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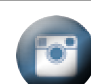

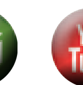
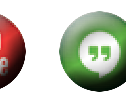

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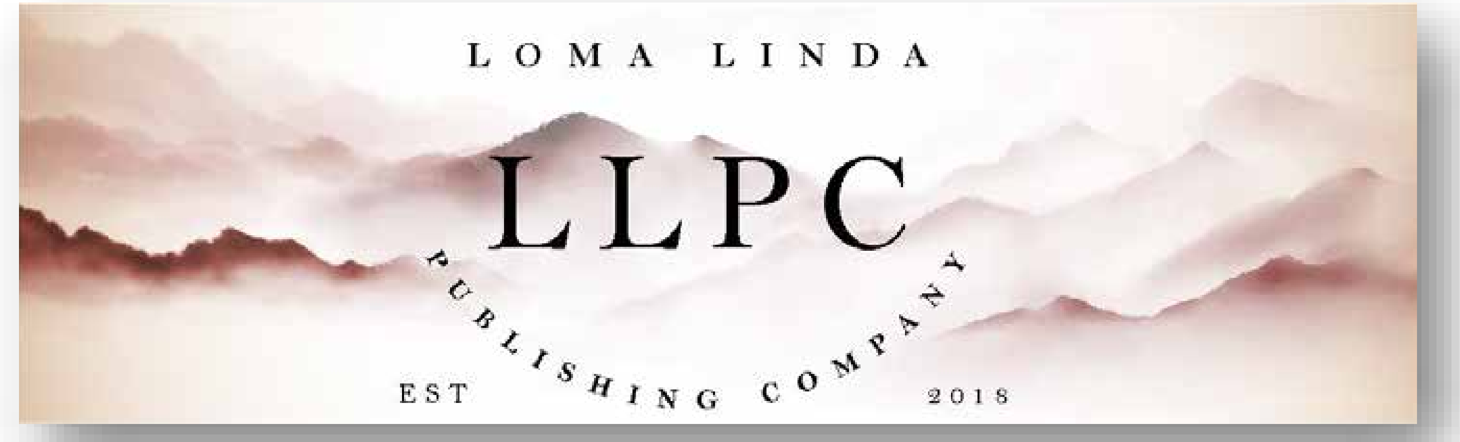

"NICU Blues": A Novel Term for Common Parental Experiences

Beth Buckingham, Ph.D., HSPP, Grace LeMasters, Ph.D., MSN

"Approximately one in ten babies will spend time in a newborn intensive care unit (NICU). (1) Studies indicate that preterm birth significantly contributes to infant morbidity and mortality. Though mortality rates have been declining for preterm infants, there remains a significant percentage of infants born at the earliest gestational age who die in the NICU."

Approximately one in ten babies will spend time in a newborn intensive care unit (NICU). (1) Studies indicate that preterm birth significantly contributes to infant morbidity and mortality. Though mortality rates have been declining for preterm infants, there remains a significant percentage of infants born at the earliest gestational age who die in the NICU. (2) Regardless of gestational age or medical diagnosis, NICU parents often fear their baby's neonatal death or severe morbidity. There commonly exists some level of acute disorienting parental distress. (3)

A single definition of parental distress in the NICU does not exist. (4) A novel non-pathological term, "NICU blues," is proposed to identify common parental experiences specific to the newborn intensive care unit. Giving a name to "NICU blues" for parents provides optimal understanding, relief, and meaning for parents and caregivers moving through a unique NICU journey. Over several years, confidential comments were collected by the principal author from parents with newborns in a Level III family-centered care NICU. These condensed comments, shown in quotes, are many shared voices of pain, including reflecting parental narratives used in developing the term "NICU blues" Parents in the NICU described numerous symptoms of psychological distress not fully meeting specific pathological psychiatric diagnoses in the Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5). However, the clinical reflection of these vulnerable expressions of NICU parental distress helped us formulate the proposed conceptualized term "NICU blues" to shape those collective narrative stories.

Parental "NICU blues" are defined by the intersection of four factors in figure 1: NICU trauma, baby blues, postpartum mood and anxiety disorders (5), and NICU grief. NICU blues may contain varying levels of these four factors. Both parents are included in this biopsychosocial, transitory, and non-pathological model of predicted cogent symptoms in the NICU. NICU blues normalize feelings of being out of control emotionally and behaviorally with responses and experiences for any parent in the NICU. The concept of NICU blues sets an initiative-taking stage for the healthcare professional to offer adaptive coping responses and interventions within the NICU setting. Parents were suffering from extreme emotional pain, a sense of hopelessness, and despair in response to a potential NICU death or long-term morbidity of their newborn we view as an *expected* and *understandable* transitory state of parental functioning. The proposed term "NICU blues" gives voice to the logical collective voices of "feeling like I am crazy and losing my mind." Hence, we define "NICU blues" as *a condition unique to the NICU setting that includes* ***common*** *emotional and behavioral responses to a succession of abnormal parenting events and experiences. These responses include parental guilt, specifically maternal guilt as it relates to pregnancy loss and the baby's NICU admission, father's guilt as it relates to not protecting his family from the NICU stay, negative cognition and mood, decreased interest, anger, concentration problems, sleep disturbances, and struggles to experience positive emotions.*

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NICU blues provides a paradigm for validating parental adaptation experiences within a NICU setting and is viewed similarly to the transitory phenomena of matrescence described by anthropologist Dana Raphael. (6) Maltrescence is a typical physical, emotional, hormonal, and social process of transitioning into motherhood. In this sense, NICU blues is a typical process of psychosocial adjustment into parenthood occurring within the NICU. The term NICU blues normalizes perceived "out of control and helplessness emotions," but with awareness and interventions, these emotions can transition to periods of adaptation.

Parents in the NICU need a meaningful relationship with their baby to establish a sense of parenthood, and their baby needs parental contact for optimal physiologic and psychoemotional development. Parents in the NICU often feel an additional layer of angst and guilt with physical separation from their baby. Research documents the interrelationships between NICU parents' mental health on the functioning of their infants' physical and psychological development.

Postpartum mothers in the NICU may try to numb the intense emotional pain of "not wanting to deal with the possible mortality of their precious long, imagined baby." Fathers in the NICU may experience a sense of panic and doom with potential mortality for their partner and his baby, "I'm going to lose my entire family." Parents often spend infinite initial hours in the NICU without regard for their own needs, "wanting a parent to be with the baby

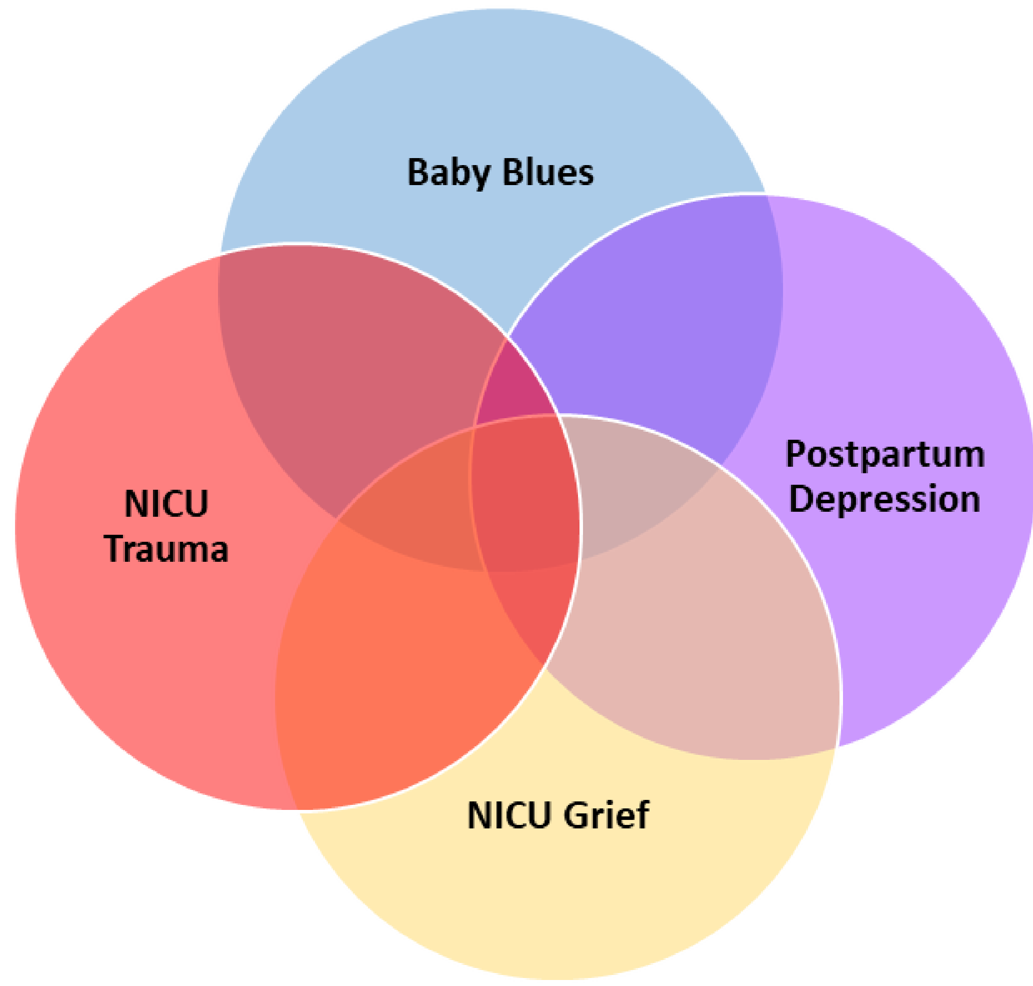

Figure 1: Conceptualization of NICU blues as a function of NICU trauma, baby blues, PMADs and NICU Grief

if they die." This perception, real or imagined, adds to the NICU blues. Often, the father may undertake to stay in the NICU as the mother cannot leave the postpartum floor until physically mobile. The father may or may not be able to express feeling alone and isolated without his partner.

"Most research on NICU parents has focused on the high prevalence rates of postpartum mood and anxiety disorders (5) and post-traumatic stress disorder (PTSD). (7-9) We strongly support the National Perinatal Association (NPA) 2015 recommendations for universal screening and treatment protocols for both parents in the NICU to identify mental health challenges."

Most research on NICU parents has focused on the high prevalence rates of postpartum mood and anxiety disorders (5) and post-traumatic stress disorder (PTSD). (7-9) We *strongly* support the National Perinatal Association (NPA) 2015 recommendations for universal screening and treatment protocols for both parents in the NICU to identify mental health challenges. Studies reveal elevated levels of depression, anxiety, and trauma symptoms shortly after their baby's birth. Without screening and identification of common parental distress, we will be unable to support the mental health needs of our parents in the NICU as partners in their newborn care.

We propose a novel term, NICU blues, for consideration by the NICU team within an ongoing supportive relationship with our parents. Identifying and treating complex emotional and mental health needs, such as NICU blues, provides parents in the NICU with additional consideration for robust universal standards of family-centered care. Figure 1 captures the interrelationship of clinical factors, including NICU trauma, baby blues, postpartum mood and anxiety disorders (5), and NICU grief, to identify a theoretical construct of a transitional, typical, and expected "NICU blues" paradigm.

NICU Trauma:

Considerable evidence exists that both parents in the NICU are

at risk for psychological symptoms from traumatic birth events, including acute stress disorder (ASD) and post-traumatic stress disorder (PTSD). We suggest that NICU psychological trauma symptoms may overlap with clinical symptoms in addition to and separate from NICU blues in Figure 1. There exists an intersection of NICU trauma symptoms, including actual or threatened mortality and morbidity for the baby or mother, with symptoms of NICU blues. Parents in the NICU may have the perception and experiences birth trauma events without meeting DSM-5 diagnostic criteria. In this sense, our psychological approach is expanded beyond the narrow psychiatric diagnosis focused solely on ASD or PTSD. In our clinical experience, NICU blues symptoms for parents include attributions of self-blame for their baby's NICU admission, guilt, fear/horror, feeling detached from self and others, avoidance behaviors from the NICU, decreased parental involvement with their baby, struggles to focus while in the NICU and sleep disturbance.

"A parent in the NICU needs a meaningful, loving, and nurturing relationship with their baby. In Ainsworth and colleagues' classic maternal attachment studies,(10) maternal attachment involves physical and psychological accessibility."

A parent in the NICU needs a meaningful, loving, and nurturing relationship with their baby. In Ainsworth and colleagues' classic maternal attachment studies,(10) maternal attachment involves physical and psychological accessibility. Parents of babies in the NICU are largely limited from these crucial parental attachment behaviors. Bonding may be at risk. As mothers may be recovering from a traumatic delivery, fathers may typically be the first visitor to the NICU.

Qualitative research identifies themes for fathers in the NICU. (11-13). Fathers may believe they need to be stoic for their family, often hiding feelings of anxiety, fear, helplessness, disconnection, powerlessness, and being out of control. They encompass charting unfamiliar waters, including being the backbone of the family, shouldering heavy responsibilities alone, being torn between his partner and baby in the NICU, and the unexpected journey as an active and possibly only participant. (14) Parents may question how their involvement and participation in the NICU is important in seeing nurses and others fulfill their caregiving roles.

Trauma during a newborn's medical stay is now considered an adverse childhood experience (ACE).(15) Toxic stresses or adverse childhood experiences (15) are strongly linked to poor health outcomes. For optimal physiologic and psychoemotional development, a baby may need buffering protection from a lack of parentally connected caregiving.(15) The dearth of physical and emotional closeness between infants and their parents and parental distress can negatively affect the relationship and the infant's developmental outcomes. Research links possible long-term protective factors for parents who participate in NICU infant care.

Psychosocial education and intervention using the paradigm of the NICU blues are paramount at these initial stages for *normalization* and *validation* that these distressing thoughts and feelings are common for most parents in a NICU setting. Unique clinical themes and identification of NICU blues provide parents with alternative schemas for assimilation and adaptation.

Discussion of NICU blues normalizes parents' turmoil as understandable and *predictable* within the NICU. Early attunement and co-regulatory caregiving are the foundation for attachment and bonding. We provide a new lens of parenting in the NICU with these caregiving-bonding discussions. In highlighting NICU blues, parents are more apt to discover "what's lovely about their baby at this moment" apart from the barrage of NICU equipment and stressful environment. Normalization of NICU blues promotes parental discovery of their baby's physical and emotional nuances.

Parents often need a pause for adaptation from the many successive invasive medical procedures with their babies. With this conversation of NICU blues, parents have reported a much greater understanding of commonly shared universal NICU trauma reactions. With ongoing discussions by the staff of NICU blues, parents gain some psychological distance from their trauma symptoms, reporting greater acceptance, psychological flexibility, and adaptation for continued engagement in the NICU. In our clinical experience, identification of NICU blues sets a family-centered stage for later engagement with parents for other bedside compassionate family-centered interventions and connection between staff and parents in the NICU.

Baby Blues and Postpartum Mood and Anxiety Disorders: (5)

Baby blues, also known in the literature as postpartum blues or postnatal blues (with these latter terms excluding the father), is a mild transient disruption of mood occurring several days following delivery. It is imperative for NICU psychologists and medical and nursing staff to help parents make sense and meaning of their initial distress specific to identifiable physical changes, situational stressors, and loss (16). Parents often express relief in knowing that predictable NICU blues may be additive to or better explained to both parents than the term baby blues in addition to hormonal changes.

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Parents in the NCIU report that discussion of possible NICU blues around admission to the NICU gives them a sense of hope and being understood. Our clinical impression is that this initial connection with parents in the NICU gives clarity to an internal disruption not fully understood. Perhaps with this safe therapeutic, nourishing NICU staff-parent connection, parents may be better able to bond with their babies. In our discussion of NICU blues with parents, relationship building for parent-child bonding and meaningful parent-NICU staff communication begins another positive launch for family-centered care.

Baby blues is identified as one potential risk factor for postpartum depression. These authors posit that the risks of developing perinatal mood and anxiety disorder (PMAD) may be lessened or eliminated when identifying NICU blues or baby blues. Early parental psychological identification and intervention by the psychological, medical, and nursing staff is key. Research studies indicate that *both* parents of babies in the NICU are at risk for postpartum depression and anxiety. There currently does not exist a DSM-5 diagnosis specific to postpartum depression. (17) There is a specifier of "with peripartum onset" with symptom onset during pregnancy or in the four weeks following delivery, with the focus generally on the mother.

"PMAD symptoms fail to voice the entire story of NICU parents. Underlying parental NICU distress reveals clinical themes. Using a 4-stage model by Beck, research authors identify maternal loss of control as the underlying problem with a NICU postpartum depressive experience. (18)"

PMAD symptoms fail to voice the entire story of NICU parents. Underlying parental NICU distress reveals clinical themes. Using a 4-stage model by Beck, research authors identify maternal loss of control as the underlying problem with a NICU postpartum depressive experience. (18) Beck identified a 4-stage process termed "teetering on the edge" between sanity and insanity with stages of (1) encountering terror, (2) dying of self, (3) struggling to survive, and (4) regaining control. (19) The author described stages with four identifying themes: incongruity between expectations and the reality of new motherhood, a spiraling downward process, pervasive loss, and making gains. Like Beck's proposed process of "teetering on the edge of insanity," parents in the NICU express "a sigh of relief knowing sanity exits and feelings expected within the term NICU blues."

A Father's expectations of ideal fatherhood may, too, be affected by the fears and challenges of parenting a medically fragile baby in the NICU and supporting a mother who is not coping well. (20) Themes of loss fill the NICU room with both parents experiencing the loss of the "perfect" birth to the shocking experiences of seeing their fragile baby for the first time, often with tubes that may affect parental identity and self-esteem. (21) Paternal feelings of helplessness may be incredibly overwhelming.

Parental suffering is often silent. NICU parents may encounter various symptoms, including NICU blues, baby blues, or PMADs. In our clinical experience, parents present with some level of emotional and behavioral NICU distress. They commonly experience an intrusive cognitive disruption to their expected and perceived positive parental role.

Parents often experience elevated levels of negative self-blaming and misattributions for the baby's NICU admission exacerbating parental guilt. Dreams of completing a term pregnancy, of expecting a typical delivery complete with physically holding your baby in the delivery room, are abruptly crushed. Multiple losses for any NICU parent are monumental. Parents do not dream of finding themselves as a family in a NICU. As staff present to parents the clinical term NICU blues as a *common* reaction to their loss of a normal newborn experience, they often feel understood and comforted. In ruling out psychiatric pathology, NICU blues provides an intersecting paradigm of composite reactions, including baby blues and postpartum mood disorder, guilt, sadness, and feelings of parental worthlessness.

NICU Grief:

Parents in the NICU may experience an avalanche of immense losses accompanied by grief associated with those losses. Significant losses for parents may include sudden pregnancy termination, medical complications, loss of anticipated motherhood and fatherhood roles, and loss of hopes and dreams of a highly anticipated future with a healthy full-term baby coming home shortly after delivery.

Symptoms of NICU blues for parents may be further conceptualized within Kubler-Ross's model of grief and loss.(22) Those stages include shock/denial, anger, bargaining and self-blaming, depression, and acceptance with the recent inclusion of an additional newly defined stage, meaning. Overlap of NICU blues symptoms with stages of Kubler-Ross's model of grief exists, as shown in Figure 1. As Kubler-Ross's model reflects, these symptoms of grief are experienced in stages without the nuance of diagnostic pathology. Considerations for different cultural, ethnic, and races may also affect expressions of grief and stressors within the NICU setting.(3)

These disorienting grief responses may disrupt parental NICU involvement in baby care bonding behaviors. Parents may further isolate themselves from family and peers, intensifying experiences of NICU blues. This withdrawal from meaningful social support fuels feelings of helplessness and shame with possible stigma adding to their secret "of being different" from other parents leaving the hospital with healthy newborn babies.

"Life in the NICU does not make sense. Many parents express negative self-blaming attributions for "causing" their baby's NICU admission and stay. These parental experiences seem to coincide with feelings and thoughts of NICU blues. We suggest that parental expressions of grief, loss, and shame are strong predictive variables contributing to NICU blues."

Discussion:

Life in the NICU does not make sense. Many parents express negative self-blaming attributions for "causing" their baby's NICU admission and stay. These parental experiences seem to coincide with feelings and thoughts of NICU blues. We suggest that parental expressions of grief, loss, and shame are strong predictive variables contributing to NICU blues. There is no clear clinical definition for the array of parental psychological distress unique to the NICU. Identifying the NICU blues seeks to add to the understanding of psychological distress as a *common* contextual response. Thus, parental adaptation to the NICU is viewed as adaptive versus non-adaptive. Awareness of these parental responses by NICU staff and early intervention can ease the experi-

ence of NICU blues, foster increased bonding between parent and baby, increase interactions among NICU staff and between staff and parents, and promote an overall more positive parental NICU experience. However, this new paradigm and theoretical concept "NICU blues" for parental distress, needs further empirical qualitative and quantitative evaluation to determine its efficacy and effectiveness for NICU family-centered clinical standards of care.

