizational, physical structures for the operations of organizations, infrastructures may better be understood by how society uses the infrastructure. This “inverted” approach demonstrates that infrastructure emerges for people in practice and is connected to activities and structures. The organization uses infrastructure as a set of techniques and classification systems to apply science and technology for operations, problem-solving, and connecting people in practice to activities and structures. Infrastructure is the invisible glue that holds

the system together (36). Understanding the change in infrastructure brought on by a disaster brings better integration of medical care into disaster operations. An adverse, hostile, and austere environment will compromise effective and efficient healthcare without such integration.

Neonatologists operating in the NICU focus on reducing *mortality and death due to disease*. A disaster brings death from physiological, physical, social, or behavioral threats within the disaster environment. This functional and ecological definition directs our attention to the abrupt change in the NICU environment. No longer does the Neonatologist control the environment around the infant. *Survivability is the reduction of death after the event*. Survivability describes the effect of the environment on mortality as a comorbidity or the impedance connecting necessary medical care to the victim (34). Our goal in the NICU is survivability, preventing deaths resulting from post-disaster events.

“The uncontrolled environment can rapidly change neonatal physiology. The environment then becomes an independent pathology, increasing neonatal mortality and reducing neonatal survivability. Unfortunately, triage systems in use during disasters derive from adult pathology and physiology (17), creating a gap in understanding by disaster professionals for supporting the NICU.”

Translating the risks that extended travel poses to a premature infant is problematic for various reasons, but it can be reduced by understanding the various missions in a disaster and the use of ‘boundary objects’ (29, 37, 38). Description of the consequences, including *how* death could occur, and accurately describing what is necessary to prevent death, along with private anecdotes, can facilitate collaborative action by making it a common problem (39).

Boundary Objects

‘Boundary objects’ facilitate communication across disciplines and organizations while operating in a new boundary infrastructure. Boundary objects are ambiguous yet constant objects shared by adjacent categories, allowing their use by several communities of practice. Boundary objects facilitate local understanding by reframing the object into a broader context of joint activity. Boundary objects contribute to cooperation and communication across borders, often without the need for different groups to communicate, and can help manage the tension between divergent viewpoints (37, 38).

Government agencies focus on survivability and the reduction of death *after* the event. Survivability describes the effect of the environment on mortality as a comorbidity or to impede connecting necessary medical care to the victim (34). Neonatologists focus on reducing mortality and death *due to disease*. Death, then, becomes an effective boundary object for communication.

Structured Lessons Learned

A Lesson Learned must have *significance, validity, and applicability* and *reduce potential failures*. Significance comes from its usefulness in influencing everyday operations. It gains validity in that it is factually and technically correct. Applicability identifies a specific process to address. Reducing or eliminating the potential for failures or reinforcing a positive result is the purpose of a Lesson Learned (5).

Functions of a Lessons Learned Capability

While the military describes six basic functions of a Lessons Learned program (Collect, Analyze, Share, Archive, Resolve, and Assess), we find three elements will help healthcare professionals better understand Lessons Learned: Analysis of observed data, Corrective actions/recommendations, and the Process of Lessons Learned.

Analysis of observed data. Different perspectives bring a better understanding of the data collected from a complex event such as a disaster. By appreciating different perspectives, we discover what happened and why it happened (5).

A disaster is a product of pink noise; therefore, the Gaussian distribution does not apply. More data increases variance, confounding the ability to generate conclusions. Decomposing the disaster to different segments does not support using the Gaussian distribution for statistics and probabilities. The inability to combine different probability distributions into a joint probability distribution is known as *contextuality* in quantum theory (40).

“Neonatologists operating in the NICU focus on reducing mortality and death due to disease. A disaster brings death from physiological, physical, social, or behavioral threats within the disaster environment. This functional and ecological definition directs our attention to the abrupt change in the NICU environment.”

The effect of sequence is significant in red or pink noise environments. *When* an action occurs has a significant effect on the outcome, making some assumptions or questions incompatible. This is not unsurmountable as incompatible questions provide different perspectives of an event, perspectives we need to understand the world (40).

It is relevant for us to know a person's understanding of two events in sequence. This could be understanding the beliefs or experiences of two different people working together in the same situation or the individual processing two different perspectives of the same matter. We must switch between points of view, which may not be compatible. We cannot process both perspectives simultaneously. We cannot decide a matter from more than one perspective – to decide from one perspective you are making your cognitive state dispersed (making indefinite) for the other (40).

In addition to different perspectives, a practical Lessons Learned program consults subject matter experts, deference to expertise in an HRO. Integrating Neonatology with other sciences will also advance Neonatology, extending the field into the disaster space while improving collaboration and improving care of the neonate.

William Harvey, the English physician who first described the complete systemic circulatory system and the heart as its pump, believed that “the best fertilizer for medicine is the progress of other and quite different sciences” (41).

The analysis is incomplete when viewed through constrained perspectives. Having medical, nursing, allied health, and administrative perspectives is not enough. A common problem was the use of helicopters – the NICU is accustomed to calling for helicopters to transport the neonate, while the disaster infrastructure uses helicopters for disaster survey, rescue, and delivery of vital supplies. The NICU will not integrate into the disaster infrastructure without an appreciation of the perspectives of FAA regulations, air traffic controllers, the duties of the disaster Incident Commander, and the professionalism of pilots.

“Government agencies focus on survivability and the reduction of death after the event. Survivability describes the effect of the environment on mortality as a comorbidity or to impede connecting necessary medical care to the victim (34). Neonatologists focus on reducing mortality and death due to disease. Death, then, becomes an effective boundary object for communication.”

Corrective actions/recommendations. We now organize the results of the analysis and develop recommendations. With diverse perspectives and a requisite diversity of experts, the recommendations should be intuitive. We should say what needs to be done(5).

The Process of Lessons Learned. A Lesson Learned uses knowledge acquired after an adverse experience, processes the experience, and then provides actionable recommendations causing the organization to improve. The intent is to reduce or eliminate the potential for failures or to reinforce a positive outcome. The analysis discovers what happened and why it happened. Incorporating knowledge from outside subject matter experts supports a better, effective understanding of data acquired from the disaster. Ideally, informed recommendations become intuitive, making them more readily incorporated into the organization's culture (5).

Conclusion

The intent of a Lesson Learned is to reduce or eliminate the potential for failures or to reinforce a positive outcome. This standard limited the use of published experience describing effective adherence to normative standards. In those articles, we could not identify *how* the adherence was achieved nor *how* that adherence improved disaster response. Lessons that support normative standards readily become a concept, an abstraction, something that has not, and cannot, be contextualized. Such lessons risk “conceptual arrest” (42), acceptance of concepts independent of the ability to use the concepts as contextual actions.

Creation of Lessons Learned from outside events, the spectator-observer view, relies on causation, precision, definitions, and diagnostic testing. The spectator sees no details, feels no experi-

ence, readily drawing on abstract specifications.

- Spectators outside operations focus on what they already know.
- Operators within operations focus on context and what they can learn.

Within events, the operator is pulled by the flow of local events not visible to spectators. From these intense experiences come the vibrant published descriptions we found informative for Lessons Learned. These informed recommendations are more readily incorporated into the organization's culture (5).

We distinguished Problems Encountered from Lessons Learned in the published experiences. The published Lessons Learned did not have commentary from Subject Matter Experts nor did the use of the formal structure found in military Lessons Learned. We identified Problems Encountered hidden within the articles. For the most part, the authors did not recognize the situations as problems because the authors solved the problem. Or the authors did not recognize their solutions or the science supporting their work.

“In addition to different perspectives, a practical Lessons Learned program consults subject matter experts, deference to expertise in an HRO. Integrating Neonatology with other sciences will also advance Neonatology, extending the field into the disaster space while improving collaboration and improving care of the neonate.”

These articles brought out the debilitating physical nature of the disaster environment. They described the quandary and confusion of staff figuring out how to do their job and what to do for their families. They captured the difficulty of evacuate-or-shelter decisions and the ambiguity of information. Most significant is the *value* of information: *Does it help or hurt the neonate? Will it help or hurt the neonate?*

“Within events, the operator is pulled by the flow of local events not visible to spectators. From these intense experiences come the vibrant published descriptions we found informative for Lessons Learned. These informed recommendations are more readily incorporated into the organization's culture (5).”

However, the most vital lesson from these articles is the performance of staff solving problems at the bedside. Their problems,

concerns, actions, and improvisations are not found in the literature from experts. Their articles have kept their voices from becoming hidden.

Better questions for disaster response planning and research: How do we learn from the richness of their experience? Why aren't we reasoning and thinking how they reasoned and thought? Why aren't we treating each other every day like they treated each other?

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Disclosure: The authors have no disclosures.

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Acknowledgments

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

Errol van Stralen, Ancora Education

William J. Corr, formerly with the Los Angeles City Fire Department, now deceased

Dan Kleinman, Operations Section Chief, National Incident Management Organization (retired)



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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/)

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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



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.

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Randall Bell, Ph.D.

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The Nano-Prem: Smaller Presents Big Challenges

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.

“The resuscitation of infants at ≤ 23 weeks PMA (referred to as “nano-prems”) is a relatively new practice for most clinicians if where they practice offers resuscitation to these babies at all. Aside from the challenges of keeping these babies alive, other factors make it difficult to avoid major morbidities.”

The resuscitation of infants at ≤ 23 weeks PMA (referred to as “nano-prems”) is a relatively new practice for most clinicians if where they practice offers resuscitation to these babies at all. Aside from the challenges of keeping these babies alive, other factors make it difficult to avoid major morbidities.

The skin of these babies is very immature. Even the electrode gel used for heart monitoring and temperature probe covers used to keep temperature probes in place often produce chemical burns. The result is an increased risk of acquiring infection trans-dermally and undoubtedly is a source of pain for the baby and stress for parents. In addition, fixation rings for transcutaneous monitoring are also unkind to their fragile skin. The adhesive often causes abrasions and skin tearing, while the probes' heat may cause thermal burns.

Given the propensity for bradycardic events common to all premature infants, not monitoring heart rate is not an option. Heart rate can be monitored via a saturation probe, but not all saturation monitors are equally adept at reporting an accurate heart rate, particularly if perfusion is poor. Heart rate can also be taken from

an arterial line. ECG electrodes for micro-prems have recently come to market that are less likely to create chemical burns.

The effects of excessively high or low PaCO₂ in all premature infants are well known. Large swings in PaCO₂ are equally damaging since the resulting changes in cerebral vascular tone result in alterations to cerebral blood flow. This often results in intraventricular hemorrhage. Monitoring a baby's PaCO₂ is necessary, and the inability to monitor it non-invasively creates the biggest challenge in ventilating safely.

“Monitoring a baby's PaCO₂ is necessary, and the inability to monitor it non-invasively creates the biggest challenge in ventilating safely.”

Frequent drawing of blood gases and adjusting ventilation help achieve a degree of stasis, but problems are also associated with this practice. A premature infant's circulating blood volume (BV) may vary significantly. One study estimated a BV of 70ml/kg. Packed cell volume (PCV) was an unreliable predictor of blood volume; PCV of 0.41 BV ranged from 50 – 105 ml/kg. Furthermore, other laboratory values are also poor indicators of BV (1). These babies have very little blood to spare, and while delayed cord clamping (DCC) increases circulating volume, it is often impossible due to the baby's status at delivery. The many benefits of DCC are well known (2); the safety and feasibility of placental blood banking for autologous transfusion have been demonstrated (3), although it has not become routine. An added potential benefit is the reduction of retinopathy of prematurity, a topic of current ongoing investigation (3,4). Placental blood banking may become a standard of care, especially when DCC is impossible. Regardless of how much BV is on board, blood sampling for lab work depletes BV like a vampire in a feeding frenzy.

“Regardless of how much BV is on board, blood sampling for lab work depletes BV like a vampire in a feeding frenzy.”

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When an umbilical arterial catheter is in situ, flushing the line after drawing represents a significant amount of total fluid intake (TFI) in a tiny baby, and if normal saline (or even half normal saline) may lead to hypernatremia. Avoiding unnecessary procedural pain during the critical first 72 hours of life is an undeniable benefit to having an arterial line. Because there may be a tendency to draw more blood when an arterial line is available (exacerbating iatrogenic anemia), they should be removed as soon as possible. Capillary sampling avoids the problem of excess TFI and sodium overload, but sampling from tiny heels quickly results in bruising (especially when perfusion is poor), reducing the accuracy of some laboratory measurements.

There are automatic blood measuring systems that result in virtually no blood loss, but these still require about 0.5 mls of flush with each measurement to clear the line. These devices perform well (5) but require indwelling arterial access. Anyone who has inserted umbilical or arterial lines in a sub-500-gram baby can attest that successful placement is far from guaranteed.

Regardless of how blood gases are obtained, they are a snapshot of the baby's state. A baby's position may be changed after a blood gas is drawn. Given the positional nature of endotracheal tubes (especially when orally placed in tiny babies), this may result in a significant increase or decrease in PaPCO₂, which will go undetected until the next gas is taken.

“Regardless of how blood gases are obtained, they are a snapshot of the baby’s state. A baby’s position may be changed after a blood gas is drawn. Given the positional nature of endotracheal tubes (especially when orally placed in tiny babies), this may result in a significant increase or decrease in PaPCO₂, which will go undetected until the next gas is taken.”

How can we maintain stability in these babies when our most commonly used tool cannot be used? End-tidal CO₂ monitors (EtCO₂) are accurate proxies of PaCO₂ for trending in the pediatric and adult population, as well as in the neonatal population, albeit with exceptions (6). The validity of EtCO₂ in the latter population notwithstanding, several obstacles exist to their use in the NICU.

Patient triggering in the adult world is accomplished either by negative pressure generated by the patient or by flow sensed by the ventilator as a decrease in bias flow. In the neonatal population, the small flow rate and minimal negative pressures a baby generates cannot trigger most ventilators. As technology improves, this may change, but until then, neonatal ventilators rely on flow sensors located at the patient wye. These sensors provide signals for cycle triggering in conventional modes. They also measure volumes to adjust pressure to approximate a requested target volume and calculate leaks around the ETT.

Current EtCO₂ monitors utilise infrared absorption technology, ei-

ther using an inline measuring device or an external device that aspirates gas from the circuit for measurement. Inline devices add significant dead space since they are situated between the ETT and the circuit wye, and devices that aspirate gas from the circuit may interfere with volume and trigger measurement since the volume aspirated will be interpreted as a leak. This can be significant since volume adjustments in volume-targeted modes are as small as 0.1 MLS.

When it comes to high-frequency ventilation, the very small volumes combined with the associated rates in addition to making current EtCO₂ medical devices useless. This is a critical obstacle as HFV modes are increasingly used as a first-intention strategy.

CO₂ levels in indoor air have become a hot topic since the arrival of COVID-19, and low-cost monitors to detect it are now widely available. Rather than display partial pressure, these devices display CO₂ measurements in parts per million, typically from 0 to 5000 ppm. It stands to reason that a device sensitive enough to detect CO₂ levels as low as 0 ppm will also detect the difference between ambient bias flow levels and that of ambient gas combined with exhaled tidal volumes, although device response times are likely too slow to measure breath-to-breath changes.

One way around this limitation might be to analyse the CO₂ level in an expiratory gas reservoir and compare this reading to ambient air. Correlation between reservoir readings and PaCO₂ measurements taken from blood gases may or may not be demonstrable but could be trended. To my knowledge, this has never been attempted and begs investigation.

“One way around this limitation might be to analyse the CO₂ level in an expiratory gas reservoir and compare this reading to ambient air. Correlation between reservoir readings and PaCO₂ measurements taken from blood gases may or may not be demonstrable but could be trended.”

Dissolved CO₂ in water condensate in the expiratory limb of a ventilator circuit and water traps is reflective of EtCO₂ (7). CO₂ levels could be trended like gas reservoir analysis. Again, investigation of the feasibility of this method is lacking, but if investigation shows it to be feasible, it offers a potential solution to our current monitoring deficit.

Perhaps the most straightforward solution regarding the TcPCO₂ fixation problem would be to find a method of applying the probe without using skin-destroying adhesive rings. Additionally, decreasing the temperature of the heating element should be possible since the immaturity of the nano-prem's skin allows for easier diffusion of CO₂. Decreasing probe temperature also requires clinical validation.

Medical devices are expensive to bring to market, and the nano-

prem population is likely too small to make developing a new monitor profitable for a company. Finding a friendlier fixation device represents the least expensive and most elegant solution.

The ingenuity of bedside clinicians (can you say “Respiratory Therapists?”) has long been a source of discovery. The task at hand is awaiting our ingenuity and acceptance of the challenge.

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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

Corresponding Author



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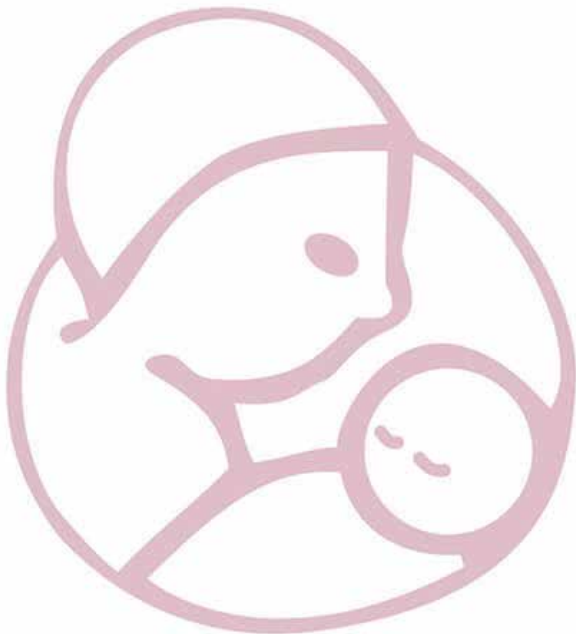
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Thirteen-year-old Emily Rose Shane was tragically murdered on April 3, 2010 on Pacific Coast Highway in Malibu, CA. Our foundation exists to honor her memory.

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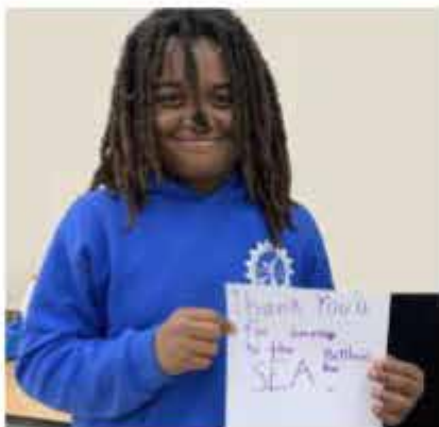
Each year, the Emily Shane Foundation SEA(Successful Educational Achievement) Program provides academic and mentoring support to over 100 disadvantaged middle school students who risk failure and have no other recourse. We have served over 700 children across Los Angeles since our inception in the spring 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.**

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1 week _____	\$30
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1 semester_____	\$540
1 year_____	\$1,080
Middle School_____	\$3,240

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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

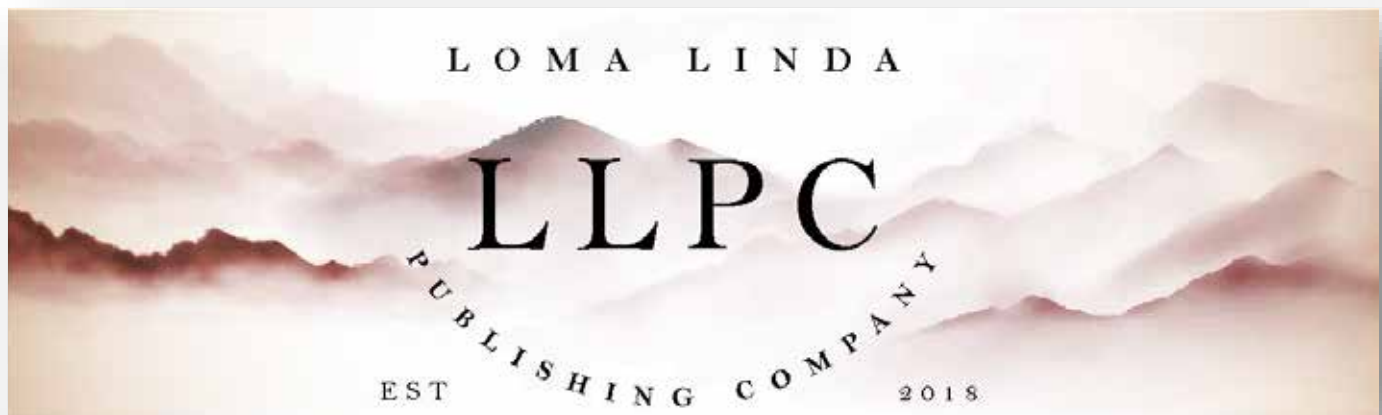
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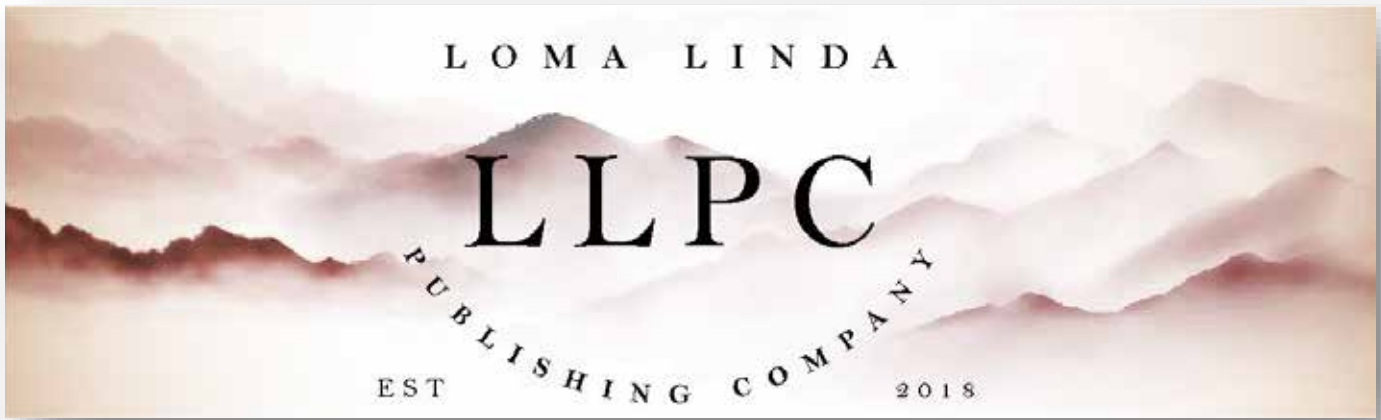
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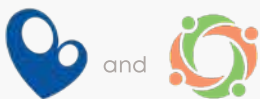
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My Perinatal Network and My NICU Network are products of a collaboration between NPA and NPN.

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

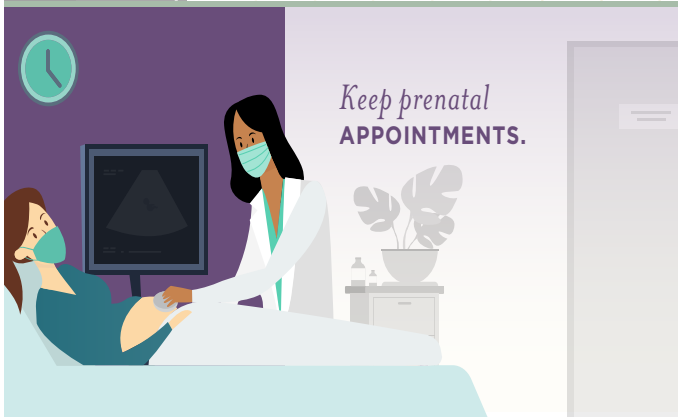
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GET INFORMED ABOUT THE **RISKS + BENEFITS**

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



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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.



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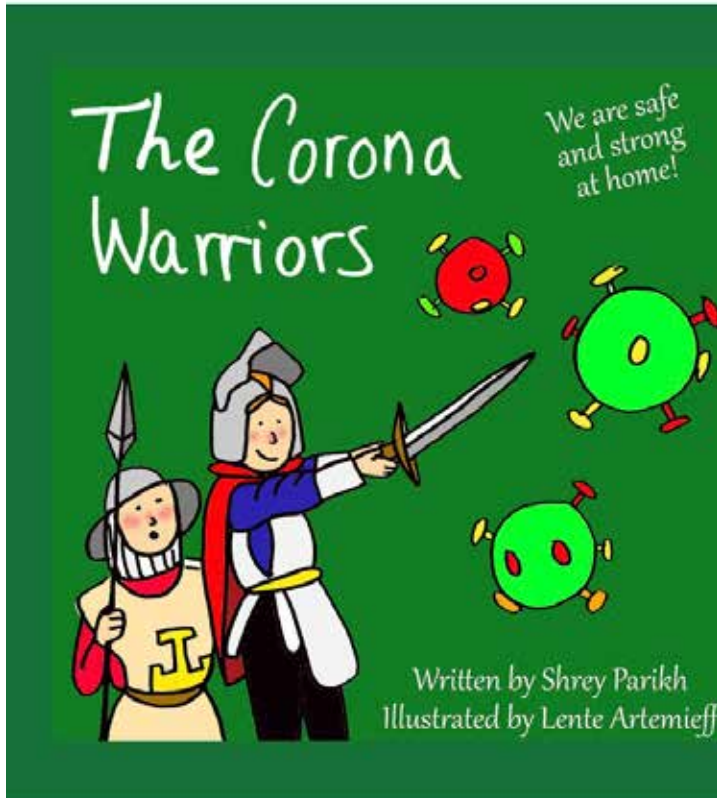
Raising Global Awareness of RSV

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 5th 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 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.





National Perinatal Association
PERINATAL MENTAL HEALTH

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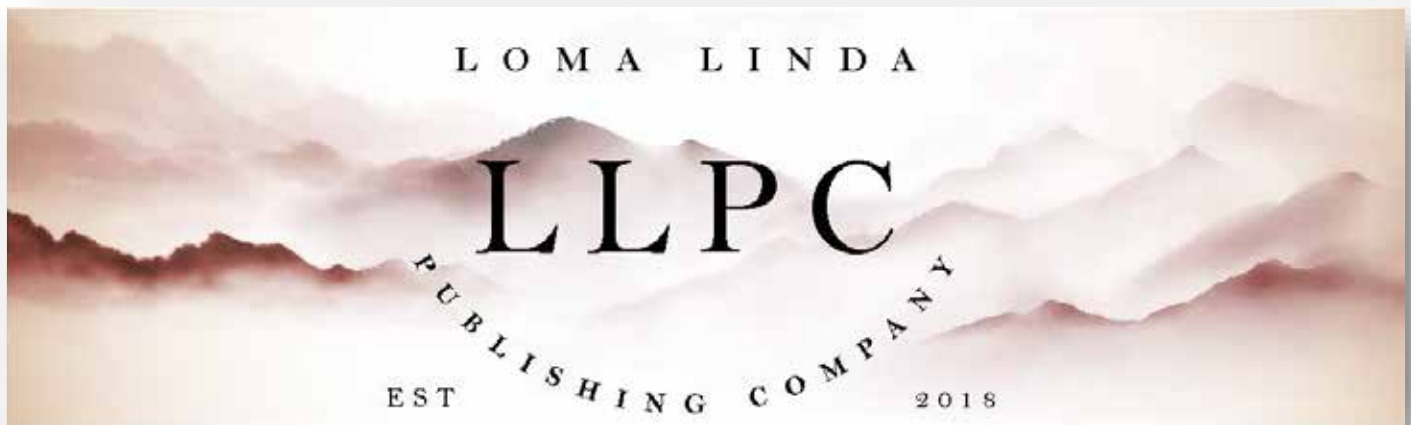
SCREEN DADS TOO

10% of fathers experience depression and anxiety during the perinatal period.



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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!