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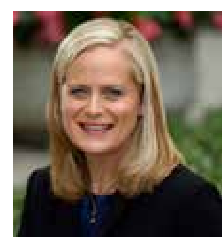

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Letters to the Editor

Implementing the Transcript for Neonatology. Comment on "The Transcript of Jane Velez-Mitchell's Interview with Neonatology Today"

Dear Editor:

We read "The Transcript of Jane Velez-Mitchell's Interview with Neonatology Today" with great interest (Hillyer, K. NT Behind the Scenes: Jane Velez-Mitchell of the Unchained TV Network Discusses Pig Little Lies. Neonatology Today. 2022;17(10):33-46.). This interview, conducted by Dr. Kimberly Hillyer, focused on animal activism, vegetarian/veganism, and health through Velez-Mitchell's new reality show, "Pig Little Lies," on "Unchained TV." The interview concluded that widespread vegetarian/veganism could help remedy global issues like climate change, hunger, and animal abuse. Vegetarianism/veganism is also reported to improve people's health by lowering cholesterol levels and decreasing occurrences of heart disease, cancer, and other systemic diseases. We, too, are passionate about bettering health worldwide and are inspired by challenging the status quo. However, there was no mention of how veganism is related to neonatology or perinatal health, even when there are known benefits. Because we see possible advantages of this diet in neonatal and perinatal health, we encourage a more focused approach that would enhance the journal, perhaps related to the specific effects of a plant-based diet in pregnancy and postpartum.

"Because we see possible advantages of this diet in neonatal and perinatal health, we encourage a more focused approach that would enhance the journal, perhaps related to the specific effects of a plant-based diet in pregnancy and postpartum."

We agree that current animal agricultural practices are concerning and demand change. A plant-based diet can cause pregnant women to be deficient in many vitamins and minerals, such as iron, vitamin D, calcium, iodine, omega-3, and vitamin B12 (1, 2). Fortunately, in modern society, it is possible to maintain a well-balanced vegetarian/vegan diet with the correct supplemental additions. A balanced diet could lower risk factors such as preeclampsia, ultimately improving maternal and infant outcomes (2). Interestingly, Abbasi et al. conducted a case-control study comparing the dietary patterns of 510 pregnant females which the participants were divided into three different groups consisting of the Western diet (high in red meat and processed meat), the Iranian diet (high in eggs, and legumes), and Healthy diet (high in fruits, low-fat dairy, dried fruits, nuts, vegetables, fruit juice, liquid oil, and tomatoes). They found a statistically significant difference in which the Western diet had a 5.99 times greater increase in preeclampsia odds than the Healthy diet (3).

"A plant-based diet can cause pregnant women to be deficient in many vitamins and minerals, such as iron, vitamin D, calcium, iodine, omega-3, and vitamin B12 (1, 2). Fortunately, in modern society, it is possible to maintain a well-balanced vegetarian/vegan diet with the correct supplemental additions."

Some parents may also have concerns regarding breast milk composition when nursing their infant on a plant-based diet. However, suppose the mother understands keeping a balanced diet by supplementing certain fatty acids, vitamin B12, and other minerals. In that case, there should similarly be no issues. Breast milk will have the nutritional value necessary to sustain a growing infant (4). In addition to the above, further literary research could depict how a vegetarian/vegan diet could even be beneficial in decreasing the occurrence of some pediatric conditions. As Pistollato et al. described, the maternal intake of certain vegetarian/vegan foods in 763 Japanese mother-child pairs shows this relationship between vegetarian/vegan diets and decreased incidence of pediatric wheezing, asthma, and eczema in ages 16-24 months (5).

"In conclusion, we believe that adapting further interviews to neonatal and perinatal health will enhance the impact a transcript can have in "Neonatology Today." We look forward to future developments in the field of diet and health."

In conclusion, we believe that adapting further interviews to neonatal and perinatal health will enhance the impact a transcript can have in "Neonatology Today." We look forward to future developments in the field of diet and health.

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Sincerely,

Davit Orujyan, Edward Lee, Daniela Sharp, Sandeep Lankireddy

Western University of Health Sciences, Pomona, CA

Dear Davit Orujyan, Edward Lee, Daniela Sharp, and Sandeep Lankireddy:

Thank you for taking the time to review this manuscript. Indeed, the effect of a well-balanced plant-based diet has improved adult patients' health. Sophisticated protein needs and other growth benefits are best provided to newborns through their mother's breastmilk. However, there are certain conditions, including milk protein allergies and metabolic disorders, which preclude the use of human milk. In this case, it can be argued that the advancement of Vegan and Vegetarianism lifestyles has improved protein science and potentially offered options for these most at-risk newborns. Even though breastmilk is decidedly not a Vegan product, most Vegan parents do recognize the superiority, albeit no longer necessarily a requirement of breastmilk in their newborn's diet. Still, especially with Vegan parents, proper dietary supplementation (1) must occur in the mom for the breastmilk to contain the necessary nutrition. (2) Where this is not achievable or acceptable, soy and elemental formulations are available.

"Still, especially with Vegan parents, proper dietary supplementation (1) must occur in the mom for the breastmilk to contain the necessary nutrition. (2) Where this is not achievable or acceptable, soy and elemental formulations are available."

Although there may be benefits in the long term, term outcomes for the children of parents who have a Vegetarian or Vegan diet, the risks of undernutrition in Vegan patients may outweigh the benefits. In these situations, again, formula supplementation may be preferable. There have been discussions of post-expression supplementation in Vegan moms to ensure adequate nutrition. (3) This practice needs to be approached on a case-by-case basis, as it may be more appropriate to improve the mom's nutrition which would then concomitantly provide enhanced or appropriate nutrition to the newborn.

All of these considerations notwithstanding, eliminating mom's milk from the newborn's diet will have another potentially far-reaching effect in so far as the lack of an immunologic component from the newborn's diet. Certain infections, including seasonal viral infections like RSV, can be mitigated by the transfer of maternal antibodies. (4) With the risk of severe infection and yet unknown or evolved viruses, mom's own milk is the best defense against these potential infections.

"Certain infections, including seasonal viral infections like RSV, can be mitigated by the transfer of maternal antibodies. (4) With the risk of severe infection and yet unknown or evolved viruses, mom's own milk is the best defense against these potential infections."

The association of various immune-mediated diseases with maternal consumption of animal proteins has significant support in the literature and deserves attention. However, the concern regarding possible nutritional deficiencies may outweigh the benefit, especially when adequate prenatal care cannot be assured and monitoring for nutritional deficiencies is beyond the scope of those providing prenatal care. (3, 5)

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Editor in Chief

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Erratum (Neonatology Today September, 2022

Neonatology Today is not aware of the erratum affecting the September, 2022 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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Neonatology Today welcomes your editorial commentary on previously published manuscripts, news items, and other academic material relevant to the fields of Neonatology and Perinatology.

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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Should Infants Be Separated from Mothers with COVID-19?

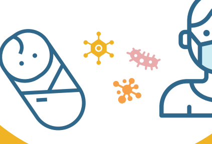
FIRST DO NO HARM

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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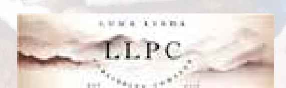

“Storyteller” painting by Sharron Montague Loree, 1982

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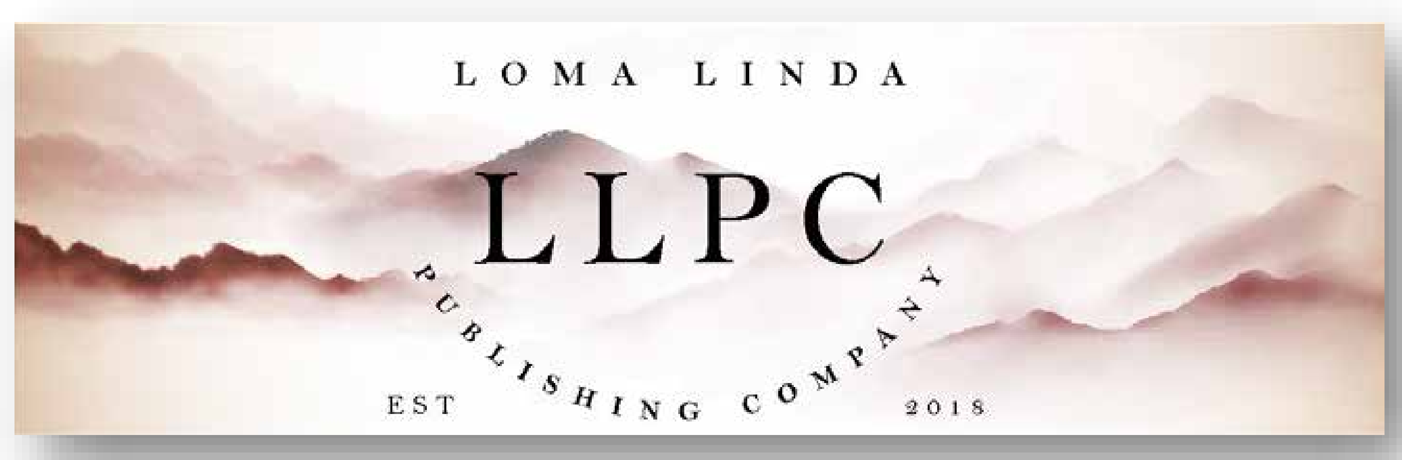

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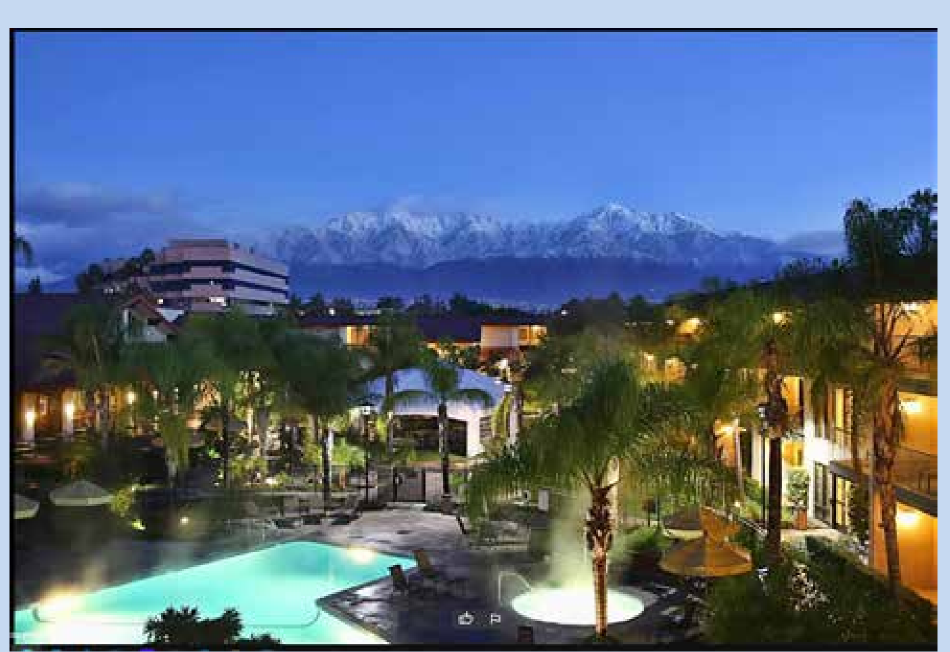

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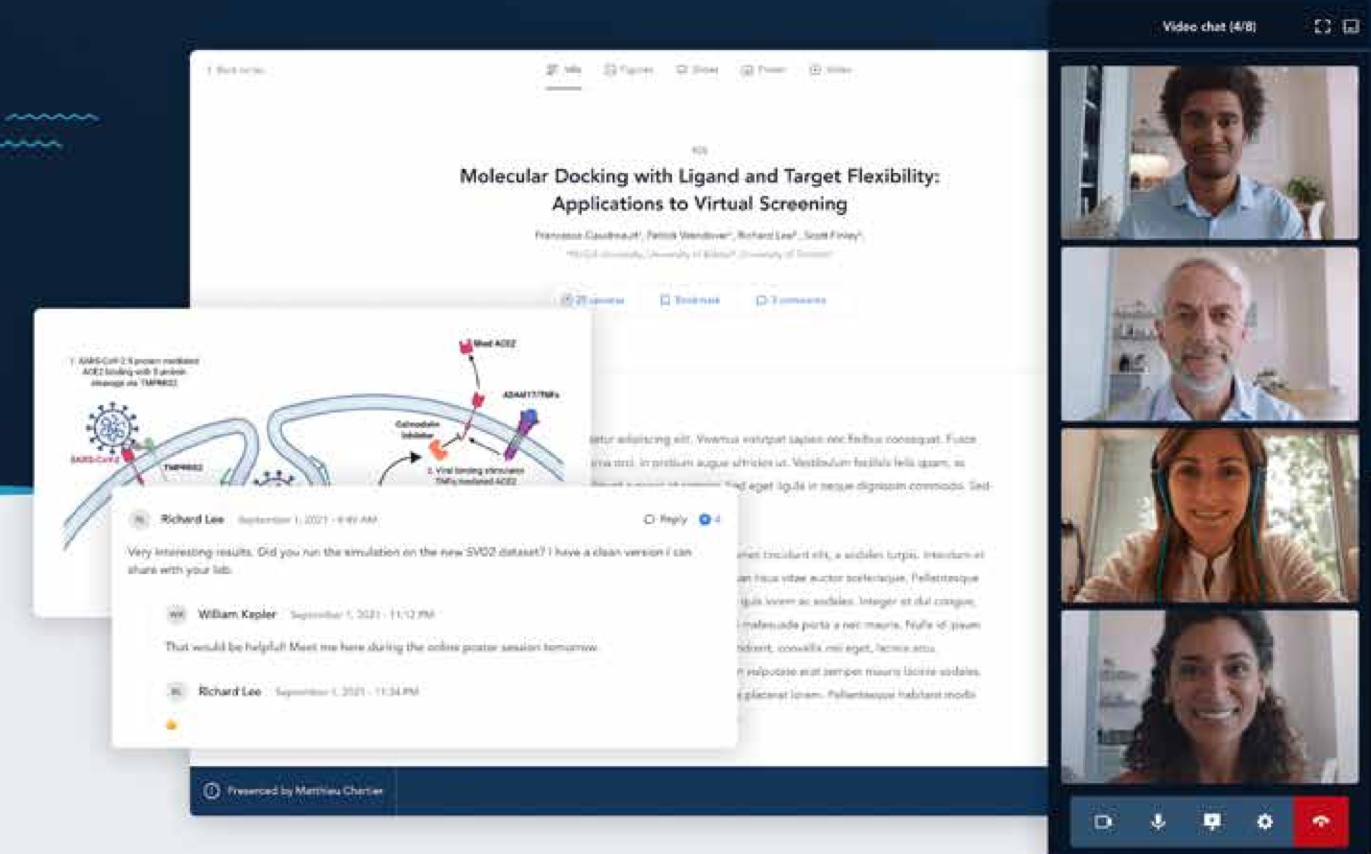

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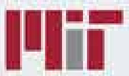

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High-Reliability Organizing (HRO) for Disasters: Capability and Engagement

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

Abstract:

We reviewed first-person accounts of NICU staff who experienced disasters and were published in the medical literature. A disaster comes from stochastic environmental noise acting as 'forcing functions,' the strength of the environment to force a system or population to respond. The sensory effects in a disaster are overpowering – sounds, temperature, smells – and can degrade performance. A disaster brings together diverse infrastructures of organizations and disciplines accustomed to collaborating. A disaster is an environmental disruption of medical care, a victim generator that disrupts the ability to treat multiple patients. Our goal becomes survivability, preventing deaths that result from post-disaster events. Of over 400 affected neonates, only two deaths occurred during these disasters, and no deaths occurred during evacuations. These disasters revealed the effective actions and contextual leadership of the typical Neonatal caregiver, clearly demonstrating HRO as natural human actions when freed from convention and central authority.

"These disasters revealed the effective actions and contextual leadership of the typical Neonatal caregiver, clearly demonstrating HRO as natural human actions when freed from convention and central authority."

Introduction: The Most Extreme and Brutal Audit

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 infrastructure for managing the disaster. The government aims to return the community to routine operations and increase *survivability*. The medical response most often relies on the pre-disaster healthcare infrastructure, a continuation of medical care, and the goal of *reducing mortality* by treating factors that cause death (1). When these goals and infrastructures conflict, one group's infrastructure, and goals become another group's barrier (2).

More commonly identified as shared physical structures for the operations of organizations and society, infrastructures may better be understood by how society uses the infrastructure. This "inverted" approach demonstrates how 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, technology, and problem-solving to connect people with activities and structures. Infrastructure is the invisible glue that holds the system together (3).

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Understanding the change in infrastructure brought on by a disaster brings better integration of medical care into disaster operations. Without such integration, an adverse, hostile, and austere environment will compromise effective and efficient healthcare.

Neonatologists operating in the NICU focus on reducing *mortality,* which is *disease-related death*. 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 describes the effect of the environment on mortality as comorbidity or the impedance connecting necessary medical care to the victim (4). *Survivability* is the *reduction of death after an event.* Our goal in the NICU is survivability, preventing deaths resulting from post-disaster events (5).

" Survivability is the reduction of death after an event. Our goal in the NICU is survivability, preventing deaths resulting from post-disaster events (5)."

Death is an effective boundary object for communication between healthcare and disaster infrastructures (6). Neonatologists, NICU staff, helicopter pilots, and government disaster agencies want to reduce death, but they see death differently: reducing *mortality* by treating factors that cause death versus increasing *survivability* by preventing deaths that result from post-disaster events (1). In a disaster, it becomes gratuitous to differentiate death from a disease from death due to the environment.

One significant difference, however, is the level of analysis. Along with our functional and ecological definitions of disasters, legal and administrative definitions of disasters are necessary for out-of-area resource allocation. The Neonatologist operates with a shorter time horizon of minutes and hours in a small geographic area and focuses on individual patients. Initially, the Disaster Incident Commander (Disaster IC) operates over hours and days yet is mindful that duration, geographic area, and severity are uncertain, and groups and communities of people are in peril. "Failure to identify levels of analysis ... can create false debates," Scott A. MacDougall-Shackleton (7).

A disaster presents the most severe consequence in organizational operations – community death – and the hardest gap to the bridge – the gap separating belief and the environment (8, 9). We will use the *Neonatology Today Disaster Series,* written from primary experience in disasters, to add coherence to NICU disaster

management. This will review disasters as abrupt or approaching events and the presentation of the quandary to evacuate or shelter in place. The environment is both physical and experienced with the determinants necessary to appreciate for planning and training. The NICU can readily integrate into disaster systems and infrastructure through boundary objects, thus obviating the need to learn a new jargon or slang. The concept of survivability can be appreciated sufficiently to include it in NICU disaster preparation.

"The NICU can readily integrate into disaster systems and infrastructure through boundary objects, thus obviating the need to learn a new jargon or slang. The concept of survivability can be appreciated sufficiently to include it in NICU disaster preparation."

NICUs in Disaster

We reviewed first-person accounts of NICU staff who experienced disasters and were published in the medical literature. Press accounts provided supplemental information. The experiences occurred during15 events from 1994 to 2020 and included 416 neonates, 400 of whom were evacuated [**Table 1**] (5, 10, 11). No neonate died during the evacuation, but two infants died during hurricanes (12, 13).

"While it may seem intuitive to prepare for specific types of disasters, the published experiences show the effectiveness of individuals self-organizing to engage in events as they emerge (30)."

While it may seem intuitive to prepare for specific types of disasters, the published experiences show the effectiveness of individuals self-organizing to engage in events as they emerge (30). These are two levels of analysis. The *type of disaster* assists government agencies and organizations in planning and preparation, giving them the disaster infrastructure for what can be expected. Individuals caring for neonates without power and water have other problems. These individuals, their actions described in the various articles, engaged like the Los Angeles City firefighter who arrived on the scene to assist one of the authors (DvS) on a rescue: "I don't know what's happening, but I know what to do."

Table 1: NICU Evacuation and Sheltering

Cause	Year	Location	Evacuate/Shelter	Neonates	Deaths
Earthquake (14)	1994	Northridge, California	Evacuate	22	0
Earthquake (15)	2016	Kumamoto, Japan	Evacuate	38	0
Internal structure fire (16)	2000	Toronto, Canada	Evacuate	29	0
Unexploded WWII bomb (17)	2007	Trier, Germany	Evacuate	6	0
Internal flooding (18)	2014	Cologne, Germany	Evacuate	26	0
Wildland fire (19)	2003	San Diego County, California	Shelter	n/a	0
Wildland fire (20)	2007	San Diego County, California	Evacuate Mother-baby dyads	n/a	0
Wildland fire (21)	2020	Oregon	Evacuate	14	0
Wildland fire (21)	2020	Oregon	Shelter	16	0
Hurricane (13)	2001	Houston, Texas	Evacuate	79	1
Hurricane (22-25)	2005	New Orleans, Louisiana	Evacuate One sheltered ECMO	97	0
Hurricane (26)	2005	Galveston, Texas	Evacuate	8	0
Hurricane (27, 28)	2011	New York, New York	Evacuate	30	0
Hurricane (27)	2012	New York, New York	Evacuate	21	0
Hurricane (29)	2013	Central Philippines	Evacuate	n/a	0
Hurricane (12)	2019	Beira, Mozambique	Evacuate	30	1

Table 2. Patterns and Characteristics of Noise (33)

Color	Structure	Variance	Distribution
White	No frequencies dominate Flattened spectrum	Data *decreases* variance	Gaussian distribution - Elements fully independent - No autocorrelation
Red	Low frequencies dominate Long-period cycles	Data *increases* variance	Power law distribution - Elements *not* independent - Mutual/ reciprocal relations
Pink	The midpoint of red noise The slope lies *exactly* midway between white noise and brown (random) noise	Data *continuously increases* variance Distinguishes pink noise from reddened spectra	Power law distribution - No well-defined long-term mean - No well-defined value at a single point

"What you do every day is what you do in an emergency," Jim Denney, Capt., LAFD, a veteran of two Vietnam combat tours and numerous disasters. Denney offered this observation to reassure paramedics and firefighters yet to experience a disaster, instill trust in lower-ranking members' capabilities, bring disaster plans closer to routine operations, and sway training away from any specific "disaster" thinking and behaviors. In discussions with one of the authors (DvS), Denney aimed to teach routine actions that adapt to a crisis. He worked against the idea that organizations have an "emergency" mode they shift into during a crisis. If this were true, people in a group would unreliably change their behaviors because the change would be contingent on the individual recognizing the disaster. Such identification depends entirely on the person's perceptions of the situation, restricted experience, and limited capabilities.

"If this were true, people in a group would unreliably change their behaviors because the change would be contingent on the individual recognizing the disaster. Such identification depends entirely on the person's perceptions of the situation, restricted experience, and limited capabilities."

In abrupt disasters, the environment intrudes into the NICU, making it inoperable. There is no forewarning and no immediate emergency assistance. We reviewed the experience of five NICUs that experienced abrupt disasters – earthquakes, internal fire and flooding, and a discovered WWII unexploded bomb (5). Four of the NICUs began evacuation before the completion of damage assessments. We found little difference in their reasoning and actions compared to what they do daily.

More problematic is the approaching threat, which is too easily discussed from an external, decontextualized view, unaffected by the dissipated energy of the disaster. This is where central leadership in an organization often operates and where plans originate. The value of the external specification is that it has multiple points for analysis and the ability to observe the rate of change of the system due to the disaster. However, those operating against the disaster act within the contextual flow of events experiencing local dissipation of environmental energy (9). This gap between decontextualized disaster management and contextualized disaster engagement is what disaster infrastructure bridges.

"The multiple data points for analysis seduce those outside of a High-Reliability Organization. Stable environments are those environments where elements do not change in response to internal feedback (autocorrelation). Data will reduce variance and produce a Gaussian distribution with descriptive statistics and predictive probabilities."

The multiple data points for analysis seduce those outside of a High-Reliability Organization. Stable environments are those environments where elements do not change in response to internal feedback (autocorrelation). Data will reduce variance and produce a Gaussian distribution with descriptive statistics and predictive probabilities. Increased data, then, improves the reliability of analyses.

The distant, decontextualized view can too readily become rich in concepts and amenable to data analysis, such is the value of the Gaussian distribution for certitude. "A story always sounds clear enough at a distance, but the nearer you get to the scene of events, the vaguer it becomes" (31). The risk is the adoption of beliefs that motivate reasoning (32), which then creates a gap in the environment. An abrupt catastrophe brutally makes visible

these shortcomings.

The 'color' of environmental noise describes the effect of periods on the environment. Time segments and elements are independent without feedback, hence the Gaussian distribution and calculated statistics and probabilities. The presence of feedback in a system causes autocorrelation and frequency changes. Low-frequency events bring a greater force into the system [**Table 2**].

The lack of significant entropy and the absence of entropic or stochastic noise fluctuations in routine operations, or the lack of its recognition, allow routine organizational operations to disregard the color of noise. An organization is then unprepared for the significant forcing functions of red noise or the abrupt catastrophe of pink noise. The effective use of everyday actions by those within the contextual flow of events, operating against the disaster, saved the lives of many neonates.

> ***"Out of this concern that operational failures can result in dangerous and harmful consequences, business and management science distinguishes the concepts of risk, error, and hazard (8)."***

The Environment

The environment has always intruded into healthcare in some form, often becoming a part of healthcare, such as public health. Aerospace medicine provides medical care when the patient is healthy, but the environment has the pathology, a useful analogy for medical care during a disaster. The strength of the intrusion is entropic, something we have no control over. Energy dissipation can intrude slowly or abruptly and recede quickly or have an extended resolution.

Oscillations and oscillatory processes are fundamental to the functions of life and the physical world. After oscillations gain stochastic resonance, the power spectrum increases in lower frequencies – as environmental stochastic noise, uncommon events gain greater influence on the system. Even weak or relatively small stochastic noise can create and sustain significant oscillations.

> ***"Stochastic environmental noise can act as a 'forcing function,' the strength of the environment to force a system or population to respond. The noise process is independent of timescale or magnitude."***

Stochastic environmental noise can act as a 'forcing function,' the strength of the environment to force a system or population to respond. The noise process is independent of timescale or magnitude. We need not characterize normal environmental variation differently from catastrophes (34).

Viewed this way, we can discuss a disaster as stochastic noise in a stochastically noisy system. This background noise comes from everyday stochastic processes that corrupt the actual-world application of scientific studies. Fluctuating entropy in our open environment amplifies this natural noise. We routinely operate with fluctuating environmental stochastic noise, exceeding our ability to respond readily.

We can describe a disaster as an abrupt, severe 'forcing function' onto a system already buffeted by environmental stochastic processes. ("External forcing by environmental noise alters the qualitative nature of the dynamics" (35)) Stated in this simplistic way, one might presume healthcare systems need only to expand operations to extend medical care into the disaster environment while, simultaneously, the outside environment temporarily intrudes into healthcare. This idea misses the difference between a normal environment consisting of multiple *independent* stochastic processes and an environment of intermittent *correlated* stochastic processes. Correlation amplifies stochastic processes. The first has some degree of predictability, while the latter does not. The difference has profound effects on how systems adapt to each environment. 'Environmental stochasticity' reflects the unpredictability of the environment (36).

We sacrifice accuracy for conceptual tractability when we separate the organization from the environment. The gaussian distribution of white noise environments supports discrete concepts, hierarchical systems, and linear thinking independent of context or the environment. The observer's frame of reference moves outside the flow of events and becomes fixed as Eulerian specificities (37). Authorities use this external reference frame to create models for the reddened environment. However, the reddening of the environment increases variance, dissolving gaussian distributions and creating unpredictability (34).

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Environment as Pathogen

Environmental extremes can cause unrecognized disease processes in adults. A 'normal' environment for adults is an extreme environment for a premature neonate. Therefore, a disaster creates a toxic environment for the neonate. Loss of insulation from the environment places the neonate in an extreme environment with findings that may be missed or misattributed to other diseases.

A disaster creates two environments – a physical environment and a mental environment. The physical environment of uncontrolled energy experiences volatility, uncertainty, complexity, ambiguity, threat, and time compression (VUCA-2T). The resulting change creates a new mental environment characterized as a liminal zone

of abrupt new structures and rules (6)

> ***"A disaster makes the environment an open system. The NICU environment becomes open to environmental energy, and staff becomes open to interactions with other, often nonmedical, systems. The hospital's environmental insulation for neonates is lost (6)."***

Physical Environment

A disaster makes the environment an open system. The NICU environment becomes open to environmental energy, and staff becomes open to interactions with other, often nonmedical, systems. The hospital's environmental insulation for neonates is lost (6).

Thermodynamics of the disaster now govern the exposure of neonates to the five forms of energy: thermal, chemical, electrical, kinetic, and, less commonly, ionizing radiation. The thermal energy of fires creates toxic fumes or inspired particulates (5, 10). The kinetic energy of earthquakes or hurricanes exposes neonates to cold temperatures (5, 11). The kinetic energy from moving neonates can become damaging energy within the neonate's body (5, 11).

Information also has entropy that follows the calculus thermodynamic entropy equation. Increasing entropy for energy is its dissipation. For information, increasing energy is its corruption within the message. This corruption occurs during transmission to communicate with others (38).

Outliers, however, pose a problem in disasters. Accustomed to using probabilities and *p* values from medical research, healthcare providers may too easily disregard outliers as random, independent events. High-Reliability Organizations and those working in dangerous contexts evaluate the outlier as a possible precursor event, an early herald of further crisis. "If it happened once, it could happen again; if it happens again, it will happen worse."

There also may be a tendency to rely on Bayes' Theorem for predictions or to update probabilities of events. Bob Bea, Professor Emeritus, Civil Engineering, University of California, Berkeley (8/8/2007, personal communication), (39) underscored that Bayes' Theorem "should only be used to update *epistemic* or model-parameter uncertainties." These are 'information sensitive' uncertainties from imperfections of the model. Increasing information reduces uncertainty. In a disaster, uncertainties are "inherent or natural uncertainties that are fundamentally information insensitive" (Bob Bea, 8/8/2007, personal communication). Acquiring more information does not necessarily reduce uncertainty.

VUCA-2T

Disasters create a new environment within our familiar, formerly safe work environment. We can better understand this abrupt change using the military concept of "VUCA," an acronym created in 1995 by US Army researchers in the Carlisle (Pennsylvania) Barracks, US Army War College. They had identified that national security threats had changed at the end of the Cold War from identifiable aggressor nations to threats that are Volatile, Uncertain, Complex, Ambiguous, VUCA (40, 41).

As a military model, VUCA implicitly assumes "threat," which is not translated into civilian applications (42). Also not translated is the operational concept of time compression. Events change during decisions and before actions are completed (4, 42, 43). A special group in SOCOM (Special Operations Command) used "VUCAT" but found the element of time compression to have such importance that it should stand alone (Sean McKay, personal communication). We find adding Threat and Time Compression, creating VUCA-2T, to have more descriptive power.

- *Volatility* comes from rapid and abrupt changes in events.
- *Uncertainty* describes the lack of precise knowledge about the situation, our need to obtain more information, and the unavailability of the necessary information.
- *Complexity* refers to the large number of interconnected and changing parts that come together to create the situation.
- *Ambiguity* describes how multiple interpretations, causes, or outcomes may be possible for one situation.
- *Threat* impairs cognition and decision-making.
- *Time compression* describes the limitations on acquiring information, deciding, or acting before consequential circumstances change. Time compression is not a quality of time dependence or time limitation.

> ***"The incomplete translation of VUCA, liminality and HRO theory into the practice of reliability and safety comes with the loss of nuance and missed subtle environmental cues (44). Unrecognized is the loss of neuromodulation as a skill and method for its acquisition (45) "***

The incomplete translation of VUCA, liminality and HRO theory into the practice of reliability and safety comes with the loss of nuance and missed subtle environmental cues (44). Unrecognized is the loss of neuromodulation as a skill and method for its acquisition (45)

Mental environment

Being thrust into a disaster situation, particularly in our routine workplace, discomfits us – we are not meant to be there. The discomfort arises from the loss of context and the unrecognized triggering of the sympathetic nervous system. Such 'liminal zones' expose us to other, quite different experiences. The liminal zone is that space between a world we know and a world we do not, where our old rules do not apply and we have not learned the new rules (46). The liminal zone challenges our leadership and us. We cannot rely on plans or our experience (47). In a disaster, we find that we must engage circumstances, whether we stay or leave, but we do not yet know what works (47).

The liminal experience shapes the individual due to the environment (47). The more severe the environment of the disaster, the more profound the effect on the individual. Engagement in the situation, rather than passive endurance, changes not only the cog-

nitive domain but also the affective domain. Engagement reduces the immediate emotional load and long-term consequences.

The common themes across work domains in dangerous contexts include suppression of fear, trust, helping the novice, protecting your partner, recognizing fear in fellow workers, and following local leadership. Experienced workers accept the reality of the threat, taking personal responsibility to teach the new worker how to work around the threat (45). The ethics of kindness are specific to operators in liminal environments (48). "Both the historical tradition among seafarers of all nations and the International Law of the Sea require mariners and aviators to respond to any life-threatening and significant damage events at sea, even among vessels and aircraft of adversarial countries. This responsibility to save life whenever remotely possible includes situations where there is a significant risk, cost, distance, and schedule impact on your own ship or aircraft." Mountaineers will come to the aid of injured or stranded climbers, even at considerable risk to themselves. "And of all the principles we hold, the first is that of mutual help," George H. Leigh-Mallory, mountaineer, British Mount Everest expeditions (49).

One maladaptive approach to a liminal event is to remove oneself as a participant through decontextualization of the experience (50). Becoming a dissociated spectator limits the influence of the affective domain but gives a false sense of cognitive control. Reducing emotions to only the motor component gives the feeling of objective thought and actions through the false sense of emotional control.

" Becoming a dissociated spectator limits the influence of the affective domain but gives a false sense of cognitive control. Reducing emotions to only the motor component gives the feeling of objective thought and actions through the false sense of emotional control."

The Sensory Environment

The sensory effects of a disaster are overpowering. This reflects both our lack of experience in disasters and how our subcortical brain interprets environmental stimuli – as noise or as signals. Public safety and military veterans are more likely to have experienced the effects of the sensory environment on performance (personal experience of the authors). Despite the extensive experience, the sensory environment can affect operators, as in this description of the San Bernardino Terrorist Shooting on December 2, 2015:

> "The first officers quickly formed a contact team and…entered an extremely difficult operating environment with the fire alarm sounding, water gushing from a broken fire suppression line, smoke, the smell of gunpowder, and seriously injured victims begging for help." Some responders described the slipperiness of bodies wet from blood and water. The room was quiet, except for the alarms.
>
> "Law enforcement, fire, and EMS personnel emphasized the need for realistic physically and mentally challenging training" (51).

The officers involved in the terrorist shooting described above had extensive years, if not decades, of experience in a criminally violent area of the city. Nevertheless, they had limited experience with the simultaneous stimulation of all their senses. Few emergency responders do. This is an unrecognized and undiscussed topic that led to the following Lessons Learned:

"The ability to understand and apply response strategies in a high-stress environment improves performance. With emphasis from the authors, training should attempt to create as much sensory deprivation or stimulus as possible to simulate real-world scenarios" (51).

These physical sensations are more than distractions. The penetration of the outdoor environment into the well-controlled NICU environment degrades the hospital's security and comfort. The sensations do enter the mind, interfering with thought. This is not to say a professional cannot function, but to say that prolonged sensory stimulation contributes to subcortical stress responses and possibly late mental sequelae. Awareness of these effects and the ability to articulate their liminal experience without needing interpretation or judgment will support staff to continue operations (52).

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Prolonged intensive care becomes exhausting. With the added pressure of concern for the safety of family members, one hospital learned from experience to limit shifts to six hours during a storm (53).

> "The noise is deafening… Most of the building is intact, but the sound of smashing windows and papers, furniture, and files blowing around on the upper levels is frightening. Suction from a blown-out window prevents opening doors in one area…The lights flicker, the air conditioning cuts out, and generator power kicks in. The elevators stop working most of the time. Temperatures in some areas fluctuate between 100° F and *cold* as mechanics work on the cooling system. The heat on the upper floors is intolerable."
>
> Hurricane Katrina (54)
>
> "I was worried but not in panic. I sang every Sunday school song I'd learned as a kid to drown out the noise." "Unbearable noise spewed from the warning alarms on ventilators and other life-support devices. Two cardiopulmonary monitors and two computer screens gave us some light."
>
> Hurricane Allison (13)

Even silence creates a liminal state where we do not seem to belong:

> Two RNs arrived and "climbed the seven flights of stairs to the NICU in the dark. [They] were immediately hit by hot, humid air and pitch-black darkness. The usual noises were strikingly silent: none of the cardiopulmonary monitors, ventilators, radiant warmers, or incubators worked."
>
> Hurricane Allison (13)

"Continuing to work in these environments is a relentless assault on the senses and the body. The variability and uncertainty conflict with the belief, "OK, I can deal with this," because soon, "this" is different."

Continuing to work in these environments is a relentless assault on the senses and the body. The variability and uncertainty conflict with the belief, "OK, I can deal with this," because soon, "this" is different.

> "Without water pressure, toilets could not refill… A few hours later, there was discolored water [from an onsite well] flowing from the taps, and toilets once again could be flushed."
>
> "Because of the heat, a cold well-water shower was a luxury item… By early evening, the temperature in the NICU was above 95 degrees… The general activity of all the health care workers and equipment kept our area from ever feeling any flow of air, not even warm, humid outside air. The building was designed, like many others, for air conditioning, so windows do not open."
>
> Hurricane Katrina (22)
>
> "Because running water and sewerage were not available, personal hygiene was limited. Alcohol-based hand sanitizers were used in abundance. The various smells—floodwaters, generator exhaust, body odors, and wastes—were persistent."

Hurricanes disrupt medical care for multiple patients, the definition of disaster used for this set of articles (6). Not only the delivery of care, but our patients experience the same disaster environment that we do.

> "Sponge baths [for the infants] were not feasible because of the unknown elements in the well water. The baseline body temperatures of the infants began to rise despite being clothed only in diapers. Many of the infants became increasingly irritable and then feeding-intolerant."
>
> Hurricane Katrina (22)
>
> "The area in L&D where our babies were located was becoming extremely hot because of lack of ventilation. Some of our babies experienced elevated temperatures and were growing lethargic. One baby began to have symptoms indicating a surgical emergency."
>
> Hurricane Katrina (53)

The Problems of Disasters

The embedded problem is ill-structured or ill-defined (55) and embedded in the environment (44). The environment contains information while influencing the structure of the problem. Multiple objectives compete or conflict with each other. The boundary between problem and context is fuzzy and vague. Such problems have no clear problem definition, their goal state is not defined clearly, and the means of moving towards the (diffusely described) goal state are not clear.

An ill-structured problem is a problem without a clear goal. Because algorithms are not available, we must learn while problem-solving, a process Herbert Simon and Allen Newell (56) called heuristics. The 'heuristic search' is to learn and make discoveries during the process, producing a more accurate search within a complex environment (57). While there is a fear of heuristic bias, recognizing errors provides safety and guide accuracy (58). The ill-structured problem does not fit the classification, making the boundary between ill-structured and well-structured problems vague.

For tractability, we too easily convert an ill-structured problem to a well-structured problem through linearization of the curve or decontextualization. However, the system becomes susceptible to errors from the frame problem, which does or does not change after an action (59). The well-structured problem is amenable to rules, protocols, decision trees, and algorithms, forming a hierarchy for decisions and who decides. The danger is loss of information and context, with the operator becoming a spectator (50, 60), unable to interact in real-time with the environment.

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A disaster is an environment embedded into already embedded problems. It brings together diverse organizational infrastructures that have different purposes and missions in response to a common threat. The diverse missions mean the organizations operate in different contexts. For example, a governmental agency that administers EMS may direct area disaster operations and task helicopters customarily used by the NICU for interfacility transport with rescue operations or movement of critical supplies. Conflicts and disputes develop not from system or personality issues but different contexts and infrastructures (2, 61, 62).

Medical care is accustomed to 'well-defined problems.' The problems in a disaster are not only ill-defined but they are also embedded in the environment with the free exchange of energy. Emergency plans presuppose effective courses of action. Jens Rasmussen (63) describes the importance of people in the field:

> "Operators are maintained in [complex technological] sys-

tems because they are flexible, can learn and do adapt to the peculiarities of the system, and thus they are expected to plug the holes in the designer's imagination."

"A functional description of disasters focuses on the damage produced rather than how the damage was caused. Neonatologists in situations within the disaster space respond to local threats to create a trajectory of stabilization and recovery."

The Human Response

Functional Description

A functional description of disasters focuses on the damage produced rather than how the damage was caused. Neonatologists in situations within the disaster space respond to local threats to create a trajectory of stabilization and recovery. At the same time, they maintain medical care for their patients. This Lagrangian flow specification contradicts the Eulerian specification from a fixed point of reference outside the flow of events (37) (**Table 3**). This facilitates practical descriptions of what to expect, such as the nature of increases in demand, the appearance of novel demands, and the decrease in resource availability. Operators within a disaster focus on context and what they can learn; outsiders will focus on what they already know.