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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: Supporting and Enhancing NICU Sensory Experiences (SENSE) program- an evidence-based guideline for daily parent-delivered positive multisensory exposures for infants in the NICU

Marinthea Richter, OTD, OTR; Polly Kellner, MSOT, OTR/L; Roberta Pineda, PhD, OTR/L, CNT

Abstract

The Supporting and Enhancing NICU Sensory Experiences (SENSE) program was developed in 2017 to guide parents in providing age-appropriate positive sensory exposures to their preterm infants each day of NICU hospitalization. The development of the guideline followed a systematic process with an integrative review to identify evidence-supported sensory exposures, interviews and focus groups with stakeholders, and a pilot study and a randomized controlled trial. Recently, another integrative review was conducted to identify newly published studies on sensory exposures in the NICU, and a SENSE advisory team was recruited to inform updates to the guideline to ensure that the latest evidence related to sensory exposures in the NICU was incorporated. Daily sensory activities that are supported by evidence are listed in the parent education booklet, allowing parents autonomy in selecting appropriate sensory activities to engage in with their infants as they grow and develop in the NICU, as well as enabling choices of activities to provide for infants with different levels of medical support. The healthcare team regularly monitors infant tolerance and development as described in the SENSE implementation manual. While implementation training is available, the program can be implemented by NICUs following a self-paced review of the implementation materials. The SENSE program implementation aims to optimize the NICU environment to improve infant brain development and parent confidence while facilitating their transition into their parental roles.

Keywords: high-risk infants, parenting, NICU, sensory stimulation, environmental modification, program, premature

“The SENSE program implementation aims to optimize the NICU environment to improve infant brain development and parent confidence while facilitating their transition into their parental roles.”

Introduction:

High-risk infants receiving care in the NICU are exposed to significant stressors, including painful procedures, disruption of expected sensory experiences, and parent-infant separation. (1,2) The time in the NICU is a period of rapid brain development when neural networks rely on sensory exposures to develop optimally(3). Positive sensory exposures and parent-infant interaction are crucial in an environment where stimuli are primarily adverse and can impact attachment and neurodevelopmental progression. (4–6)

“Positive sensory exposures, such as massage, auditory exposure, and skin-to-skin care, have been related to better parent and infant outcomes.”

Positive sensory exposures, such as massage, auditory exposure, and skin-to-skin care, have been related to better parent and

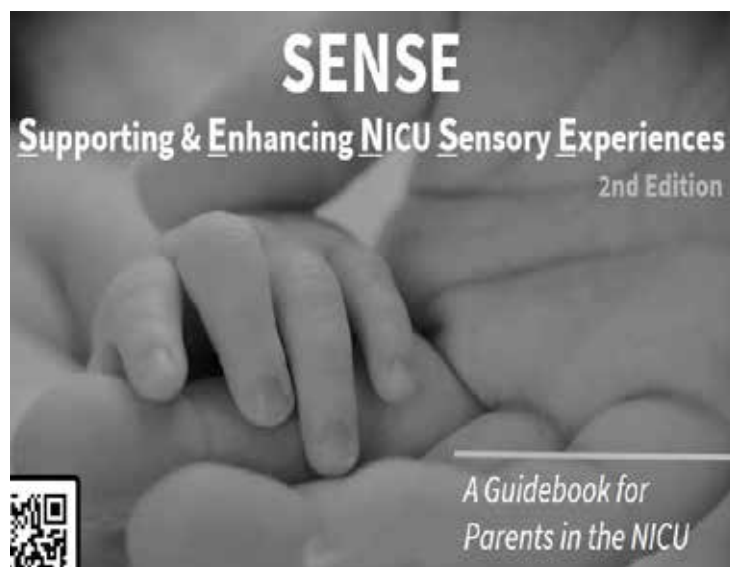







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Figure 1. Parent education materials with table of contents

Sensory Support: 32 Weeks*

*Denotes change from previous week

Here are some things to do with your baby each day this week
(as long as tolerated)

 <p>Touch</p> <p>Give at least 2 hours of positive touch each day by doing one or more of these things:</p> <ul style="list-style-type: none">• Provide a hand hug.• Do kangaroo care (skin-to-skin) for at least 1 hour.• Hold your baby in a blanket for 15 minutes at a time, or longer if your baby's temperature remains stable.• Do massage for up to 15 minutes.	 <p>Hearing</p> <p>Give at least 1 ½ hours of positive sound each day by doing one or more of these things:</p> <ul style="list-style-type: none">• Read, sing, and/or speak to your baby (can be broken up into <u>30 minute</u> periods several times per day).• Play soft music or recorded voice. <p><i>*At the sound of a whisper or quiet conversation.</i></p>	 <p>Smell</p> <p>Provide at least 3 hours per day of parent scent or the smell of breast milk.</p>	 <p>Seeing</p> <ul style="list-style-type: none">• Cycle light to your baby with natural light (or lights on, when there is no natural light) during the day and dim light or darkness at night.• Avoid direct and bright lights.	 <p>Movement & Body Awareness</p> <ul style="list-style-type: none">• Unwrap your baby and allow stretching and free movement for at least 2 minutes prior to a diaper change at least 3 times per day.• Allow your baby to experience being in at least 2 different positions for at least 10 minutes each.• Rock during holding for at least 3 minutes.
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Figure 2. Example of weekly sensory guide

infant outcomes. (7,8) The Supporting and Enhancing NICU Sensory Experiences (SENSE) program was developed in response to the need for a guideline or program that defines specific doses and targeted timing of evidence-based sensory exposures across all the days, weeks, or months of hospitalization. The SENSE program guides the clinician and parent in optimizing the early NICU environment. (9)

“Prior to the development of the SENSE program, a literature review revealed that positive sensory exposures in the NICU were done for limited periods that encompassed only a fraction of the infant's time spent in the NICU.”

Properly timed and age-appropriate positive sensory experiences can decrease stress and optimize positive learning experiences during this critical period of brain development. However, the type and timing of sensory exposure must match the level of maturity based on the infant's postmenstrual age (PMA) and should be modified according to individual infant cues. The evidence-based SENSE program was developed to define positive sensory exposures for each PMA. (9) The SENSE program engages the parent in providing appropriate types and amounts of stimulation and is promising as a modality for optimizing neurodevelopment and parent mental health. (10,11) The amounts of sensory stimuli defined in the program are intended to be targets for the minimal amount

of sensory exposure each day of hospitalization. Prior to the development of the SENSE program, a literature review revealed that positive sensory exposures in the NICU were done for limited periods that encompassed only a fraction of the infant's time spent in the NICU. (12) These exposures were also not systematically changed based on what is age-appropriate across PMA and were limited in their applicability to co-occupations of parenting and activities of daily living within the context of the NICU environment. (13) Differences in the use and interpretation of available evidence, parent education, and empowerment in the NICU lead to variability in how different NICUs implement sensory interventions, often reducing their benefit to the most vulnerable infants. (14) The SENSE program is unique because it aims to modify the early sensory environment by applying positive sensory exposures daily during NICU hospitalization.

“The standardized guideline can be initiated immediately after birth and used throughout NICU hospitalization. It identifies specific target amounts of positive tactile, auditory, visual, olfactory, and kinesthetic interventions for the infant.”

Description of the SENSE program:

The SENSE program is a cohesive, evidence-based, parent-de-

Parent Log

Week of _____

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Day of Week	Who did it today? (Check all that apply)	Time in NICU (Check all that apply)	Tactile (Check all that apply)	Auditory (Check all that apply)	Olfactory (Check all that apply)	Visual (Check all that apply)	Movement (Check all that apply)
			*Recommend at least 3 hours per day.	*Recommend at least 3 hours per day.	*Recommend at least 3 hours per day.		*Recommend at least 2 minutes prior to every diaper change. *Recommend tummy time and at least 3 other positions for at least 10 minutes each per day. *Recommend at least 7 minutes per day.
Friday	<input type="checkbox"/> Mom <input type="checkbox"/> Dad <input type="checkbox"/> Non-Binary Parent <input type="checkbox"/> Grandparent <input type="checkbox"/> Sibling <input type="checkbox"/> Other: _____	<input type="checkbox"/> Morning <input type="checkbox"/> Afternoon <input type="checkbox"/> Evening <input type="checkbox"/> Night Total time in NICU: _____ hrs _____ mins	<input type="checkbox"/> Hand Sugs _____ hrs _____ mins <input type="checkbox"/> Kangaroo Care _____ hrs _____ mins <input type="checkbox"/> Blanket Holding _____ hrs _____ mins <input type="checkbox"/> Massage _____ hrs _____ mins Total Time: _____ hrs _____ mins	<input type="checkbox"/> Reading _____ hrs _____ mins <input type="checkbox"/> Singing _____ hrs _____ mins <input type="checkbox"/> Talking _____ hrs _____ mins <input type="checkbox"/> Recorded Voice _____ hrs _____ mins <input type="checkbox"/> Music _____ hrs _____ mins Total Time: _____ hrs _____ mins	<input type="checkbox"/> Scent Cloth _____ hrs _____ mins <input type="checkbox"/> Breast Milk _____ hrs _____ mins Total Time: _____ hrs _____ mins	<input type="checkbox"/> Protected baby's eyes from direct or bright light. <input type="checkbox"/> Cycled light.	How many times did you allow baby to move freely for at least 2 minutes? What positions did baby spend at least 10 minutes in? <input type="checkbox"/> Tummy <input type="checkbox"/> Back <input type="checkbox"/> Left Side <input type="checkbox"/> Right Side <input type="checkbox"/> Kangaroo Care <input type="checkbox"/> Supported sitting (upright position with head/neck support) How many minutes of rocking did baby receive? _____ mins
Saturday	<input type="checkbox"/> Mom <input type="checkbox"/> Dad <input type="checkbox"/> Non-Binary Parent <input type="checkbox"/> Grandparent <input type="checkbox"/> Sibling <input type="checkbox"/> Other: _____	<input type="checkbox"/> Morning <input type="checkbox"/> Afternoon <input type="checkbox"/> Evening <input type="checkbox"/> Night Total time in NICU: _____ hrs _____ mins	<input type="checkbox"/> Hand Sugs _____ hrs _____ mins <input type="checkbox"/> Kangaroo Care _____ hrs _____ mins <input type="checkbox"/> Blanket Holding _____ hrs _____ mins <input type="checkbox"/> Massage _____ hrs _____ mins Total Time: _____ hrs _____ mins	<input type="checkbox"/> Reading _____ hrs _____ mins <input type="checkbox"/> Singing _____ hrs _____ mins <input type="checkbox"/> Talking _____ hrs _____ mins <input type="checkbox"/> Recorded Voice _____ hrs _____ mins <input type="checkbox"/> Music _____ hrs _____ mins Total Time: _____ hrs _____ mins	<input type="checkbox"/> Scent Cloth _____ hrs _____ mins <input type="checkbox"/> Breast Milk _____ hrs _____ mins Total Time: _____ hrs _____ mins	<input type="checkbox"/> Protected baby's eyes from direct or bright light. <input type="checkbox"/> Cycled light.	How many times did you allow baby to move freely for at least 2 minutes? What positions did baby spend at least 10 minutes in? <input type="checkbox"/> Tummy <input type="checkbox"/> Back <input type="checkbox"/> Left Side <input type="checkbox"/> Right Side <input type="checkbox"/> Kangaroo Care <input type="checkbox"/> Supported sitting (upright position with head/neck support) How many minutes of rocking did baby receive? _____ mins
Sunday	<input type="checkbox"/> Mom <input type="checkbox"/> Dad <input type="checkbox"/> Non-Binary Parent <input type="checkbox"/> Grandparent <input type="checkbox"/> Sibling <input type="checkbox"/> Other: _____	<input type="checkbox"/> Morning <input type="checkbox"/> Afternoon <input type="checkbox"/> Evening <input type="checkbox"/> Night Total time in NICU: _____ hrs _____ mins	<input type="checkbox"/> Hand Sugs _____ hrs _____ mins <input type="checkbox"/> Kangaroo Care _____ hrs _____ mins <input type="checkbox"/> Blanket Holding _____ hrs _____ mins <input type="checkbox"/> Massage _____ hrs _____ mins Total Time: _____ hrs _____ mins	<input type="checkbox"/> Reading _____ hrs _____ mins <input type="checkbox"/> Singing _____ hrs _____ mins <input type="checkbox"/> Talking _____ hrs _____ mins <input type="checkbox"/> Recorded Voice _____ hrs _____ mins <input type="checkbox"/> Music _____ hrs _____ mins Total Time: _____ hrs _____ mins	<input type="checkbox"/> Scent Cloth _____ hrs _____ mins <input type="checkbox"/> Breast Milk _____ hrs _____ mins Total Time: _____ hrs _____ mins	<input type="checkbox"/> Protected baby's eyes from direct or bright light. <input type="checkbox"/> Cycled light.	How many times did you allow baby to move freely for at least 2 minutes? What positions did baby spend at least 10 minutes in? <input type="checkbox"/> Tummy <input type="checkbox"/> Back <input type="checkbox"/> Left Side <input type="checkbox"/> Right Side <input type="checkbox"/> Kangaroo Care <input type="checkbox"/> Supported sitting (upright position with head/neck support) How many minutes of rocking did baby receive? _____ mins

Notes:

Figure 3. Example of weekly parent sensory exposure log

livered guideline for consistently applying positive multisensory exposures every day in the NICU. The standardized guideline can be initiated immediately after birth and used throughout NICU hospitalization. It identifies specific target amounts of positive tactile, auditory, visual, olfactory, and kinesthetic interventions for the infant.

“Although specific doses of positive sensory exposures are identified in the SENSE program, the program is designed to be individualized for each infant based on the preferences of the family and/or the medical status/tolerance of the infant.”

As the program is intended to be completed by parents, parent education materials constitute a significant component of the program when possible. These materials can be accessed via a QR code on parents' smartphones or tablets or given to parents as printed booklets. The parent-education booklet has seven chapters (see Figure 1) with educational content on medical terminology, fetal development in the final months of pregnancy, the sensory environment of the NICU, sensory development, reading

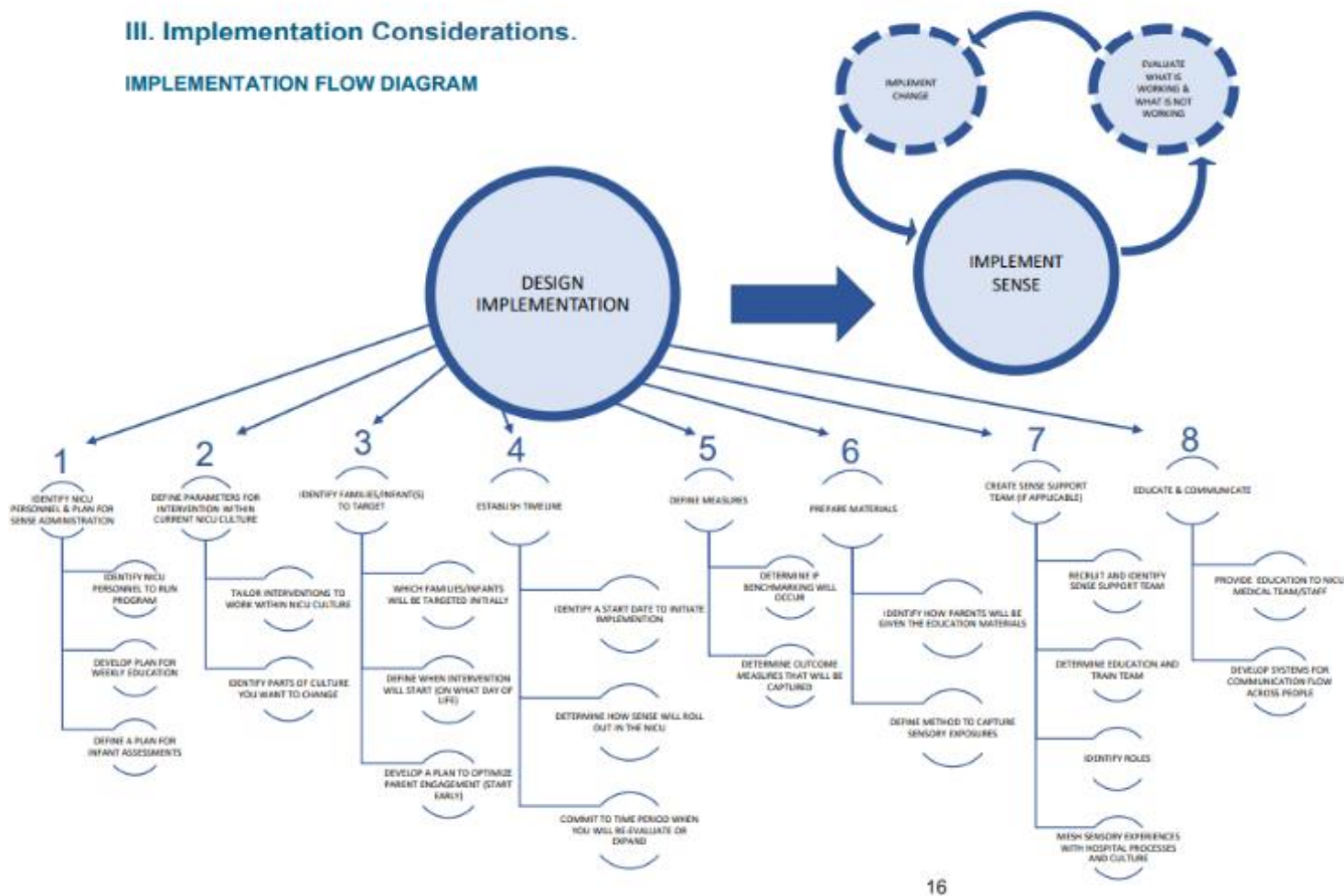
infant cues, identifying readiness for sensory exposures, instructions for how to provide different sensory exposures, a week-by-week guide on specific doses and timing of sensory exposures to ensure consistent and developmentally appropriate delivery of positive sensory experiences at each PMA (see figure 2 for an example), and instructions for how to conduct the sensory exposures defined. The web-based materials also have video tutorials to guide parents in specific activities, such as skin-to-skin care and positive touch. Although specific doses of positive sensory exposures are identified in the SENSE program, the program is designed to be individualized for each infant based on the preferences of the family and/or the medical status/tolerance of the infant. Log sheets are available to aid parents, health care professionals, and volunteers in tracking positive sensory exposures provided to the infant to define achievement of the goal amounts or identify opportunities for more positive sensory exposures throughout each day (see Figure 3).

“The SENSE program differs from the standard of care because it defines specific targeted amounts of sensory exposures to be delivered daily during hospitalization.”

The implementation and administration guide is designed to walk

III. Implementation Considerations.

IMPLEMENTATION FLOW DIAGRAM



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Figure 4. SENSE Implementation Flow Diagram

NICUs through integrating the SENSE program into their units with a diagram and checklist with implementation considerations. This manual also contains the infant assessment intended to aid clinicians in assessing infant tolerance for different sensory exposures at least weekly to recommend appropriate adaptations to the program when necessary. The implementation flow diagram identifies different steps along the continuum to implementation, including the identification of key personnel, considerations regarding the NICU culture, identifying families/infants who will receive the program in the first phase of implementation, establishing a timeline for implementation, developing benchmarking strategies, considerations around the use of a sensory support team, and education and communication with NICU team members (see figure 4).

“A new integrative review and consultation with a SENSE advisory team is planned every five years to ensure the program remains current and applicable based on emerging evidence.”

How does the SENSE program differ from the standard of care?

The SENSE program differs from the standard of care because it defines specific targeted amounts of sensory exposures to be delivered daily during hospitalization. This is in contrast to the standard of care, where a lack of intentionality in delivering positive sensory exposures can lead to days or weeks without positive sensory exposures. In addition, the types, frequency, and duration of appropriate exposures are tailored to the infant's PMA and modified based on medical status and behavioral cues. This ensures that the types and timing of different sensory exposures are appropriate for the maturity level of each infant. The SENSE program is intended to be integrated into the daily flow of the NICU, where multimodal sensory exposures occur in the context of daily care and parent engagement.

Development of the SENSE program:

The SENSE program was developed using a stepwise, rigorous, and scientific process that included defining evidence on sensory exposures with preterm infants, expert opinion, and parent input regarding developmentally appropriate and timed exposures. The initial integrative review included 88 articles on sensory-based NICU interventions applied to preterm infants. (7) Focus groups and interviews followed this review to gather input from multidisciplinary healthcare professionals who helped to define different sensory interventions done in NICUs and critically evaluate the proposed guideline. (9,15) Parents of preterm infants discharged

from the NICU were also interviewed to gather their opinions on the proposed guideline. (16) Following this rigorous development process; a pilot study was conducted with 80 infants (30 infants who received the SENSE program compared to 50 historical controls) to assess the feasibility of implementing the SENSE program in a level IV NICU and evaluating preliminary outcomes. (10) This study highlighted a positive relationship between SENSE programming, parent confidence, and infant neurobehavior. (10) Following the pilot study, a randomized clinical trial compared the effect of SENSE programming to standard of care in preterm infants born less than or equal to 32 weeks gestation, demonstrating on univariate analysis a positive effect on language outcomes at one year of age. (11) The research team continues to follow up with the infants enrolled in the pilot study and randomized controlled trial to monitor longitudinal developmental outcomes via parent report surveys. The program was further evaluated by applying an implementation framework, which found that the program was adopted with good fidelity, with most infants receiving and tolerating the program as defined within a large, Level IV NICU. (17) A second integrative review has since been undertaken to update the SENSE guidelines with input from a SENSE advisory team of multidisciplinary healthcare providers and parents of preterm infants or NICU graduates. (18) A new integrative review and consultation with a SENSE advisory team is planned every five years to ensure the program remains current and applicable based on emerging evidence.

Advantages of the program:

- Descriptive and comprehensive education aimed at informing and engaging parents in providing developmentally appropriate sensory exposures to their infant(s)
- Evidence-based week-by-week sensory interventions that change based on PMA.
- The sensory interventions are designed to be provided by parents, but the medical team and/or volunteers can also be engaged to ensure the sensory needs of each infant are met.
- Sensory exposures can be individualized based on the needs of each NICU (based on concurrent medical factors, parent choice, and infant behavioral signs).
- The written materials available in the SENSE package include a booklet for parents, log sheets to track sensory exposures and a weekly infant assessment. An electronic version of the SENSE program is also available through a QR code. The electronic version has videos that demonstrate the described interventions.
- The SENSE program parent education materials have been translated into Spanish, French, Hindi, Chinese, Korean, Hebrew, and Arabic as of 2023.

“The written materials available in the SENSE package include a booklet for parents, log sheets to track sensory exposures and a weekly infant assessment.”

Ongoing research:

The SENSE program research team is currently conducting an

NIH-funded study that aims to enroll 215 preterm infants and compare parent (mental health, confidence, and stress) and infant outcomes (electrocortical activity, neurobehavior, and developmental outcomes through age 2 years) of those who receive the SENSE program compared to standard of care. In addition, infants will receive amplitude-integrated electroencephalography with an exploration of electrocortical activity concerning positive sensory exposures as a possible mechanism toward improved outcomes.

Resources:

For more information on the SENSE program, please visit <https://chan.usc.edu/nicu/sense>.

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Disclosures: Bobbi Pineda and Joan Smith are authors of the SENSE program. The program user fee is charged 'at cost', and the authors do not directly benefit financially from the distribution of the program.

NT

Brief Biography of Corresponding Author

Dr. Pineda is an Associate Professor at the University of Southern California. She received her PhD in 2006 from the University of Florida. Her research interests include the study of the early NICU sensory environment, therapy service delivery and programming to improve access, and early oral feeding in preterm infants in the NICU. She has more than 60 peer reviewed publications and presents nationally. Dr. Pineda is a previous co-chair and board member of the Neonatal Therapy Certification Board, which aims to validate the experience and knowledge of those practicing as therapists in the advanced practice area of the NICU. She has personally experienced being the mother of a preterm infant who was in the NICU for 5 weeks and now she aims to support clinical practices in the NICU that are better for babies and families.



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Gravens Diversity Travel Award

As part of an initiative to increase diversity at the Gravens Conference, the Gravens Diversity, Equity, Inclusion, and Justice (DEIJ) Committee will provide travel awards to individuals from historically underrepresented groups (i.e., people from racially and ethnically diverse backgrounds, members of the LGBTQ+ population, individuals with cognitive disabilities, individuals with physical disabilities). Applications will open for the 2024 Gravens Diversity Travel Awards on **August 21, 2023**. Applications should be submitted no later than **Monday, October 30, 2023, at 5:00pm EST**.

Several competitive travel awards are expected to be given. The amount awarded will be based on the award availability for that year. Notice of awards are expected to be made no later than December 15, 2023. Please contact Kelly McGlothen-Bell (mcglothen@uthscsa.edu) or Christie Lawrence (Christie.Lawrence@rush.edu) for questions regarding your application.

Eligibility:

- Identify as a member of a historically underrepresented group.
- Must serve the neonatal and/or pediatric intensive care population in a professional capacity.

Application:

- Completion of Gravens Diversity Travel Award Survey, which provides contact information for the applicant and specifies the applicant's eligibility for the award.
- CV or Resume
- Submission of written or video response to the following statements:
 - Describe your personal and professional background.
 - Describe how you believe you will benefit from attending the Gravens Conference.
 - Describe how you'd like to advance DEIJ initiatives for the care of infants and their families.
- Letter of Support detailing the following attributes:
 - Administrative support from applicant's leadership team to participate at the Gravens Conference.
 - Evidence of the applicant's skills, knowledge, experiences in research, practice, service/volunteering, and/or leadership.
 - Commitment to support commitment to DEIJ in practice.

Awardee Responsibilities:

- Plan to attend the full 2024 Gravens Conference.
- Engage with an assigned Gravens Conference buddy.
- Provide post-conference statement (written or video) about the conference experience and how they plan to adopt or incorporate what they've learned at the conference into practice.
- Awardees are highly encouraged to submit an abstract to the subsequent Gravens Conference.



Our message to the supporters, attendees, and participants in the Gravens conferences.

We want to acknowledge concerns regarding holding the 2024 meeting in Florida. For all those who have communicated your thoughts about attending the meeting, we want you to know that we appreciate your forthrightness and wish to offer a statement of our collective thinking on this crucial matter. As our society grows more diverse and connected, we must acknowledge how the social and political climates continue to affect how we live, move, and interact.

Our Gravens community seeks to affirm our commitment to addressing issues of racism and bias and audit our systems to ensure that we are proactive in implementing strategies that promote health equity and social justice. We strive to provide a supportive, inclusive, and welcoming space to all individuals involved in the physical and developmental environment of the neonatal intensive care unit (NICU), including family members, healthcare providers, designers, and industry supporters.

The Gravens community approach is to remain non-political. However, some of the current policies and practices in the state where the Gravens conference is historically held are not consistent with the ideals and values of the Gravens community. The Co-Chairs and Planning Committee are reviewing all opportunities to ensure that the individual identities and lived experiences of those most impacted by the current political landscape are valued and respected.

Should you choose to attend the conference in Clearwater in person, we hope you recognize that there are those whose livelihood depends on tourism and who do not hold the same views as Florida's current prevailing social and political environment. That way, you can support small businesses, specifically those owned by people of color.

As we plan for upcoming Gravens meetings, our priority is to ensure that all attendees can participate in a safe and welcoming environment. The Planning Committee for the 2024 Gravens Conference has discussed the pros and cons of going forward with holding our meeting in Florida, given the recent political decisions that threaten an open and inclusive society. We have explored the possibility of moving the conference to another state; however, we will not be able to do so for the 2024 conference due to fiscal and contractual obligations. We are actively exploring alternative sites for future meetings.

We understand that diversity, equity, inclusion, and justice are principles that must work together to result in fair treatment, access, opportunity, and advancement for all. Therefore, we respect each participant's decision to attend the conference in person or virtually, and we hope you will join us in whatever format suits you best. Through our perseverance and dedication to advancing the care of infants and families, we aim to continue to promote our message of inclusivity and health equity.

Regardless of your position on attending the Gravens conference, you might like to use these strategies right now to make a difference:

- Commit to learning and reflecting on how racism and bias impact us today and how our history led us here.
- Vote for political candidates that are in line with your values.
- Use your voice, lived experience, and privilege to bring awareness and action to address health outcomes and healthcare quality disparities.

We are continuing to work to ensure that the co-chairs, planning committee, and conference attendees reflect both the workforce and the people they serve so that we can best meet the needs of our field. You can support the Gravens Conference Diversity Fund to help ensure the participation and growth of our ever-changing society.

Together, we can create environments where every individual or group will be fully and authentically welcomed, respected, supported, and valued to shape the world for future generations equitably.

For questions or comments, please contact lomalindapublishingcompany@gmail.com.

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.

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National
Perinatal
Association

Fragile Infant Forums for Implementation of IFCDC Standards: A Collective Effort to Improve the Experience of NICU families between the National Perinatal Association's Discharge NICU Discharge Preparation and Transition Planning Guidelines and Recommendations as well as the Standards, Competencies, and Recommended Best Practices for Infant and Family-Centered Developmental Care in the Intensive Care Unit

Brigitte C. Desport, DPS, OTR/L, BCP, ATP and Vincent C. Smith, MD, MPH



Overview

When families think about their experience preparing to transition from the NICU (Neonatal Intensive Care Unit) to home, most families generally do not use the terms “joyful,” “easy,” or “perfect.” More often, families use terms like “quick...sudden,” “lonely,” and “scary.” Some families wonder if they even had a discharge preparation plan at all. Several organizations have worked to improve the overall experience for families in the NICU and the progress at home.

The healthcare professional's responsibility is to create supportive environments for families to experience a comprehensive and smooth transition from the NICU to home. The objective is to create opportunities for the families to participate in discharge and transition activities and build confidence in their ability to care for their babies at home. In this article, we discuss the following standards:

- NICU Discharge Preparation and Transition Planning (1, 2): Guidelines and recommendations.
 - <https://www.nicutohome.org/>

- For the sake of this article, we will refer to these as the “Discharge Planning Guidelines.”

- Recommended Standards, Competencies, and Best Practices for Infant and Family Developmental Care in Intensive Care in the Intensive Care Unit (3, 4).

- <https://nicudesign.nd.edu/nicu-care-standards/>

- For the sake of this article will refer to these as the “Developmental Standards”

“In this article, we discuss the following standards: NICU Discharge Preparation and Transition Planning: Guidelines and recommendations and Recommended Standards, Competencies, and Best Practices for Infant and Family Developmental Care in Intensive Care in the Intensive Care Unit.”

Because both sets of recommendations have been described in detail in previous Neonatology Today articles (7-10) and other press 11, we will assume the reader is familiar with both. The current article aims to address the interplay and parallel process between the Developmental Standards and the Discharge Planning Guidelines. For the sake of this article, “Standards” are defined as safe, evidence-based expectations or measures of best practice. Similarly, “Competencies” refer to the action, or sequence of actions, that constitute the performance of the standard.

Developmental Standards are divided into the following domains:

- Systems thinking in complex adaptive systems
- Positioning and touch for the newborn
- Sleep and arousal interventions for the newborn
- Skin-to-skin contact with intimate family members
- Reducing and managing pain and stress in newborns and families
- Management of feeding, eating, and nutrition delivery

Discharge Guidelines are divided into the following sections:

Basic information for all families

Anticipatory guidance

Family and home needs assessment

Transition and coordination of care

Other important considerations

Families with limited English proficiency

Military families

LGBTQIA+ headed families

Parents with disabilities

Families with distinct cultural and/or philosophical beliefs

The Developmental Standards and Discharge Planning Guidelines followed a similar process for their creation. Both took between 3 and 5 years to develop using multidisciplinary teams, using the best evidence available at the time of development. They both make evidence-based statements about best practices. Both sets of recommendations were also designed to address literature gaps and be actionable at multiple levels (bedside, administration, etc.). They provide details about the topic but have enough flexibility to be implemented with locally appropriate resources.

“Both sets of recommendations emphasize the importance of including families as key stakeholders in applying the recommendations. Similarly, they make recommendations that include the transition from the NICU to home, emphasizing the importance of parental involvement..”

Both sets of recommendations emphasize the importance of including families as key stakeholders in applying the recommendations. Similarly, they make recommendations that include the transition from the NICU to home, emphasizing the importance of parental involvement. These recommendations provide a wonderful opportunity to ensure a smooth transition from the developmental and family-centered practices in the NICU to support at home. (9)

“At present, neither set of recommendations directly addresses the implementation of the recommendations. Formulating recommendations and guidelines that will apply to each clinical setting and environment can be very challenging.”

Implementation guidance

At present, neither set of recommendations directly addresses the implementation of the recommendations. Formulating recommendations and guidelines that will apply to each clinical setting and environment can be very challenging. Neither set of recommendations is intended to be prescriptive. Instead, both recommendations describe the concepts and factors that should be considered. The work involved in implementing the recommendations at any local institution or clinical setting would have to be done by someone familiar with the resources available at the institution or clinical setting and the stakeholders who would participate in the process. To that end, the Fragile Infant Forums for Implementation (FIFI-S) workshops were initiated recently, guiding small groups of professionals on evidence-based systems change, assuring that conditions and local resources are considered. (7, 8)

“Although implementing the recommendations is a process that requires planning and collaboration, it is attainable, and the result will be a significant contribution and benefit to the recipients of the services.”

Although implementing the recommendations is a process that requires planning and collaboration, it is attainable, and the result will be a significant contribution and benefit to the recipients of the services. The organizations that created both sets of recommendations are available and willing to provide individual consultations to clarify the meaning of any specific recommendations.

“One common challenge that must be addressed as part of implementing the recommendations is ambivalence. Even if they agree with the need for evidence-based practice, it will not be apparent to some individuals or systems that they can bring about change. For progress towards a comprehensive model at an institution, sentiments like ‘there is nothing that I can do’ or ‘this is someone else’s problem’ will have to be anticipated and addressed.”

Implementation challenges

One common challenge that must be addressed as part of implementing the recommendations is ambivalence. Even if they agree with the need for evidence-based practice, it will not

be apparent to some individuals or systems that they can bring about change. For progress towards a comprehensive model at an institution, sentiments like “there is nothing that I can do” or “this is someone else’s problem” will have to be anticipated and addressed, perhaps at different stages of the process. To support your organization in the implementation process, we would like to offer the following suggestions:

- Include families as key stakeholders in the process
- Use a multidisciplinary team approach of invested stakeholders
- Be open to input from the stakeholders by readily including simple suggestions that can be implemented tomorrow
- Be willing to engage in honest conversations with team members and families about system factors challenging implementation and commit to addressing them
- Consider environmental and contextual factors that are supports and/or barriers during assessment and intervention planning (12)
- Develop a process that is structured and organized, and avoid making it too prescriptive
- Focus on what can be accomplished with existing resources
- Make use of free publicly available resources such as <https://www.nicutohome.org>.
- Partner with another organization for help with implementation.
- Use the two organizations that created both sets of recommendations as resources—<https://www.nationalperinatal.org/programs> and <https://nicudesign.nd.edu/nicu-care-standards/>. They are available and willing to provide individual consultations to clarify the meaning of any specific recommendations.

“Both resources emphasize how parents and family members should be included and involved in all aspects of their baby’s care and discharge planning. The charge is to build capacity instead of expecting families to conform to the NICU structure (e.g., environment) and its discharge planning and transition processes or accept what is considered appropriate or right.”

Summary and conclusions:

The two resources described above are available and provide evidence-based guidelines for NICU developmental care and discharge planning. Both resources emphasize how parents and family members should be included and involved in all aspects of their baby’s care and discharge planning. The charge is to build capacity instead of expecting families to conform to the NICU structure (e.g., environment) and its discharge planning and

transition processes or accept what is considered appropriate or right. Together, these standards and guidelines provide guidance that, with acknowledgment of locally available resources, can and should be implemented to improve the care and support of babies and families.

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Disclosures: There are no reported disclosures

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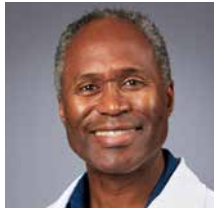


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Associate Dean of Strategic Initiatives
SOHP Associate Professor
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Respiratory Syncytial Virus

Really Serious Virus

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



Vincent C. Smith, MD, MPH
Division Chief of Newborn Medicine
Professor of Pediatrics
Boston Medical Center
Boston, Massachusetts

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

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Statement by The National Perinatal Association on the Israel-Gaza Conflict

Viveka Prakash-Zawisza, MD, MS, MBA,
Mitchell Goldstein, MD, MBA, CML

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.



“NPA unconditionally condemns antisemitism, terrorism, Islamophobia, and all acts of violence, particularly those that deliberately harm innocent civilians. Our hearts go out to all those affected by these distressing events.”

The National Perinatal Association (NPA) is deeply saddened by the recent violent atrocities and the tremendous loss of life in Israel and Gaza. We stand united with the global community in mourning the devastating impact of this ongoing conflict. NPA unconditionally condemns antisemitism, terrorism, Islamophobia, and

all acts of violence, particularly those that deliberately harm innocent civilians. Our hearts go out to all those affected by these distressing events.

The consequences of this conflict have been far-reaching, with a profound impact on public health infrastructure, causing the displacement of millions from their homes and resulting in human rights violations. We recognize that these consequences disproportionately affect pregnant and postpartum individuals, newborns, and young children. It is with great concern that we acknowledge the safety and well-being of pregnant people and medically fragile infants who cannot access reliable perinatal healthcare due to the evolving humanitarian crisis in the region.

“In these challenging times, we urge all parties to prioritize the well-being and safety of all individuals, particularly those most vulnerable, including pregnant and medically fragile individuals and infants... We believe that every individual should have access to essential healthcare and support regardless of their circumstances.”

In these challenging times, we urge all parties to prioritize the well-being and safety of all individuals, particularly those most vulnerable, including pregnant and medically fragile individuals and infants. NPA is committed to advocating for the provision of adequate support for medical and psychological services for all those in need during this crisis. We believe that every individual should have access to essential healthcare and support regardless of their circumstances.

We also strongly advocate for the safe return of hostages taken during this conflict. We call on all parties to ensure their safe and swift return to their families and loved ones.

“NPA stands firmly in the hope for a peaceful resolution to this conflict, which respects the rights and dignity of all people involved. We call on the international community to unite and work towards a lasting and just peace.”

NPA stands firmly in the hope for a peaceful resolution to this conflict, which respects the rights and dignity of all people involved. We call on the international community to unite and work towards a lasting and just peace. We must ensure that the suffering is alleviated and that the most vulnerable in this crisis receive the care and support they urgently require.

Lastly, we emphasize the importance of self-care and mental well-being during these trying times. The trauma resulting from the events in Israel and Gaza is not limited to those directly affected, as it can also affect those who witness these distressing events. We encourage everyone to prioritize their mental health and seek support and resources.

In summary, NPA condemns all acts of terrorism, any form of hostility or bias based on race or religion, and denounces all instances of violence, particularly those that intentionally target innocent civilians. We stand in solidarity with all affected individuals, remain committed to working towards a peaceful resolution, and call for the safe return of hostages. We also emphasize providing essential healthcare services for those in need during these challenging times.

#StandForPeace #ProtectTheVulnerable
#NPAforPerinatalHealth

Disclosures: There are no reported disclosures

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Corresponding Author



Viveka Prakash-Zawisza, MD, MS, MBA
Past-President, National Perinatal Association
E-mail: viveka.zawaszka@gmail.com

Position Statement:

The National Perinatal Association is devastated by the violent atrocities and tremendous loss of life in Israel and Gaza. NPA unconditionally condemns antisemitism, terrorism, Islamophobia, and all acts of violence, particularly those which target innocent civilians. The destruction of public health infrastructure, displacement of millions from their homes, and human rights violations disproportionately affect pregnant and postpartum individuals, newborns, and young children. NPA is especially concerned for the safety and well-being of pregnant people and medically fragile infants who are not able to access reliable perinatal healthcare due to the evolving humanitarian crisis in the region. NPA hopes for a peaceful resolution to this conflict and for the provision of adequate support for medical and psychological services for all who need them.



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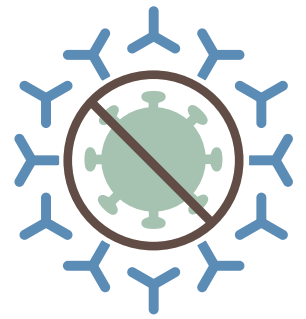


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Protecting your baby and family from

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.

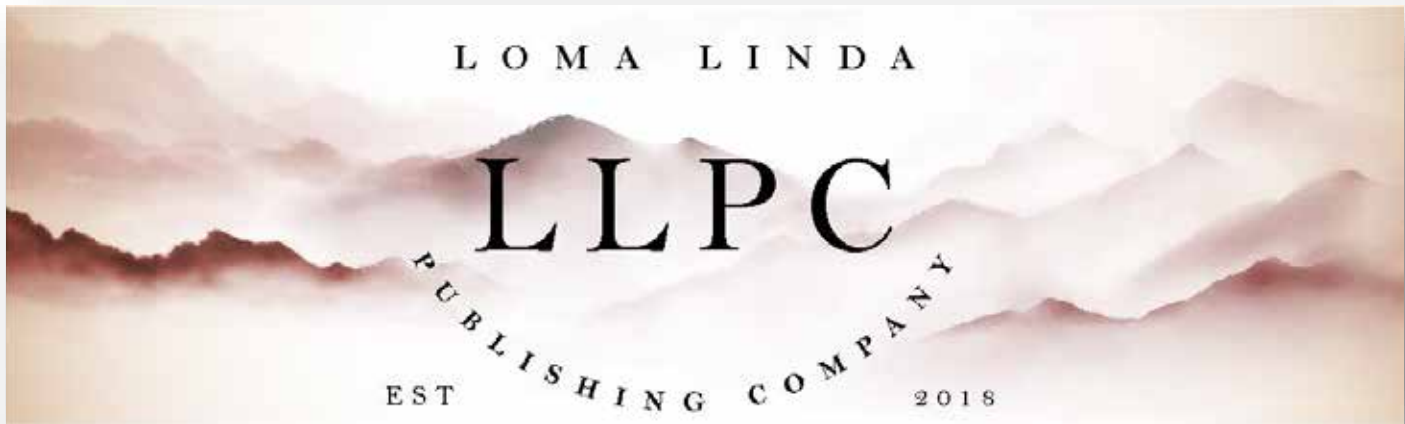


Babies older than 6 months can get a flu shot and COVID-19 vaccinations. There is no vaccine for RSV, but monthly antibody shots during RSV season can help protect them.



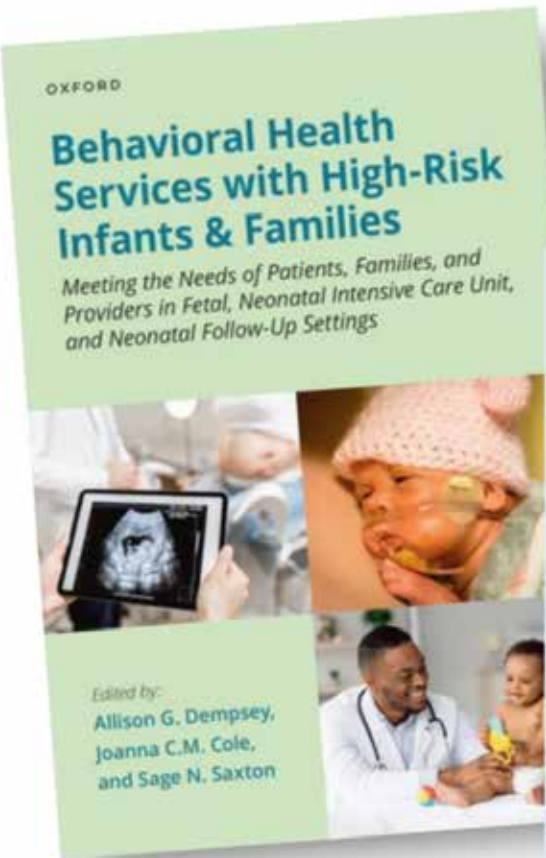
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Environment Of Care For
High Risk Newborns:

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Or Virtual**

Wednesday - Saturday
March 6-9, 2024
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WHY YOU SHOULD ATTEND

- Get updated on the most recent evidence for your work in supporting babies and families in intensive care.
- Have conversations with leaders in the field of developmentally supportive, family centered care and NICU design.
- Share your passion for optimizing the environment of care for babies, families and staff.
- Network with colleagues, family members and experts in the field who share similar ideas about supporting babies and families in intensive care.
- Take back ideas for change to your NICU policies and care practices.

GENERAL INFORMATION

Location

Sheraton Sand Key Resort
1160 Gulf Boulevard
Clearwater Beach, FL 33767
Hotel Phone: (727) 595-1611
www.sheratonsandkey.com

In the event in-person attendance is canceled or capacity limits modified per CDC or public health guidelines, the conference will be modified accordingly or presented entirely as a live virtual activity.

Conference Registration

We suggest you register early.

To register online, please go to:

Conference Registration, please register:
<https://www.eventbrite.com/e/the-37th-annual-gravens-conference-tickets-668446410207?aff=oddtcreator>

Or scan QR code



Refund Policy

Refund & Cancellation Policy: Cancellations must be requested in writing via email to gpakhanyan@paclac.org, and received by February 06, 2024 in order to receive a refund. A \$100 cancellation fee will be assessed to cover administrative costs. There are no refunds for no-shows or for cancellations received after Feb. 06, 2024; however, substitutions are welcome without penalty. Eventbrite's fee is nonrefundable.

Conference Agenda

<https://paclac.org/wp-content/uploads/2023/08/Gravens-Agenda-2024-1.pdf>

Submit an abstract at:

<https://event.fourwaves.com/gravensconference2024/pages>

SHERATON SAND KEY RESORT

Accommodations

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It is strongly advised that you make room reservations early.

Sheraton Sand Key Resort

A limited number of rooms have been reserved for this meeting at a special rate of \$224 (plus tax). For reservations, call the hotel directly* at (727) 595-1611 (not the national sales office) and identify yourself as a participant of the Gravens Conference to receive the special group rate.

*If no one picks up at the local number, the call is automatically transferred to the national reservation line. The phone reps at the national reservations line will not know of the group and special rate. Continue to call the local number.

If you prefer to make online reservations,

Online Reservations

<https://www.marriott.com/event-reservations/reservation-link.mi?id=1688650684784&key=GRP&app=resvlink>

Book your group rate for Annual Gravens Conference (This will avoid the problems with reaching the national reservations line.)

The deadline to receive the group rate is February 4, 2024. This assumes the block has not sold out. If so, you will be quoted the standard rate, which is considerably higher than the group rate. The hotel sells out every year. Do not wait until the last minute. (The status of the pandemic will impact how quickly the room inventory sells out. Still, better to reserve the room in advance. You can always cancel, so long as it is within the allowable window.)

The hotel sells out every year.

Dress is casual throughout the conference. Please bring a jacket to the meeting rooms, as they are often cold. Physical distancing will be observed. Masks are optional.

The hotel has complimentary parking.

Airport & Ground Transportation

The two airports nearest the hotel are Tampa International Airport (TPA) and St. Petersburg/Clearwater airport (PIE). Both airports offer car rental.

Taxi fare from Tampa airport can exceed \$60. Uber and Lyft average around \$35 ish, before tips.

For more information on Tampa airport, visit <https://www.tampaairport.com/guest-services> and the St. Petersburg/Clearwater airport, visit <http://www.fly2pie.com/>

Diversity Scholarship Information

The Gravens Diversity, Equity, Inclusion, and Justice (DEIJ) Committee will provide travel awards to individuals from historically underrepresented groups (i.e., people from racially and ethnically diverse backgrounds, members of the LGBTQ+ population, individuals with cognitive disabilities, individuals with physical disabilities). Please contact Kelly McGlothen-Bell (mcglothen@uthscsa.edu) or Christie Lawrence (Christie_Lawrence@rush.edu) for questions regarding an application.

37TH ANNUAL GRAVENS CONFERENCE ON THE ENVIRONMENT OF CARE FOR HIGH RISK NEWBORNS

Conference Background

In a perfect world, there would be no need for a NICU. Yet our reality is that babies continue to be born too sick, too soon, and with medical conditions requiring hospitalization. Activities in the NICU have a profound impact on the babies, their families and the staff. What you do matters. Your work has the potential to impact a neonate's health outcome, as well as that of the family and staff in the NICU.

Since the 1980s, neonatal care providers have worked to mitigate the stress experienced by babies, parents and providers. Doing so has involved change and its inherent struggles, but eventually we have adapted our NICU culture, policies and approach. We strive to nurture the developmental needs of babies and the emotional and informational needs of their parents through evidence-based knowledge in neurodevelopmental science, developmental care, healthcare design, and family support. This work continues at The 37th Annual Gravens Conference.

Registration Fees

You will have access to recorded presentations after the conference is over.

Early Bird Full Conference In-Person Registration Early Bird Ends 1/22/2024	\$725.00
Remote, in real time	\$725.00
Full Time Students/Trainee Registration In-Person	\$300.00
Group In-person Registration 3 and more	\$650.00
Nurses/Allied Health Professionals In-person	\$595.00
Nurses/Allied Health Professionals Remote in Time	\$525.00
Single Day In-person Registration	\$250.00
NICU Parent Registration In-person	\$300.00
NICU Parent Registration Remote in Time	\$300.00
Full Conference In-person 3/6-3/9	\$800.00
Institutional Group Zoom Registration (10 Attendees)	\$2,500.00
Institutional Group Zoom Registration (50 Attendees)	\$10,000.00
International Low Income Country Zoom Registration	\$85.00
International Zoom Registration	\$250.00
Diversity Scholarship Participants	\$300.00
Donation	

Course Objectives

- At the conclusion of the program, participants should be able to:
- Relate rationale for implementing optimal family centered, developmentally supportive care standards and environmental design approaches in newborn intensive care units.
- Describe rationale and evidence to keep parents and babies consistently together from delivery to discharge
- Identify current environmental design for newborn intensive care units that benefit babies, families and staff.
- Compare and contrast evidence based developmental and family centered care programs.
- Implement evidence based infant and family centered developmental care changes in your unit.

Target Audience

This program has been developed to meet the educational needs of healthcare practitioners such as Neonatal Nurses (RNs, NNPs, ARNPs), NICU Therapists, Neonatologists, Pediatricians, Psychologists, Occupational Therapists, Physical Therapist, Speech-Language Pathologist, Family Support Staff, Architects, Hospital Administration, Infant & Child Development Specialists, Social Workers & Counselors, Parents and Family members and other professionals working with high-risk infants, their families or their physical environment.

Competencies to be addressed

PATIENT CARE AND PROCEDURAL SKILLS;
Medical knowledge; Systems-based practice; Professionalism; Interpersonal and communication skills.

DISCLAIMERS:

Final number of continuing education credits maybe changed based on speakers objectives. PAC/LAC reserves the right to amend speakers, topics and scheduling at any time.

GRIEVANCES:

Any grievances may be made to info@paclac.org

Continuing Education

PAC/LAC is accredited by CMA to provide continuing medical education for physicians.

PAC/LAC is an approved provider by the California Board of Registered Nursing, Provider number CEP 5862.

Pending accreditation approval (application in process)

- Occupational Therapy
- Respiratory Care Therapist
- Documentation will be provided for self-reporting:
- Physical Therapy
- Architect
- Speech/Language and Audiology Therapists

Certificate Policy:

After completion of the course evaluation, you will be provided with a continuing education certificate. Make sure to save your certificate.

PAC/LAC will assist you with finding your certificate for up to 1 year from the event without cost. For assistance with any certificates older than 1 year from the time of the event, PAC/LAC charges \$20 for the first certificate, and \$15 for each additional certificate requested each calendar year. A \$10 processing fee will be added to requests needing fulfillment within 24 hours.

Equal Opportunity & Accommodations for Disabilities:

PAC/LAC is an Equal Opportunity /Affirmative Action / Equal Access Institution.

For disability accommodations contact PAC/LAC at 818-708-2850, or email Gayane Pakhanyan at gpakhanyan@paclac.org a minimum of fifteen (15) working days in advance of the event



For accommodations email info@paclac.org
A minimum of ten (15) working days in advance.

Faculty

Andy Gomm, MSW

Brian Goldman, MD

Britt Pados

Carol Jaeger, DNP, RN, NNP-BC

Carol McNair RN(EC), PhD, NNP- BC, NP-Peds

Christine Lawrence, DNP, RNC-NIC, APN/CNS

Cuyler Romeo , MOT, OTR/L, SCFES, IBCLC

Cynthia Sparer

Elizabeth Rogers, MD

Erick Ridout

Erin Ross, PhD, CCC-SLP

Gloria Yennaco, RNC-NIC, C-ELBW, BSN

Jean Powlesland

Jeffrey R. Alberts

Jim Greenberg, MD

Juzer Tyebkhan, MBBS, MRCP(UK), FRCP(C)

Kelly McGlothen PhD, RN, IBCLC

Kimberly Novod, MPA

Kristina Reber, MD

Laura Poltronieri, AIA

Malathi Balasundaram, MD, FAAP

Mardelle McCuskey Shepley, D.Arch., FAIA

Mitchell Goldstein MD, MBA, CML

Mia Malcolm, BS

Nathalie Maitre

Raylene Phillips, MD, MA, FAAP, FABM, IBCLC

Rebecca Ames, MS

Robert White, MD

Paige Church MD

Petra Huppi

Co-Chair Executive Planning Committee Members

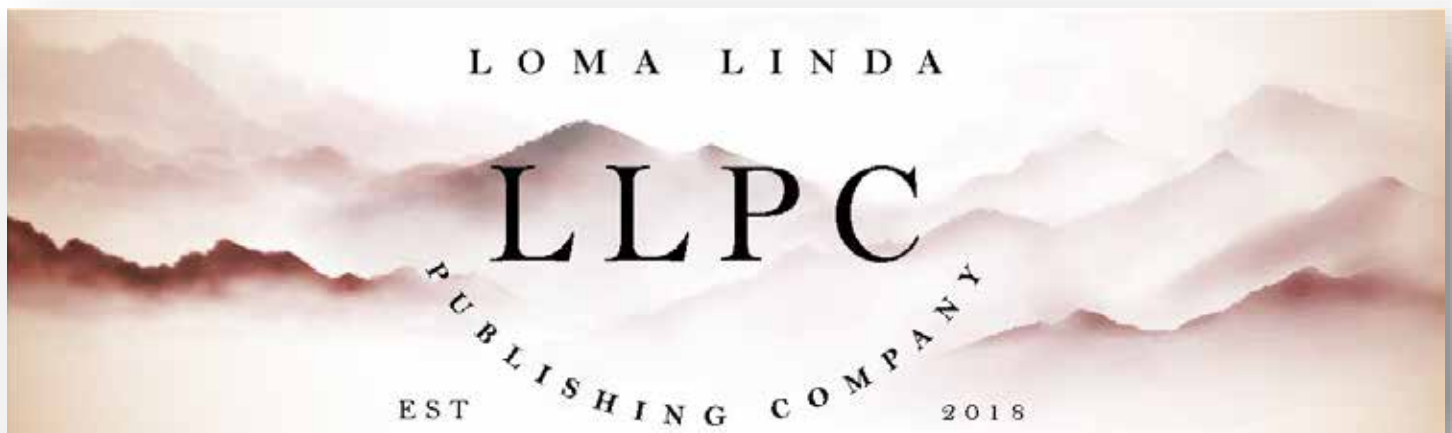
Robert White, MD

Mitchell Goldstein, MD, MBA, CML

Joy Browne, Ph.D, PCNS, IMH-E

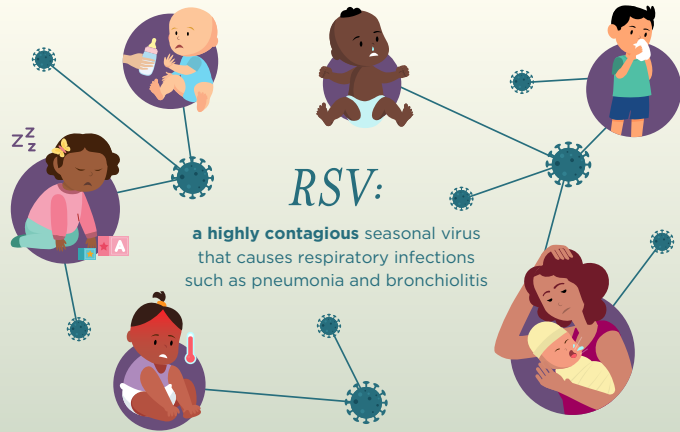
Vincent C. Smith, MD MPH

Please click on the QR Code then click on the Faculty Tab to view Biography and view our Planning Committee Members



Respiratory Syncytial Virus

DID YOU KNOW?