Table 3: Eulerian and Lagrangian Specifications (64)

Eulerian, quantitative	Langrangian, qualitative
Decontextualized	Contextual
External, fixed point Focus on a specific location	Within flow Focus on the individual moving parcel
Flow	Trajectory
Multiple fixed positions	Continuous measure with position and pressure
Rate of change of system	Individual parcels

Ecological Description

An ecological description underscores that damage from the event creates its environment. The damage is unpredictable. The severe damage or penetration of the elements within a hospital may be predictable, but damage to a specific area of the NICU is not predictable. This may contribute to planning that focuses on what caused the disaster, for example, a hurricane or an internal water leak. An ecological approach brings to the Neonatologist's attention the more open environment and the need to identify new or hidden risks to the neonate. Taken together, the Neonatologist can better identify methods to increase the capability of the NICU and staff to evacuate or shelter neonates during the disaster.

An ecological description also helps differentiate plans in the context of the disaster environment. Planning for structure and order fits a Euclidean space, the three-dimensional space comprising points and distance measurements that readily accommodate classification and categories. From Euclidean space and Newtonian physics, we have quantitative measures, hierarchy, metrics as points and lines, and discrete representations. We use classical logic and deductive reasoning to make the necessary inferences (65).

"On the other hand, an ecological environment has more of a topological orientation based on relations, contiguity, and relative position rather than actual metric measurements that would indicate an absolute position. In a topology, elements maintain continuity of connectedness despite deformations."

On the other hand, an ecological environment has more of a topological orientation based on relations, contiguity, and relative position rather than actual metric measurements that would indicate an absolute position. In a topology, elements maintain continuity of connectedness despite deformations. The focus is on how the elements are connected, for example, the closeness of connection or overlapping connection (66). Topology replaces precise characterizations with a topological differentiable state representing possible variable states. Ecology has used object-oriented network topology and dynamic system field-oriented topology (67).

"The order also comes out of chaos through self-organization (68). These systems stabilize and develop order by self-organizing through local, nonlinear feedback. Positive feedback contributes to growth and structure, while negative feedback restricts growth. These oscillatory, self-organizing processes bring stability and order to the environment, but the nonlinear interactions degrade any ability for predictions."

Self-Organization

The order also comes out of chaos through self-organization (68). These systems stabilize and develop order by self-organizing through local, nonlinear feedback. Positive feedback contributes to growth and structure, while negative feedback restricts growth. These oscillatory, self-organizing processes bring stability and order to the environment, but the nonlinear interactions degrade any ability for predictions. Environmental self-organizing processes create stochastic noise that can increase to a level that forces

a system or population to respond. The system or population responses to these forcing functions are also self-organizing oscillatory processes with poor predictability of outcomes. The noise process is independent of timescale or magnitude. We need not characterize normal environmental variation differently from catastrophes (34). A disaster is an open system where energy and entropy freely flow.

> ***"When a NICU experiences a disaster, the external environment enters the NICU (6), and the isolated system, which constrains the flow of energy and entropy, becomes an open system. Energy and entropy freely flow in or out."***

When a NICU experiences a disaster, the external environment enters the NICU (6), and the isolated system, which constrains the flow of energy and entropy, becomes an open system. Energy and entropy freely flow in or out. Entropic energy, the energy not available for useful work, changes order within the NICU system to disorder. Entropy, such as scattered, randomized elements, is not a measure of disorder in the moment. Instead, entropy is a disorder with poor predictability because of an *increasing* number of possible permutations or possible futures. The *more random* the system becomes, the greater the number of possibilities that develop and the greater the increase in entropy. The forcing function of stochastic environmental energy drives the disaster in the NICU, forcing the NICU to become an open system and increasing the permutations with which the Neonatologist must contend.

Self-organizing systems are dynamic, requiring continual interactions. The disaster environment is an open system with a continual flux of energy and matter. Reactions, therefore, can occur away from their equilibrium state. Structures – termed dissipative structures – emerge through nonlinear kinetics. Patterns then arise from energy dissipation into the environment (69).

> ***"Self-organization creates the oscillations and waveforms that disrupt the environment, forcing responses from populations. Self-organization is also the response of populations to reduce the effect of environmental oscillations."***

Self-organization creates the oscillations and waveforms that disrupt the environment, forcing responses from populations. Self-organization is also the response of populations to reduce the effect of environmental oscillations. The flow of energy and entropy alter the self-organization of these oscillations. *Stochastic environments become stable from the oscillations of self-organization; populations maintain stability through the oscillations of self-organization.*

Self-organization can develop through behaviors due to decisions, such as a termite mound where termites deposit material from local physical cues. "Individual organisms may use simple behavioral rules to generate structures and patterns at the collective level that are relatively more complex than the components and processes from which they emerge" (69). This is from nonlinear amplification and cooperativity, which makes the results sensitive to the initial state.

Disaster Systems

Abrupt change thrusts you into a physical environment with new structures, rules, and threats. You are also thrust into a system of multiple, distinct disaster infrastructures that arise from preexisting infrastructures – emergency and disaster transport and operations while you strive for continuity of neonatal care. You are not in one system or infrastructure – transport, emergency operations, and continuity of care have distinct infrastructures. Disaster infrastructure is new to the Neonatologist but well used by disaster responders, hence the importance of boundary objects. When misunderstood, the disaster infrastructure can quickly become your difficulty rather than enabling your success (1).

Operations in disasters have a distinct language and lexicon. They match capability to risk in dangerous contexts and support medical care and public health in austere environments. Leadership for disasters is vigilant for signs of stress and impaired capability in members. Outliers such as discrepancies or local disruptions are regarded as potential early heralds of new problems rather than disregarded as random events.

A central government agency will control air transport, and FAA rules and procedures will become more visible. Ground transport services by ambulance will change from interfacility transport rules to EMS and disaster control by a central government agency.

> ***"A helicopter within the medical infrastructure is used for transporting critically ill patients, while in the disaster infrastructure, the helicopter is used for surveying the area and search and rescue. Infrastructure shapes and is shaped by the discipline's conventions of practice, embodying standards specific to the discipline (62)."***

A helicopter within the medical infrastructure is used for transporting critically ill patients, while in the disaster infrastructure, the helicopter is used for surveying the area and search and rescue. Infrastructure shapes and is shaped by the discipline's conventions of practice, embodying standards specific to the discipline (62). Failure to integrate into the disaster infrastructure can be deadly.

One person's infrastructure can become another person's barrier (2). Boundary objects facilitate communication across disciplines and organizations while operating in a new boundary infrastructure.

Disaster infrastructure

As in any system, hospitals and NICUs operate in a relatively closed environment with established infrastructure. A disaster brings in other infrastructures (emergency operations) accustomed to collaborating in hazardous, austere environments. Rather than identifying, developing, and adhering to decontextualized

standards, perhaps we can borrow from disaster infrastructures.

Infrastructure is built from an existing base and does not grow *de novo.* Infrastructure, part of the human organization rather than dispassionate design, reaches beyond the single event. Though not noticed by members, even though present, an organization's infrastructure is noticed by those outside the system.

A disaster brings together diverse infrastructures, but they are infrastructures of organizations and disciplines accustomed to collaborating. Infrastructure builds a community viewed as relations. New for NICU sheltering or evacuation are the organizations and infrastructures they utilize.

The disaster is a liminal zone, and disaster operators are accustomed to working with liminal people inexperienced or unaware of the dangers. Inflexibility in shifting from the hospital infrastructure will quickly be identified. In dangerous contexts, such individuals can bring harm to others (45, 48, 70). The loss of contextual awareness in this new disaster context can collapse sensemaking with a poor outcome (50, 71). Integrating the NICU and hospital infrastructure into the disaster infrastructure is vital for continuing operations.

"Infrastructure viewed as relations with different contexts illustrates the activity during a disaster. A disaster can have unforeseen effects on the context or bring two contexts with unexpected interactions."

Infrastructure viewed as relations with different contexts illustrates the activity during a disaster. A disaster can have unforeseen effects on the context or bring two contexts with unexpected interactions. "The discontinuities are not between system and person, or technology and organization, but rather between contexts" (2). These discontinuities lead to disputes when disciplines use the same information differently or have different problem-solving methods.

What is not apparent in these disputes is the effect of different infrastructures. Infrastructure is embedded into a discipline's technology and social system and is learned as the individual acculturates. Infrastructure shapes and is shaped by the discipline's conventions of practice, embodying standards specific to the discipline (62).

Disaster infrastructures create friction for the Neonatologist. Friction is the natural resistance that develops as teams work toward a common goal but with different perspectives and capabilities. Friction in these circumstances is limited but alerts operators to important discrepancies. Self-interest and competing goals create friction that can rapidly increase, impairing operations. We reduce friction by communicating across infrastructures through boundary objects. Death is a boundary object for communicating between those infrastructures that increase survivability and those that reduce mortality.

Boundary Objects

Boundary objects are ambiguous yet constant objects inhabiting diverse domains, satisfying the informational requirements for each, allowing their use by several communities of practice. Boundary objects allow cooperation between differing domains, facilitating local understanding through reframing the object into a broader context of joint activity (72).

Boundary objects facilitate communication across disciplines and organizations while operating in a new boundary infrastructure. Different communities working in the same space may or may not cooperate. While various domains will classify elements with different criteria, some objects are found in adjacent classifications of different groups. By inhabiting both domains, boundary objects are ambiguous yet satisfy the informational requirements for each, allowing the two domains to cooperate. (72).

In a disaster, the environment can kill. Death becomes a boundary object shared by the Neonatologist, NICU nurse, helicopter pilot, and government disaster agencies. Each will see death differently: reducing *mortality* by treating factors that cause death or increasing *survivability* by preventing deaths that result from post-disaster events (1).

A community of practice can interface with the information system shared in the disaster to form a boundary infrastructure. The Neonatologist would identify the kinds of information objects necessary that can be useful as boundary objects. The concept of boundary infrastructure recognizes the different information objects within the diverse communities of practice that now share a disaster infrastructure (62).

While who "owns" a problem is locally determined, another organization may be the solution in a disaster, or the solution may be distributed. Boundary objects that bridge these gaps have sufficient ambiguity to connect several domains yet enough fidelity to the problem that the key points are not lost. Accuracy will have greater force. Precision can mislead or intimidate outsiders, decreasing the chance of receiving assistance.

During a disaster, boundary objects are more likely to be ill-structured problems one group has, yet the solution must come from an outside group. This has contributed to conflict and friction in disasters. Boundary objects can contribute to communication and understanding in unstandardized, unstable situations when the boundary object is transient (61).

"During a disaster, boundary objects are more likely to be ill-structured problems one group has, yet the solution must come from an outside group. This has contributed to conflict and friction in disasters."

Boundary objects can facilitate medical care for non-compliant patients. By using a vague boundary object used by the physician, patient, or parent, the discussion shifts toward the actions they have in common rather than the beliefs that keep them apart.

- Self-explanation, rather than narrative, is more likely to occur one-on-one. This may contain personal or privileged information to share the meaning of the situation.
- Inclusion to create alliances brings an outside group's unique capabilities or resources by making them part of the solution.
- The compilation brings together the information necessary to create alignment with both groups.

- Structuring, significant for competing interests, establishes order and identifies principles to coordinate activities.

In communicating the situation of the NICU, rather than describing diseases or the technological needs of a neonate, the Neonatologist can accurately and dispassionately describe what will kill the child. As coarse as this sounds, the disaster agencies are working to reduce the disaster's death toll and can more easily support the Neonatologist to find resources that prevent death. This brings a joint focus to survivability.

"In a disaster, the environment can kill. Death is a boundary object shared by the Neonatologist, EMS, public safety agencies, and government disaster agencies. Each will see death differently. The Neonatologist extends medical care to neonates born prematurely in a 'death zone' (48, 73)."

In a disaster, the environment can kill. Death is a boundary object shared by the Neonatologist, EMS, public safety agencies, and government disaster agencies. Each will see death differently. The Neonatologist extends medical care to neonates born prematurely in a 'death zone' (48, 73). EMS extends medical care into the field to engage physiological threats, preventing death that can respond to straightforward early field interventions. The fire service engages in physical threats causing death and solves ill-structured problems the public cannot or will not solve themselves (William J. Corr, Captain, LAFD). The government has a legal duty to reduce premature death for the common welfare. Government disaster agencies focus on reducing death from the disaster.

Death becomes a boundary object shared by the Neonatologist, NICU nurse, helicopter pilot, and government disaster agencies. Each will see death differently: reducing *mortality* by treating factors that cause death or increasing *survivability* by preventing deaths that result from post-disaster events (1).

Survivability

Our goal becomes survivability, preventing deaths that result from post-disaster events. Survivability also includes pre-disaster actions such as planning, training, and structural design, but for our purposes, we discuss the actions the Neonatologist can take to reduce fatalities once the sequence of events has commenced.

The infant with survivable pathology may die from environmental exposure or the lack of access to necessary care. The environment can act as an independent contributor to mortality and comorbidity that we must treat. The disaster environment can interfere with the logistics of bringing medical supplies or specialists to the infant or evacuating the infant to a higher level of care. This spatio-temporal mismatch of physiological demands and medical care is common to all disasters and, when combined with the boundary object of potential fatality, can drive effective communication.

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 (61). Government agencies focus on survivability and reducing death *after* the event. Survivability describes the effect of the environment on mortality as comorbidity or impeding connecting necessary medical care to the victim (4). Neonatologists focus on reducing mortality and death *due to disease*. Death, then, becomes an effective boundary object for communication.

In communicating the situation of the NICU, rather than describing diseases or the technological needs of a neonate, the Neonatologist can accurately and dispassionately describe what will kill the child. As coarse as this sounds, the disaster agencies are working to reduce the disaster's death toll and can more easily support the Neonatologist to find resources that prevent death. This brings a joint focus on survivability

" As coarse as this sounds, the disaster agencies are working to reduce the disaster's death toll and can more easily support the Neonatologist to find resources that prevent death. This brings a joint focus on survivability"

Conclusion

The NICUs worked alone. They engaged and solved problems as they arose, then moved to the next problem.

> "Operators are maintained in [complex technological] systems because they are flexible, can learn and do adapt to the peculiarities of the system, and thus they are expected to plug the holes in the designer's imagination."
>
> Jens Rasmussen (63)

We do in an emergency what we do every day. Studying disasters as they occurred in the actual world reveals the effective actions and contextual leadership of the typical Neonatal caregiver. What stands out is that the Neonatal operators lacked *extensive* training and experience in disasters. However, of over 400 affected neonates, only two deaths occurred during the disaster, and no deaths occurred during evacuations.

Disasters make visible the gap between belief and the environment (9). Firmly held belief in tightly coupled concepts or theories leads to planning in the form of algorithms for the well-structured problem. Planners rely on structure, hierarchy, "chain of command," and protocols. This assumes that human behavior, responses, and actions can be predicted. A disaster is viewed as a situation that will respond to rules and plans. Jim Denney, Capt. LAFD reminded paramedics and firefighters, "The emergency has a vote in your plans."

The HRO focuses on increasing the capabilities of individuals toward effective engagement. The environment is something we engage to prevent consequences (8, 74) and a disaster brings the most extraordinary consequences. Through HRO methods and structures, individuals in these disasters extended Neonatal care into the austere, adverse disaster environment (73). Demonstrated in the Neonatology response to disasters, this happened by engaging the gap between concepts or beliefs and the environment (44).

More vital to such engagement was the demonstrated reciprocal

feedback used to improvise solutions – a clear demonstration of HRO as natural human actions when freed from convention and central authority. Visible in the commentary of those who engaged and maintained that engagement despite repeated failures was the development and reward of moral agency. Patricia Benner (75) described the *moral agency* as a result of the individual acting independently, then observing that the actions made someone's life better. Benner placed the development of moral agency at the crossing of the gap between simple competence and the richness of expertise. The moral agency gives meaning to one's actions, either internalized by the individual or interpreted for the individual by a leader. *Meaning giving* can reduce the effects of stress that may develop into post-traumatic stress (76).

The disasters these individuals responded to were unexpectedly and abruptly thrust into the NICU or approached the NICU over hours to days. In most cases, not only was the internal environment of the NICU broached, but often the external environment was dangerous to the neonate and, in some cases, Neonatal staff. There was little mention of disaster plans or attempts to maintain disaster standards.

"This makes sense when we accept the effect of the color of noise. Red noise comprises human behavior and is typical of the frequencies found in physiology and the earth sciences. Red noise creates forcing functions that the NICU staff must respond to."

This makes sense when we accept the effect of the color of noise. Red noise comprises human behavior and is typical of the frequencies found in physiology and the earth sciences. Red noise creates forcing functions that the NICU staff must respond to. For example, neonates developed hypothermia following an earthquake (in cold weather) or hurricane (in warm weather) regardless of the forcing function. Pink noise is the noise of abrupt catastrophes. It is reassuring that regardless of the abrupt catastrophe, NICU teams worldwide responded effectively and with similar patterns.

Instead, the most effective operators focused on providing good care to the neonate by improvising methods to deliver that care. This is significant because hospital administrators operate at a different level of analysis by design. They work outside the context of patient care. Outside assistance was hours away and often seemed to ignore the NICUs, a perception that arose from the lack of understanding of the disaster infrastructure.

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We recommend educating Neonatologists in disaster infrastructures and identifying those boundary objects that facilitate communication with disaster response services. Shifting the goal of the NICU from reducing mortality to ensuring survivability may drive improvisation. It was an improvisation that appeared to rescue most neonates from death, an improvisation by those Neonatal caregivers that held the neonate's life in their hands as they held the neonate in their hands.

"We recommend educating Neonatologists in disaster infrastructures and identifying those boundary objects that facilitate communication with disaster response services. Shifting the goal of the NICU from reducing mortality to ensuring survivability may drive improvisation."

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NT Behind the Scenes: Jane Velez-Mitchell of the Unchained TV Network Discusses Pig Little Lies

Kimberly Hillyer, DNP, NNP-BC

In this segment of Neonatology Today Media, I thought I would venture out from the world of healthcare. I talked to Jane Velez-Mitchell, the Founder of Unchained TV Network, a digital news network for animal rights. Our discussion was meant to focus on her animal activism and a new reality show, Pig Little Lies, debuting on her network. As I took a glimpse into her world, I discovered that the interactions between humans, animals, and the world we live in does indeed blend in with the healthcare field. Living in Loma Linda, California, a Blue zone community where people have low rates of chronic disease and live longer than anywhere else, I moved the discussion to incorporate the impact of the Vegetarian or Vegan lifestyle.

> *"Our discussion was meant to focus on her animal activism and a new reality show, Pig Little Lies, debuting on her network. As I took a glimpse into her world, I discovered that the interactions between humans, animals, and the world we live in does indeed blend in with the healthcare field."*

The following is an amended transcript for Neonatology Today Media of Dr. Kimberly Hillyer and Jane Velez-Mitchell.

Click this link to go directly to our YouTube channel, Neonatology Today Media. Please subscribe and hit the notification button to enjoy viewing the interview when it is available. We would love to hear your thoughts, so leave a comment.

Introduction:

Thank you for joining us on today's broadcast. I'm Dr. Kimberly Hillyer, a Nurse Practitioner and the Media Correspondent for Neonatology Today. This segment features Jane Velez-Mitchell, Founder of Unchained TV. Jane is a long-time animal rights, addiction, and social justice activist. She is an experienced television journalist who has hosted her own show on HLN. She was also a recurring host on multiple networks, including CNN, TruTV, and E! She is the author of four books, including a memoir and a New York Times Bestseller. She has also received multiple awards for her animal right activism. Her commitment to various humane causes has led her to become a Vegan, one of the highlights of her digital network.

Dr. Kimberly Hillyer: Hello, Jane. Thank you for joining us on today's broadcast. I am excited to venture out from the world of medicine into a topic that globally affects humanity. As a well-known journalist who has had her own television series on HLN and as an author of five books, you have become a voice for many issues. Currently, you have been focusing on your new network, Unchained TV, which deals with your vegan lifestyle and works as an animal activist. How did you become an animal activist?

Jane Velez-Mitchell: Well. My mom was born in 1960 before women even had the right to vote in Vieques, Puerto Rico, which is an island off the mainland of Puerto Rico, a beautiful island. She had what she thought was a pet pig or a pig who was a friend. One day she came home as a young child, and the pig had been slaughtered for food, and she literally fainted. When she came to, she shunned meat. So, she came to New York on a boat at the height of the Great Depression and became a successful dancer Latin dance troop. She met my dad, who was an Irish American advertising executive who also liked to dance. What they had in common was their dancing obsession. They would go out, and that was back in the day when they had bands in restaurants.

> *"I grew up in a mostly pescatarian household. We even thought we were kind of vegetarians, but we weren't. Suffice it to say that I knew that bacon and hot dogs don't fall from the bacon and hot dog trees and that there are these animals."*

I grew up in a mostly pescatarian household. We even thought we were kind of vegetarians, but we weren't. Suffice it to say that I knew that bacon and hot dogs don't fall from the bacon and hot dog trees and that there are these animals. Our society is really suffering because we're all living in the meat matrix. Every so often, something happens where that meat matrix is ripped open, and we see the reality, and it horrifies us. There was a woman eating at a fast-food restaurant the other day, and it was all on

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the news that she was eating her sandwich, and all of a sudden, she realized on the Deli slice there was a nipple that was popping out, and she freaked out and screamed. Now my question to her is, well, who did you think you were eating, right? So that's when that matrix gets ripped open, and you see a new reality. So, I think it's incumbent upon all of us to think for ourselves and not just accept what people who are making huge fortunes off of animal agriculture are telling us. Which is, this is normal, you should do it. Anybody who says you shouldn't eat animals is somehow weird or different.