The Gap Baby: An RSV Story



Infants under age 1



RSV is the leading cause of hospitalization



16x more likely to get RSV than the flu



Postpartum Revolution

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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

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Retinopathy
of Prematurity

1.0 credit hour

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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

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National Perinatal Association and NICU Parent Network
mynicunetwork.org

COVID-19

National Network of NICU Psychologists


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Download at 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 | Phone: (626) 578-0833

Featured Conference: Agenda for the 40th Advances In Neonatal And Pediatric Cardiorespiratory Care

Donald Null, MD, MBA, Mitchell Goldstein, MD, MBA, CML,
Arun Pramanick, MD

Wednesday, January 31, 2024

Time	Title	Speaker
7:00am	Registration and Refreshments	
Presentations: Moderated by Moderated by		
8:00am	Opening Remarks	Donald Null, MD Emeritus Professor of Pediatrics University of Utah
8:15am	<i>Special Lecture</i> NonInvasive Ventilation: What is New in 2024	Rangasamy Ramanathan, MD. Professor of Pediatrics Division Chief, Division of Neonatal Medicine, LAC+USC Medical Center & PH Good Samaritan Hospital Director, NPM Fellowship & NICU Director, Neonatal Hemodynamics Program & Neonatal Respiratory Therapy Services, LAC+USC Medical Center Keck School of Medicine of USC
9:05am	Special Lecture HFJV: Insight into Flow, Frequency, & Time	Keith Kohutek, BSRC, RRT-NPS Senior Clinical Specialist Bunnel Incorporated
9:50am	ABSTRACT	
10:00am	BREAK	
10:20am	Special Lecture Why HFOV is not Working and How to Fix it	Donald Null, MD Emeritus Professor of Pediatrics University of Utah
11:10pm	Special Lecture Management Strategies for Neonatal NAVA: what are the nuances?	Kimberly S. Firestone, MSc, RRT Akron Children's Hospital Director, Respiratory Care & Clinical Outreach Service
11:50am	ABSTRACT	
1:00pm	Special Lecture Update on PDA Occlusions in very low birth weight infants	Frank Ing, MD Chief, Co-Director, Division of Pediatric Cardiology Pediatric Heart Center UC Davis Health Center

40th Advances in Neonatal and Pediatric Cardiorespiratory Care
Hilton Los Angeles North/Glendale, Glendale CA

1:50pm	Special Lecture Hypotension in Preterm infants: Diagnosis and Management	Shahab Noori, MD, MS CBTI, RDCS Professor of Pediatrics Keck School of Medicine, USC
2:45pm	ABSTRACT	
2:55pm-3:10pm	BREAK	
3:10pm	Special Lecture Neonatal PICC Lines are not Benign	Frank Ing, MD
3:50pm	Special Lecture Neonatal Neuromonitoring in the Critically Ill Infant	Valerie Chock, M.D., M.S. Epi Arline and Pete Harman Endowed Faculty Scholar, Stanford Maternal & Child Health Research Institute Associate Professor of Neonatology Stanford University School of Medicine
4:45pm	ABSTRACT	

***Agenda is subject to change without notice.**

40th Advances in Neonatal and Pediatric Cardiorespiratory Care
Hilton Los Angeles North/Glendale, Glendale CA

Thursday, February 1, 2024

Time	Title	Speaker
7:00am	Registration and Refreshments	
Presentations: Moderated by Moderated by		
8:00am	Special Lecture Technology Competencies for Pediatric Trainees	Colleen A. Kraft, MD, MBA, FAAP Professor of Pediatrics Keck School of Medicine at the University of Southern California Division of General Pediatrics Children's Hospital Los Angeles 2018 President, American Academy of Pediatrics
8:55am	Special Lecture Nutritional Management of the NANO Preterm Infant	Amy B. Hair, M.D. Associate Professor Program Director of Neonatal Nutrition Co-Director of NICU Intestinal Rehab Team Director of MCH Neonatal Nutrition Training Program Division of Neonatology
9:50am	ABSTRACT	
10:00am	BREAK	
10:20am	ABSTRACT	
10:35am	ABSTRACT	
10:50am	Special Lecture Update on Neonatal Seizures	Arthur Partikian, MD Clinical Associate Professor of Pediatrics & Neurology Keck School of Medicine of USC Director, Division of Child Neurology at LAC+USC Medical Center
11:45am	ABSTRACT	
12:00pm	LUNCH	
1:00pm 2:20pm 3:40pm	Recurring Workshops A. Functional Echocardiography	A. Dr. Yogen Singh, Dr. Shahab Noori, Dr. Rangasamy

***Agenda is subject to change without notice.**

**40th Advances in Neonatal and Pediatric Cardiorespiratory Care
Hilton Los Angeles North/Glendale, Glendale CA**

	<p>B. Lung US C. aEEG /NIRS Workshop D. Noninvasive Ventilation</p>	<p>Ramanathan, Dr. Mahmood Ebrahimi</p> <p>B. Dr. Amy Yeh & Dr. Jennifer Shepherd</p> <p>C. Dr. Valerie Chock & Kathi S. Randall, MSN, NNP-BC</p> <p>D. Dr. Manoj Biniwale</p>
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***Agenda is subject to change without notice.**

Hilton Los Angeles North/Glendale, Glendale CA

Friday, February 2, 2024

Time	Title	Speaker
7:00am	Registration and Refreshments	
Presentations: Moderated by Moderated by		
8:00am	ABSTRACT	
8:15am	Special Lecture Nutritional approach for neonates with congenital heart disease	Cynthia L Blanco, MD Professor, Department of Pediatrics Chief, Division of Neonatology Director, Neonatal Nutrition and Bone Institute, University Health System Greehey Family Foundation Chair in Neonatology Research The University of Texas Health Science Center San Antonio
9:00am	<i>Robert A deLemos Memorial Lecture</i> Is there a Role of Inhaled Nitric Oxide in Premature Infants-Revisited?	Arun Pramanik, MD, DCH, FAAP, FIAP Professor of Pediatrics LSU Health, Shreveport, LA
9:50am	BREAK	
10:10am	Special Lecture RSV New Therapies	Mitchell Goldstein, MD, MBA, CML Professor of Pediatrics, Loma Linda University School of Medicine
10:50am	Special Lecture Fetoscopy and stem cells in fetal surgery	Shinjiro Hirose, MD Vice Chair Dept of Surgery Chief Div. of Pediatric Surgery UC Davis Medical Center
11:50am	ABSTRACT	
12:00pm	LUNCH	
1:00pm	ABSTRACT	
1:15pm	Special Lecture Quantum Mechanics and High Frequency Ventilation	Mitchell Goldstein, MD, MBA, CML

*Agenda is subject to change without notice.

40th Advances in Neonatal and Pediatric Cardiorespiratory Care
Hilton Los Angeles North/Glendale, Glendale CA

		Professor of Pediatrics, Loma Linda University School of Medicine
2:00pm	Special Lecture Physiology Based Management of Septic Shock and Cardiocentric Management	Yogen Singh, MBBS, MD Professor, Pediatrics, Neonatology Division, Loma Linda University School of Medicine
2:45pm	ABSTRACT	
3:00pm- 3:15pm	BREAK	
3:15pm	ABSTRACT	
3:30pm	Antibiotic Stewardship: The Good the Bad and the Ugly	Donald Null, MD
4:20pm	ABSTRACT	
4:35pm	Closing Remarks	Donald Null, MD

***Agenda is subject to change without notice.**

Corresponding Author



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Arun Pramanik, MD
Professor of Pediatrics
Division of Neonatology
Department of Pediatrics
Louisiana State University
Shreveport, LA

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

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40th Advances in Neonatal and Pediatric Cardiorespiratory Care

Attend in person

Jan 31 - Feb 2, 2024

Location:
Hilton Los Angeles
North/Glendale
Glendale, CA



This conference is unique because it focuses on physiology based patient care

Confirmed Guest Speakers

- Frank Ing
- Donald Null
- Colleen Kraft
- Shahab Noori
- Amy B. Hair
- Rangasamy Ram
- Mitch Goldstein
- Kevin Kohutek
- Valarie Y-L Chock
- Cynthia L. Blanco
- Shinjiro Hirose
- Arthur Partikian
- Kimberly Firestone
- Arun Pramanik
- Yogen Singh

Hands-on Practice Sessions for FECHO/LUS/aEEG

WHY YOU SHOULD ATTEND?

- Hands on experience with the latest ultrasound techniques for cardiopulmonary hemodynamic assessment using state of the art simulation equipment.
- Hands on experience with the use of various ventilators including the use of nasal high frequency ventilation.
- Learn how technology can help address health disparities in children.
- Trauma and Critical Care in an austere or out of hospital environment.
- Management of Post Discharge Bronchopulmonary Dysplasia associated Pulmonary Hypertension and pediatric patients with pulmonary hypertension.

GENERAL INFORMATION

Agenda

Agenda 2024

<https://paclac.org/wp-content/uploads/2023/08/Agenda-2024-2.pdf>

Location

Hilton Los Angeles North/Glendale
100 W. Glenoaks Blvd.
Glendale, CA 91202

In the event in-person attendance is canceled or capacity limits modified per CDC or public health guidelines, the conference will be modified accordingly or presented entirely as a live virtual activity.

Registration

We suggest you register early.

Online – To register online, please go to:

<https://www.eventbrite.com/e/40th-advances-in-neonatal-and-pediatric-cardiorespiratory-care-tickets-653266115537?aff=oddtcreator>

Conference Parking

Self Parking: \$10.00

Valet Parking: \$29.00

Transportation

Metro: 400 W. Cerritos Ave., Glendale, CA. 91204

UBER/LYFT: Estimate \$10-\$12.00

The nearest airports are:

Hollywood Burbank Airport (BUR) - 12.8km/8mi

Los Angeles International (LAX) - 43.5km/27mi

Ontario International Airport (ONT) - 72.42km/45mi

Long Beach Airport (LGB) - 56.32km/35mi

Refunds

Cancellations must be received in writing by January 2, 2024 and will be subject to a \$75 processing fee. No refunds will be given after that date.

Hilton Los Angeles North/Glendale

Accommodations

We have a room block reserved at the Hilton Los Angeles North/Glendale in Glendale for January 31 2024 through February 2, 2024. Booking your room is simple, just select "Book a Room" to receive your group's preferred rate. Use link to book your room: Booking Link: <https://www.hilton.com/en/book/reservation/deeplink/?ctyhocn=BURHGHF&groupCode=PAC&arrivaldate=2024-01-30&departuredate=2024-01-31&flexibleDates=true&cid=OM,WW,HILTONLINK,EN,DirectLink&fromId=HILTONLINKDIRECT>

Rate: \$189 +Tax

Group Code: PAC

Arrival Date: January 30, 2024

Departure Date: February 2, 2024

There is a 72hr cancellation policy for reservations.

It is strongly advised that you make room reservations early.

With a stay at Hilton Los Angeles North/Glendale in Glendale (Downtown Glendale), you'll be within a 15-minute drive of Universal Studios, Hollywood and Crypto.com Arena. This hotel is 11.9 mi (19.1 km) from University of Southern California and 8.4 mi (13.5 km) from Universal CityWalk.

Popular sites/entertainment in the Glendale and Southern CA locations:

- **Disneyland**
- **Beaches**
- **Americana at Brand**
- **Gene Autry Museum**
- **Los Angeles Zoo**
- **Magic Castle**
- **Descanso Gardens**



COURSE DIRECTOR

Donald M. Null, Jr. MD
Emeritus Professor of Pediatrics,
University of Utah

FACULTY

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Professor of Pediatrics,
LSU Health, Shreveport, LA

Mitchell Goldstein, MD, MBA, CML
Professor of Pediatrics,
Loma Linda University School of Medicine Director,
Neonatal ECMO Program Division of Neonatology,
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Loma Linda, California

Rangasamy Ramanathan, MD
Professor of Pediatrics Division Chief, Neonatal Medicine,
LAC+USC Medical Center Director, NPM Fellowship,
Program and NICU Keck School of Medicine of University
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Colleen A. Kraft, MD, MBA, FAAP
Professor of Pediatrics Keck School of Medicine at the
University of Southern California Division of General
Pediatrics Children's Hospital Los Angeles,
2018 President, American Academy of Pediatrics

Amy B. Hair, MD
Associate Professor
Program Director of Neonatal Nutrition,
Co-Director of NICU Intestinal Rehab Team, Director of
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Keith Kohutek, BSRC, RRT-NPS
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Senior Clinical Specialist
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UC Davis School of Medicine
Professor and Chief - Division of Pediatric
General, Thoracic, and Fetal Surgery
UC Davis Health, School of Medicine,
Department of Surgery
Director of Pediatric Surgery – Shriners
Hospitals for Children – Northern
California

Kimberly S. Firestone MSc, RRT
Director of Respiratory Care and Clinical
Outreach Services
Akron Children's Hospital

Yogen Singh, MBBS, MD
Professor, Pediatrics, Neonatology Division, Loma Linda
University School of Medicine

Workshops

A. Functional Echocardiography

B. Lung US

C. aEEG /NIRS

D. Noninvasive Ventilation

Dr. Yogen Singh, Dr. Shahab Noori, Dr. Rangasamy Ramanathan,
Dr. Mahmood Ebrahimi, Dr. Manoj Biniwale, Dr. Amy Yeh,
Dr. Jennifer Shepherd, Dr. Valerie Chock, Kathi S. Randall, MSN,
NNP-BC

40th Annual Conference, January 31-February 2, 2024

DESCRIPTION

40th Advances in Neonatal and Pediatric Cardiorespiratory Care Conference (formerly: High-Frequency Ventilation of Infants, Children & Adults) will present high quality education and networking opportunities to healthcare professionals who provide care for critically ill neonatal and pediatric with a focus on advances in therapeutics and technologies. Along with featured speakers, the conference includes abstract presentations on research on advances in these areas.

TARGET AUDIENCE

Geared towards multidisciplinary teams of caregivers from neonatal units that include: neonatologists, pediatricians, neonatal nurse practitioners, advanced pediatric providers, registered nurses and respiratory care practitioners.

Attendees who choose to attend the live virtual activities will receive a virtual meeting link and password to access the live virtual conference.

All registrants (live or virtual) will be provided the opportunity to review recorded sessions up to 3 weeks following the conference.

Attendees will be awarded CME credit commensurate with the extent of their participation in the live activity (either in-person or virtual). The recorded sessions are not certified for CME credit.

DISCLAIMERS:

Final number of continuing education credits maybe changed based on speakers objectives. PAC/LAC reserves the right to amend speakers, topics and scheduling at any time.

GRIEVANCES:

Any grievances may be made to info@paclac.org

FEES

MD and PhD Registration	\$500.00
RN, RT & Residents	\$300.00
MD & PhD Group Rate 4+ Attendees	\$400.00
RN, RT & Residents Group Rate 4+ Attendees	\$250.00
Students	\$100.00
MD & PhD 1 Day Registration	\$200.00
MD & PhD 2 Days Registration	\$350.00
RN, RT and Residents 1 Day Registration	\$200.00
RN, RT and Residents 2 Day Registration	\$250.00

COURSE OBJECTIVES

At the conclusion of the program, participants should be able to:

- 1) Discuss new options for RSV prophylaxis, how does everything fit together.
- 2) How to improve antibiotic stewardship in the NICU.
- 3) Describe new concepts in Nasal Ventilation in newborns, including setup strategies and risks.
- 4) Understand the latest thinking in Neuro monitoring and Neonatal seizures.
- 5) Identify new strategies in the feeding of the "Nano" preemie.
- 6) Understand how to use the different ventilator modalities, including Jet, NAVA, HFOV, and their indications.
- 7) Incorporation of Point of Care Ultrasound in NICU practice.
- 8) Describe the new technology competencies for pediatric Trainees.
- 9) Understand new advances in fetal surgery.
- 10) Understand the benefits of a breastmilk in the management of infants with complex congenital heart disease.
- 11) Hypoxemic Respiratory Failure in very Preterm, Late Preterm & Term Newborns: Diagnosis and Management Consideration.
- 12) Understand Management of Pulmonary Hypertension in the preterm, the role of iNO.
- 13) Relate the complications of PICC lines.
- 14) Discuss the management of hypotension in the preterm infant.
- 15) Describe the latest innovation in PDA occlusion.
- 16) Hands-on workshops with the latest equipment in Neonatal, Pediatric, and Adult Critical Care Medicine including functional cardiac, lung ultrasound, AEEG, and noninvasive ventilation.

CONTINUING EDUCATION

PAC/LAC is accredited by the California Medical Association (CMA) to provide continuing medical education for physicians.

The Perinatal Advisory Council-Leadership, Advocacy and Consultation (PAC/LAC) is an approved provider by the California Board of Registered Nursing, Provider Number CEP-5862

Application has been made to the American Association for Respiratory Care (AARC) for continuing education contact hours for respiratory therapists.

CERTIFICATE POLICY:

After completion of the course evaluation, you will be provided with a continuing education certificate. Make sure to save your certificate. PAC/LAC will assist you with finding your certificate for up to 1 year from the event without cost. For assistance with any certificates older than 1 year from the time of the event, PAC/LAC charges \$20 for the first certificate, and \$15 for each additional certificate requested each calendar year. A \$10 processing fee will be added to requests needing fulfillment within 24 hours.



For accommodations email info@paclac.org
A minimum of ten (15) working days in advance.

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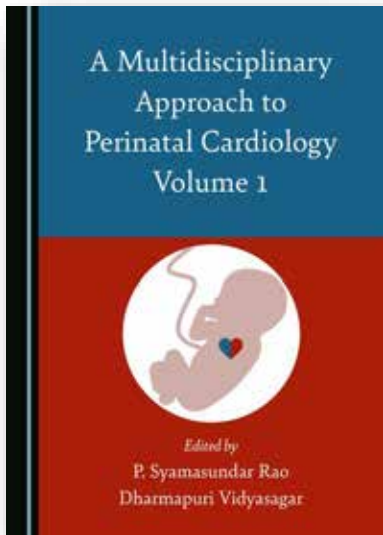
Second Edition

**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



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 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 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.

Follow us online at @MyNICUNetwork

www.myperinatalnetwork.org Phone: 805-372-1730



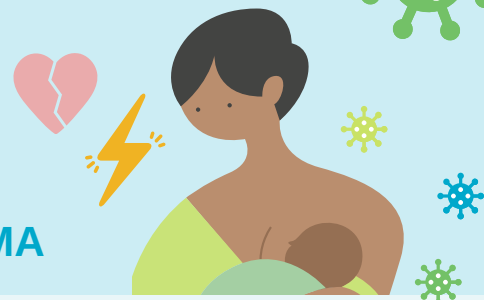
SHARED DECISION-MAKING PROTECTS MOTHERS + INFANTS

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**SSASS 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 nationalperinatal.org



National
Association of
Neonatal
Nurses



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



New Hope for Postpartum Depression Treatment

Josie Cooper

The Alliance for Patient Access (allianceforpatientaccess.org), 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 (IfPA), a related 501(c)(3) non-profit corporation. In keeping with its mission to promote a better understanding of the benefits of the physician-patient relationship in the provision of quality healthcare, IfPA sponsors policy research and educational programming.



The [FDA has approved](#) the first oral medication to treat postpartum depression, marking a major breakthrough for maternal mental health. (1)

Like other kinds of depression, postpartum depression can overwhelm a new mother with sadness, feelings of inadequacy, and fatigue. Treatment previously was available only through an IV administered in a clinical setting, which can be challenging to access, time-consuming, and inconvenient for busy families caring for a newborn.

“Treatment previously was available only through an IV administered in a clinical setting, which can be challenging to access, time-consuming, and inconvenient for busy families caring for a newborn.”

A Paradigm Shift in Treating Postpartum Depression

Patients given the oral medication once daily for two weeks experienced reduced symptoms of postpartum depression. That effect lasted up to a month after the final dose. After two randomized, double-anonymized, placebo-controlled trials – the gold standard for clinical research – the treatment received FDA approval under the [Fast Track](#) designation. (2)

“After two randomized, double-anonymized, placebo-controlled trials – the gold standard for clinical research – the treatment received FDA approval under the Fast Track designation. (2)”

However, while medical breakthroughs are exciting, actual progress in reducing postpartum depression in the United States requires more than just new treatments.

Screening, early intervention, and access to care are crucial to transforming the lives of new mothers and whole families through better mental health support.

More Screening, Less Stigma

Improved screening for depression during pre- and postpartum care could help connect patients to treatment. It could also reduce the stigma around mental health challenges for new mothers. Establishing a baseline for maternal mental health before the third trimester, for example, may help clinicians identify women who are struggling or at risk for postpartum depression.

“Improved screening for depression during pre- and postpartum care could help connect patients to treatment. It could also reduce the stigma around mental health challenges for new mothers.”

Treating postpartum depression is important not only for mothers' mental health but also for infants' development. The relationship between mother and newborn is critical for emotional bonding and long-term well-being. Leaving postpartum depression untreated raises the risk of developmental delays.

About Postpartum Depression

About [15%](#) of new mothers experience symptoms of postpartum

depression. (3)

Without treatment, depression can escalate to life-threatening levels: suicide is the second leading cause of postpartum death.

“Even with these well-known risks, surveys indicate one in eight women will not even be asked about their emotional health during postpartum appointments. (4)”

Even with these well-known risks, surveys indicate one in eight women will not even be asked about their emotional health during postpartum appointments. (4) The resulting underdiagnosis and undertreatment can be addressed through an improved standard of care.

References:

1. <https://www.fda.gov/news-events/press-announcements/fda-approves-first-oral-treatment-postpartum-depression>
2. <https://www.fda.gov/patients/fast-track-breakthrough-therapy-accelerated-approval-priority-review/fast-track>
3. <https://my.clevelandclinic.org/health/diseases/9312-postpartum-depression>
4. Kuehn BM. Postpartum Depression Screening Needs More Consistency. JAMA. 2020;323(24):2454. doi:10.1001/jama.2020.9737

Disclosure: Josie Cooper is executive director of the Alliance for Patient Access. This article was also published at healthpolicytoday.org.


NT

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SHARED DECISION-MAKING

PROTECTS PARENTS + BABIES COVID-19

INFORMED PROVIDERS

Seek participation
Help explore options
Assess preferences
Reach a decision
Evaluate the decision

CARE DELIVERY REQUIRES **PARTNERSHIP**



 NPA
 NANN

nationalperinatal.org/NPAandNANN

99nicu

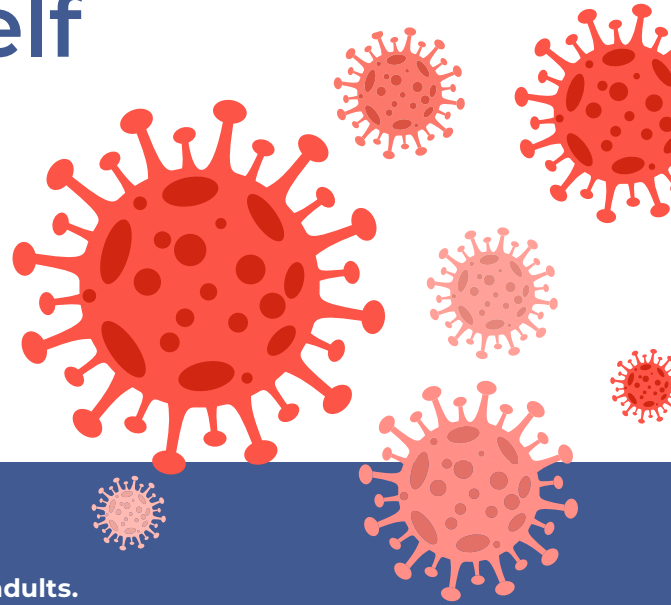
Sign up for free membership at 99nicu, the Internet community for professionals in neonatal medicine. Discussion Forums, Image Library, Virtual NICU, and more...”

www.99nicu.org

Immunizing Yourself Against COVID-19

COVID-19 vaccines have been shown to:

- ✓ Lessen the severity of symptoms¹
- ✓ Reduce disease transmission³
- ✓ Reduce risk of mortality²
- ✓ Make communities healthier and safer⁴



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.⁵

Safe and Sound

COVID vaccines have been:



Thoroughly tested

through multi-phase trials with tens of thousands of participants⁶



Proven safe and effective

for adults as well as children⁷



Vetted and approved by the US FDA and EMA and endorsed by the WHO⁸⁻¹⁰

Get Your Job

Vaccines are available at your:



Doctor's office



Neighborhood pharmacy



Community health center



Talk to your health care provider or pharmacist about which vaccine is right for you.

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



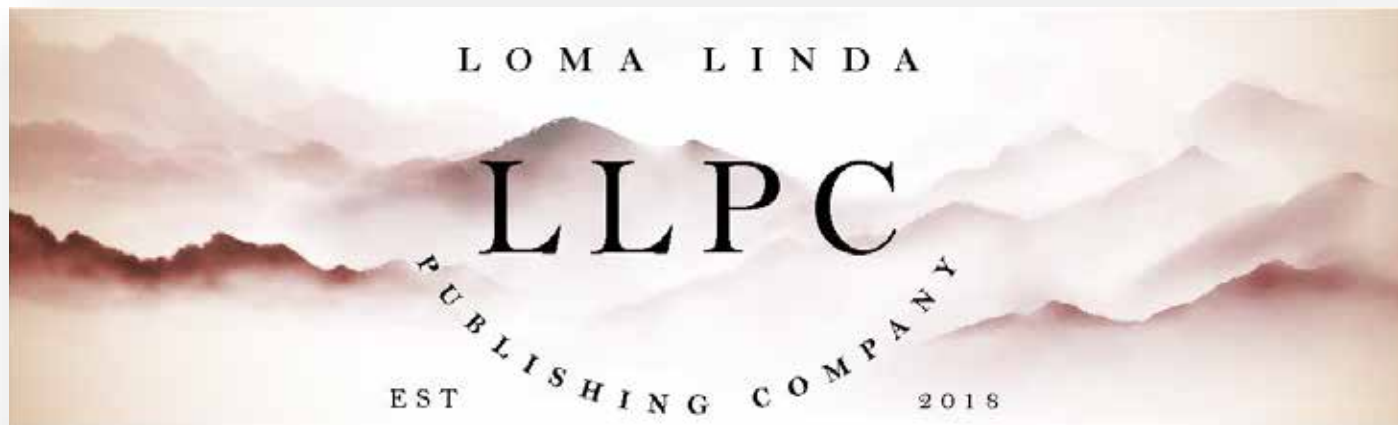
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For the 37th International
GRAVENS meeting on the
Environment of Care for
High Risk Newborns and
their Families

March 6-9, 2024



Sheraton Sand Key Resort
Clearwater Beach, Florida

For more information go to <https://paclac.org/https-paclac-org-gravens-conference/> or PACLAC.org
Abstracts due October 1, 2023



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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



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

iCAN's Journey to Empowerment: The Latest Updates and Exciting Events

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. Our organization empowers all pediatric patients worldwide by facilitating their active participation in innovation, research, and medicine.”

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 empowers 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 to learn more about our mission, various programs, and initiatives. Join us to ensure that every child’s voice is heard and that their unique experiences are taken into account to improve healthcare outcomes for all pediatric patients.

Discover Your Path to Impactful Healthcare through our iCAN Curriculum at this Month’s Ask the Experts.



We are excited to announce our upcoming “Ask the Expert” session, which will take place on October 28 on Zoom at 11 AM EST, 8 AM PST. This session will delve into the captivating world of careers in medicine, advocacy, and innovation. Our expert speaker, Sabina Schmidt Goldstein-Becerra, a seasoned teacher with five years of experience in healthcare education and curriculum development, will guide us through the unique and promising opportunities presented by the iCAN Curriculum.

“Our virtual seminar is open to all, and the best part is that it is entirely free! We invite everyone to seize this unique opportunity to delve into the exciting advancements in healthcare technology and share their thoughts and insights. This monthly series is designed to bring together luminaries from diverse fields, including healthcare, technology, innovation, and even patients.”

Our virtual seminar is open to all, and the best part is that it is entirely free! We invite everyone to seize this unique opportunity to delve into the exciting advancements in healthcare technology and share their thoughts and insights. This monthly series is designed to bring together luminaries from diverse fields, including healthcare, technology, innovation, and even patients. We wholeheartedly encourage you to secure your spot for the upcoming ATE session in October by registering on our website, icanresearch.org, or <https://www.icanresearch.org/events-1/ask-the-experts-october-2023>.

Upcoming ATE Sessions to Look Forward To

We are delighted to present an exciting series of monthly sessions in the coming months, all scheduled for 11 AM EST or 8 AM PST on Saturdays. These sessions have been thoughtfully curated to encompass various subjects, spanning medicine, advocacy, innovation, research, and leadership. We aim to provide you with the knowledge and inspiration needed to empower your personal and professional journey.