"The truth is that for most of human history, we did not eat this way. Industrialized animal agriculture is a very new phenomenon. Fast food, which is how most people consume all this food, is a very new phenomenon, and it's killing us."

The truth is that for most of human history, we did not eat this way. Industrialized animal agriculture is a very new phenomenon. Fast food, which is how most people consume all this food, is a very new phenomenon, and it's killing us. As one of my heroes, Dr. Sailesh Rao, who has an organization called Climate Healers and Food Healers, says, "we're all being factory farmed," not just the animals in their terrible condition. But the farmers and ranchers are put in terrible debt; they are pitted against each other in something called tournaments. They are essentially indentured servants of this machine. Consumers are also exploited because they need us to become overweight. We need to get sick. We need to develop diseases, so they can sell us pills and do operations on us. Preventative medicine is not focused on in this country. We wait till people are sick. Even in the hospitals, we feed them bad food.

"So, we're all being factory farmed for what? The percentage of people who are actually making money on this is minuscule. And guess what? They all have their private chiefs, and their kids aren't eating a bad diet. They're eating healthy, so it's a social justice issue, and it is a racial issue because fast food is targeted to communities of color."

So, we're all being factory farmed for what? The percentage of people who are actually making money on this is minuscule. And guess what? They all have their private chiefs, and their kids aren't eating a bad diet. They're eating healthy, so it's a social justice issue, and it is a racial issue because fast food is targeted to communities of color. Food deserts are instituted and maintained, and it is destroying our environment.

Animal agriculture is a leading cause of climate change that is not discussed. Yesterday I read a Vox article that said this great climate bill that they're passing doesn't address one of the leading causes, which is animal agriculture. So, it's doing all these things. People love to talk about fossil fuels not everybody can afford to go out and buy a Tesla. Still, everybody can afford to make better, smarter, healthier, and more environmentally sustainable choices. Three times a day when they eat food.

"I started this in my quote-unquote, "retirement," a nonprofit news network. I've never worked harder, to be honest with you, called Unchained TV, and we want to unchain the animals. We want to unchain the brains of people who are beating their chests in advocating for the very thing that is killing them."

I've been a journalist who worked in mainstream media for 40 years. I worked at CNN. I worked at a whole bunch of local stations in New York and LA, etc. I started this in my quote-unquote, "retirement," a nonprofit news network. I've never worked harder, to be honest with you, called Unchained TV, and we want to unchain the animals. We want to unchain the brains of people who are beating their chests in advocating for the very thing that is killing them. Well, it's a choice; everything's a choice. Driving the wrong way down the freeway is a choice, not a smart one. So, what people don't realize is they think they're exerting their free will. But in reality, they've been conditioned to want something that's not good for them, and that's called brainwashing. We are societally brainwashed. I wrote a book called Addict Nation. It says we live in a discogenic culture because there's no better customer than an addict. They come back over and over again for the fast food, for the pills, for the alcohol, for the drugs. The dichotomy is that the only power you have is to realize you're powerless against certain things and walk away from them. So that is the big picture of our network, Unchained TV. But we have more than 600 videos, and we realize that we can't just lecture people. We have to entertain them. That's why we did the world's first reality series starring pigs. Pig Little Lies is now streaming on Unchained TV, which is a free network. You can download it on your phone for free just go to your app store UnchainedTV. One word. You can get it online at UnchainedTV.com; click. Watch now on UnchainedTV.com, or

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Dr. Kimberly Hillyer: So, your network, Unchained TV, is really trying to establish a platform where not only are you able to help out people and society but also these animals. The show that you're talking about it is six series episodes.

Jane Velez-Mitchell: It's five. Five episodes and they're micro episodes. They're about 11-12 minutes each, but it is the world's first reality series starring a family of pigs. I can tell you the story of how it came to be. If you want.

Dr. Kimberly Hillyer: I do want to hear that.

Jane Velez-Mitchell: Well, most of these networks are spending billions of dollars starting similar networks. The major networks are starting things like Peacock is, they spend 2 billion dollars in one year. We did this for tens of thousands of dollars, but essentially, it's the same technology. So, most of these networks are made by one hit series, whether it's Succession or House of Cards or The Morning Show. It's something that is on everybody's lips. You got to check this out right! So, I call my friend Simone Reyes, who has been on reality shows before. She's an animal activist and a vegan. I say, Simone. We need a reality show. That's what we need to launch our network. She said, "I can't talk right now. I'm trying to rescue 2 pigs, bonded pair. They're in a high-kill shelter, and they're going to be killed tonight. I can't talk to you!" I said, "wait for a second. That's our reality show!"

"So that's exactly what we did. We got those pigs out, and that's not so easy. You rescue a dog, you put a leash on a dog, and you walk out with the dog. But with a pig, these animals are large. These potbellied pigs. I'll tell you all about the scam that has people buying infant pigs falsely marketed as adult pocket pigs."

So that's exactly what we did. We got those pigs out, and that's not so easy. You rescue a dog, you put a leash on a dog, and you walk out with the dog. But with a pig, these animals are large. These potbellied pigs. I'll tell you all about the scam that has people buying infant pigs falsely marketed as adult pocket pigs. There's no such thing, and so we got the two out and then this wonderful Lady Cindy Brady, who runs a micro sanctuary just about half an hour's drive from the Hollywood sign. She has goats and horses. She said I'll take them in. She put the mother in the Laundry Room. The mother's name is Beatrice. The Daddy Pig is named Dante. They're named after Dante's Inferno, the famous medieval poem. Dante went into a nice little area with some goats, and he got some hay, and all of a sudden, she realized Mama Beatrice was pregnant. Oh, my God! So, she didn't just rescue two pigs. She rescued. Well, it turns out to be fourteen pigs after Mama Beatrice gives birth.

What I took away from it was that I was out there numerous times participating as a cast member, also the executive producer, and the founder of Unchained TV. What really struck me was how much these families want to be together. How much they love each other. How much the mother protects, Mama Beatrice protects her babies. How much the babies want to be with their mommy. It's just like human beings. They have eyes, they have hearts, they feel terror, they feel loneliness. At one point, we had to take Mama Beatrice to get spayed, and also, her tummy was sagging, so we weren't sure maybe she had a tumor. She didn't want to leave her kids, she did not want to leave her babies, and she didn't know. And what was so amazing was that Cindy, after they're such smart pigs had the emotional and intellectual development of toddler humans. They're considered the fifth smartest animal when it comes to intelligence. So finally, after outwitting several people trying to get her in the crate, Cindy got on her knees, and she said, Look, "B: that's what she called her. Beatrice, I promise you. This is yours forever home. You will return to your babies. Trust us. We're just trying to get you to the doctor to take care of some problems. Now. B. Doesn't speak English, we know that, but she clearly heard the feelings, the emotions, and she came down. And she backed into that crate. It brings tears to my eyes.

"Because these animals have so much in common with us humans. The mothers want to be with their babies. The babies want to be with their mothers, but industrialized animal agriculture keeps mother pigs and something called pig gestation crates the size of their bodies."

Because these animals have so much in common with us humans. The mothers want to be with their babies. The babies want to be with their mothers, but industrialized animal agriculture keeps mother pigs and something called pig gestation crates the size of their bodies. They can't turn around even to scratch themselves, and they chop on the bars in front of them, and they break their teeth because they go mad. If you did it to a dog for 5 days. You'd be arrested and charged with animal cruelty, and they are doing this took billions and billions of pigs. They're called pig gestation crates, don't take my word for it. Go online and Google it. The first time I saw a pig gestation crate about 25 years ago, I said, No, this is not possible the humans would not create this obvious torture machine and design it. And then I went to the next video, and I saw 20,000 of them in a warehouse. Now we wonder why are we being punished? Why are we suffering from COVID? Why are we suffering from fires and floods, and drought? Well, Mother Nature. Okay, I think he has had it. With our arrogance as a species and the cruelty which we condone when we make these choices, and we go in and say, well, I'm going to have bacon, I'm going to have a hot dog, I don't care, society is told me that their suffering doesn't count. Wrong. It does count. And now it's coming back to haunt us.

Dr. Kimberly Hillyer: Yeah, I would definitely agree with that, but to be honest, one of the things that I was most surprised about while enjoying your series was that you were rescuing pigs from

shelters. Now, I'll be honest I've volunteered at shelters in my area, and you usually see cats and dogs. So, I was really surprised that there would be pigs in the shelter. When I did a little bit of research, looking into where did this come from, this idea of micro pigs, teacup pigs that were now being purchased. Thanks to celebrities, maybe unbeknownst to them. Endorsements of these cute little animals. These cute little pigs that were going to stay this size, and then it turns out. No, they're potbelly pigs that are going to be 100 lbs. or more. That was very, very surprising to me. Where did, as far as you know, this whole establishment of micro-preemie pigs or teacup pigs come from?

" These cute little pigs that were going to stay this size, and then it turns out. No, they're potbelly pigs that are going to be 100 lbs. or more. That was very, very surprising to me. Where did, as far as you know, this whole establishment of micro-preemie pigs or teacup pigs come from?"

Jane Velez-Mitchell: Greedy breeders who want to make money will take infant piglets who are adorable, absolutely adorable, and they will market them to unsuspecting people. Sell them sometimes for thousands of dollars. As fully grown adult micropigs, pocket pigs, and teacup pigs, they have all sorts of names for them. Whenever you see animal cruelty, always follow the money. So, what happens is, and you're right, celebrities encourage this. I've seen TV shows where, Oh, look at the little piggy, but who knows what happens to that pig? Once the cameras stop rolling anyway.

"People buy them and think that this is a fully grown pig. Then the pig starts to grow and grow, then they say, I've got to dump this pig at the shelter. It's too big for my apartment. It's too big for my small home. It also is heartbreaking for the kids because, in one case, we rescued a pig who had nipped at the kids after the kids tried to put clothes on the pig."

People buy them and think that this is a fully grown pig. Then the pig starts to grow and grow, then they say, I've got to dump this pig at the shelter. It's too big for my apartment. It's too big for my small home. It also is heartbreaking for the kids because, in one case, we rescued a pig who had nipped at the kids after the kids tried to put clothes on the pig. Now, yeah, you shouldn't be trying to dress up the pig. Then the kids who had formed an emotional bond with this pig, just like my mother, back in 1920, when she formed an emotional bond with a pig, only to see the pig slaughtered. These kids are devastated when their parents say, oh, yeah, whatever the pigs' name is, they've got to go off to the farm. You know how parents are; it's always going to a farm, and it's all a lie. Then the kids don't trust the parents because they know on some level the parents are lying, and the parents dump the pig at the shelter. It's terrible on so many levels. It's actually traumatic for the children. It can also be traumatic for adults. I mean, they were scammed. They're not bad people, but they can't handle a pig.

Some of these pigs get to be more than 200 lbs. I'm talking about potbelly pigs. For the children, it's very terrible, the children who bond. The same thing about these programs where children are encouraged to raise an animal and then sell them and then give the animal away to be slaughtered. It really is this sense of betrayal, and also, it shatters trust because, on some level, the child thinks. Wait a second. You brought this being into your home; you purported to love the being. And now you're giving the being a way to be killed; where does that lead me? If I mess up, could I suffer the same fate? So, from a psychological standpoint, it is truly devastating because it's betrayal. It shatters trust, and it makes you wonder about your parents. You know? Are they lying to me? Can I trust what they say? There are many, many negative repercussions to the humans involved also. So, what we say is never buy an animal, don't buy a dog, don't buy a cat, don't buy a pig. Don't buy a horse. If you are hell-bent on having a particular species. Go to a shelter or go to a rescue. Actually, you can virtually foster all the children of Dante and Beatrice, and they have adorable names like Valentino. I'm fostering Valentino, but there are also waffles, and she came up with some really adorable characters.

"Now, if I live in an apartment, there's no way that I can foster an animal. Is there another way that we can foster and help these pigs? And then, if you don't mind telling me, what does it take to care for and raise one of these piglets? "

Dr. Kimberly Hillyer: Now, if I live in an apartment, there's no way that I can foster an animal. Is there another way that we can foster and help these pigs? And then, if you don't mind telling me, what does it take to care for and raise one of these piglets?

Jane Velez-Mitchell: Well, great question because you can virtually foster them. If you go to Tinymasters.org, you'll see the website, and you'll see all the babies and its cuteness overload, and you can virtually foster. I send $50 a month to foster Valentino, but you could send $5 a month; you could send $10 a month. The point is these animals need hay. The cost of hay is skyrocketing, accelerated by climate change. I work with a sanctuary in Texas; they're already halfway through all their winter. Because the hay has gotten so expensive. So, you see, ranchers and farmers are now exiting that business.

Animal agriculture will have to end it. It will end either with our extinction or it will end with the planet just becoming too hot to support all these animals already. I don't know if you saw that it wasn't in the news per se, but it was on social media; in Kansas,

thousands of cows keeled over and died from the heat. They just killed over, and somebody went and took a video from their car driving a good mile, at least, with cows, thousands of cows, literally with their legs up in the air, dead from the heat. So, what we are barreling towards is a climate apocalypse. There is one underlying false assumption at heart and at the root of so many of our societal problems; that false underlying assumption is that we need to kill animals to survive. We need to eat them. We need to wear them. We need to experiment on them. The truth is, we're 8 billion humans; that's the global world population today, and we are raising and killing. Do you want to guess how many animals per year are for food globally? Take a guess.

"There is one underlying false assumption at heart and at the root of so many of our societal problems; that false underlying assumption is that we need to kill animals to survive. We need to eat them. We need to wear them. We need to experiment on them. The truth is, we're 8 billion humans; that's the global world population today, and we are raising and killing. "

Dr. Kimberly Hillyer: I would have to say it would have to be three times. Our population, people consume like you, said the fast food. I can only imagine how many animals are required to keep a fast-food chain open. So, I'm going to go with nine billion.

Jane Velez-Mitchell: 80 billion animals are killed every year for food. A vast majority of them are chickens. So, we are taking a huge percentage of the food that has grown globally and putting it into the world's most inefficient food source, animals. You can quibble about the numbers. It could be two, it could be five, it could be eight. It could be 25 lbs. of grain to make 1 lb. of meat, depending on what type of meat? Okay, a sirloin is different than a burger. Maybe, but it is an inefficient food source.

"Meanwhile, there are children in Afghanistan and Somalia right now dying of malnutrition and hunger because we are supporting the world's most inefficient food system."

Meanwhile, there are children in Afghanistan and Somalia right now dying of malnutrition and hunger because we are supporting the world's most inefficient food system. If you took more than 80% of all soy produce fed to farmed animals, this is true of a lot of commodity crops. A huge percentage of the food is fed to farmed animals. If you diverted that food away from farmed animals, we could live in a world of natural abundance where nobody is dying of hunger.

That's why I work with Dr. Sailesh Rao, who said, "we're all being factory farmed." I consider him a genius. I did a documentary about him on Unchained TV called 'Countdown to Year 0.' He's starting this whole movement called Food Healers because he believes food is a right. Just like air is a right, water is a right, and food is a right. You can only survive a few seconds without air. You can only survive a few hours or days, maybe a day, without water. I don't have the exact statistics, so don't quote me. I'm not a scientist, nor do I pretend to be. You can't survive very long without food. These should be central human rights. And what creates profit? Scarcity! So, animal agriculture creates a scarcity that allows for profit. You notice there are no commercials on TV for apples. There are no commercials on TV for carrots. It's all, for generally meat and dairy with the French fries grown in. So, we are pushing the most inefficient food source that is also terrible for our health. One out of every 4 people dies of heart disease. Heart disease is caused by plaque; plaque is what clogs the arteries. Plaque comes from cholesterol. There is no cholesterol in plants. Animals produce cholesterol; we're animals, and we produce our own cholesterol. Unless you're one of the rare individuals with a genetic predisposition for high cholesterol. If you have high cholesterol, chances are it's because you're eating too much meat and dairy products.

"Then there's cancer. The World Health Organization has officially determined that processed meat, hot dogs, bacon, and deli slices, are officially cancer-causing. It's a carcinogen. All of this information is out there. Do you hear it? No. Why? Because who pays the bills on advertiser-based media? Meat, dairy, and pharmaceuticals."

Then there's cancer. The World Health Organization has officially determined that processed meat, hot dogs, bacon, and deli slices, are officially cancer-causing. It's a carcinogen. All of this information is out there. Do you hear it? No. Why? Because who pays the bills on advertiser-based media? Meat, dairy, and pharmaceuticals. They might as well be in the one-in-the-same industry because a lot of the pills, like the cholesterol-lowering pills and the erectile dysfunction pills. Erectile dysfunction is a precursor of our disease. So, when the body is getting clogged with excess cholesterol, it's systemic. It's not just happening to cause heart attacks. It's causing other things like erectile dysfunction. And again, I'm no doctor, no scientists, but there are studies, and there is new research into the effect of the skyrocketing so-called dementia because there are vessels in our brains as well. And they're getting clogged. I don't know about you, but when I was a kid, everybody's parents didn't have dementia. Now every person I talk to, their parents are out of it, they've got Alzheimer's or Dementia, or how you want to characterize it. Well, what's going on? The rise of these problems is absolutely parallel with the rise of fast food?

So, you talk about human health. The healthcare crisis, the

healthcare costs, our deficit. You talk about climate change. We are giving; here's the thing that nobody talks about. Everybody will beat their chest about fossil fuels. But nobody talks about the fact that trees absorb carbon. We have essentially given planet Earth a buzz cut, not to do development. We think it's development because we all live in cities for the most part, and we see all these buildings. We go the development is what's taking away the trees. No, farmland to grow crops to feed 80 billion animals and cattle grazing land. Now that's not me saying it. The amazon rainforest is being destroyed, and thousands of football fields are every time you turn on the news. I don't have the exact numbers, but it's like a punch to the stomach. When you see the numbers, it's being destroyed for cattle grazing land. Now they like to say, well, it's logging. Logging is a byproduct. The reason they are destroying it is cattle raising and who is consuming the cattle. Americans. JBS is one of the biggest cattle and meat companies in the world, Brazilian or from that part of the world. But we are the consumers; we're consuming all this stuff. Meanwhile, we're fomenting about their destroying the rainforests. Don't destroy the rainforest but wait for a second look at the mirror; who are they destroying it for?

"But we are the consumers; we're consuming all this stuff. Meanwhile, we're fomenting about their destroying the rainforests. Don't destroy the rainforest but wait for a second look at the mirror; who are they destroying it for?"

Dr. Kimberly Hillyer: You're talking about looking in the mirror. You brought up something that really connects with me, as I work in the healthcare field, about pharmaceutical companies and their involvement. But as I'm listening to you, I'm also thinking about how medicine as a whole also participates in it or the healthcare industry participates in it. You mentioned cancer; there's a cancer research and medical research that uses animals. Have you done a dive into that part of the healthcare industry? Medical research with animals' necessities or not necessarily. Because I feel like, basically, I remember hearing someone from the NIH saying that it was not really necessary to do this. We were finding cures in some of these animals that weren't translating to our species. We were giving the species diseases and cancers and different things like that, but it wasn't necessarily translating. So maybe animal research was not the way to go. Have you done a little research on that as well?

"Because I feel like, basically, I remember hearing someone from the NIH saying that it was not really necessary to do this. We were finding cures in some of these animals that weren't translating to our species."

Jane Velez-Mitchell: Oh, yes, for decades. I was a reporter in Philadelphia when somebody sent me a cassette tape of one of the most horrifying things. It really turned me into an animal activist. It was a head injury, experiments being done on primates, and you throw the word science out there. Everybody says, "well, we can't ask questions." It's science; it's research. They were bashing in primates' heads with ginormous, "ginormous" powerful objects that had whatever Gs' of force. They were playing rock music, and they were joking. Then they would lift the animal's hand like this and go look and drop it. It was sadism on a level that I could not even begin to comprehend.

A lot of the people who run organizations, like White Coat Waste, which is run by a guy named Anthony Bellotti, who actually had a summer internship at a laboratory, and he said what he saw horrified him. He decided to devote his entire life to ending animal experimentation. The truth is that we're not animals in that sense. Yes, we're animals, but we don't have tails, we don't have paws, we don't have snouts. If I feed my dog chocolate, my dog could be poisoned. Unfortunately, I eat a lot of chocolate, and nothing bad happens to me except I put on a couple of pounds. So, we are not animals, and what happens to animals doesn't impact us. Most of the drugs that work on animals don't work on people. This is a scientific fact.

"So, either way, our disregard of other species and other beings came back to haunt us in the form of the pandemic. Of course, no news media talks about that because, once again, that would rip open the meat matrix and have people wondering. Well, maybe this is not in my best interest to do this."