“We are delighted to present an exciting series of monthly sessions in the coming months, all scheduled for 11 AM EST or 8 AM PST on Saturdays. These sessions have been thoughtfully curated to encompass various subjects, spanning medicine, advocacy, innovation, research, and leadership.”

1. November 18th YARR Session

Topic: Empowering Teen Advocates: Navigating Legislative Advocacy, School Leadership, and Community Engagement

In our November 18th session, we will explore empowering young advocates. The discussion will revolve around the intricacies of legislative advocacy, the art of school leadership, and the impact of community engagement, all through the lens of our future leaders.

2. December 16 Session

Topic: Revolutionizing Healthcare: A Journey with Joe Kiani, CEO of Masimo, and His Trailblazing Innovations

We have a remarkable session in store as we wrap up the year in December. Join us as we embark on a journey with Joe Kiani, the visionary CEO of Masimo, to delve into his groundbreaking innovations that are revolutionizing the healthcare industry.

These sessions promise to be informative and inspirational, and we invite you to mark your calendars and join us in these engaging discussions.

At the heart of iCAN's mission lies an unwavering dedication to providing a platform for experts to share their wisdom and perspectives. If you possess expertise in pediatric healthcare, whether in innovation, medicine, or technology, we wholeheartedly invite you to contribute as a speaker for our ATE sessions. For additional information and to express your interest, please contact us at abbyclark@icanresearch.org.

Engaging with Pediatric Experts and Advocates at AAP 2023:



iCAN was honored to be a part of the American Academy of Pediatrics (AAP) event, which took place from October 20 to 24 in Washington, D.C. At that gathering, we were not merely attending; we actively connected with colleagues and immersed ourselves in thought-provoking educational sessions. We extend a heartfelt thank you to our sponsors who made our participation in this annual event possible.

Visiting the AAP Booth #1841:

Many attendees had the opportunity to stop by our booth, where we proudly shared our mission with the global pediatric community. It was a hub of inspiration, where we engaged with healthcare professionals, advocates, and individuals who, like us, were dedicated to improving pediatric healthcare.

Staying Informed:

For those who joined us at the AAP event or could not make it this time, we encourage you to watch for updates on upcoming events and our ongoing mission to empower young voices and enhance pediatric care globally. Our commitment to these ideals remains as strong as ever, and we look forward to future opportunities to collaborate, learn, and make a positive impact in pediatric healthcare.

KIDS Houston's Inaugural Meeting Series Featuring Sneha Dave:
A Remarkable Start to Inspiring Conversations



**KIDS HOUSTON
MEETING SERIES**



GUEST SPEAKER: SNEHA DAVE



On October 11, KIDS Houston proudly launched its inaugural webinar series, featuring accomplished guest speaker Sneha Dave, an Indiana University graduate majoring in Chronic Illness Advocacy and Journalism. Sneha Dave, the creator of Generation Patient and the Crohn's and Colitis Young Adult Network, stands out for her unwavering commitment to their independence from the pharmaceutical industry. With experiences such as an undergraduate research fellowship at Harvard T.H. Chan School of Public Health, an internship at Pfizer, and speaking engagements on Capitol Hill, her expertise is nationally recognized, and she contributes to publications like U.S. News and World Report.

Additionally, Sneha actively serves on the FDA Patient Engagement Collaborative and the Robert Wood Johnson Foundation grantmaking committee, earning recognition as the most influential teen in 2018 by the We Are Family Foundation. Sneha's impactful presence during the webinar made it a resounding success. Follow @icankidshouston for updates on our upcoming webinars featuring more incredible guest speakers.

Youth Council Update: Empowering Tomorrow's Leaders



<https://www.icanresearch.org/ican-youth-council>

Calling all youth members and those curious - join us! Dive deeper into our mission, make an impact in pediatric medicine, and be part of a passionate community.

Latest: October 14th Meeting Recap

Our recent meeting was a vibrant exchange of ideas, with enthusiastic Youth Council members shaping the future of pediatric medicine. If you missed it, no worries - you can catch up by watching the video linked above!

Mark Your Calendar: December Meeting

Do not miss our December meeting, a hub for unique perspectives and innovative ideas. Your voice and passion matter as we collectively make a difference in pediatric medicine.

For inquiries or to express your interest, contact Youth Council Chairs:

Meghan- meghanmherrington@gmail.com

Ella- ella.m.schaffer@gmail.com

Exciting News: 2024 Summit Set to Inspire in Bari, Italy!



We are brimming with enthusiasm as we prepare for our annual summit, and this time, we are heading to the captivating city of

Bari, Italy, from July 15th-July 19th! The excitement among our young members is electric as they eagerly look forward to this exceptional event. Nonetheless, we understand that we depend on your support and active participation to ensure this occasion becomes truly memorable.

Our annual summit has a rich history of providing invaluable opportunities for our youth akin to those previously offered by Empath Labs and Pfizer. It stands as a transformative platform, nurturing innovation, compassion, and collaboration within pediatric healthcare.

If you share our belief in the transformative power of education and inspiration, we invite you to be an integral part of this life-changing event. There are two distinct ways you can contribute to the success of the 2024 Summit:

“We are brimming with enthusiasm as we prepare for our annual summit, and this time, we are heading to the captivating city of Bari, Italy, from July 15th-July 19th! The excitement among our young members is electric as they eagerly look forward to this exceptional event.”

1. Sponsorship Opportunities:

By becoming a sponsor, you assume a pivotal role in supporting the logistical and organizational aspects of the summit. Your generous contribution will enable us to craft an impactful and seamless experience for all participants. To explore sponsorship opportunities and get involved, please contact Sabina Schmidt Goldstein at sabinaschmidtgoldstein@icanresearch.org.

2. Sponsor a Child's Attendance:

Your sponsorship can directly impact a child's life, affording them a once-in-a-lifetime chance to participate in the Bari Summit. Your support will cover their travel, accommodation, and participation fees, allowing them to immerse themselves in a world of learning, inspiration, and empowerment. To sponsor a child's attendance, please visit our donation page at <https://www.icanresearch.org/donate>.

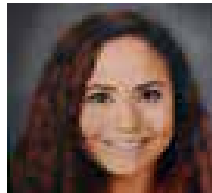
Together, we can shape a brighter future for pediatric healthcare by nurturing the boundless potential of our young members. Regardless of its size, your contribution will play a significant role in paving the way for innovative advancements in the field.

We extend our heartfelt gratitude for considering this opportunity to support the next generation of healthcare leaders. Let us come together in Bari, Italy, and create an unforgettable summit experience that will continue to inspire and empower young minds for years to come! Join us on this incredible journey toward a brighter future in pediatric healthcare.

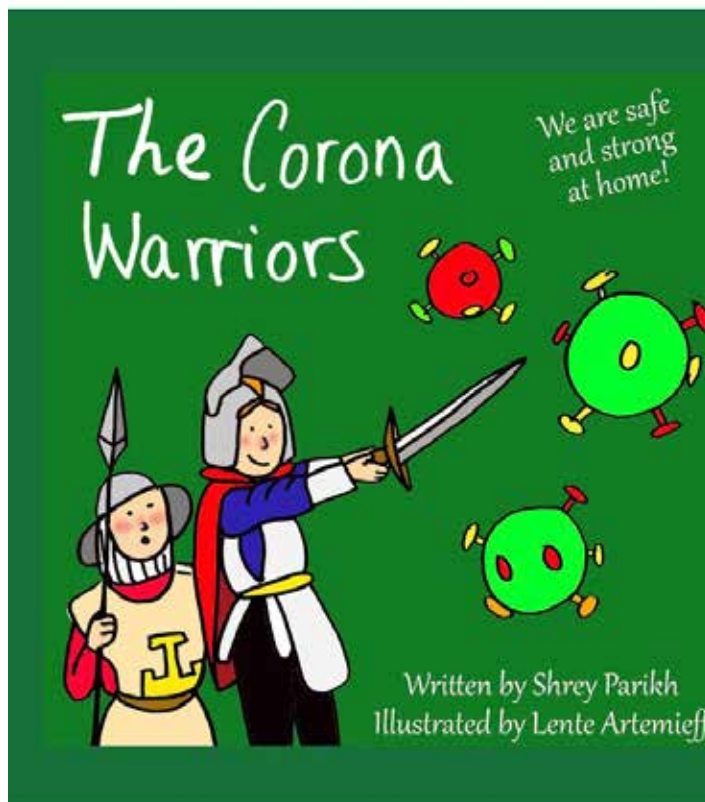
Disclosures: There are no reported disclosures

NT

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Readers can also follow

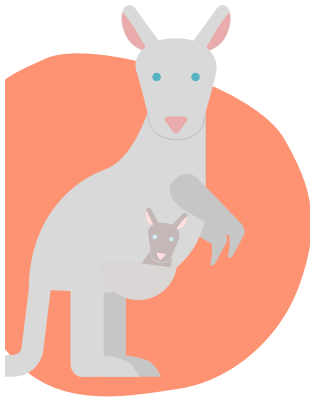
NEONATOLOGY TODAY

via our Twitter Feed

@NEOTODAY

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



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



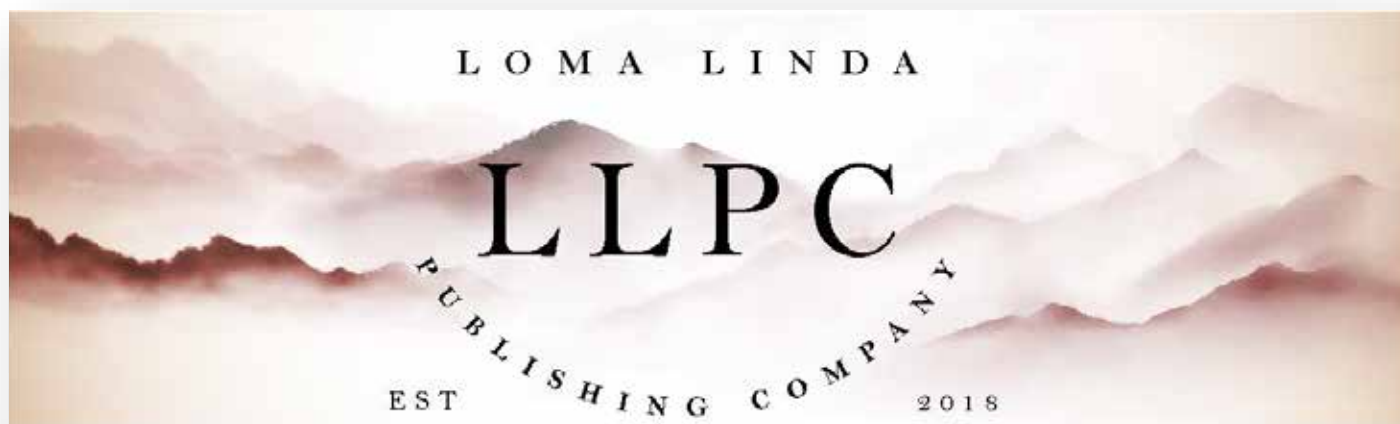
nicuparentnetwork.org
nationalperinatal.org/skin-to-skin



Academy of Perinatal Harm Reduction



www.perinatalharmreduction.org | www.nationalperinatal.org



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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?

- SEEK PARTICIPATION
- HELP EXPLORE OPTIONS
- ASSESS PREFERENCES
- REACH A DECISION
- EVALUATE 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

National Perinatal Association

nationalperinatal.org

Thank You, from iCAN



#iCANMakeADifference

Continue to Support at iCAN.health

*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

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



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

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

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



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

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:



NCfIH National Coalition for Infant Health
Promoting Access for Preventive Infections through Age Two

Learn More about RSV at www.infanthealth.org/RSV

Survey survey conducted September 2018. Excludes 17% specialty health care providers and 60% parents of children 4 and under.

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:



Jaundice



Feeding issues



Respiratory problems

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.

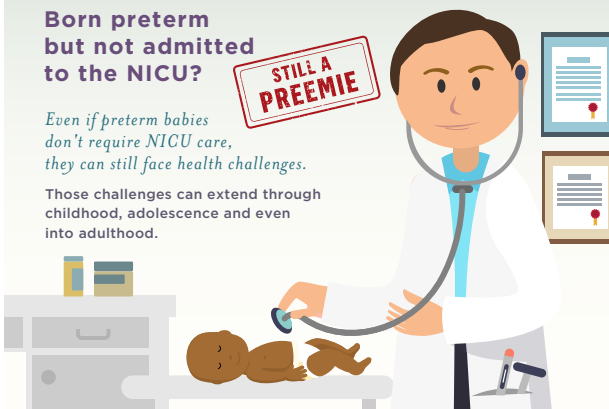


Born preterm but not admitted to the NICU?

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

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

National Perinatal Association



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 Sandeep Lankireddy, BA, OMS IV

Three-year follow-up results of two children born from a transplanted uterus

NEWS PROVIDED BY

[Palacky University Olomouc via NIH](#)

by Jan Janota, Ekaterina Orlova, Marta Novackova, Roman Chmel, Radim Brabec, Zlatko Pastor, Roman Chmel

October 25, 2023

Abstract

Aims: To evaluate the 3-year follow-up results of two children delivered at our institution in 2019 from mothers with a transplanted uterus.

Methods: Observational data on pregnancy outcomes, neonatal course, and growth trajectory in two children born to mothers after uterus transplantation, including 3-year follow-up and neurodevelopmental status assessed using the Bayley Scales of Infant and Toddler Development, third edition (Bayley-III).

Results: Both children were born prematurely via uneventful caesarean sections, to mothers with Mayer-Rokitansky-Küster-Hausler syndrome and a transplanted uterus. An acute caesarean section was performed in one mother because of the onset of regular uterine contractions at 34 weeks and 6 days of pregnancy; in the other mother, an elective caesarean section was performed at 36 weeks and 2 days of gestation. The children were born healthy with no congenital malformations. They had an uneventful postnatal course and showed a normal growth trajectory during 3 years of follow-up. The Bayley-III neurodevelopmental scores of both children were within the normal ranges at ages 2 and 3 years.

Conclusion: Though pregnancy after uterus transplantation is associated with the risk of premature delivery, no abnormalities were observed in the neonatal course and 3-year follow-up results, including the neurodevelopmental status, of two children born prematurely to mothers with a transplanted uterus. This is the first report on neurodevelopmental outcomes in children born after uterus transplantation. More data on children born after this radical procedure of uterine factor infertility treatment are required to support our promising results.

Keywords: Bayley-III scales; absolute uterine factor infertility; assisted reproduction; neurodevelopment; uterus transplantation.

Neonatal Hypothermia: Not an Issue to Simply Blanket Over

NEWS PROVIDED BY

[American Academy of Pediatrics](#)

by Eli Cahan, MD, MS

August 17, 2023

Editor's Note: Eli Cahan is a resident physician in pediatrics at The Boston Combined Residency Program at Boston Children's Hospital and Boston Medical Center, and an investigative journalist whose work focuses on the intersection of health equity and social justice. - Rachel Y. Moon, MD, Associate Editor, Digital Media, Pediatrics

As a pediatrics resident learning the neonatal resuscitation program (NRP) for the first time, there's lots to remember: PIPs (peak inspiratory pressures) and PEEPs (positive end-expiratory pressures), bulb suction and deep suction, CPAPs (continuous positive airway pressures) and C-MACs (video laryngoscopes).

However, every NRP session starts the same, by turning on the infant warmer. Babies don't like the cold, instructors say, citing surface area-to-volume ratios.

Neonatal hypothermia, however, continues to be an issue. Historical studies in the US have found increases in mortality of up to 30% per degree below the low end of normal body temperature. Other studies have found maintenance of normothermia can reduce mortality by 19% per degree above hypothermia. Still others have found specific interventions—like thermal mattresses and heated wraps—can together reduce mortality by nearly 50%.

Despite the importance of neonatal hypothermia, large-scale studies—both domestically, and abroad, including in low- and middle-income countries—aiming to quantify its prevalence and illness course are scarce.

In an article being early released this week in Pediatrics, Frade Garcia and colleagues set out to answer these questions by extracting data on over 200,000 premature and/or small for gestational age newborns from 34 hospitals between 2018-2021 (10.1542/peds.2023-061607).

They found that almost two-thirds of newborns in middle-income countries (MICs) experienced hypothermia within an hour of birth; in high-income countries (HICs), almost 30% of newborns did so. Furthermore, the in-hospital mortality rates of hypothermic neonates in MICs were 21% above those of eutermic neonates. In HICs, the differences were even more pronounced; infants who

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

were hypothermic had mortality rates 26% higher than their eutermic peers. All told, each additional degree reduced mortality rates by around 10% in both MICs and HICs.

The authors were careful to caution that hypothermia may be a product, rather than a cause, of underlying illness that can increase mortality risk. Nonetheless, they highlight the importance of attentiveness to hypothermia as a key method in newborn management.

“Hypothermia remains a common problem in both MICs and HICs,” the authors wrote, “urging the medical community caring for newborns around the globe to renew their focus on this often-neglected vital sign is a key strategy to improve outcomes.”

Clinicians across the practice spectrum interested in advancing the short- and long-term wellbeing of neonates can read more in the September issue of Pediatrics.

NT

Into the Unknown: Coping With the Un- knowable

NEWS PROVIDED BY

[American Academy of Pediatrics](#)

by Cara L. Coleman, JD, MPH, Associate Editor, Pediatrics

September 19, 2023

Editor's Note: In March 2017, Ms. Coleman's daughter Justice Hope, who was medically complex and had multiple disabilities, died at age 11. She was the sunshine in the lives of many and communicated using a thousand smiles.

Family Connections with Pediatrics

Sometimes I wonder if I had a superpower, what would I want it to be? Maybe the ability to fly? I watch birds fly by and wonder what it would feel like to soar through the air, free. Or maybe supersonic hearing, so I could catch every mumble or grumble.

Most often, I wish I could see the future—just a quick glimpse to see what is coming, how it will work out, or most commonly, I wish I could see the future with my children. And then I return to reality, and accept that I cannot, and will not, ever know everything.

In medicine, there is a lot of uncertainty. As the mother of a child with complex medical needs, this often seemed like the only certainty. When issues arose as early as pregnancy with my daughter's health, we were introduced early and often to sometimes having more questions than answers. While the challenges and uncertainty did not resolve over time, our ability to talk about and deal with them grew (and in a way became a new superpower: flexibility and accommodation). In this month's Pediatrics Ethics Rounds section, authors of 'When the Unknown is Unknowable: Confronting Diagnostic Uncertainty,' use the case of Evangelina, and her parents Nathalia and Daniel, to explore how to work through a search for diagnosis, the unknowable, and doctor reflections on how they might respond to an unknown diagnosis (10.1542/peds.2023-061193).

Are there different types of uncertainty?



Join  NPA

www.nationalperinatal.org/mental_health

The authors, Dr. Feudtner and Dr. Janvier, who both have interest and tremendous experience in medical ethics, acknowledge that despite advances in medicine, uncertainty has always been present, plentiful, and in many aspects of health-care. They point out that much of the focus of uncertainty in medicine has to do with prognosis or predicting what may happen with an illness or disease. They identify 2 types of uncertainty in medicine:

1. Aleatory uncertainty: when you may be able to use probabilities (for example, use information from scans, labs, and symptoms) to learn some information about the unknown diagnosis
2. Epistemic uncertainty: when you do not have any way to figure out the unknown diagnosis

People respond to these types of uncertainty differently. The second type of uncertainty- the unknowable unknown- can be harder emotionally, and to reach decisions about care. Values and trust may be all one has when a diagnosis and/or prognosis cannot be known. The authors note that doctors are often trained in communicating uncertainty, but not always well trained in asking about patient or family values.

How is uncertainty discussed in this article?

We are introduced to Evangelina, born at 35 weeks via emergency c-section, with a number of medical issues, including a number of masses on her body, massive bleeding, shock, and the need for resuscitation. Although she had many tests and more than 10 doctors consulting, her diagnosis was unknown. The doctor in charge was not sure how to tell Evangelina's parents that he did not think Evangelina would live when he did not know her diagnosis.

The article goes on to ask two doctors how they would talk to this family and ultimately shares Evangelina's outcome. Dr. Feudtner walks us through how to move forward amidst uncertain diagnosis. Dr. Janvier's response focuses on shifting the doctor's role to support and clear communication about life and death.

What can you do with this article?

For many families, the discussion in this article may sound and feel similar to experiences had with your own child. To others, it may read as conversations you do not wish to have or ones you have tried to start but haven't been sure how to begin. Sometimes in uncertainty, and in healthcare, we find ourselves surrounded by people, but we feel alone at the same time. However this article lands, know that you are never alone. Perhaps this article can help you understand uncertainty, how it is communicated, and the decision-making process, or maybe this can be a good starting point for setting up a conversation with your child's doctor about questions you may have.

NT

Intracranial infection and sepsis in infants caused by *Salmonella* derby: A case report

NEWS PROVIDED BY

[World Journal of Clinical Cases via NIH](#)

by Jing-Lu Yu, Li-Li Jiang, Rong Dong, and Si-Yu Liu

October 6, 2023

Abstract

Background: *Salmonella* derby (*S. derby*) is a Gram-negative diplococcus that is common in the digestive tract. Infected patients generally experience symptoms such as fever and diarrhea. Mild cases are mostly self-healing gastroenteritis, and severe cases can cause fatal typhoid fever. Clinical cases are more common in children. The most common form of *S. derby* infection is self-healing gastroenteritis, in which, fever lasts for about 2 d and diarrhea for < 7 d. *S. derby* can often cause bacterial conjunctivitis, pneumonia, endocarditis, peritonitis and urethritis. However, intracranial infections in infants caused by *S. derby* are rare in clinical practice and

have not been reported before in China.

Case summary: A 4-mo-old female infant had recurrent fever for 2 wk, with a maximum body temperature of around 39.4°C. Treatment for infectious fever in a local hospital was ineffective, and she was admitted to our hospital. Before admission, there was one sudden convulsion, characterized by unclear consciousness, limb twitching, gaze in both eyes, and slight cyanosis on the face. Cerebrospinal fluid (CSF) culture was positive for Gram-negative bacilli, which conformed to *S. derby*. After treatment with meropenem and ceftriaxone antibiotics, the patient was discharged home in a clinically stable state after 4 wk of treatment.

Conclusion: We reported a rare case of *S. derby* cultured in CSF. *S. derby* enters the CSF through the blood-brain barrier, causing purulent meningitis. If not treated timeously, it can lead to serious, life-threatening infection.

Keywords: Case report; Cerebrospinal fluid; Infants; *Salmonella* derby.

NT

Helping Parents Rewrite Their Story When the Diagnosis is Unknown

NEWS PROVIDED BY

[American Academy of Pediatrics](#)

by Krista Roncone, MD

September 14, 2023

Editor's Note: Dr. Krista Roncone is a third-year resident physician in pediatrics at the University of Virginia. She is interested in medical education and health disparities research, and is planning to specialize in pediatric critical care. -Rachel Y. Moon, MD, Associate Editor, Digital Media, Pediatrics

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As I come to the final chapter of my pediatric residency, now more than ever I recognize what my medical training has attempted to prepare me for—not the moments when I can identify and elect the “correct” answer or action in a patient scenario, but rather when I can tread through depths of uncertainty with the appropriate tools. While I am learning to provide concrete knowledge and information to patients and families, I am also developing the skill set necessary to walk alongside them as they experience each new page turn in a story no one ever anticipated having to tell.

Perhaps one of the most unnerving uncertainties a physician can face is an absence of diagnosis in the face of potential death or end of life care. Dr. Giulia Fiason and colleagues from Loma Linda University, University of California-Irvine, Children’s Hospital of Philadelphia, and the Université de Montréal, in an Ethics Rounds that is being early released in Pediatrics, entitled, ‘When the Unknown is Unknowable: Confronting Diagnostic Uncertainty’ offer the novel argument that diagnostic uncertainty does not necessarily equate to prognostic uncertainty (10.1542/peds.2023-061193).

The authors distinguish:

- Aleatory uncertainty: defined as the knowable unknown, from
- Epistemic uncertainty: defined as the unknowable unknown.

As the authors point out, most medical literature targets aleatory uncertainty by attempting to define probabilities of the knowable unknown. To this extent, we have learned to grow comfortable with a measured amount of discomfort. Epistemic uncertainty, however, is unlike its counterpart and is greeted with a much different quality of intellectual and emotional discomfort.

How do we navigate the unknowable unknown?

In this Ethics Rounds, the authors present a case of a newborn with an unknown diagnosis, but with grave end-point physiology comprising of hemorrhagic shock and its consequences. The authors make the case that, in situations in which a diagnosis is unknown, a lack of diagnosis should not necessarily hinder our ability to prognosticate, and more importantly, should not hinder our ability to guide fami-

lies through an unspeakably difficult experience.

The authors emphasize that in these situations where we have a lack of citations to reference, we must instead reference parental values and trust.

Additionally, two authors share their different perspectives about this case.

Dr. Chris Feudtner, a palliative care physician and medical ethicist at the Children’s Hospital of Philadelphia, employs a corollary of false-positive and false-negative statistical principles to guide us through why a diagnosis is not obligatory for prognosis. As a resident interested in critical care, I appreciated how Dr. Feudtner provided a script of his potential discussion with the family in the case, highlighting key moments where he would take strategic pauses and leave blank space for family response, questions, or emotions.

Dr. Annie Janvier from the Université de Montréal offers expertise, not only as a neonatologist and ethicist, but also as a parent. Dr. Janvier emphasizes that, particularly in end-of-life care, the role of the physician is to “help [parents] re-write their story”. We are the fated co-authors of a story that no one wanted to write, and we create a memory for a family that they will have to live with forever. We have the immense privilege and responsibility of making the story as healing and bearable for them as we can. At times a formal diagnosis is part of this complicated narrative, but perhaps it is not as necessary to a family’s grieving process as we might think.

Dr. Janvier also puts name to a concept I do not often see touched on, which is that of injustice. We regularly touch on the sentiments of grief, sadness, anger, and confusion as it pertains to death or poor outcomes, but we less frequently acknowledge feeling the absence of justice. There is no justice when a child dies. As a resident, I have struggled with grief and sadness that comes with the loss of a patient, but I find what keeps me from sleeping or focusing on my day-to-day life is the incommunicable sense of injustice. Seeing this articulated in this article was validating.

Please read this important article. I hope you will hang on to every word in the way that I did, or potentially incorporate this case and discussion as a tool for medical

education and further discussion.

NT

Evaluation of Airborne Chemicals from Neonatal Incubators - Letter to Health Care Providers

NEWS PROVIDED BY

[U.S. Food and Drug Administration](#)

Update: October 16, 2023

The FDA is providing an update since June 2023. External Link Disclaimer, based on new information from GE HealthCare for its newly manufactured neonatal incubators. GE HealthCare has implemented a process to reduce the levels of formaldehyde from new neonatal incubators before distribution.

New GE HealthCare Giraffe OmniBed Carestations or Giraffe Incubator Carestations:

- Received after September 5, 2023, do not need to run for a week before clinical use.
- Received before September 5, 2023, that have not been put into clinical use, please assemble the new incubator with all components and run it for a week in a well-ventilated space with maximum heat and humidity, and portholes and bedside panels closed, prior to clinical use.
- Contact your local GE Healthcare representative if you have any questions about your new neonatal incubator.

If your incubator is in clinical use, continue to use it. Incubators are critical for neonates (infants less than four weeks old) that cannot maintain their body temperature.