Look at the pandemic. There was an article in the New York Times on February 27. That, said the scientific community, has concluded that in all likelihood. However you want to phrase it, they didn't say necessarily by a preponderance of the evidence or beyond a reasonable doubt. But they said it was very clear that COVID almost certainly started at the Wuhan wet market. Where wild animals and domestic animals, blood, guts, feces, urine, pus, and every other thing is mixed together. People said, well, what about the lab? The lab theory? Well, even if you looked at the lab theory, what were they doing there? They were experimenting on bats. So, either way, our disregard of other species and other beings came back to haunt us in the form of the pandemic. Of course, no news media talks about that because, once again, that would rip open the meat matrix and have people wondering. Well, maybe this is not in my best interest to do this. Do you know that the mainstream media does not use the word slaughterhouse? When COVID swept through the slaughterhouses, that became a big issue for the slaughterhouse workers. The rank and file were dying overwhelmingly. People at the lowest rung of the social order -- Immigrants people, who have just been released, for example, from prison. Often the only job they can get is killing animals for a living. There was an order sign saying this was

essential and they needed to keep working. The news media did a report on it a little bit, but they didn't say slaughterhouse. They said food processing facilities or meat processing facilities. Okay, so meat packing plants won't use the word slaughterhouse. Why? Because that breaks open the meat matrix again, and people start thinking, well, whoa! What actually happens there? Oh, slaughter; animals are killed!

"So, if people would switch to a plant-based diet, if you just gave them the facts, we'd all be vegan because you'd have to be living under a rock not to see some of these videos already. PETA does an amazing job."

So, if people would switch to a plant-based diet, if you just gave them the facts, we'd all be vegan because you'd have to be living under a rock not to see some of these videos already. PETA does an amazing job. PETA and other organizations get the word out there. We have some serious documentaries that we show on UnchainedTV; we have "Dominion," and we have "Earthlings." We have more light-hearted fare like "Vegeducated," where a group of hardcore meat eaters is put through a Vegan boot camp, and hilarity ensues. So, we have various shows. We have a lot of vegan cooking shows.

It's the conditioning of our society. I still have cable, and I see these commercials pop up with the dripping meat, etc. These high-priced movie directors are hired to do commercials. They can subliminally connect these pieces of meat with everything, from sex appeal to upward mobility, to keeping up with the Jones to social status, patriotism, femininity for women, and masculinity for men. They are experts at it. Okay, we're being conditioned.

Dr. Kimberly Hillyer: That is very true. Some of the commercials really hit me growing up. Things like seeing these celebrities or supermodels in little bikinis with the big hamburger in their mouths. I'm hearing what you're saying and processing it. I realize you're saying how much influence these companies have in sending out their message. So, it's good to have an alternate platform like your network whose able to get out the truth. How do you feel like you are able to utilize that to maybe even move past just messaging one-on-one but to make a difference on the legislative side?

"So, it's good to have an alternate platform like your network whose able to get out the truth. How do you feel like you are able to utilize that to maybe even move past just messaging one-on-one but to make a difference on the legislative side?"

Jane Velez-Mitchell: Well, yes, the reason I did this. I was in mainstream news media. For 40 years, I worked at CNN. I worked at local TV stations around the country. I worked in syndicated television. I've written 4 books, including 2 New York Times bestsellers. You know, after 40 years of really working hard, I think I may have taken like a dozen lunch breaks in that time. I'd like to be out on the beach reading a trashy novel and having some Vegan bonds.

But this has to be done because there are too many people on this planet to talk to them one-on-one. We must use the most effective means, which is a video showing people the reality of modern-day factory farming, which is morally reprehensible, showing them the joys of vegan cooking. Which we also do on Unchained TV. We have hundreds of Vegan cooking shows. We got a guy named Derek Sarno, who makes mushrooms, and turns he turns mushrooms into these incredible stakes and all sorts of meat in, and you look at any way that's a steak. No, it's a mushroom. We have "Soulicious" vegan, so delicious! And she does these incredible dishes that are absolutely like they're just delectable. This is not a sacrifice. See, the other thing that we've been conditioned to believe is that somehow eating fruits, vegetables, nuts, grains, and legumes which is what Nature put there for us to consume, is some terrible sacrifice. No, the food that we make is absolutely delicious. And again, that's part of changing the conditioning. I have cookouts all the time. I invite people over and make all sorts of food, and the veggie burgers, and everybody eats every last bit. Then, I say, you know, by the way, there's not a single animal product in any of this. So, you can still have your mayonnaise. Hellmann's has vegan mayonnaise. You could have your butter, Meokos butter, or many other brands. Yeah, you do have to find the brands you like. Cheese, by the way, is extraordinarily addictive. There's a book called the Cheese Trap by Dr. Neal Barnard because Nature put a morphine-like substance in cow's milk, cows, breast milk, to encourage the baby calf to drink the cows' breast milk; and what happens?

"See, the other thing that we've been conditioned to believe is that somehow eating fruits, vegetables, nuts, grains, and legumes which is what Nature put there for us to consume, is some terrible sacrifice. No, the food that we make is absolutely delicious. And again, that's part of changing the conditioning."

Is that addictive substance also addictive to humans? Why does it apply to cheese, particularly because that's compressed milk? It compresses, and it's a concentrated amount of that substance now, and that's why people sometimes find It's the hardest of all to give up cheese. It's no accident, so you should check out the book the cheese scrap, written by a doctor. Okay, I'm not a doctor, and I always say that, but he is. And he wrote this incredible book that explains it. So, you go out there, and you go. Well, I didn't like that. Vegan cheese Well, do you like every cow-based cheese you have ever tasted?

No, okay. Some people don't like him, and there, so you got to find the products you like but see when there's no argument that works. Then you've got to ask yourself, wait for a second, is it me? I'll say this: I'm a recovering alcoholic, 27 years sober, and back when I was in my disease. There was no argument that anybody could make that would convince me that I didn't need to have a drink if it was a good day. I needed to celebrate by having a drink. If it was a bad day, I needed to comfort myself with a drink. If it was raining, I needed to drink as it was ready. If it was sunny, I needed to have a drink because it was sunny. So, what happened was I hit bottom and made a full myself at a party in Hollywood. I had a moment of clarity, and then I had a shift in my perspective, and I realized it's not that I won't drink tonight. It's that I don't have to that change right totally shifted my mentality. It was like a psychic shift or even a spiritual shift. What we need to do it's the same thing with these meat and dairy products. People are clinging. To them, as If they're the solution, when in fact, they're the problem. I used to cling to alcohol like it was a solution when in fact, it was the problem, and that's the dichotomy. Then I tried to negotiate with it and manage it, and I never won, and people are trying to negotiate and navigate from meat to dairy, and they never win.

"But for those individuals who did not grow up Vegan or vegetarianism, how do we take those steps? I know we can start by looking up the recipes from your chefs, but how do we take those steps?"

Dr. Kimberly Hillyer: So outside of these wonderful programs, I'm definitely very interested in viewing those. I did notice them when I was going through the programming that you have. How would you say that someone would start now? I live in the blue zone area of Loma Linda, known for being the blue zone partly due to, as you said, the healthy lifestyle, healthy eating, vegetarianism, or veganism. That really kind of, I think, was established well within Loma Linda itself. But for those individuals who did not grow up Vegan or vegetarianism, how do we take those steps? I know we can start by looking up the recipes from your chefs, but how do we take those steps?

Jane Velez-Mitchell: Well, look, I know it's a process. I wasn't born Vegan. Then I was, I don't want a curse here, but half-ass vegetarian. I think I could say get away with that until I met a fourth-generation cattle rancher named Howard Lyman. I was a local news anchor here in California, working out of the Paramount studios. He had recently been on Oprah. This is a quarter of a century ago when he revealed the secrets. He was a fourth-generation cattle rancher who got sick, and as he was going into surgery, he made a pack with God. He said, "God, if you get me through this surgery alive, I will reveal the terrible secrets of my industry." He wrote a book called Mad Cowboy. He went on Oprah and revealed the secrets, and she famously said that just stopped me cold from eating another burger. Because he talked about the babies ripped from their mothers. For us to drink cow's milk, those babies can't have that milk, so they have to be separated from their mothers, and the mothers grieve, and the babies grieve. The boys have no need for them in the dairy industry, so they either stick them in veal crates, or sometimes they shoot them, or sometimes they throw them on dead piles and let them die. Okay, they don't need them in the dairy industry, so the boys are just trashed.

"Just like chicks in the egg industry, people say, well, eggs, there's no problem with eggs, right? Well, all the male chicks are ground up alive in macerators. They don't need male chicks. You can see the videotape of all these workers; they're just looking for males and females. Man and the boys go like this, and they go right into the macerators"

Just like chicks in the egg industry, people say, well, eggs, there's no problem with eggs, right? Well, all the male chicks are ground up alive in macerators. They don't need male chicks. You can see the videotape of all these workers; they're just looking for males and females. Man and the boys go like this, and they go right into the macerators. In fact, there's a documentary out of Israel where the macerator company calls the police on activists who have stopped the macerating machine with all these chicks. She's going to be grounded up alive. The police come in, and the activist says, well, if you think this is okay, you press the button and start the machine. And the cop couldn't do it.

"He said, "do you eat dairy? I hear you're a vegetarian," and I said, "yes," and he said, "do you eat dairy?" I kind of hung my head because he just told me about all these horrible things that they do to separate the mothers and the babies and the boy calves. And I said, "yes." He looked at me, and he put his finger right on my nose, and he said, liquid, meat, like that. And that was the moment I went vegan, like more than, well, about 25 years."

So, what Howard Lyman said to me that day that I interviewed him after he became a cause Celeb with his book, after being on Oprah. He said, "do you eat dairy? I hear you're a vegetarian," and I said, "yes," and he said, "do you eat dairy?" I kind of hung my head because he just told me about all these horrible things that they do to separate the mothers and the babies and the boy calves. And I said, "yes." He looked at me, and he put his finger right on my nose, and he said, liquid, meat, like that. And that was

the moment I went vegan, like more than, well, about 25 years. I wish I had my Vegan date the way I have my sobriety day, which is April Fool's Day. By the way, perfect date. God, I made a fool myself, and I still do, but I remember it now.

"But you can buy your chicken nuggets. They've done them now where it's really impossible to tell the difference. So, if you can't tell the difference, if it's going to save the planet, allow you to live longer and healthier, and cause much less suffering to animals, why not now? "

So, you know. I think it's a process, but it could have to be a long process. Look, getting back to the alcohol analogy when you give up drinking. You don't leave bottles of alcohol around the house. What you do is, and how many movies have you seen this? You take the bottles, and you go, and you pour them down the sink. It's the same thing with this. Yeah, you take out your dairy and your meat from your refrigerator and your cupboard, and you put it in a big box, and you give it to some homeless person who might need it or give it to a food pantry. Then you replace it with Vegan products. You can get your Vegan Hellmann's mayonnaise; you can get your soy milk. You can get your vegan butter; you can get your Vegan cheese. You can get your veggie burgers that are becoming increasingly sophisticated because the substance that makes meat look, taste, and smell like meat is called Heme. Heme exists independent of just animals. You can create Heme, and you will get that same meaty taste. That's why Impossible Foods is very successful because they use Heme in their products. So, you can replace it. You can have your veggie burgers. I don't like all those so much, you know, like the nuggets and all that, because I didn't grow up eating those things. But you can buy your chicken nuggets. They've done them now where it's really impossible to tell the difference. So, if you can't tell the difference, if it's going to save the planet, allow you to live longer and healthier, and cause much less suffering to animals, why not now?

"So, if you can't tell the difference, if it's going to save the planet, allow you to live longer and healthier, and cause much less suffering to animals, why not now?"

Dr. Kimberly Hillyer: We've looked at that aspect but going back to your pig reality show, Little Pig Lies. How do we take that same responsibility when it comes to pet ownership? And ownership of animals that aren't meant to be domesticated, or even those that we say, are meant to be domesticated. How can we be responsible?

Jane Velez-Mitchell: Well, I think responsible pet ownership is really important. These are members of your family. Okay, I'm going to grab my little guy right here. This is little Rico, and he's a rescue from Puerto Rico. He's an old guy; he was my mother's dog, and when my mother passed away in '99, I took Rico in. He's a family member, and there's nothing I would not do for him.

A lot of people got pets during the pandemic because they were at home. Now the shelters are filling up with pets because they're going back to work. People say to me, "Oh, I'm moved into an apartment. It doesn't take pets. I got to get rid of my…." No, if you moved, why did you move into that? I'm not, I have compassion for people because I know that housing is a very critical situation, and often it's really hard for people with companion animals to get homes. But that's why we fight for legislation that would prohibit rental apartments and say, you can't have dogs or cats here in California.

I went to a Vegan Restaurant many years ago called Real Food Daily, and I was friends with the owners, and I saw they had a 'B.' I knew they were a very, very clean restaurant. I said, Gosh! Why do you have a 'B.' He said you won't believe this. There was a little dog outside on the terrace, outside our terrace area. He went through the bars and sat inside the terrace, and a health inspector came along and gave us a 'B' for that. I said that's outrageous, and I got really mad. I called my friend Judie Mancuso, who runs Social Compassion Legislation, and I said that's ridiculous. I said we are so Speciesism in this society. It's like we demonize animals.

"They couldn't stop the people from taking selfies with the walrus, so their response was to kill the walrus. We posted it on Unchained TV Instagram, and I just said, this is murder. That's what I texted right before. It's murder. This epitomizes our arrogance toward other species, and it will come back to haunt us because we are destroying wildlife at such an alarming rate."

I sleep with my dogs every night. I've never gotten sick from dogs. Oh, I've gotten sick from people, believe me. So, I said we need a law. She proposed the dining with Dogs Law, which allows outdoor restaurants in California if they choose to accept animals into their outdoor patios. It passed with flying colors. It got a lot of publicity because people loved the idea. There were all sorts of stories about dogs dressed up for dinner, and there were comparisons to Paris. Then we passed it in New York. Okay, New York State. There are many people who have contacted me. We need to pass it in Texas. We need to pass it, but it really changed the culture. Now here in California, people don't think of you coming in with your dog, but not until that law was passed. Now there's a whole new attitude and guess what? Nobody's suffering. Nobody killed over because you're in some store with your dog.

See, we have to start thinking differently about these other ani-

mals with whom we share our planet. We've got to stop. We've got to start respecting them. Just before we went on, the story of the Norwegian authorities killing this walrus because people were taking selfies with the walrus. They couldn't stop the people from taking selfies with the walrus, so their response was to kill the walrus. We posted it on Unchained TV Instagram, and I just said, this is murder. That's what I texted right before. It's murder. This epitomizes our arrogance toward other species, and it will come back to haunt us because we are destroying wildlife at such an alarming rate. That's not me saying it; it's the Worldwatch Institute.

At the rate we're going, we're going to have almost essentially no animals in a decade. I'm talking about no giraffes, no lions, and no tigers. Now we like to say, oh, it's the hunters; and I'm no friend of hunters. I detest them, but it's really the destruction of the habitat of these animals that are causing climate change and wildlife extinction.

I've gone to conservation events where they're raising a lot of money, and conservation events tend to attract very wealthy people. I've noticed they're raising a whole bunch of money to save animals in different parts of the world. But they're serving meat at their Gala. I went up to the head of one of these in Beverly Hills, and I said, Why are you serving meat; if you're trying to conserve these animals? He just brushed me off. People don't want to make the connection.

"They couldn't stop the people from taking selfies with the walrus, so their response was to kill the walrus. We posted it on Unchained TV Instagram, and I just said, this is murder. That's what I texted right before. It's murder. This epitomizes our arrogance toward other species, and it will come back to haunt us because we are destroying wildlife at such an alarming rate. "

The main reason why we're barreling towards extinction. With these, the species extinction at an alarming rate. Don't take my word for it. There are extinction clocks online that you can go visit. It's because we're destroying their homes. Right here in Los Angeles today, before I got on this call, I testified at a hearing because they are trying to destroy LA's last coastal wetlands. The Ballona Wetlands, it's one square mile; it's an ecological reserve that is supposed to be there for the animals. There are 1,700 species, including threatened and endangered species, who live there. There's a plan that was concocted by private industry and developers to quote-unquote "restore it." It doesn't need to be restored. Sure, it needs some TLC. They've now allowed RVs; they are kind of trying to make it look like it's deteriorated by letting the perimeter deteriorate. But the truth is that these animals live there. We have timestamp photographs of these animals, and I testified at a hearing for California Fish and Wildlife. I was like, this is a phony restoration. It's a 10-year, 250-million-dollar bulldozing project it is going to chase all these animals out. They have nowhere else to go, and this is a landing spot for migratory birds.

So, our whole society is playing with this idea that if there is land that's not being used by people, somehow, it's a waste. It's the exact opposite; we need that land. In fact, there is a whole movement in New Zealand. I just read an article about how they are paying farmers to stop farming and grow trees for carbon offset. So, they can make more money doing the carbon offset by planting trees. Then they can actually produce either crops or farmed animals.

__Dr. Kimberly Hillyer:__ Soy and corn that's needed to feed the animals.

So you talked about one of the legislation pieces of legislation that you know was implemented here in California, widely accepted, and widely passed by Californians. New York is far as having their pets and animals able to be at the restaurants' outside area. Is there any legislation that's on the horizon that you know of that we should be keeping an ear out for to really push, whether here in California or nationally even?

__Jane Velez-Mitchell:__ Well, Prop. 12 was passed by the voters of California. Let me be very clear, we are people who are generally good. I believe it's the systems that are bad. So, overwhelmingly Californians passed Prop 12, which would ban the sale of animal products produced through cruel means of confinement. Like those pig gestation crates that I talked about earlier. So, the pork industry has gone to court to try to do an end to or run around it. They are trying to say they have all sorts of arguments. I actually work with one of the lawyers who work with meaning in a nonprofit fashion; who's fighting this? I just read his brief; I mean, the people of California do not want these cruel confinement systems.

"Let me be very clear, we are people who are generally good. I believe it's the systems that are bad. So, overwhelmingly Californians passed Prop 12, which would ban the sale of animal products produced through cruel means of confinement. "

California is the fifth largest economy in the world, so when California says it's done, it's done. We saw that with the Cruelty-Free Cosmetics Act that we passed. Same organization, social compassion, legislation at PETA, People for the Ethical Treatment of Animals. We passed the California Cruelty-Free Cosmetics Act, and that has had a ripple effect even as far as China. Which had required cosmetic testing on animals but is now rethinking it in the wake of this legislation. So, the old saying, what happens in California, spreads everywhere.

So, we really need to worry about the effort to undo the voice of the people in Prop 12, which said we do not want products made from these cruel, terrible, cruel confinement methods. Where

animals can't turn around. What you said, well, why would they want to do that? Because all they want to do is fatten them up for slaughter. Most pigs are slaughtered around the age of 6 months. Okay, they're babies; they're terrified babies.

What happens when you move around, you burn calories. So that costs, right? So, if you keep them immobilized, you can control pigs because pigs are very, they can be very large, and they can be very strong. So, you keep them immobilized, and you fatten them up for slaughter. It is morally reprehensible. Okay, I'm not saying that's, oh, that's just my opinion. No, I think anybody who looks at pig gestation crates and says this is okay. Needs to go see a therapist because it is just not okay.

"So, if you keep them immobilized, you can control pigs because pigs are very, they can be very large, and they can be very strong. So, you keep them immobilized, and you fatten them up for slaughter. It is morally reprehensible."

Dr. Kimberly Hillyer: Now you said there is work that is being done to change laws. You know that individuals are going through court, going to judges to overturn certain legislation. How do we get information on this? I know you have your information on Unchained TV, but is there a place that we can go to. So that we are aware of which representatives in our districts, in our areas, are working towards our interests. As people, as our animals, our pets, undoing cruelty, helping with climate change, all these things are a circle in the cycle. How do we find information about the judges? So, we are making sure that not only are we addressing the Props that come to the ballot but also the people that come to the ballot.

Jane Velez-Mitchell: Yes. Well, I have to say UnchainedTV.com. We put out an article every week on the very latest in our movement. For example, this isn't legislation, but I have two articles up right now that are really fascinating.

We could feed the entire world using fermentation processes like microalgae. It is one of the oldest substances on earth, and it is something that can be replicated and fermented, and it's high in protein in large vats. Now they figured out a way; it's an Israeli company; we did an interview with them. They can brew it in large vats, and it's a high protein source of food that could feed the earth. You can also add any additive you want to make it taste like, whatever you want. It's kind of like tofu, except it's made out of microalgae, and that is a huge breakthrough.