Unique Device Identifier (UDI) information provided by GE HealthCare:

- Giraffe OmniBed Carestation: 00840682116862
- Giraffe Incubator Carestation: 00840682116855

GE HealthCare has not received any reports of patient injury or adverse effects related to potential exposure to formaldehyde in incubators. At the present time



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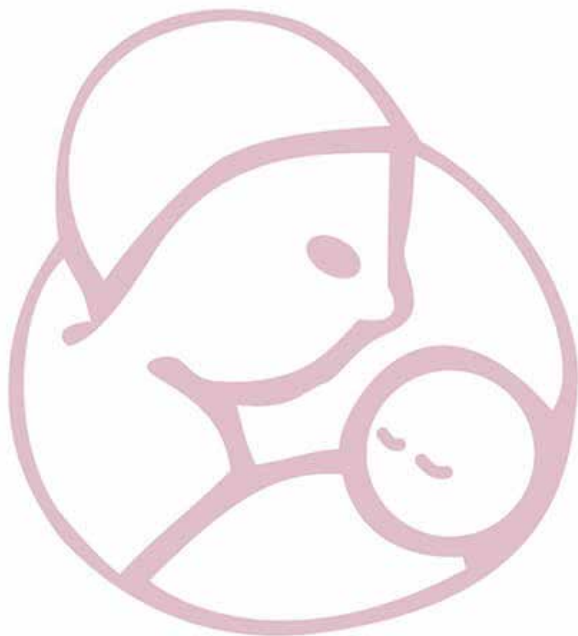
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there is not evidence that the levels of formaldehyde observed in GE Health-Care incubators have led to adverse health effects.

The FDA continues to collect and analyze data to evaluate the potential for exposure to airborne chemicals that may be released from neonatal incubators. The FDA will continue to keep health care providers informed as additional information becomes available.

NT

Studies on Infants Have Considerable Room for Growth

NEWS PROVIDED BY

[American Academy of Pediatrics](#)

by Eli Cahan, MD, MS

August 29, 2023

Editor's Note: Eli Cahan is a resident physician in pediatrics at The Boston Combined Residency Program at Boston Children's Hospital and Boston Medical Center, and an investigative journalist whose work focuses on the intersection of health equity and social justice. —Rachel Y. Moon, MD, Associate Editor, Digital Media, Pediatrics

The singularity, fragility, and preciousness of neonates—have historically made the field of neonatology a difficult, and ethically fraught one in which to conduct prospective research. Due to poor clinical trial design—for example, studies are often small and/or single-center, and those addressing the same clinical question often report different and dissimilar outcomes—some 60% of Cochrane reviews in neonatology are inconclusive.

Such a limited conclusive evidentiary foundation upon which to base clinical practice likely contributes in part to why significant variation in treatment and outcomes of certain neonatal populations, like extremely preterm infants, persists across the US.

In the effort to evaluate the weaknesses in present-day neonatal research—and to attempt to put forward solutions to strengthen the evidentiary base for the treatment of newborns—the Core Out-

come Reporting in Neonatal Trials group published two reviews that are being early released this week by Pediatrics. One addresses shortcomings in primary outcome reporting among neonatal trials (10.1542/peds.2022-060751), while the other endeavors to promote strategies for strengthening neonatal trial reporting (10.1542/peds.2022-060765).

In the former article, Baba and colleagues evaluated 36 recent, large neonatal trials—presumably, some of the most robust and most recent reports in the field. They found that, of these, the majority failed to report outcomes in a way consistent with the 2022 Consolidated Standards of Reporting Trials. Moreover, they found that studies often did not describe, nor report the validity or reliability of, instruments used to measure primary outcomes.

“Reporting of primary outcomes in neonatal trials often lacks key information needed for interpreting results, knowledge synthesis, and evidence-informed decision-making in neonatology,” the authors concluded.

In the latter article, Webbe and colleagues offer recommendations for alleviating these observed shortcomings. To start, they cite the Core Outcomes in Neonatology project, which identified 12 outcomes deemed essential for inclusion in all forthcoming neonatal trials. Subsequently, they reanalyzed the 36 aforementioned studies in order to identify gold-standard reporting techniques from the strongest of these. One such gold-standard technique, in the area of methodology, was specifying definitions of diagnostic endpoints, such as specifying sepsis to be either 1 positive blood culture with a high C-reactive protein (CRP) or 2 positive cultures within 2 days.

“Any research manuscript is a conversation between the researchers and their target audience,” the authors wrote, “if clinical research results are to influence clinical practice, sufficient information relating to trial outcomes must be communicated in a transparent fashion from researcher to readers.”

Clinicians interested in better understanding the contemporary challenges of neonatal research—and trialists interested in combatting them—can and should review these studies in further depth in the September issue of *Pediatrics*.

NT

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!

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Towards a harmonized bronchopulmonary dysplasia definition: a study protocol for an international Delphi procedure

NEWS PROVIDED BY

[BMJ Paediatr Open via NIH](#)

by Trixie A Katz et al.

October 2023

Abstract

Introduction: Bronchopulmonary dysplasia (BPD) remains the most common

complication of preterm birth with lifelong consequences. Multiple BPD definitions are currently used in daily practice. Uniformity in defining BPD is important for clinical care, research and benchmarking. The aim of this Delphi procedure is to determine what clinicians and researchers consider the key features for defining BPD. With the results of this study, we hope to advance the process of reaching consensus on the diagnosis of BPD.

Methods and analysis: A Delphi procedure will be used to establish why, when and how clinicians propose BPD should be diagnosed. This semi-anonymous iterative technique ensures an objective approach towards gaining these insights. An international multidisciplinary panel of clinicians and researchers working with preterm infants and/or patients diagnosed with BPD will participate. Steering committee members will recruit potential participants in their own region or network following eligibility guidelines to complete a first round survey online. This round will collect demographic information and opinions on key features of BPD definitions.



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Subsequent rounds will provide participants with the results from the previous round, for final acceptance or rejection of key features. Statements will be rated using a 5-point Likert scale. After completing the Delphi procedure, an (online) consensus meeting will be organised to discuss the results.

Ethics and dissemination: For this study, ethical approval a waiver has been provided. However, all participants will be asked to provide consent for the use of personal data. After the Delphi procedure is completed, it will be published in a peer-reviewed journal and disseminated at international conferences.

Keywords: Data Collection; Neonatology; Qualitative research.

NT

Stopping the Hurt: A NICU Quality Improvement Project to Reduce Postoperative Pain

NEWS PROVIDED BY

[American Academy of Pediatrics](#)

by Lydia Furman, MD

July 6, 2023

In this recently released Pediatrics article, Dr. Roopali Bapat and colleagues, from neonatal intensive care units (NICUs) within the Children's Hospitals Neonatal Consortium (CHNC) that care for infants with complex surgical needs, engaged in an ambitious collaborative quality improvement project, Erase Postoperative Pain (10.1542/peds.2022-059860). Twenty-six of 34 CHNC NICUs decided to participate: teams committed to reducing infant postoperative pain through collaboration, education, tests of change, and reporting

improvement metrics all working under a central project management group.

Salient features of this collaborative QI project included development of an evidence-based clinical practice recommendations document, use of validated pain assessment tools, strategies to support pain score documentation and discussion on rounds, family involvement in pain management, creation of a multi-disciplinary stakeholder team, and development of a pain treatment algorithm with both pharmacologic and non-pharmacologic treatments. The initiative included both helpful flexibility and structure. On one hand, centers were not asked to embrace the clinical practice recommendations as an all-inclusive intervention bundle, but rather to use those elements of the guidance document that best fit locally, including choosing their own pain assessment tool. On the other hand, the central project management team provided support and structure to teams, including monthly one hour learning webinars, biweekly thirty minute "huddle" calls to share lessons learned, and faculty advisors who aided in monitoring monthly center data and self-assessments. This unique approach combined central guidance with hospital team "permission" to "personalize" the interventions; this seemed particularly effective in pushing the project forward.

The primary outcome measure was to decrease the percentage of patients with unrelieved postoperative pain in the first 24 hours, and in fact, this percentage decreased by 35% from 19.5% to 12.6%. The secondary outcome was, notably, a parent and family driven measure to improve family satisfaction with pain management in the first 24-hour postoperative period, and already high family satisfaction (93%) stayed high (96%). I think you will enjoy reading about the many nuanced and innovative changes and processes described. The collaborative project management group emphasized to members that each baby matters using a huddle presentation called "Baby Steps to Big Improvements" so teams could "...visualize how one less patient with consecutive pain



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scores achieves a big impact on the project..." What a positive approach! Enjoy this great article and let us know what your NICU is doing to ease postoperative pain.

NT

More than 100 grants and 16 years later, ICATCH at work in 42 countries

NEWS PROVIDED BY

[American Academy of Pediatrics](#)

by Alyson Sulaski Wyckoff, Associate Editor

August 1, 2023

ICATCH Grant Success Stories

ICATCH thrives because of the skill, dedication, and vision of its grantees, selected carefully by our team of volunteer physicians and supported with technical advice as well as funds. Here are stories of three recently completed grant projects.

Assistive Devices for Children With Physical Disabilities in Zambia

In 2018, a team led by Sister Clara Mulenga and Sister Rabecca Mwansa, both of whom are Catholic nuns as well as health-care professionals, applied to ICATCH with a project idea centered at the John Paul II Orthopedic Mission Hospital in urban Lusaka, Zambia. They had identified that the prevalence of disability was 14.5%, and of this population, roughly 15% were able to access assistive devices. In addition, a lack of educational facilities means children with disabilities are often unable to attend school. In part as a result of inadequate access to care and education, children with disabilities were kept home by parents fearing public stigma. The project's main objective was therefore clear: to help children with disabilities who required orthopedic intervention receive compre-

hensive care, orthopedic interventions, accommodation, physiotherapy, and education, plus assistive devices.

The team worked in phases: first identifying the population needing help, then providing transportation from different regions in Zambia to their hospital in Lusaka, giving shelter to families, and training caregivers in the physiotherapy strategies to apply at home after surgical interventions. They also implemented a program to provide these patients with the assistance devices they required: walkers, prosthetic limbs, and wheelchairs, among others.

The first yearly goal of providing support to at least 150 children was easily surpassed, and the beginning of the second year looked promising. Unexpectedly, the global impact of COVID-19 affected project plans. Nevertheless, Sisters Clara and Rabecca actively encouraged volunteers to help, and with their assistance, they expanded to a broader area of Zambia. Through their tenacious approach, they identified even more new patients, who received the comprehensive care the sisters intended by the time the grant ended in 2021.

Overall, the project is a reminder of how passionate work has the potential to create a long-lasting impact in the lives of children.

Growing Health: A Grant Project That Grew Well

Rwandan government hospitals are unable to provide meals for hospitalized patients. Many inpatients cannot afford food in addition to medicine and hospital expenses, and many thus experience long periods of food insecurity during hospitalization. This not only impairs their ability to recover and prolongs hospitalization but also can have negative physical and developmental impacts that ripple out through their lifetimes.

Dr. Emily Esmaili, a general pediatrician and global health fellow at Duke University, used funding from ICATCH to bring together a team in Huye, Rwanda, to start Growing Health, Inc., also known as Kuza-

mura Ubuzima. The initiative transformed unused land near Centre Hospitalier Universitaire du Butare in Huye into a productive garden that now provides produce for meals served to hospitalized patients.

Under the guidance of Ms. Laurette Mushi-miyimana, the Growing Health president and program coordinator in Huye, the team expanded to include 23 farmworkers, 3 cooks, an agronomist, 5 managers, coordinators, and educators.

In 2019, they harvested 19,051 kg of produce (beans, sweet potatoes, kale, sorghum, bananas, avocados, passion fruit and more). An irrigation system was installed to increase productivity in 2020.

In addition, they started an outreach program in 3 nearby villages, aiming to serve 75 families that were former beneficiaries of the program. They visited these villages periodically, delivering fuel-efficient stoves and follow-up trainings on nutrition, perma-gardening, and preventive health. As their grant period concluded, they hoped to continue to expand, ultimately providing healthy, sustainable food to all patients in need at Centre Hospitalier Universitaire de Butare.

Growing Health indeed grew well!

Pediatric Preventive Health Radio for Indigenous Communities in Bolivia

Using radio to share pediatric health prevention messages with indigenous communities in Bolivia In 2015, two cousins, Maya Masterson, MS, and Erin Masterson, PhD, MPH, spent several months in the Bolivian Amazon collaborating with Dr. Tomas Huanca, PhD, Esther Conde, and their local team from the Centro Boliviano de Investigacion y Desarrollo Socio Integral (CBIDSI; the Bolivian Center for Investigation and Comprehensive Partner Development) to collect data for a research study focused on adolescent health. During visits in dugout canoes to 15 remote Tsimane' villages, the team presented a brief health educational workshop to these indigenous communities, sharing the message in the native Tsimane' language

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through the team translators and using visuals drawn on large poster boards. Afterward, the community members, leaders, teachers, and the tribe's governing body, the Gran Consejo Tsimane', enthusiastically requested continuation and expansion of these health messages.

With the support of ICATCH funding, this team developed, translated, recorded, and broadcast four educational health messages between 2016 and 2019. Their chosen themes covered oral health, sanitation and hygiene, infectious illness, water care, and traditional and market foods. They recorded radio programs at a local station and studio. The recording was taken to the Tsimane' radio program to be broadcast throughout the Tsimane' territory five times per week. They targeted peak listening times, during the weekend, for airings. The team also hand-drew large poster books that CBIDSI uses as visuals for sharing these messages when their team was in the communities with visiting researchers. By the end of the grant, the team began working on producing DVDs to distribute to leaders and teachers in rural communities with electricity, for further health education.

Sustaining ICATCH's Success

ICATCH will award its 100th grant in 2023. As we look forward to this momentous achievement, we are grateful for the volunteers, donors, and amazing grantees who helped us get here. To find out more about our grants, see our grant information page. If you'd like to help ICATCH grow, please donate.

NT

Improving the Rate of Delayed Cord Clamping in Preterm Infants: A Quality Improvement Project

NEWS PROVIDED BY

[American Academy of Pediatrics](#)

by Shannon Chan, MD, Meghan Duck, MS, RNC-OB, CNS; Kate Frometa, CNM; Melissa Liebowitz, MD; Melissa G. Rosenstein, MD, MAS; Martha Tesfalul, MD; Ma-

rie-Coralie Cornet, MD; Katelin P. Kramer, MS, MD

Objective

Delayed cord clamping (DCC) provides many benefits for preterm infants. The aim of this quality improvement project was to increase the rate of DCC by 25% within 12 months for neonates <34 weeks' gestation born at a tertiary care hospital.

Method

A multidisciplinary team investigated key drivers and developed targeted interventions to improve DCC rates. The primary outcome measure was the rate of DCC for infants <34 weeks' gestation. Process measures were adherence to the DCC protocol and the rate of births with an experienced neonatology provider present at the bedside. Balancing measures included the degree of neonatal resuscitation, initial infant temperature, and maternal blood loss. Data were collected from chart review and a perinatal research database and then analyzed on control charts. The preintervention period was from July 2019 to June 2020 and the postintervention period was from July 2020 to December 2021.

Results

322 inborn neonates born at <34 weeks' met inclusion criteria (137 preintervention and 185 postintervention). The rate of DCC increased by 63%, from a baseline of 40% to 65% ($P < .001$), with sustained improvement over 18 months. Significant improvement occurred for all process measures without a significant change in balancing measures.

Conclusion

Using core quality improvement methodology, a multidisciplinary team implemented a series of targeted interventions which was associated with an increased rate of DCC in early preterm infants.

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Does faster weight trajectory lead to improved neurodevelopmental outcomes in ELBW infants with bronchopulmonary dysplasia?

NEWS PROVIDED BY

[Journal of Perinatology via NIH](#)

by Fernando A Munoz, Emily Hawkins Carter, Erika M Edwards, Maggie Jerome, and Jonathan S Litt

October 28, 2023

Abstract

Objective: Examine the relationship be-

tween weight trajectory and 2-year neurodevelopmental outcomes for extremely low birthweight (ELBW) infants with BPD.

Study design: Secondary analysis of infants born from 2010 to 2019. The predictor was BPD severity and the outcome was neurodevelopmental impairment, defined as any Bayley Scales of Infant Development (BSID) III score <70 at 24 months' corrected age. Repeated measures logistic regression was performed.

Results: In total, 5042 infants were included. Faster weight trajectory was significantly associated with a decreased probability of having at least one BSID III score <70 for infants with grade 1-2 BPD ($p < 0.0001$) and an increased probability of at least one BSID III score <70 for infants with grade 3 BPD ($p < 0.009$). There was no significant association between weight trajectory and BSID III score <70 for infants with grade 0 BPD.

Conclusion: The association between postnatal weight trajectory and neurodevelopmental outcome in this study differs by BPD severity.

NT

Prematurity and Low Birth Weight and Their Impact on Childhood Growth Patterns and the Risk of Long-Term Cardiovascular Sequelae

NEWS PROVIDED BY

[Children \(Basel\) via NIH](#)

by Iwona Jańczewska, Jolanta Wierzba, Alicja Jańczewska, Małgorzata Szczurek-Gierczak, Iwona Domżalska-Popadiuk

September 25, 2023

Abstract

Preterm birth (before 37 completed weeks of gestation) is a global health problem, remaining the main reason for neonatal

mortality and morbidity. Improvements in perinatal and neonatal care in recent decades have been associated with a higher survival rate of extremely preterm infants, leading to a higher risk of long-term sequelae in this population throughout life. Numerous surveillance programs for formerly premature infants continue to focus on neurodevelopmental disorders, while long-term assessment of the impact of preterm birth and low birth weight on child growth and the associated risk of cardiovascular disease in young adults is equally necessary. This review will discuss the influence of prematurity and low birth weight on childhood growth and cardiovascular risk in children, adolescents and young adults. The risk of cardiovascular and metabolic disorders is increased in adult preterm survivors. In early childhood, preterm infants may show elevated blood pressure, weakened vascular growth, augmented peripheral vascular resistance and cardiomyocyte remodeling. Increased weight gain during the early postnatal period may influence later body composition, promote obesity and impair cardiovascular results. These adverse metabolic alterations contribute to an increased risk of cardiovascular incidents, adult hypertension and diabetes. Preterm-born children and those with fetal growth restriction (FGR) who demonstrate rapid changes in their weight percentile should remain under surveillance with blood pressure monitoring. A better understanding of lifelong health outcomes of preterm-born individuals is crucial for developing strategies to prevent cardiovascular sequelae and may be the basis for future research to provide effective interventions.

Spectral features of non-nutritive suck dynamics in extremely preterm infants

NEWS PROVIDED BY

[Pediatric Medicine via NIH](#)

by Steven M Barlow et al.

Background: Non-nutritive suck (NNS) is used to promote ororhythmic patterning and assess oral feeding readiness in preterm infants in the neonatal intensive care unit

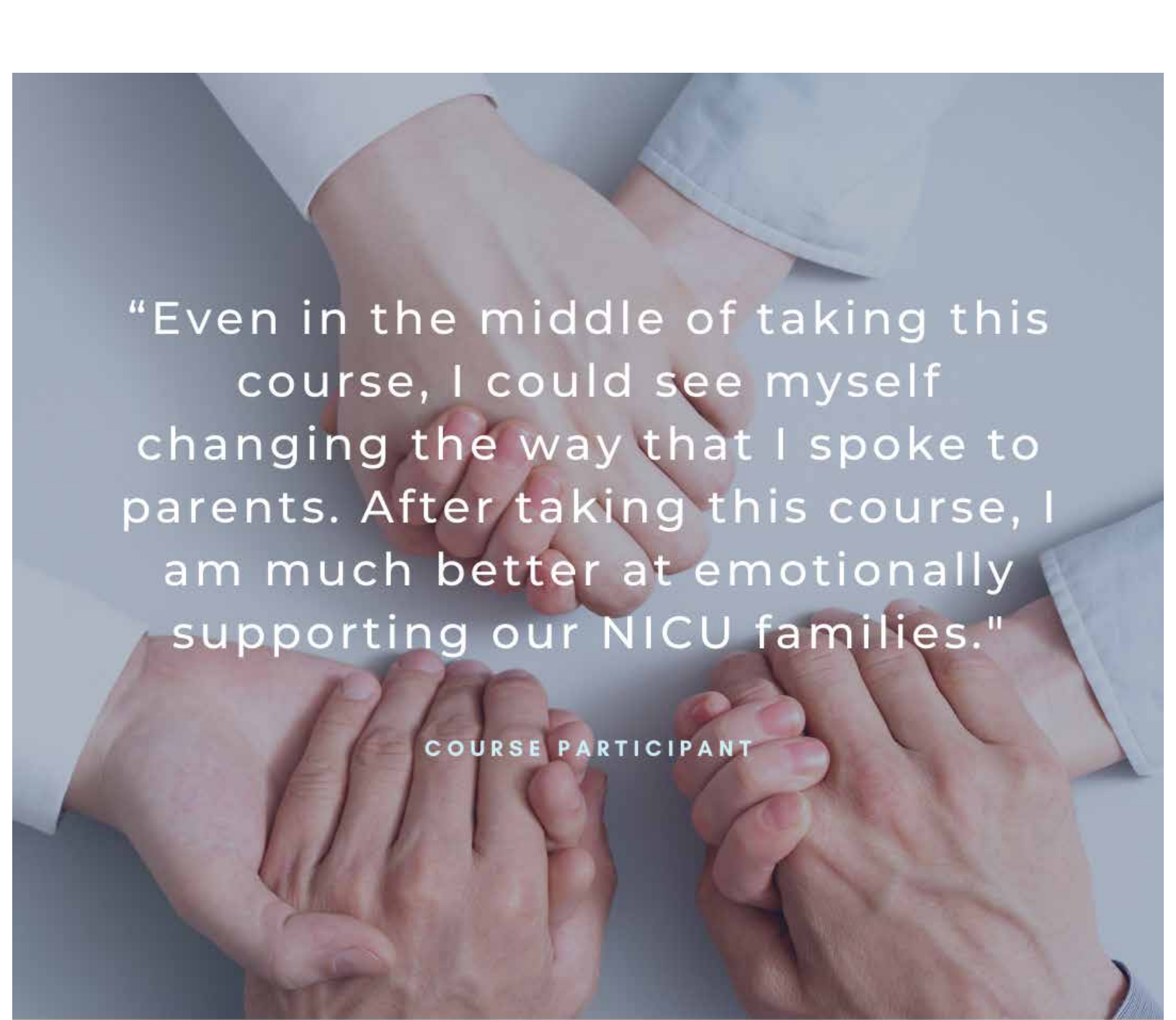
(NICU). While time domain measures of NNS are available in real time at cribside, our understanding of suck pattern generation in the frequency domain is limited. The aim of this study is to model the development of NNS in the frequency domain using Fourier and machine learning (ML) techniques in extremely preterm infants (EPIs).

Methods: A total of 117 EPIs were randomized to a pulsed or sham orocutaneous intervention during tube feedings 3 times/day for 4 weeks, beginning at 30 weeks post-menstrual age (PMA). Infants were assessed 3 times/week for NNS dynamics until they attained 100% oral feeding or NICU discharge. Digitized NNS signals were processed in the frequency domain using two transforms, including the Welch power spectral density (PSD) method, and the Yule-Walker PSD method. Data analysis proceeded in two stages. Stage 1: ML longitudinal cluster analysis was conducted to identify groups (classes) of infants, each showing a unique pattern of change in Welch and Yule-Walker calculations during the interventions. Stage 2: linear mixed modeling (LMM) was performed for the Welch and Yule-Walker dependent variables to examine the effects of gestationally-aged (GA), PMA, sex (male, female), patient type [respiratory distress syndrome (RDS), bronchopulmonary dysplasia (BPD)], treatment (NTrainer, Sham), intervention phase [1, 2, 3], cluster class, and phase-by-class interaction.

Results: ML of Welch PSD method and Yule-Walker PSD method measures revealed three membership classes of NNS growth patterns. The dependent measures peak_Hz, PSD amplitude, and area under the curve (AUC) are highly dependent on PMA, but show little relation to respiratory status (RDS, BPD) or somatosensory intervention. Thus, neural regulation of NNS in the frequency domain is significantly different for each identified cluster (classes A, B, C) during this developmental period.

Conclusions: Efforts to increase our knowledge of the evolution of the suck central pattern generator (sCPG) in preterm infants, including NNS rhythmogenesis will help us better understand the observed phenotypes of NNS production in both the frequency and time domains. Knowledge of those features of the NNS which are relatively invariant vs. other features which are modifiable by experience will likewise inform more effective treatment strategies in this fragile population.

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A Newborn with Difficult Intubation Diagnosed with Treacher Collins Syndrome and Detection of a Novel Pathogenic Variant in TCOF1

Hua Wang, M.D., Ph.D., Enas Louzy, GC., MSc.

Abstract

*This case report highlights the challenges encountered during the intubation of a newborn presenting with distinctive features, prompting consideration of Treacher Collins syndrome (TSC). Subsequent genetic testing identified a novel heterozygous and pathogenic variant in TCOF1, specifically c.3671dup (p.Leu1225Alafx*16), conclusively confirming the diagnosis. Given the rarity of TSC, the significance of early diagnosis cannot be overstated, as it significantly enhances clinical management. Additionally, the unique nature of the TSC necessitates specialized intubation techniques.*

Introduction

Treacher Collins syndrome (TCS; OMIM #154500), also called mandibulofacial dysostosis (MFD), was described in 1900. It is a rare autosomal dominant disorder that profoundly impacts craniofacial development during early embryogenesis. This syndrome is distinguished by a characteristic array of bilaterally symmetric features, encompassing downward-slanting palpebral fissures, coloboma of the lower eyelids, hypoplasia of midfacial bones, cleft palate, and anomalous development of the external and middle ear structures, often resulting in conductive hearing loss (1). With an estimated incidence of 1 in 50,000 individuals, TCS predominantly emerges sporadically, affecting more than 60% of cases without any discernible familial antecedents, typically arising from de novo mutations (2). Here, we report a new case of Treacher Collins syndrome and the detection of a novel pathogenic variant.

“[Treacher Collins syndrome] is a rare autosomal dominant disorder that profoundly impacts craniofacial development during early embryogenesis...Here, we report a new case of Treacher Collins syndrome and the detection of a novel pathogenic variant.”

Case Description:

This Hispanic male, born only hours ago, was transferred to LLUH NICU due to a challenging intubation history and the presentation of distinctive facial features requiring further assessment and management. Delivered via Cesarean Section at 38 weeks due to maternal HELLP Syndrome, the 26-year-old primigravida mother experienced an uneventful pregnancy until the 38th week. Two ultrasound studies at the 20th and 30th weeks of gestation revealed no abnormalities. The newborn exhibited poor color/tones, absence of spontaneous cry, and heightened work of breathing. At the originating hospital, prior to transfer, the resuscitation pro-

cess endured for about 25 minutes, culminating in successful intubation after two failed attempts and subsequent decompensation. Upon admission to LLUCH NICU, the infant remained ventilated and received nutrition through an OG tube. A genetic consultation was promptly initiated. Clinical examination revealed marked dysmorphic facies (see Fig.1), encompassing bilateral down-slanting palpebral fissures, bilateral lower lid coloboma, bilateral ptosis, more pronounced lagophthalmos in the right eye, sparse eyelashes (Fig.1a.b.c.d.), severe malar hypoplasia, a prominent beak-like nose (Fig.1d.), bilateral microtia, malformed external ears with atresia of the external auditory canals (Fig.1 e.f.), zygomatic bone hypoplasia, micrognathia, retrognathia, sparse and faint eyebrows, a large mouth with thin lips, and a short neck (Fig.1e.). Ophthalmologic examination unveiled a right exposure keratopathy with a small healing defect and mature retina. The discernible dysmorphism and the history of challenging intubation raise high suspicion of Treacher Collins syndrome (TCS). Family history provides no contributory information. An Invitae Facial Dysostosis and Facial Dysplasia Panel were ordered. Subsequent investigations, including head Echo and spine ultrasound, yielded unremarkable results.

“At the originating hospital, prior to transfer, the resuscitation process endured for about 25 minutes, culminating in successful intubation after two failed attempts and subsequent decompensation. Upon admission to LLUCH NICU, the infant remained ventilated and received nutrition through an OG tube.”

A 2D Echo displayed a foramen ovale with a small shunt. Fluorescent Swallow and Upper GI studies confirmed the infant's ability to initiate swallowing without obstruction. Multiple Chest X-rays showed no anomalies. A CT Maxillofacial examination demonstrated a constellation of findings consistent with TCS (see Fig 2), including non-visualization of the vomer, soft tissue opacification of the bilateral choana consistent with choanal atresia, micrognathia, irregular/hypoplastic zygomatic arches, aplasia of the external auditory canals, hypoplasia of the middle ear canals with absent middle ear ossicles, hypoplastic mastoid air cells, unremarkable soft tissues of the face, and microtia. Micro-laryngoscopy and Bronchoscopy yielded normal results, while Nasopharyngoscopy revealed bilateral choanal atresia without clefting. A Brainstem Auditory Evoked Response (BAER) study and limited audiometric examination displayed normal findings. An extubation attempt on the seventh day of life failed, leading to tracheostomy two days later due to decompensation with non-invasive ventilation. Due to recurrent removal of the NG tube, poor feeding, and failure to



Figure 1.