Then we also interviewed a Belgium company called Paleo that is making. Get this. If you're sitting down, 100% bio-identical meat that is Vegan. What they're doing is they're using DNA sequencing. So yeah, I had the same reaction. How could you do that? Don't you need a biopsy, which would sell the base meat? They said, "No, what we do is we take the DNA sequencing. We copy the DNA sequencing, and we use another protein, in this case, yeast, and once we have that DNA sequencing, what we're producing it not just tastes sort of like, but it tastes exactly like pork, chicken, beef." They even found Mammoth DNA, and they created mammoth meat. They said that this is a substance that would be combined like any ingredient with other things. Let's say you were making a veggie burger or you were making something you wanted to have as your meat dish. Put that into the plant-based substance as an ingredient in your dish; it tastes like meat. It now tastes exactly like meat because it is bio-identical to meat. So, there are all these incredible things happening that are on the horizon, and they are the solution.

Sure, I'm all for protesting and demanding action, but I think technology is going to solve this problem. Millions and millions of dollars are being poured into all of these systems. And you might say, "Well, that's not natural." Well, is it natural for you to jump on a plane and fly across the world? Is it natural for me to have two lights staring at me? No!

Okay, so I think that technology is going to offer the solution. As far as getting involved, if something you've heard today says this is not right, I agree. I have to tell you along with UnchainedTV.com, which is our website. The PETA people, just PETA.org, make it so easy. Let's face it, we're not in the day and age where people sit down and write letters to their congressmen. That's like back from the turn of the century. So, PETA, you sign up, and they send you a text, and you just go like this, and it sends a letter to twelve members of Congress boom. No matter what I'm doing. I'm on the PETA list, and anytime I get it. I know that all I have to do is go on online. They send me emails. They also send me a text, and I click, click, click like that. I say letters to twenty people of influence, and I can personalize them if I want. If I don't have time, I would say definitely go to PETA.org and sign up for their mailing list because they're on top of all this. A lot of these groups. It's the work of PETA. I've worked with them against animal experimentation.

I was at the Hispanic journalist conference in Puerto Rico. I think it was back in 2009 when these two lawyers from the Amorites subcommittee of the Puerto Rican Bar Association came up to me. They said, Oh, they built a laboratory monkey breeding facility here in a small town, and we can't stop it. They've already built it. We're devastated. I said, never concede defeat before you've even started to fight. I said let's go to the Legislature. We literally drove to the Legislature of Puerto Rico. We walked around we found animal-loving legislators. We enlisted them. PETA filed lawsuits. They have nineteen lawyers challenging this construction, which happened to turn out was without the proper permitting. Everything was blown wide open. It went all the way up to the Puerto Rican Supreme Court, and they were not allowed to open the facility, even though they had already constructed it. So, I can tell you that PETA is extraordinary, like a machine. I've supported them from the beginning. I deal with a lot of organizations, hundreds. I deal with them and profile them, and I have to say it is the most effective organization.

"So, if you care about animals, if you care about even health, if you care about the planet, certainly check out UnchainedTV.com. Check out not just our articles but also our 600 videos."

So, if you care about animals, if you care about even health, if you care about the planet, certainly check out UnchainedTV.com. Check out not just our articles but also our 600 videos. Download our app you can watch it on TV. There's a lot of fun, and we have a lot of documentaries. I was up until one in the morning uploading new documentaries. People think I have a team. People are always we'll have your IT team do it. No, I mean, we've got four people. We're doing this network; it's 24 hours a day. I don't take a salary. This is a labor of love. I am doing it for one reason only. We have to change, or we are going to go extinct, as Dr. Sailesh Rao said. You know we, in our arrogance, think that the human species can't go extinct, but if the temperatures get too hot on this planet to support human life, we could.

Dr. Kimberly Hillyer: Unfortunately, we are doing it to ourselves.

Jane Velez-Mitchell: Yep.

Dr. Kimberly Hillyer: I want to thank you for your time. Thank you for your information, especially for giving us information about your website. The videos, the blog. Information about PETA that I wasn't aware of. I'm gonna make sure I sign up for those messaging systems because they're making it so easy. Why would you not use it to make a difference? Because our planet needs us. These animals need us. Our future generation needs us. So, I want to thank you again, Jane, for joining us at Neonatology Today Media.

I look forward to having a movement that you've started with this Unchained TV network is making a difference in multiple species' lives.

Jane Velez-Mitchell: I want to thank you, Kimberly, for a great interview, for caring and being on top of it, and for being willing to discuss this issue. You know, there's really a whole sort of, I would say, prejudice against anything involving animals. As if serious people can't discuss it. There's a sort of inherent condescension. Oh, oh, I love your passion! When they don't realize it is the most

important issue. I really respect and appreciate the fact that you recognize that and took the time to do this.

Dr. Kimberly Hillyer: No problem, and I really appreciate your time. I'm glad we could also highlight the medical, science, and research aspects because that hits home. It's one of the things that we just have accepted, and we shouldn't, and we need to challenge it.

Jane Velez-Mitchell: Absolutely.

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About the Author: Kimberly Hillyer, DNP, NNP-BC:

Title: NT News Anchor and Editor

Title: Neonatal Nurse Practitioner & News Anchor, Editor for Neonatology Today

Organization: Loma Linda University Health Children's Hospital

Neonatology Today in partnership with Loma Linda University Publishing Company.

Bio: Kimberly Hillyer, RN LNC, NNP-BC DNP, completed her Master's degree specializing as a Neonatal Nurse Practitioner in 2006 and completed her Doctorate of Nursing Practice (DNP) at Loma Linda University in 2017. She became an Assistant Clinical Professor and the Neonatal Nurse Practitioner Coordinator at Loma Linda University. Her interest in the law led her to attain certification as a Legal Nurse Consultant at Kaplan University.

As a Neonatal Nurse Practitioner, she has worked for Loma Linda University Health Children's Hospital (LLUH CH) for twenty years. During that time, she has mentored and precepted other Neonatal Nurse Practitioners while actively engaging in multiple hospital committees. She was also the Neonatal Nurse Practitioners Student Coordinator for LLU CH. A secret passion for informatics has led her to become an EPIC Department Deputy for the Neonatal Intensive Care at LLUH CH.

She is a reviewer for Neonatology Today and has recently joined the Editorial Board as the News Anchor.

About the Author: Jane Velez-Mitchell

Jane Velez-Mitchell is the founder and content editor of UnChainedTV, a multi-platform social media news outlet that produces original video content on animals rights and the vegan/compassionate lifestyle.

Jane has won four Genesis Awards/commendations from the Humane Society of the United States for her reporting on animal issues. VegNews named Velez-Mitchell Media Maven of the Year in 2010. In 2013, Mercy for Animals awarded her the Compassionate Leadership Award. In 2014, she was honored for fighting animal abuse by the Animal Legal Defense Fund. In 2015, she received the Nanci Alexander Award at PETA's 35th anniversary.

For six years she hosted her own show on CNN Headline News, where she ran a weekly segment on animal issues. Previously, Velez-Mitchell reported for the nationally syndicated Warner Brothers/Telepictures show Celebrity Justice, where she did numerous stories on animal issues championed by celebrities.

Previously, Velez-Mitchell was a news anchor/reporter at KCAL-TV in Los Angeles and WCBS-TV in New York. She is the winner of a Los Angeles Emmy and a New York Emmy for her reporting. Velez-Mitchell is a graduate of New York University and began her career with reporting stints in Ft Myers, Florida, Minneapolis, and Philadelphia.

Velez-Mitchell is the author of four books. Her 2014 nonfiction New York Times bestseller, Exposed: The Secret Life of Jodi Arias offers a detailed psychological analysis of a salacious trial that gripped the American public.

Her other New York Times bestseller is her memoir, iWant: My Journey from Addiction and Overconsumption to a Simpler, Honest Life.

Secrets Can Be Murder delves into the secrecy and deceit embedded in tragic scenarios.

Addict Nation: An Intervention for America with co-author Sandra Mohr focuses on our culture's addictive nature and our obsession with overconsumption.

Velez-Mitchell directed and produced the documentary Anita Velez: Dancing Through Life which won a Gracie

Award in 2001. In 2019, she produced the award-winning UnChainedTV documentary Countdown to Year Zero, now streaming on Amazon Prime.

Through UnChainedTV, in conjunction with Inspired, she is the co-executive producer of New Day New Chef. This vegan cooking series has won two Taste Awards, considered the Oscars of food and streams on Amazon Prime and public television stations across the U.S.

She lives with her 3 companion animals in Los Angeles

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READ NPA's statement: BLACK LIVES MATTER

Fellow's Column: Neonatal Atrial Flutter Detected by CCHD: A Case Report.

Benjamin H. Tan, DO, Catlyn E. Blanchard, MD, Kirk N. Liesemer, MD

Abstract:

Universal pulse-oximetry screening has been implemented to detect cyanotic heart lesions; however, no universal screening test has been developed to detect arrhythmias in newborns. We report a case of atrial flutter (AF) in a neonate with a structurally normal heart detected by routine pulse-oximetry screening.

"Universal pulse-oximetry screening has been implemented to detect cyanotic heart lesions; however, no universal screening test has been developed to detect arrhythmias in newborns."

Introduction:

The incidence of arrhythmias is 1% in neonates and 1-3% in late pregnancy (1), with about 1-5% of newborns exhibiting an arrhythmia in the first ten days of life. Most often, these arrhythmias are supraventricular beats, or premature atrial contractions (PACs), that will disappear over the first month of life with minimal clinical significance. Without congenital anomalies or maternal connective tissue disease, hemodynamically significant arrhythmias typically result from an atrioventricular reentry pathway (AVRT) or AF (2). Atrial flutter constitutes about 20-30% of all neonatal arrhythmias (2) and is associated with high morbidity (3). AF is characterized by saw-tooth waves with an underlying atrial rate of 300-500 beats per minute (BPM) and often has an accompanying AV block causing a slower ventricular rate manifesting as a monitored heart rate of 150-250 BPM. While often asymptomatic, severe or prolonged presentations of AF can result in heart failure, sometimes requiring digoxin or amiodarone in the neonate. More commonly, AF is amenable to cardioversion and only rarely requires long-term antiarrhythmic medications. Roughly 15% of neonatal arrhythmias are associated with congenital heart disease (1, 4, 5), conditions often identified either prenatally or through routine critical congenital heart disease (CCHD) screening via pulse oximetry. AF is usually diagnosed by electrocardiogram (ECG) and is not typically associated with congenital structural abnormalities (6). To our knowledge, CCHD has never been used to identify AF. This report presents a case of atrial flutter identified through standard newborn CCHD screening following concerns during the auscultation exam.

Case Presentation:

The patient was a 1-day-old female infant born to a 28-year-old G3P2 woman whose pregnancy was uncomplicated, except for maternal depression and excessive weight gain. An anatomy scan at 21+4 weeks EGA showed normal fetal growth and cardiac anatomy. Delivery was induced at 41+3weeks EGA due to post dates and resulted in an uncomplicated spontaneous vaginal delivery. APGARs were noted to be 8 and 9 at 1 and 5 minutes, respectively. The newborn was macrosomic, weighing 4530g. During her first examination after delivery, she was noted to be tachycardic (160-180 BPM) with frequent ectopic beats via auscultation. An initial ECG was obtained, which demonstrated what appeared to be a sinus rhythm with frequent premature atrial contractions amid copious artifacts. The infant remained otherwise well-appearing and appropriately responsive; however, pre and post ductal saturation screening were performed due to the persistence and frequency of the ectopy. This demonstrated concordant saturation of around 95% without splitting. No further action was taken then as the infant continued to feed appropriately and remained well-perfused with no signs of respiratory distress.

"At 24 hours of life, routine CCHD screening was performed; however, this time, she could not maintain pre- and post-ductal saturations above 90% during the testing period. A second attempt was made with no change to the outcome. "

At 24 hours of life, routine CCHD screening was performed; however, this time, she could not maintain pre- and post-ductal saturations above 90% during the testing period. A second attempt was made with no change to the outcome. She was transferred to the NICU, placed on monitors, and experienced persistent desaturations to ~80%s. She was subsequently placed on supplemental nasal cannula oxygen, which improved her oxygen saturation to greater than 95% in both her upper and lower extremities. An echocardiogram was performed to evaluate cardiac anatomy and function. No structural abnormality was observed. However, an abnormal myocardial movement was noted by the sonographer.

"During brief ventricular pauses (possible vagal events), atrial flutter was noted via the cardiac monitor. A formal 12-lead ECG demonstrated variable motion artifact and suspected AF rhythm buried beneath her tachycardia. In increasing doses, adenosine was given for diagnostic purposes and revealed a distinct AF pattern (figure1)."

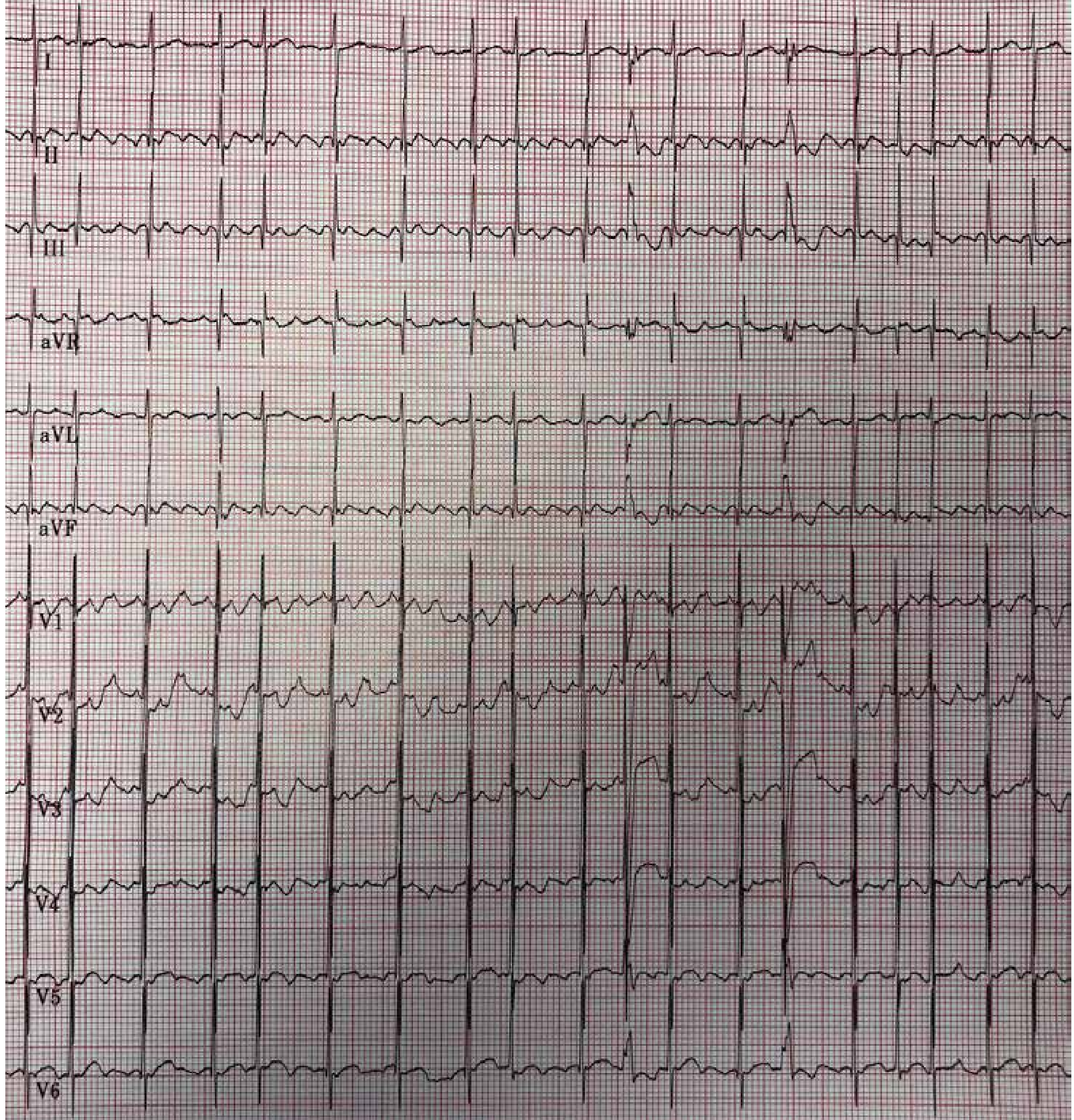

***Figure 1**: Atrial Flutter ECG Following Adenosine Administration. 12 lead EKG with 2-3:1 atrial flutter as revealed following adenosine administration. Classic sawtooth pattern is most prominently seen in lead II, however atrial flutter is exhibited in every lead.*

During brief ventricular pauses (possible vagal events), atrial flutter was noted via the cardiac monitor. A formal 12-lead ECG demonstrated variable motion artifact and suspected AF rhythm buried beneath her tachycardia. In increasing doses, adenosine was given for diagnostic purposes and revealed a distinct AF pattern (figure1). A decision was made to perform synchronized DC cardioversion. The infant was sedated and successfully converted to sinus rhythm via a single 0.5 joule/kg synchronized cardioversion (figure 2). She remained admitted to the NICU for an additional 24 hours for monitoring. A repeat ECG the next day demonstrated a normal sinus rhythm. Follow-up evaluations over the next several months (to include ambulatory monitoring) have all been reassuring, with no evidence of recurrence.

Discussion and Conclusion:

Atrial flutter is a common tachyarrhythmia in neonates, constituting approximately 32% of all neonatal arrhythmias, and typically

occurs in the first 7 days of life (7). AF can occur in the fetus or perinatally and can be associated with high morbidity depending on the duration of the flutter, degree of ventricular response, and when the flutter began, be it prenatal or neonatal (2). Associated known risk factors for neonatal AF include macrosomia or infants of diabetic mothers [12]. When persistent AF is found in utero, antiarrhythmic drugs can be used to prevent serious sequelae such as hydrops fetalis. However, for neonatal AF, synchronized cardioversion is the preferred treatment modality. Studies have shown that conversion to sinus rhythm is achieved 90% of the time (2, 8). Long-term treatment with antiarrhythmic drugs is generally not needed in cases of isolated AF.

"Studies have shown that conversion to sinus rhythm is achieved 90% of the time (2, 8). Long-term treatment with antiarrhythmic drugs is generally not needed in cases of isolated AF. "

Congenital heart disease affects nearly 9 of every 1000 infants born, with about 25% of those being from critical congenital heart disease (9, 10). Infants are often initially well-appearing in the first 12-24 hours of life with no overt signs of heart disease. They may not be identified until they become symptomatic. Traditionally, heart defects causing CCHD have been detected through prenatal ultrasound and newborn examination. In 1995, the first report of pulse oximetry screening (POS) to detect CCHD in newborns was published and thus began a 23-year process to develop and institute universal newborn screening. In 2011, POS was added to the Recommended Uniform Screening Panel as States that had mandated CCHD screening saw a 33% reduction in early cardiac deaths. Shortly after, the universal adoption of CCHD screening occurred in 2018 (11). Additionally, screening is highly specific for detecting CCHD, has a low cost, and has high availability, all ideal aspects for universal screening. To date, POS has not been described as a mechanism to identify arrhythmias and, to our knowledge, has not identified an infant with clinically relevant atrial flutter.

"This case illustrates that clinicians should maintain a high index of suspicion for any concerns of neonatal arrhythmia. Abnormal CCHD testing may be a sensitive screen for more than underlying cyanotic heart disease."

Our case was significant for macrosomia. However, it lacked other known risk factors associated with AF, such as gestational diabetes in the mother. Neonatal atrial flutter was deemed idiopathic and has not recurred in follow-up. This case illustrates that clinicians should maintain a high index of suspicion for any concerns of neonatal arrhythmia. Abnormal CCHD testing may be a sensitive screen for more than underlying cyanotic heart disease.

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

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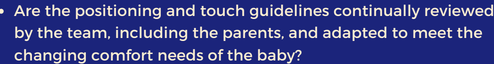
INFANT AND FAMILY-CENTERED DEVELOPMENTAL CARE (IFCDC)

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/

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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.

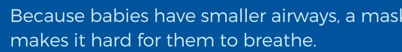
Take Care of Yourself

- 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.

– Christine Theard, M.D.

Post-Traumatic Thriving

The Art, Science, & Stories of Resilience

Randall Bell, Ph.D.

Peer Reviewed

Briefly Legal: OB Case with Possible Lazarus Syndrome Snags Neonatologist in a Lawsuit

Robert Stavis, PhD, MD, Barry Schifrin, MD, Maureen Sims, MD

Introduction:

A defendant Obstetrician diagnosed an intrauterine fetal demise at full term. One hour and fifteen minutes later, the baby was born alive and developed a severe and chronic hypoxic-ischemic encephalopathy with an adverse long-term outcome. The case resulted in an award in excess of $50 million. (Some details have been changed to maintain the anonymity of the case.)

"A defendant Obstetrician diagnosed an intrauterine fetal demise at full term. One hour and fifteen minutes later, the baby was born alive and developed a severe and chronic hypoxic-ischemic encephalopathy with an adverse long-term outcome."