*Bilateral down-slanting palpebral fissures, bilateral lower lid coloboma, bilateral ptosis, bilateral lagophthalmos more evident on the right eye, sparse eyelashes (Fig.1 a.b.c.d.), severe malar hypoplasia, large prominent beak-like nose (Fig.1 d.), bilateral microtia, malformed external ear with atresia of the **external** auditory canals (Fig. 1 e.f.), hypoplasia of the zygomatic bones, micrognathia, and retrognathia, sparse and faint eyebrows, large mouth with thin lips and short neck (Fig.1e.).*

Note: Fig.1d.e. f photos were taken two weeks later when the patient was off ventilation with tracheotomy only.

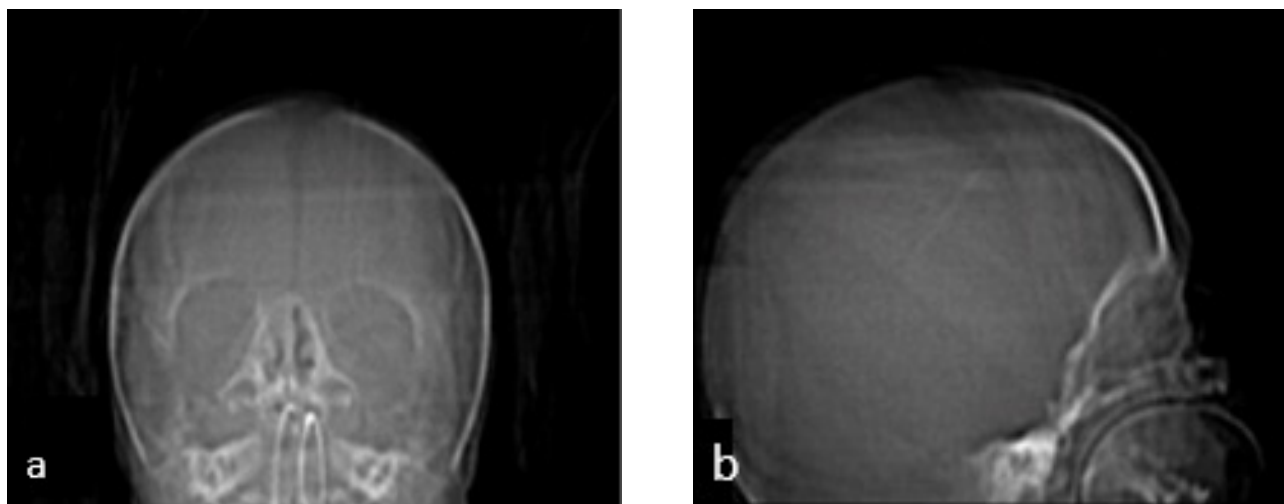


Figure 2. A CT Maxillofacial demonstrated a constellation of findings consistent with TCS including non-visualization of the vomer, soft tissue opacification of the bilateral choana consistent with choanal atresia, micrognathia, irregular/hypoplastic zygomatic arches, aplasia of the external auditory canals, and hypoplasia of the middle ear canals with absent middle ear ossicles, hypoplastic mastoid air cells, unremarkable soft tissues of the face and microtia (fig.2 a.b.)

thrive, a percutaneous endoscopic gastrostomy (PEG) tube was placed at four weeks. Plastic surgery opted not to proceed with mandibular distraction due to ongoing central apnea, recommending a re-evaluation at six months. The multidisciplinary management involves teams in Speech Therapy, Occupational Therapy, and Respiratory Therapy.

Genetic test result

The result of the Invitae Facial Dysostosis and Facial Dysplasia Panel was returned two weeks after admission, which showed a frameshift pathogenic heterozygous variant in TCOF1 gene c3671dup (p.leu1225alafs*16) (see Fig 3). TCOF1 is associated with autosomal dominant Treacher-Collins Syndrome (TCS). This pathogenic variant establishes a molecular diagnosis of TCS in the patient.

“TCOF1 is associated with autosomal dominant Treacher-Collins Syndrome (TCS). This pathogenic variant establishes a molecular diagnosis of TCS in the patient.”

The variant is localized on the 23rd exon of TCOF1. This is a known hotspot on TCOF1. It creates a premature translational stop signal, expected to result in an absent or disrupted protein product. This variant is not present in the population database (gnomAD, no frequency). Based on the above evidence, this variant has been classified as pathogenic. The variant has not been reported in the literature in individuals affected with TCOF1-related conditions. This means it is a new pathogenic variant detected for the first time in our patient, as per the laboratory report. We searched the ClinVar database, and there was no entry of the variant, which confirms that this is a newly detected TCOF1 pathogenic variant. We searched to find out if there has been evidence of genotype-phenotype correlation, but such correlation still needs to be established. However, the severity of the condition is related to the type of the mutation.

Discussion:

TCS exhibits a range of prominent characteristics, collectively giving rise to a distinct facial appearance often described as “fish-like.” These features encompass a slant of the palpebral fissure, eyelid abnormalities, facial underdevelopment (notably affecting

the mandibular and zygomatic regions), outer and middle ear malformations, conductive hearing impairment, cleft palate, and macrostomia. TCS typically exhibits high penetrance, yet there can be considerable variations in the phenotypic expression. Franceschetti and Klein (4) classified TCS into five clinical forms: (1) the complete form (displaying all recognized features), (2) the incomplete form (exhibiting varying degrees of ear, eye, zygoma, and mandibular abnormalities), (3) the abortive form (characterized by lower lid pseudo coloboma and zygoma hypoplasia), (4) the unilateral form (with anomalies confined to one side of the face), and (5) the atypical form (accompanied by additional abnormalities not typically associated with the syndrome) as outlined in Table 1. Mild phenotypes may not exhibit overt clinical characteristics.

“Individuals with a severe phenotype may face life-threatening complications such as ventilation obstruction arising from conditions like posterior nasal foramen atresia. Consequently, the exploration of genetic testing becomes especially crucial, serving as a valuable tool in the auxiliary diagnosis and guiding intervention treatments.”

Additionally, TCS shares overlapping clinical traits with other conditions, such as Nager syndrome, Miller syndrome, Goldenhar syndrome, and Burn-McKeown syndrome, posing diagnostic challenges (5). Individuals with a severe phenotype may face life-threatening complications such as ventilation obstruction arising from conditions like posterior nasal foramen atresia. Consequently, the exploration of genetic testing becomes especially crucial, serving as a valuable tool in the auxiliary diagnosis and guiding intervention treatments.

The existing literature delineates four distinct clinical subtypes of Treacher Collins syndrome (TCS): TCS1 (OMIM 154500), which arises from mutations in the TCOF1 gene (OMIM 606847); TCS2 (OMIM 613717), attributable to mutations in the POLR1D gene (OMIM 613715); TCS3 (OMIM 248390), resulting from mutations in the POLR1C gene (OMIM 610060); and TCS4 (OMIM 618939), linked to mutations in the POLR1B gene (OMIM 602000). Variants within TCOF1 and POLR1B follow an autosomal dominant inheritance pattern, whereas POLR1C variants exhibit autosomal recessive inheritance. Variants in the POLR1D gene can mani-

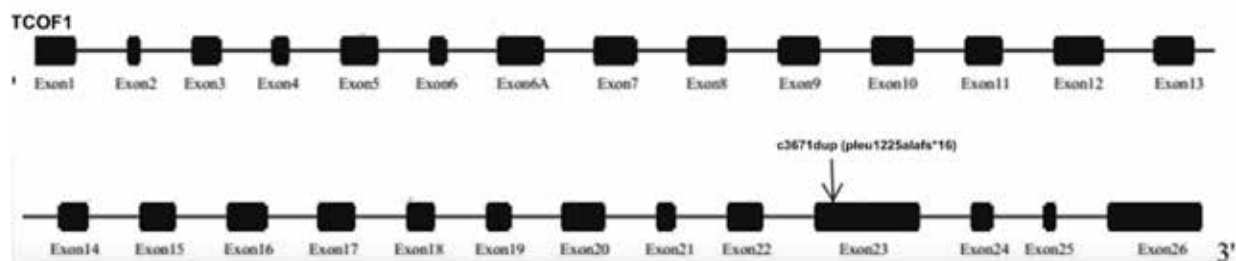


Fig 3. Illustration of the structure of the TCOF1 gene (NM_001135243.1), black boxes proportionately represent coding exons, and introns are not scaled (3). Our patient's causative mutation is in exon 23. Mutation is marked with an arrow.

fest as either autosomal dominant or autosomal recessive in their inheritance patterns. Approximately 86% of all documented TCS cases stem from mutations in the TCOF1 gene, with POLR1C mutations accounting for roughly 1.2%, POLR1D mutations representing 6%, and POLR1B mutations contributing to 1.3% of cases (6). The scientific literature has documented over 200 mutations within the TCOF1 gene. A significant proportion of these mutations consist of small deletions that lead to the generation of a premature termination codon, resulting in either a truncated protein or triggering nonsense-mediated mRNA decay. This collective evidence strongly indicates that the developmental anomalies associated with these mutations stem from the haploinsufficiency (or loss of function) of TCOF1 (7). The penetrance of genetic mutations associated with TCS is commonly regarded as high; nevertheless, this could be one of the reasons causing notable variability in phenotypic expressions, both within and among families (8). Pathologically, TCS arises due to the underdevelopment of the first and second branchial arches. The inhibition of ribosome synthesis in neural crest cells and neuroepithelial cells precipitates a reduction in the quantity of migrating neural crest cells towards the maxillofacial region, serving as the primary pathogenic mechanism (9).

“If the global incidence of CCHD reported by Quiroz et al. (16), which is 6 to 8 cases per 1000 live births, is taken, the cases of CCHD in Ciudad Juarez would range from 92.52 to 177.19 cases per year.”

As outlined by Chang et al. (Chang & Steinbacher, 2012) and Trainor (Trainor & Andrews, 2013), TCS treatment spans neonatal, infancy, childhood, and adolescence. The neonatal phase focuses on symptom relief, addressing airway obstruction and eyelid issues. Infancy centers on feeding, growth, and early interventions like cleft palate repair. Childhood involves airway monitoring, possible interventions, and otoplasty, while adolescence focuses on skeletal and soft tissue reconstruction and occlusal corrections. The comprehensive approach integrates various medical disciplines, such as oral surgery, orthodontics, ophthalmology, ear-nose-throat care, speech pathology, pediatrics, nursing, genetics, psychology, and social work. Of note, TCS poses significant challenges for anesthesiologists due to the combination of maxillary, zygomatic, and mandibular hypoplasia and a small oral aperture, high-arched palate, and temporomandibular joint abnormalities. These anatomical features contribute to difficulties in performing direct laryngoscopy and endotracheal intubation, with

the former becoming increasingly challenging as patients age. In cases where endotracheal intubation is unnecessary, the laryngeal mask airway emerges as a favorable choice for maintaining a secure airway (10).

“This is cross-sectional, analytical, and exploratory research. The main unit of analysis is the newborn in apparent good health. Similarly, information is collected from the mother of the newborn.”

Conclusion:

Our presented case exhibits typical TSC manifestations. Given its rarity, encountering difficult intubation alongside distinctive facial dysmorphism necessitates heightened awareness for prompt recognition and appropriate management. The broad clinical phenotype spectrum requires thorough differential diagnosis, with genetic testing pivotal in confirmation. While genotype-phenotype correlation remains unestablished, loss-of-function mutations are predominant, leading to typical clinical presentations. The novel variant identified here contributes to the TCOF1 mutation bank, offering potential utility in future genetic testing. Comprehensive genetic counseling was provided, with a pending parental targeted test. Ongoing follow-up in our genetics clinic will guide the family in managing, monitoring, and future pregnancies.

Practical Application:

- Treacher-Collins syndrome (TCS) is an uncommon genetic disorder.
- Evaluation for TCS is advisable in neonates presenting with challenging intubation and distinctive dysmorphic features.
- Despite the diversity in clinical phenotypes, a clinically recognizable typical feature exists, though with some overlap with other syndromes.
- Genetic testing plays a critical role in confirming a definitive diagnosis.
- De novo mutations are frequently observed, and most mutations entail loss of function.
- The multidisciplinary treatment approach necessitates specialized attention and techniques for effective intubation management.

References:

Table 1. Franceschetti-TCS Clinical Forms

Type	Clinical features
Complete form	Having all known features
Incomplete form	Presenting variably with less severe ear, eye, zygoma, and mandibular abnormalities
Abortive form	Only the lower lid pseudo coloboma and zygoma hypoplasia are present
Unilateral form	Anomalies limited to one side of the face
Atypical form	Combined with other abnormalities not usually part of the typical syndrome

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Acknowledgment: We express gratitude for the patient's family's generous consent to publish both the case details and accompanying photos.

Disclosures: There are no conflicts of interest or sources of fund-

ing to declare.

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The Importance of ICD-10 Coding in Provider and Healthcare Billing

Scott D. Duncan, M.D., M.H.A.

“The importance of correct ICD-10 coding cannot be understated, as incorrect coding may result in denial of claims at the provider level and the healthcare system. The provider is often responsible for choosing the ICD-10 code; coders typically do not extrapolate the code from provider documentation.”

Many neonatologists and advanced practice providers struggle with the International Classification of Diseases, 10th Revision (ICD-10) coding. The importance of correct ICD-10 coding cannot be understated, as incorrect coding may result in denial of claims at the provider level and the healthcare system. The provider is often responsible for choosing the ICD-10 code; coders typically do not extrapolate the code from provider documentation.

Typical ICD-10 coding errors occur in provider billing when performing prenatal consultations. Correct ICD-10 coding is based on the mother and fetal condition(s) and would include conditions found in the “O” Chapter, Pregnancy, Childbirth, and the Puerperium. Weeks of gestation are recorded using Z3A.XX. These code sets are to be used only on the maternal chart; neither are appropriate for coding on an infant’s chart.

Alternatively, errors occur in provider ICD-10 coding for attendance at delivery and NICU admissions. Codes found in Z37, Outcome of Delivery, are not to be used on the infant’s chart; these are reserved for use on the maternal record. For attendance at delivery, codes found in the Z38 code set, Liveborn infants according to place of birth and type of delivery, should be used. The use of this code set is limited to the birthing hospital.

“For attendance at delivery, codes found in the Z38 code set, Liveborn infants according to place of birth and type of delivery, should be used. The use of this code set is limited to the birthing hospital.”

Providers also struggle with the term infant of a normal birthweight. As noted above, “O” codes and Z3A.XX codes are not to be used on the infant’s chart. Current ICD-10 codes, P05-P8, Disorders of newborns related to the length of gestation and fetal growth, exist for the subset of infants who are preterm, low birthweight large for gestation, and post-dates. ICD-10 codes include:

- P05 - Disorders of newborns related to slow fetal growth and fetal malnutrition

- P05.0X - Light for gestation, weight less than 10th percentile with normal length, ranging from < 500g to > 2500g
- P05.1X - Small for gestational age, weight and length less than 10th percentile ranging from < 500g to < 2500g
- P07 - Disorders of newborns related to short gestation and low birth weight not elsewhere classified
 - P07.0X - Extremely low birth weight newborn, from <500g – 999g
 - P07.1X - Other low birth weight newborn, from 1000g-2499g
 - P07.2X - Extreme immaturity of newborn from <23 weeks to 27 weeks completed gestation
 - P07.3 - Preterm (Premature) newborn, from 28 weeks to 36 weeks completed gestation
- P08 - Disorders of newborns related to long gestation and high birth weight
 - P08.0 - An exceptionally large newborn baby, birth weight \geq 4500g
 - P08.1 - Other heavy for gestational age newborn, birth weight from 4000g – 4499g
 - P08.2X - Late newborn, not heavy for gestational age, from > 40 weeks to > 42 weeks gestational age.

Note there are no codes for term infants of normal birthweight, nor codes for microcephaly or macrocephaly in the “P” code set.

“the APS-DRG system is perhaps the most applicable for pediatrics, including neonatology. Many of the DRGs are weight-based and associated with/without complicating factors. However, for illustration purposes, this article will focus on mapping ICD-10 codes with the MS-DRG system.”

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Beyond provider billing, ICD-10 codes are essential in healthcare system billing. Many healthcare systems are reimbursed using a Diagnosis Related Group (DRG) system. While there are multiple DRG systems, some of the most common include Medicare Severity DRG (MS-DRG), All Patient DRG (AP-DRG), All Patient, Severity Adjusted DRG (APS-DRG) and All Patient Refined DRG (APR-DRG). The APS-DRG system is perhaps the most applicable for pediatrics, including neonatology. Many of the DRGs are weight-based and associated with/without complicating factors. However, for illustration purposes, this article will focus on mapping ICD-10 codes with the MS-DRG system.

“ICD-10 codes that are not neonatal-specific and do not map to the appropriate DRG can adversely impact reimbursement. Two salient examples are the inappropriate use of hypoglycemia codes E16.1 and E16.2 and jaundice code R17. In the case of isolated transient hypoglycemia, E16.1 or E16.2 maps to a DRG associated with adult and/or familial endocrine disorders or miscellaneous disorders of nutrition, metabolism, or electrolytes.”

The MS-DRG system consists of seven codes, 789-795, which includes neonates who died or were transferred, normal newborn, extreme immaturity or respiratory distress syndrome, prematurity with/without major problems, full-term neonate with major problems and neonate with other significant problems, respectively. As might be expected, the weight and gestational age codes map into the DRGs associated with prematurity or neonates with major problems.

“In the second example, neonatal jaundice is often coded R17, which does not map to a DRG. “R” codes are signs and symptoms without additional diagnosis. Appropriate use would include cases in which a specific diagnosis cannot be made after evaluation or transient signs or symptoms where a cause could not be determined—uncomplicated jaundice in a newborn, P59.9, maps to DRG 795, Normal newborn.”

ICD-10 codes that are not neonatal-specific and do not map to the appropriate DRG can adversely impact reimbursement. Two salient examples are the inappropriate use of hypoglycemia codes E16.1 and E16.2 and jaundice code R17. In the case of isolated transient hypoglycemia, E16.1 or E16.2 maps to a DRG associated with adult and/or familial endocrine disorders or miscellaneous disorders of nutrition, metabolism, or electrolytes. Without complicating factors, the correct code would be P70.4, which provides a higher level of specificity and maps to MS-DRG 791, Prematurity with major problems, or 793, Full term neonate with major problems.

In the second example, neonatal jaundice is often coded R17, which does not map to a DRG. “R” codes are signs and symptoms without additional diagnosis. Appropriate use would include cases in which a specific diagnosis cannot be made after evaluation or transient signs or symptoms where a cause could not be determined—uncomplicated jaundice in a newborn, P59.9, maps to DRG 795, Normal newborn. Jaundice associated with risk factors, such as hyperbilirubinemia associated with prematurity (P59.0), maps to DRG 794, Neonate with other major problems.

Question: As medical director of your level IV NICU and coding expert for your practice group, the hospital coding supervisor contacts you via email to discuss the persistent use of hypoglycemia code E16.2 in the NICU. Your response is:



- A. Create a snack pantry with candy infused with high fructose corn syrup
- B. Ignore the email for two weeks and hope that the coding supervisor leaves you alone
- C. Inform the coding supervisor that this is unrelated to physician billing and not your problem
- D. Recognize that improper coding can adversely impact hospital reimbursement and suggest a documentation improvement program to address improper ICD-10 coding.

Correct answer D. Although a snack pantry is always a good idea, the medical director recognizes the importance of correct coding in physician and hospital revenue and suggests a reasonable ap-

proach to improve coding and documentation.

Disclosures: There are no reported disclosures

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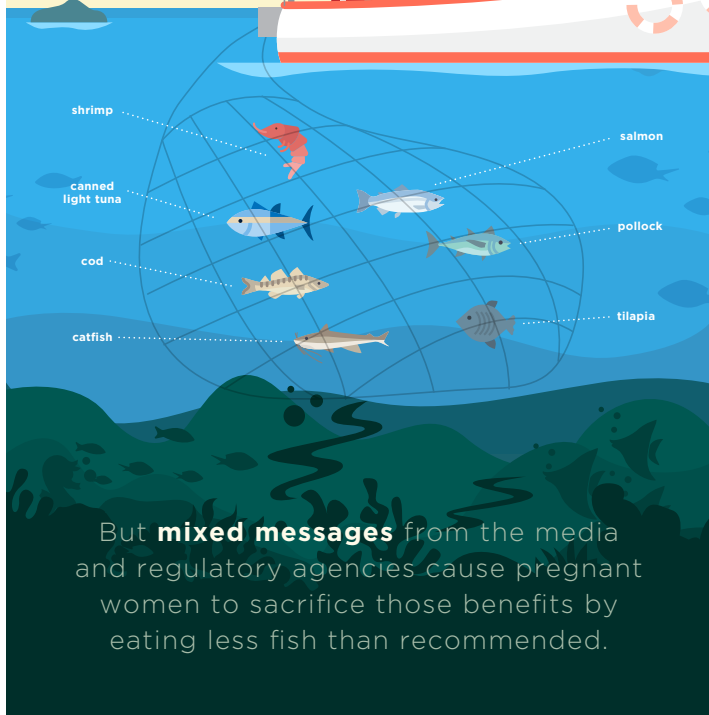
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But **mixed messages** from the media and regulatory agencies cause pregnant women to sacrifice those benefits by eating less fish than recommended.



**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

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breathe,

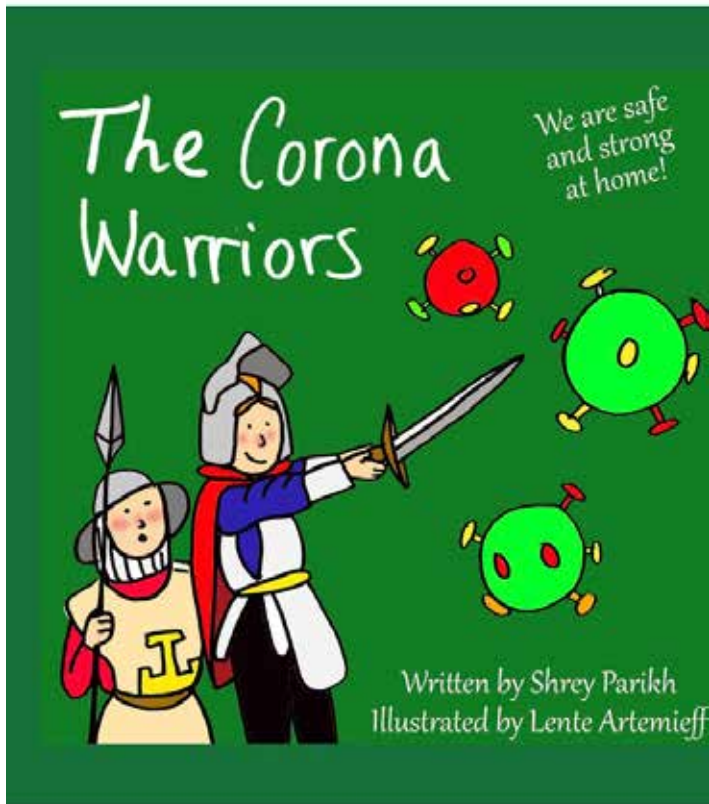
baby,

breathe!

NEONATAL
INTENSIVE CARE,
PREMATURITY, AND
COMPLICATED
PREGNANCIES

Annie Janvier, MD, PhD

Translated by Phyllis Aronoff and Howard Scott



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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/5523bf7e4b0111e688e6/562445af0134140f954206/19486891045/NCIH_Monoclonal+Antibodies+Inclusion+in+the+VFC+Program_Position+Paper_Mar+2022.pdf

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

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The Indirect Impact of RSV

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 ¾ 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 ½ 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.



Protecting Access for Premature Infants through Age Two

2024

Associate Membership & Sponsorship

Susan Hepworth, Suzanne Staebler, DNP, APRN, NNP-BC, FAANP, FAAN, Mitchell Goldstein, MD, MBA, CML

About the National Coalition for Infant Health

The National Coalition for Infant Health (NCfIH), a 501(c)(4), is a collaborative of professional, clinical, community health and family support organizations using education and advocacy to promote patient-centered care for infants and their families.

www.infanthealth.org

Introduction

Each year in the United States, parents welcome about 4 million babies. The next two years of life mark a period of extraordinary growth and development – transitioning from milk to solid foods, from baby coos to first words, from shaky first steps to independent walking.

Infants are a vulnerable and sometimes voiceless population. Promoting and protecting access to appropriate health care requires that families, advocates and health care providers unite in support of education, awareness and effective policymaking.

Whether a baby is born at term or premature, all infants deserve access to the best care possible – and so do their families.



Dr. Susan McCune ▲

of FDA speaks at the 2019
Infant Health Policy Summit


Steering Committee



Associate Membership

NCfIH sponsors educational initiatives and advocacy programs designed to encourage informed policymaking and educate on the benefits of access to patient-centered health care.

- Conducting stakeholder policy and advocacy training workshops
- Organizing stakeholder meetings with policymakers
- Producing online advocacy resources such as infographics and videos
- Participating in policy conferences and events
- Promoting expert thought leadership on unmet needs in infant and maternal health
- Offering comment or testimony on proposed legislation and regulations
- Hosting summits, roundtable meetings, webinars and other events
- Providing media outlets with opinion editorials and comment
- Conducting survey research and data analysis to inform policy



NCfIH National Coalition for Infant Health
The Burden of RSV
Impacting All Families
JUNE 2022



2022
Infant Health
Policy Summit

Why Become an Associate Member

- A** • Interact with steering committee members and broader NCfIH membership
- B** • Raise awareness among coalition membership about issues impacting infants and their families
- C** • Advise coalition leadership and membership on policies impacting the infant health community
- D** • Connect with academic and clinical leaders from across the country



infants deserve
PROTECTION

and the safest possible
HEALTH CARE

Annual Associate Membership Levels

	Start-Up \$15,000	Bronze \$25,000	Silver \$50,000	Gold \$75,000	Platinum \$100,000
Receive invitations to participate in NCfIH programming and events					
Nominate members to join NCfIH's membership					
Submit up to three questions for annual NCfIH online membership survey					
Preview draft advocacy materials and offer comments					
Suggest topics for advocacy initiatives					
Invitation to join and speak at the annual NCfIH steering committee meeting					
Submit an 8-question stand-alone survey to NCfIH membership					
One-on-one monthly meetings with NCfIH leadership					













NCfIH's programming is financially supported by grants, donations, associate membership dues and sponsorships. Its policy priorities, selection of membership and programming lie solely with NCfIH's leadership and management.

Other Sponsorships

Steering Committee Meeting

The NCfIH Steering Committee meeting, convened annually, provides the foundation for a national education and advocacy strategy to guide NCfIH’s work. The meeting features presentations on policy and advocacy matters.

Gold and Platinum associate members are considered Partner sponsors automatically.

	Friend \$5,000	Supporter \$10,000	Partner \$15,000
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Invitation to have one company representative attend the meeting			
Invitation to have up to three company representatives attend the meeting			
Submit four questions in the pre-meeting survey of Steering Committee members			
Opportunity for private 45-minute meeting with select Steering Committee members			





Clinical Proceedings | \$60,000

Clinical Proceedings are informational resources intended to raise awareness and address unmet needs in infant and maternal health. Authored by expert panelists, these white papers and webinars provide thought leadership highlighting the latest trends and topics in the field of infant and maternal health.

NCfIH will convene an expert panel to consider the clinical perspective and patient journey of a particular topic or issue in infant and maternal health. Experts will rely on their real-world experience, existing research and the perspectives of other stakeholders when developing the proceeding. From their findings, NCfIH will produce a white paper and host a webinar highlighting the white paper. Both the white paper and webinar, housed as enduring content on NCfIH's website, will be promoted through paid digital advertising and shared with stakeholders.

Focus Groups | Virtual: \$35,000 • In-Person: \$55,000

NCfIH will convene up to 12 participants to gain insights and feedback on issues in infant and maternal health. From the focus group findings, NCfIH will produce a focus group report and accompanying materials to be promoted through its network. Focus groups may convene clinical experts, advocates, parents and families, or a combination of these.

NCfIH National Coalition
for Infant Health

Protecting Access for Premature Infants through Age Two

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Contact

Contact Susan Hepworth
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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.

TAKE THE NECESSARY STEPS TO
ELIMINATE INEQUITIES



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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

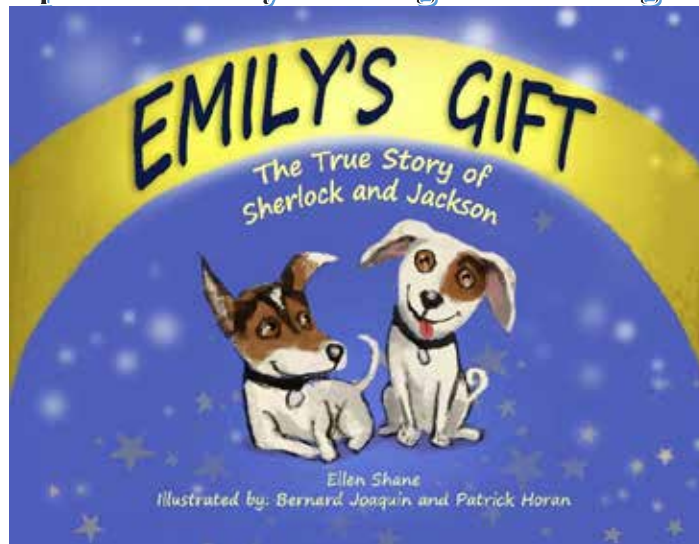
RESPIRATORY SYNCYTIAL VIRUS

is a highly contagious seasonal virus that can lead to hospitalization for some babies and young children.

Know the Signs.



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Purchases of this engaging **true story** provide disadvantaged middle school students, risking academic failure, the opportunity to attain their best personal and academic potential.

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The Premie Parent's SURVIVAL GUIDE to the NICU

By

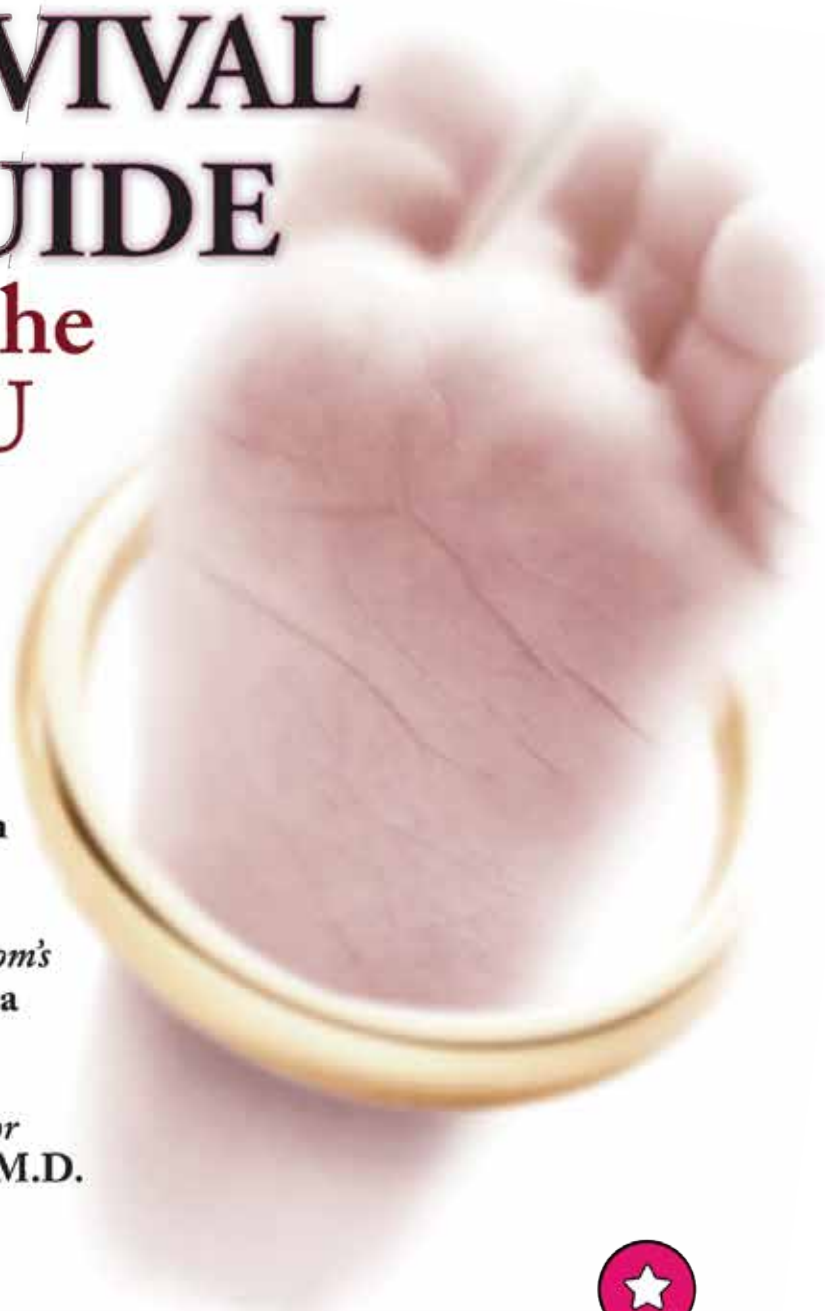
little man's
Nicole Conn

&

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Deb Discenza

with

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MAINTAIN YOUR SANITY
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second edition

Family Centered Care Taskforce September Webinar

Morgan Kowalski, Colby Day, MD and Malathi Balasundaram, MD

The Family-Centered Care Taskforce stands as a pioneering force, being the FIRST international, multicenter, collaborative initiative solely dedicated to quality improvement in family-centered care.

“The Family-Centered Care Taskforce stands as a pioneering force, being the FIRST international, multicenter, collaborative initiative solely dedicated to quality improvement in family-centered care.”

The Taskforce employs a small group model and large group webinars (10 so far and many more already scheduled), enabling effective communication and facilitating change across various healthcare settings. By sharing evidence-based practices and critical family perspectives during webinars and promoting accountability through small groups, we are creating a forward movement to close the healthcare gap. We are sharing our 10th webinar summary below; you can listen to complete recordings on the website www.fctaskforce.org, and an unedited Zoom transcript is available here. https://neonatologytoday.net/FCC/FCC_Sept_2023_webinar_transcript.pdf

“Karel identifies the principles of FICare as parent education and support, staff education support, environmental support, and psychosocial support.”

The FCC Taskforce's latest webinar occurred on September 28th, 11 a.m.-12:30 p.m. PT. These webinars are free, educational, and interactive, with lively Q&A after each presentation.

“Steps involved in implementing FICare include: 1. A guiding concept is that parents are true partners in their baby’s care and should be supported to participate to the best of their ability. 2. Create a FICare steering committee with parents, administrators, physicians, bedside nurses, and other necessary healthcare providers. 3. Planning with an assessment of your center’s current state of FICare and focusing on obtaining organizational and clinical leadership buy-in. 4. Engagement of staff and families in this work.”

“Family Integrated Care: Where are we now?” with Karel O’Brien, MD (she/her)

Karel O’Brien, MD, is a staff neonatologist at Mount Sinai Hospital and Professor of Pediatrics at the University of Toronto. Her presentation’s learning objectives included understanding essential components of Family Integrated Care (FICare), comprehending the long-term impact of FICare on infant and family health, identifying the steps involved in disseminating

Organizational Partners



this knowledge, and opportunities in medical practice to support parent engagement in care. Karel identifies the principles of FICare as parent education and support, staff education support, environmental support, and psychosocial support.

FICare impacts infants by improving growth in the NICU, resulting in more successful breastfeeding at discharge, earlier discharge home, better self-regulation at 18 months corrected age, and better motor development. FICare impacts parents by increasing hands-on skills, developing a closer emotional bond with their infant, providing more confidence and competence in taking care of their baby, decreasing stress, and creating opportunities for valued friendship and support of other parents.

Steps involved in implementing FICare include: 1. A guiding concept is that parents are true partners in their baby's care and should be supported to participate to the best of their ability. 2. Create a FICare steering committee with parents, administrators, physicians, bedside nurses, and other necessary healthcare providers. 3. Planning with an assessment of your center's current state of FICare and focusing on obtaining organizational and clinical leadership buy-in. 4. Engagement of staff and families in this work.

“Alex shared his experience as a NICU dad and the lack of support he received as a non-birthing parent. He expanded on the challenges of being there for his wife and youngest daughter in the NICU and also being the primary parent for his oldest daughter at home, naming this the ‘NICU Dad Shuffle.’”

“NICU Dad Perspective: Disparities in Family Centered Care” with Alex Zavala (he/him)

Alex Zavala founded The NICU Dad and The NICU Dad Podcast. He is a VON Family Advisor, Dell Children's Ascension NICU Network PFAC Chair, and a former NICU parent of Emerson (30 weeker) and Mia (27 weeker). With bravery and courage, Alex shared his experience as a NICU dad and the lack of support he received as a non-birthing parent. He expanded on the challenges of being there for his wife and youngest daughter in the NICU and also being the primary parent for his oldest daughter at home, naming this the “NICU Dad Shuffle.” Alex shared that on top of this, his mental load included keeping his business running smoothly, taking care of things at home, caring for pets, facilitating information from providers to his wife and loved ones, making NICU visits a good experience for his oldest daughter, and acting as a nurse, therapist, driver, and delivery guy among other tasks that come with experiencing a medical crisis. “No one checked on me,” Alex said after describing his 100lb weight gain during his

27-week infant's NICU stay, along with the resulting diagnoses of hypertension and Type 2 Diabetes as well as his rapidly declining mental health.

“Alex’s solutions to improved inclusion of dads and non-birthing parents in Family-Centered Care include changing the culture and stereotypes around uninvolved dads, creating awareness of these struggles by bringing them to the proverbial table, and promoting inclusion.”

Alex's solutions to improved inclusion of dads and non-birthing parents in Family-Centered Care include changing the culture and stereotypes around uninvolved dads, creating awareness of these struggles by bringing them to the proverbial table, and promoting inclusion. Alex says, ‘Dads are no longer smoking cigars in the lobby. They are in the delivery room. They are involved!’ Other ways to support dads and non-birthing partners include offering peer-to-peer mentoring, counseling, and ways to engage in self-care. Alex left us with this: “Family-centered care should include the whole family.”

Disclosure: The authors have no disclosures.

NT

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University of Rochester Medical Center*

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.

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 Clinical Associate Professor
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 FCC Committee Chair
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 Mountain View, CA, United States



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.

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www.nationalperinatal.org/COVID-19



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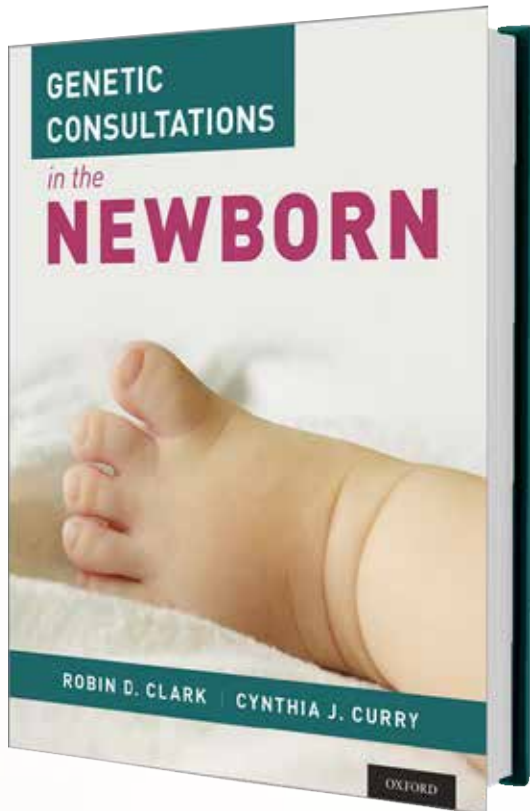


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- Includes “Syndromes You Should Know” appendix, distilling the most frequently encountered syndromes and chromosomal abnormalities in newborns
- OMIM numbers for each condition situate authors' practical guidance in the broader genetics literature, 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: Post Hemorrhagic Ventricular Dilatation Management: Neurodevelopmental Outcomes

Mingshan Lai, MBBS, Joseph R. Hageman, MD, Mitchell Goldstein, MD, MBA, CML

“Ever since I heard about IVH and PHVD, I think of all of the premature infants I cared for and wonder about their neurodevelopmental outcomes.”

As I discussed in a previous clinical pearl, after I instilled surfactant into the endotracheal tube of a 500-gram extremely premature infant born at 24 weeks gestation in 1983, we were able to wean him to room air and a rate of 3 breaths per minute by the following day. My friend and colleague, Dr. Elaine Farrell, learned the interpretation of neonatal cranial ultrasound from her husband, Dr. Jason Birnholtz, a pediatric radiologist, both of whom were at Harvard before Elaine came to work with us at the Evanston Hospital Infant Special Care Unit, wheeled the ultrasound machine to the bedside and placed the transducer on the anterior fontanelle and told me “this baby has a grade II intraventricular hemorrhage (IVH) as per the Papile classification system (1)”. I was surprised and worried that he might develop post-hemorrhagic ventricular dilatation (PHVD), which would have been classified as a grade III IVH as Papile proposed in 1978 when I was a second-year pediatric resident. Ever since I heard about IVH and PHVD, I think of all of the premature infants I cared for and wonder about their neurodevelopmental outcomes. I still remember those infants with PHVD whom I had to perform lumbar punctures and those on whom we consulted the neurosurgeons to place Ommaya reservoirs for serial taps to hopefully attenuate PHVD (2).

Here we are at a conference with an excellent presentation by Dr. Mingshan Lai, one of our very bright neonatal fellows, and he is reviewing three papers about the management of Post hemorrhagic ventricular dilatation and neurodevelopmental outcomes (4-6).

In the observational study by Shankaran et al., the authors demonstrated the impact of post-hemorrhagic ventricular dilatation (PHVD) by assessing the neurodevelopmental outcomes of a cohort of infants born ≤ 26 weeks gestation. This study included 17 centers in the NICHD network and spanned 4.5 years, divided infants based on head ultrasound findings at 28 days and 36 weeks corrected age into three groups: normal head ultrasound (62.4%), intracranial hemorrhage without ventricular dilatation (18.2%), and post-hemorrhagic ventricular dilatation (19.3%). The primary outcome of this study was death or neurodevelopmental impairment,

defined as moderate or severe cerebral palsy, Bayley III cognitive or motor scores < 70 , bilateral blindness, or profound deafness despite amplification. Of the 4216 infants included in this study, 3069 (72.8%) returned to follow-up at 18-26 months, and the primary outcome was found in 28% with normal head ultrasounds, 39% with intracranial hemorrhage without ventricular dilatation, and 68% with PHVD. Furthermore, infants with PHVD were at significantly higher risk for rehospitalization after discharge, hospitalization for seizures, needing ventriculoperitoneal (VP) shunt revisions, and smaller head circumference when compared to infants in the other two groups (6).

However, there remains no consensus among neonatologists, neurologists, and neurosurgeons on when is the best time for intervention. The Early versus Late Ventricular Intervention Study (ELVIS) trial explored this knowledge deficit with a randomized controlled trial that compared intervening on PHVD with lumbar punctures at a low threshold (ventricular index (VI) $> 97^{\text{th}}$ tile and anterior horn width (AHW) $> 6\text{mm}$) versus a high threshold (VI $> 97^{\text{th}}$ tile + 4mm and AHW $> 10\text{mm}$) with a primary outcome of death and/or VP shunt placement. Though this trial did not show a significant difference between the groups in terms of primary outcome, it did show a significant difference in Kidokoro scores calculated from brain MRIs taken at term-corrected age, with the low threshold group having lower scores ($p < 0.001$) (4).

“However, there remains no consensus among neonatologists, neurologists, and neurosurgeons on when is the best time for intervention.”

Mehmet et al. further explored the long-term impact of the ELVIS trial by assessing outcomes at two years. The composite adverse outcome was death, cerebral palsy, or Bayley composite cognitive/motor scores < -2 SDs at 24 months. This study found no difference in composite adverse outcomes between the two groups ($p = 0.07$). However, when corrected for gestational age, severity of intraventricular hemorrhage, and cerebellar hemorrhage, the low threshold intervention group was associated with a decreased risk for adverse outcomes ($p = 0.03$). Furthermore, infants in the low threshold group that required VP shunts had similar cognitive and motor scores compared to infants in the low threshold group that did not ($p = 0.3$ and $p = 0.3$, respectively).

In contrast, infants in the high threshold group that required VP shunts had significantly lower cognitive and motor scores when

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<p>Key Criteria: Ventricular size with the following</p> <ul style="list-style-type: none"> • VI <97th percentile & • AHW ≤6 mm <p>And Absence of the following clinical criteria:</p> <ul style="list-style-type: none"> • HC growth >2 cm per week • Separated sutures • Bulging fontanelles <p>Management:</p> <ul style="list-style-type: none"> • Observation in NICU • cUS twice a week until stable for 2 weeks then every 1-2 weeks till 34 weeks PMA • MRI at Term Equivalent 	<p>Key Criteria: Ventricular size with the following</p> <ul style="list-style-type: none"> • VI >97th percentile & • AHW >6 mm &/or TOD >25 mm <p>And Absence of the following clinical criteria:</p> <ul style="list-style-type: none"> • HC growth >2cm per week • Separated sutures • Bulging fontanelles <p>Management:</p> <ul style="list-style-type: none"> • Referral to a regional center for neurosurgical review • Consider LP 2-3 times • cUS 2-3X a week until stable for 2 weeks then every 1-2 weeks till 34 weeks PMA • Neurosurgical intervention when no stabilization occurs • MRI at Term Equivalent 	<p>Key Criteria: Ventricular size with the following</p> <ul style="list-style-type: none"> • VI >97th percentile + 4mm & • AHW >10 mm &/or TOD >25 mm <p>Or Any of the following clinical criteria:</p> <ul style="list-style-type: none"> • HC growth >2 cm per week • Separated sutures • Bulging fontanelles <p>Management:</p> <ul style="list-style-type: none"> • Consider LP 2-3 times • Neurosurgical intervention including either temporizing measures or VP shunt • MRI at Term Equivalent
<p>Consider alterations in NIRS (ie decrease cerebral oxygenation) or Doppler US (ie Increase in Resistive Index) as additional information that may suggest impairment in cerebral perfusion and more urgent need for intervention.</p>		

compared to infants in the high threshold group that did not require VP shunts ($p=0.01$ and $p=0.004$, respectively). Additionally, this study demonstrated that higher Kidokoro scores were associated with adverse composite outcomes ($p<0.001$), and infants with normal or mildly abnormal Kidokoro scores had higher Bayley cognitive and motor scores than infants with moderate or severe scores ($p=0.02$ and $p=0.01$, respectively). As previously stated, in the ELVIS trial, infants in the low threshold group had significantly lower scores than infants in the high threshold group. This suggests that neurodevelopmental outcomes improve by intervening earlier before the ventricles dilate to a critical state. Their finding supports that larger frontal occipital horn ratio (FOHR) was negatively associated with cognitive and motor score, irrespective of group allocation ($p<0.001$ and $p<0.001$, respectively), and infants with adverse outcomes had larger FOHR than infants without adverse outcomes ($p<0.001$) (5).

“In contrast, infants in the high threshold group that required VP shunts had significantly lower cognitive and motor scores when compared to infants in the high threshold group that did not require VP shunts ($p=0.01$ and $p=0.004$, respectively).”

In light of these new studies, El-Dib et al. suggested changes in the management of PHVD should be made, shifting away from timing intervention around clinical symptoms of increased intracranial pressure and increasing head circumference and towards utilization of cranial head ultrasound (cUS) measurements, especially VI and AHW. Their article provided tools to stratify infants with PHVD into low-, moderate-, and high-risk groups. The low-risk group (VI <97thtile and AHW ≤6mm) was recommended to obtain twice-weekly cUS until stable for two weeks, then every 1-2 weeks until 34 weeks corrected age. MRI was recommended to be obtained at term-equivalent age. The moderate-risk group (VI >97thtile and AHW >6mm) was recommended to be referred

to a regional center for neurosurgical review and to consider serial lumbar punctures as early intervention, in addition to the imaging recommendations of the low-risk group. If no stabilization occurred after serial lumbar punctures, neurosurgical intervention was recommended. The high-risk group (VI >97thtile +4mm and AHW >10mm or clinical signs of rapid head circumference growth, separated sutures, or bulging fontanelles) was recommended to consider serial lumbar punctures while planning for neurosurgical interventions. This group was also recommended to obtain an MRI at term-equivalent age (4).

Infants with PHVD are at high risk for adverse outcomes, including death and neurodevelopmental impairment, and their management requires a multidisciplinary approach and remains a developing field. Recent evidence suggests that more aggressive imaging with cUS and earlier intervention with serial lumbar punctures and neurosurgical interventions may be beneficial in avoiding adverse outcomes.

“by intervening early, before the ventricles dilate to a critical state, neurodevelopmental outcomes improve. Their finding supports this that larger frontal occipital horn ratio (FOHR) was negatively associated with cognitive and motor score, irrespective of group allocation ($p<0.001$ and $p<0.001$, respectively), and infants with adverse outcomes had larger FOHR than infants without adverse outcomes ($p<0.001$).”

“changes in the management of PHVD should be made, shifting away from timing intervention around clinical symptoms of increased intracranial pressure and increasing head circumference, and towards utilization of cranial head ultrasound (cUS) measurements, especially VI and AHW”

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Disclosures: There are no reported disclosures

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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.



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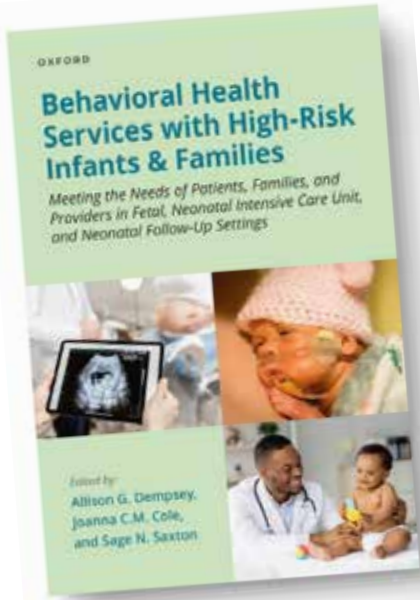
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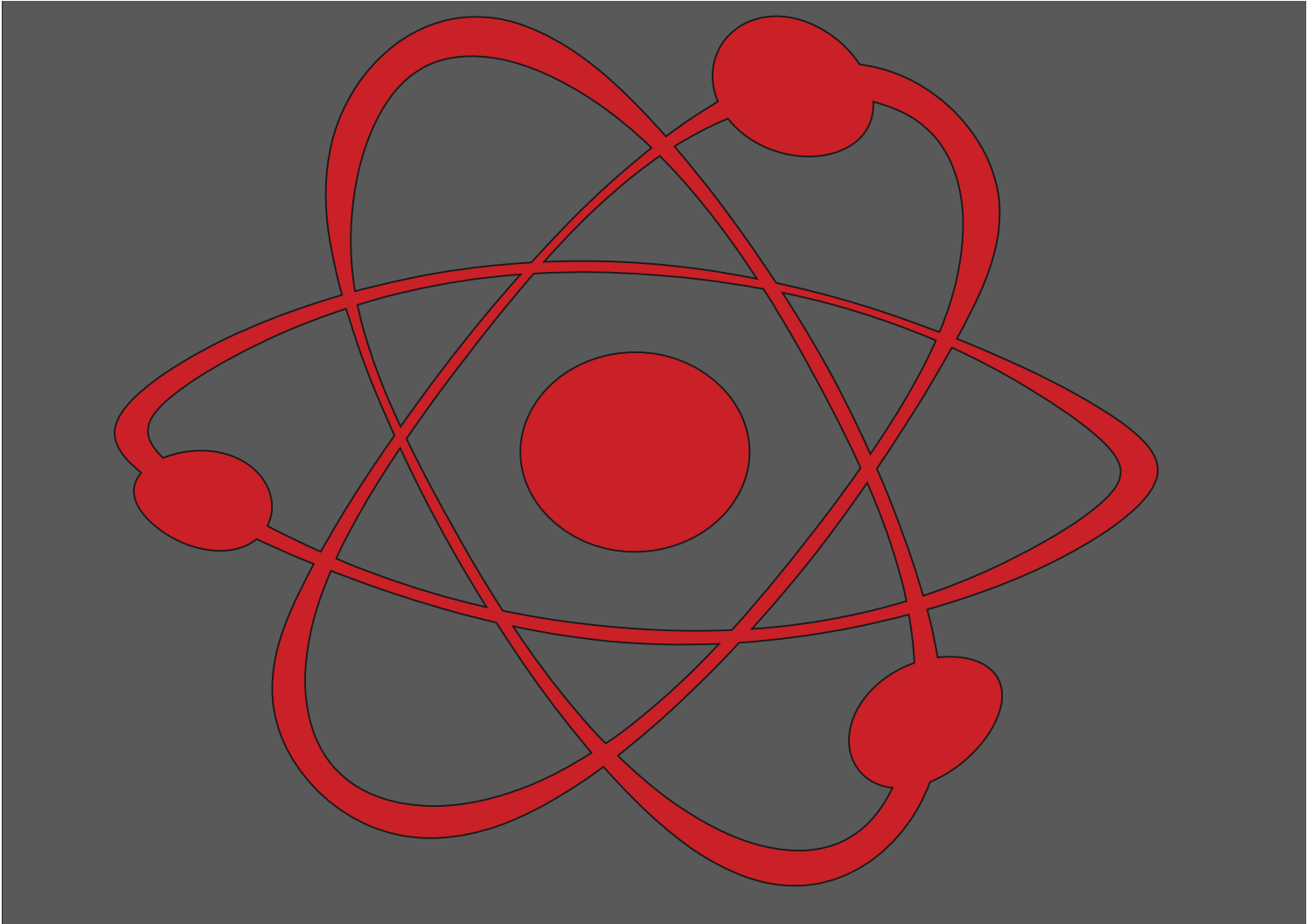
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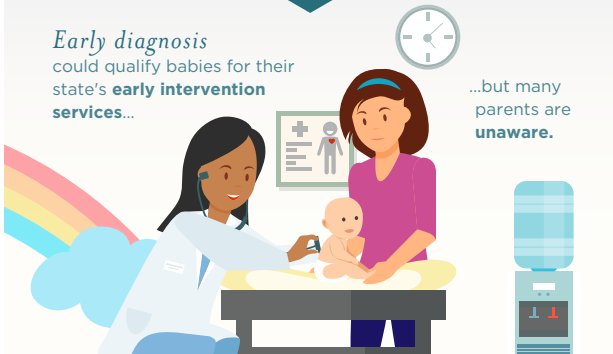
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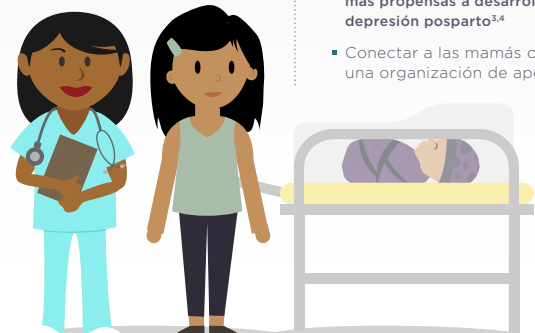
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- Conectar a las mamás con una organización de apoyo



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¹ American Psychological Association. Accessed on: <http://www.apa.org/women/resources/reports/postpartum-depression.aspx>

² National Institute of Mental Health. Accessed on: <http://www.nimh.nih.gov/health/publications/postpartum-depression-facts/index.shtml>

³ Journal of Perinatology (2015) 35, 529–536. doi:10.1097/JP.0000000000000147

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ISSN: 1932-7137 (Online). ISSN: 1932-7129 (Print). Published monthly. All rights reserved.

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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 the next to last page as well as photographs of birds on rear cover.. For this edition, our art was graciously provided by Colleen Kraft, MD. It is a work done by her son Tim. This is "Arteries and Veins." Our Bird is an Emu from my collection.

Mita Shah, MD,
Neonatal Intensive Care Medical Director
Queen of the Valley Campus
Emanate Health, West Covina, CA



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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 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 pixilation 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 7th 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.

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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



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 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.

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