A. The Facts of the Case

An obese (BMI = 43 kg/m^2), primigravid patient presented to the suburban community hospital complaining of severe (10/10) abdominal pain for the past 4 hours. The mother's blood pressure was 155/95 mm Hg upon admission. An interpretable fetal heart rate could not be detected on the fetal monitor or with a Doppler device.

The OB was immediately available and used the portable ultrasound scanner on the unit. The heart was well visualized with a 3.5 MHz probe, and there was no detectable heartbeat over a minimum of 10 minutes of observation, at least 5 minutes of which was spent specifically focused on the heart. An abruptio placenta was suspected but was not evident on the ultrasound. (Authors note Abruptio placentae is diagnosed clinically; ultrasonography is not reliable for this purpose.) The OB ordered a STAT second ultrasound to be done in the radiology department. The on-call ultrasound technician came in from home about an hour later and found that the fetal heart rate was approximately 75 bpm. The OB saw the study and promptly delivered the infant by emergency C-section. A complete abruptio placenta was found at the time of delivery.

"The records did not have information about fetal movement, but the mother testified that fetal movement was always present and continued after she was told that there was no detectable heartbeat."

The records did not have information about fetal movement, but the mother testified that fetal movement was always present and continued after she was told that there was no detectable heartbeat.

"The transport team from the community hospital-based NICU, mobilized shortly after the initial call, arrived, and it was decided to transfer the infant to a metropolitan hospital for therapeutic hypothermia (which was not available at the time in the community hospital-based NICU)."

The female infant weighed 2750 grams and had Apgar scores of 0, 5, and 7 at 1, 5, and 10 minutes of age, respectively. Umbilical cord blood gases were not obtained. The infant was immediately resuscitated with endotracheal intubation, positive pressure ventilation, and chest compressions with a good response. An Attending Neonatologist from a community hospital-based NICU was called for assistance and arrived at about 1 hour of age. A central UVC could not be placed, and the catheter was retracted to a low position. Attempts to place a UAC were unsuccessful. A radial arterial catheter was placed, and at 1.5 hours of age, the arterial pH was 6.90, pCO_2 30 mm Hg (4.0 kPa), pO_2 85 mm Hg (11.3 kPa), and BE -29.0 mEq/L. Saline and bicarbonate were given with improvement in the blood gas. The transport team from the community hospital-based NICU, mobilized shortly after the initial call, arrived, and it was decided to transfer the infant to a metropolitan hospital for therapeutic hypothermia (which was not available at the time in the community hospital-based NICU). The baby was passively cooled to 33-34° C and the infant was transferred by ambulance under direct supervision and monitoring by the Neonatologist and Transport Nurse. The baby was stable during transport on ventilatory support with a low FiO_2.

After the staff at the receiving hospital transferred the baby from the transport incubator to a radiant warmer, the baby's endotracheal tube became obstructed by bloody mucus and was replaced by a NICU physician without difficulty.

The child had a prolonged stay in the NICU and developed severe cerebral palsy.

"The child had a prolonged stay in the NICU and developed severe cerebral palsy."

B. The Lawsuit

The parents sued the birth hospital and the Obstetrician and

Neonatologist, who consulted and attended to the infant during transport. The allegations included:

- Negligent provision of an inadequate ultrasound device.
- Negligence in performing/interpreting the ultrasound examination
- Negligent delay in delivering the fetus.
- Negligent infliction of emotional distress on the mother as a result of being wrongfully told that the baby she had carried was dead.
- Negligent management of the airway and monitoring during transport by the Neonatologist and the Nurse allowed the airway to become plugged.

"In this case, the case's venue was an important issue because it was well-known that jury awards were substantially higher in the county of the metropolitan hospital than awards in the county of the community hospital."

C. The Venue

In this case, the case's venue was an important issue because it was well-known that jury awards were substantially higher in the county of the metropolitan hospital than awards in the county of the community hospital. The court noted that a correct venue for one of the defendants applied to all defendants, so by including the Neonatologist in the lawsuit and alleging negligent care in the county of the metropolitan hospital, the plaintiffs were able to file the case in the county of the metropolitan hospital.

D. Availability of Medical Records

The fetal monitor tracings were only produced long after the discovery phase of the trial, well after the experts' reports had been produced.

Notes related to the transport were not included in the medical records from the referring or receiving hospitals. There was testimony that the Transport Note from the Neonatologist and Nurse's records were given to the staff in the NICU of the metropolitan hospital and faxed to the community hospital, and the Nurse's notes were brought to the Nurse's community hospital-based NICU. None of these records were found, but a copy of the Neonatologist's Transport Note, retained by the Neonatologist, was produced during discovery.

E. The Trial

At trial, the hospital's attorney opened with arguments that the community hospital only had a Level 1 Nursery and did not have maternal-fetal medicine physicians and neonatologists immediately available, so the standard of care applicable to major referral hospitals was not applicable to them. Additionally, he proposed that the fetus had died but had miraculously been "resurrected," as had been described by a phenomenon known as "Lazarus Syndrome."

In his defense, the OB testified that he was convinced that the fetus had no signs of life when the initial ultrasound was done.

"He ordered the confirmatory ultrasound in the radiology department for documentation of the fetal demise. The technologist had to come in from home, and the study was done approximately 1 hour later. When the bradycardic heartbeat was seen, a STAT C-section was done."

To the contrary, the mother testified that when she was told that the fetus had died, she said, "You're wrong. I can feel the baby kicking. I want a C-section." The OB agreed that had there been any signs of life; an immediate C-section would have been indicated. He found no problems with the ultrasound device and said the same machine continued to be used. He did not agree that there was insufficient sensitivity or resolution to detect a slow fetal heartbeat in an obese patient. He ordered the confirmatory ultrasound in the radiology department for documentation of the fetal demise. The technologist had to come in from home, and the study was done approximately 1 hour later. When the bradycardic heartbeat was seen, a STAT C-section was done.

A second ultrasound scan was not medically necessary, and clear documentation of the findings from the first study should have been sufficient for the medical record. The OB testified that there was hysteria among the family and the mother, and he thought that ordering the study would give them some time to process the situation and discuss the next steps.

The Ultrasound Machine: A maternal-fetal medicine physician for the defense testified that the use of the ultrasound machine with a 3.5 MHz transducer was within the standard of care but was inadequate to detect a very low heart rate, particularly in an obese patient. A radiology expert for the plaintiffs said that a lower frequency transducer (2.0 MHz) was required for satisfactory penetration in an obese patient and that it was below the standard of care not to have an in-house ultrasound technologist. Experts for the defense disagreed.

The hospital's risk manager testified that the ultrasound machine required annual maintenance but had never been inspected since it was purchased ten years earlier. The machine was serviced after the case occurred (and before the lawsuit), and no adjustments were found to be necessary.

"The hospital's risk manager testified that the ultrasound machine required annual maintenance but had never been inspected since it was purchased ten years earlier."

Fetal Monitor Tracings: The fetal monitor recording was discussed extensively over several days. A maternal pulse rate (by pulse oximeter) of 90-110 bpm was recorded for about 15 minutes. During that time, four recordings of 5-30 seconds duration of the fetal heart rate (by ultrasound) were similar but distinct from the maternal trace. In addition, there were two 10-second recordings on the fetal channel at a heart rate of 160-170 bpm. The plaintiff's MFM expert pointed to the pulse oximeter and ultrasound signals and testified that the distinction in the maternal and fetal signals showed that the fetus was alive; the defense MFM and obstetric experts dismissed the short ultrasound signals as artifacts.

"When the fetal heart rate is detected by ultrasound, and the maternal heart rate is detected by pulse oximetry, it should be expected that the traces will be similar but not overlapping because the signals are detected and averaged according to different technologies and algorithms."

(Authors note when the fetal heart rate is detected by ultrasound, and the maternal heart rate is detected by pulse oximetry, it should be expected that the traces will be similar but not overlapping because the signals are detected and averaged according to different technologies and algorithms.) These differences can be easily demonstrated by applying the fetal monitor ultrasound probe over a non-pregnant subject's abdomen, adjusting the probe to pick up the aortic pulse, and comparing the ultrasound trace to the pulse oximeter trace.

Causation: A plaintiff's expert testified that the baby could not die and come back to life. He blamed the misdiagnosis of fetal death on the OB's negligence in performing the ultrasound scan. A defense expert thought there was a massive fetal insult before the mother's admission and that the heart rate may have been as low as 1 bpm. He admitted that the delay in C-section may have increased the baby's injury. The plaintiff's neonatology expert opined that the fetal heart rate in the 70s shortly before delivery was the evidence of fetal decompensation that had occurred in the hospital and that had decompensation occurred earlier, the fetus would have been dead by the time the radiology ultrasound was done. The fact that the baby's Apgar scores rapidly improved was evidence of recent deterioration. A normal hematocrit was cited as evidence that the abruptio placentae was recent.

"The plaintiff's expert testified that the baby could not die and come back to life. He blamed the misdiagnosis of fetal death on the OB's negligence in performing the ultrasound scan."

Damages: A plaintiff's expert testified that the child would have an 82-year lifespan and an economics expert presented data that the cost of caring for the child would be approximately $450 million; a defense expert estimated that the child would live for approximately 20 years.

Qualification of Previous Testimony: The OB testified again at the end of the trial and allowed the fetal heart could have been beating but was undetectable with the machine he was using.

"The expert's opinion was refuted by the Neonatologist's contemporaneous note and the Neonatologist's and Nurse's testimony. In addition, the judge and jury were provided with a tour of the ambulance, including the transport incubator and a baby mannequin with simulated audible EKG and pulse oximeter signals."

F. The Case Against the Neonatologist

The plaintiff's neonatology expert testified that the absence of documentation of the baby's condition during transport indicated a lack of attention to the baby. Furthermore, the Admitting Note at the metropolitan hospital's NICU noted respiratory distress, poor breath sounds, deep retractions, and a plugged ETT on admission, which the plaintiff's expert interpreted as evidence that the ETT had become obstructed during the transport. The expert's opinion was refuted by the Neonatologist's contemporaneous note and the Neonatologist's and Nurse's testimony. In addition, the judge and jury were provided with a tour of the ambulance, including the transport incubator and a baby mannequin with simulated audible EKG and pulse oximeter signals.

With respect to the missing records, the judge gave the jury an "adverse inference" instruction, essentially saying that they could infer that the missing records had information that would be unfavorable to the Neonatologist. (There was no evidence of spoliation, i.e., the intentional destruction of evidence. Spoliation can result in varying sanctions up to and including a directed verdict.)

G. The Award

The OB and Neonatologist were found not negligent; the community hospital was 100% liable for the baby's injuries. The total damages were well over $50 million, with approximately 80% for future medical expenses (based on a lifespan of 50 years, i.e., halfway between the plaintiff's and defense experts' estimates), 15% for the infant's pain, and suffering, 2% for the mother's pain and suffering, and 3% delay damages. The amount of the award was confirmed on appeal.

Comment:

Along the pathway to fetal death, there may be an interim stage where there is severe bradycardia — maybe a heart rate of 1 or 2 with an interval of 30-60 seconds between beats — with an ejection fraction of a few percent. At some point, the situation would be indistinguishable from a truly still heart, even to the best observer with the best technology. While this situation almost invariably progresses to death, the medically reported

Lazarus Syndrome described below and historic cases teach us that an asystolic heart can start beating again after a substantial period.

Lazarus Syndrome: The spontaneous return of circulation after the termination of resuscitation has been described in adults, and a small number of pediatric cases are called Lazarus Syndrome. A 2020 review found 53 articles that described 65 patients who had signs of life that returned following an unsuccessful resuscitation in which there were no detectable vital signs. In many cases, a heart rate was detected a few minutes after the resuscitation was stopped, but there were 5 cases in which the interval was 20-60 minutes, 1 case in which the interval was 3 hours, and 1 case in which the interval was nearly 4 hours. Three of the cases occurred in pediatric patients aged 1.5-10. Mechanisms proposed to explain Lazarus Syndrome have included hyperinflation of the lungs and hyperventilation during resuscitation, delayed drug effects, myocardial reperfusion after spontaneous dislodging of an endovascular plaque from a coronary artery, premature termination of resuscitation, or unobserved minimal vital signs due to oversight. (1) While the frequency of the phenomenon is unknown, 37–45% of Canadian, French, and Dutch intensive care or pre-hospital emergency physicians surveyed have encountered auto-resuscitation in clinical practice. (2-4)

"While published cases of Lazarus Syndrome describe a misdiagnosis of death for a relatively brief period in a medical setting, it does not capture the full range of misdiagnoses of death. "

Death, by definition, is an irreversible state, so if there are signs of life after a declaration of death, the diagnosis of death was incorrect at the time it was made. "Resurrection" in this context is a religious concept with no medical meaning. While published cases of Lazarus Syndrome describe a misdiagnosis of death for a relatively brief period in a medical setting, it does not capture the full range of misdiagnoses of death. The problem of unintentional burial of a live person has a long history (5) that the technically innovative "Safety Coffin" of the 18th and 19th centuries was designed to prevent. (6) In the modern day, there are lay press reports of a misdiagnosis of death every few years (7-10), and the book *The Lazarus Syndrome* describes scores of misdiagnoses of death over hundreds of years. (11) The definition of Lazarus Syndrome should be understood to describe the spontaneous return of signs of life following the clinical misdiagnosis of death, irrespective of whether resuscitation was performed.

Does Neonatal Lazarus Syndrome exist? A single publication describes such a case:

- A mother was hospitalized at 23 weeks gestation for preterm labor. She was treated with tocolytics and betamethasone. The baby was in a breech position. The membranes ruptured, and the baby was delivered by emergency C-section. The baby had a heart rate >100 bpm and a weak respiratory effort. The infant was intubated, ventilated, and given chest compressions and ETT epinephrine, but the heart rate continued to fall and was 40 bpm at 11 minutes. The resuscitation was terminated, and the infant was declared dead at 1 hour. Shortly after arrival in the morgue, the infant was noted to have a weak respiratory effort with grunting and a heart rate of 150 bpm. The infant survived numerous complications during the NICU course and profound long-term impairment. (12)

In addition, we know of other cases from our practices, experiences of colleagues, and medical-legal reviews that might fall into this category. (Some details may have been changed in these summaries to protect the anonymity of the case.)

"The baby was moved to a utility room, and at approximately one hour after birth, a nurse noted respirations and a heart rate. The baby was transferred to a NICU and subsequently died. After the baby was found alive, the OB inexplicably changed the 5-minute Apgar score to 1 even though he testified that the infant had no detectable vital sign"

- In the 1980s, a fetus was aborted at what the OB thought was approximately 20 weeks. The baby was subsequently found to be 1500 grams and 32 weeks gestation. The OB found no signs of life and gave the baby 1 and 5-minute Apgar scores of 0. He said that there were never any signs of life while the baby was within his proximity. The baby was moved to a utility room, and at approximately one hour after birth, a nurse noted respirations and a heart rate. The baby was transferred to a NICU and subsequently died. After the baby was found alive, the OB inexplicably changed the 5-minute Apgar score to 1 even though he testified that the infant had no detectable vital signs. (The physician was convicted of the crime of infanticide under the state's Abortion Control Act.)
- A mother delivered a premature 550-gram infant at 22 weeks at home, and paramedics arrived 15 minutes after birth. The infant was found to have a dark gray color with no movement, response to stimulation, breath sounds, or heartbeat on auscultation. The fetus was considered to be stillborn and was placed in a biohazard bag. The mother and baby arrived at an Emergency Room about 45 minutes after birth, and the baby was removed from the biohazard bag. No movement was initially present, but a short time later, the baby gasped and had a detectable heart rate. The baby was transferred to the NICU and died within a few days.
- A 24-week gestation infant was delivered and had no detectable vital signs. A Neonatologist resuscitated the infant for approximately 20 minutes without a response. The resuscitation was terminated, and about 10 minutes later, the infant started to gasp and had a detectable heartbeat. The infant was treated in the NICU and died within a few days.
- A full-term infant delivered vaginally and unexpectedly had no detectable vital signs at birth. The baby was resuscitated initially by an NNP, and a Neonatologist joined the efforts

at 20 minutes of age. The infant never had any detectable vital signs, and the resuscitation was stopped at 30 minutes. About 2 minutes later, the infant gasped and had a heart rate. Resuscitative efforts were resumed, and the infant was transferred to the NICU. The baby had congenital heart disease and severe hypoxic-ischemic encephalopathy, and support was withdrawn at two weeks.

> ***"The degree of monitoring and observations in these cases are variable and lack the technology (e.g., EKG, echocardiography, EEG) that would confirm the diagnosis of death with a high level of certainty at the time the diagnosis was made."***

The degree of monitoring and observations in these cases are variable and lack the technology (e.g., EKG, echocardiography, EEG) that would confirm the diagnosis of death with a high level of certainty at the time the diagnosis was made. Of course, such technologies are rarely used and far from the standard of care in this setting. In the NICU, with parents in abundance, such testing would likely be perceived as a "science experiment."

Does Fetal Lazarus Syndrome exist? In addition to the case that is the subject of this article, we know of a case with remarkable similarities to the case under discussion:

- At approximately 28 weeks gestation, the mother had cramping with a gush of fluid and vaginal bleeding. In the hospital, there was continued vaginal bleeding with the passage of large clots. Ultrasound by a senior resident showed a breech presentation, low fluid, and no fetal movement. There was no fetal heart rate by direct ultrasound observation and no blood flow by color Doppler ultrasound. The resident repeated the study with the same findings, and an Attending physician independently confirmed the findings. An abruptio placentae with fetal demise was diagnosed, Pitocin was given, and the fetus was delivered vaginally. Shortly after birth, the baby gasped and had a heart rate of approximately 140 bpm. The infant was resuscitated and transferred to the NICU. The baby survived with neurologic injuries.

> ***" Barriers to publication may include issues involving individual and institutional reputation, HIPAA, and litigation. We hope this article will stimulate more discussion and a deeper examination of cases in which fetal or neonatal death may have been misdiagnosed."***

Denouement:

Was this malpractice case due to fetal Lazarus Syndrome? Yes… no… maybe. It is difficult to invoke Lazarus Syndrome as the explanation when that phenomenon has such little support in the perinatal literature, but that does not make the explanation wrong. Barriers to publication may include issues involving individual and institutional reputation, HIPAA, and litigation. We hope this article will stimulate more discussion and a deeper examination of cases in which fetal or neonatal death may have been misdiagnosed.

Do you know of such cases? Please e-mail us.

Lessons for Neonatologists:

1. Medical records: If, for whatever reason, you are transporting a patient to a hospital other than your home base, keep copies of notes that you create and any notes created by others on the transport team to assure the ultimate availability of these records. There may be issues in the retention of these records by the referring and receiving hospitals and the hospital providing the transport service.

2. Venue: The venue rules differ in federal cases and vary from state to state. The rules are controlled by legislation and courts and may be subject to change. Changing a venue seeks to obtain an advantage in litigation as certain jurisdictions are defense-oriented and tend toward smaller awards, while others are more plaintiff-friendly and tend toward larger awards. Moving a patient between jurisdictions may have an impact on the outcome if there is a lawsuit.

> ***"Changing a venue seeks to obtain an advantage in litigation as certain jurisdictions are defense-oriented and tend toward smaller awards, while others are more plaintiff-friendly and tend toward larger awards. Moving a patient between jurisdictions may have an impact on the outcome if there is a lawsuit."***

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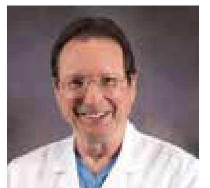

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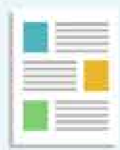
SHARED DECISION-MAKING PROTECTS MOTHERS + INFANTS DURING COVID-19

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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Gravens By Design: Addressing Challenges to Fully Incorporating Families into the NICU Care Team

Robert D. White, MD

"Family-centered neonatal care is rapidly becoming the declared standard of practice in NICUs worldwide. Several barriers still exist, however, that make this goal more aspirational than realistic in many NICUs – as much or more so in the United States as in nations with more limited resources."

Family-centered neonatal care is rapidly becoming the declared standard of practice in NICUs worldwide. Several barriers still exist, however, that make this goal more aspirational than realistic in many NICUs – as much or more so in the United States as in nations with more limited resources. An open evaluation of these barriers may help plan the way forward to fully implementing this ideal. (1)

Structural: Most NICUs were designed in an era when neonatal intensive care was not family-centered. Sufficient space and privacy at the bedside to allow extended time for skin-to-skin care, for example, was not contemplated during the design process for many of our existing NICUs, so while exemplary efforts have been made in many units to accommodate this practice, it is still far from optimal for families and therefore difficult to fully implement. (2) The trend toward single-family rooms has strengthened over the past 20 years, but even now, NICUs are being built with limited support for full family participation – some of these rooms do not have a bathroom or a comfortable sleep surface, for example, making it more difficult for families to commit to being fully engaged with the care of their baby. Until NICUs are designed to accommodate families in the best way possible, including couplet care rooms in hospitals with a delivery service, family-centered care will not reach its full potential. (3)

Operational: More often than not, including families in caring for their newborns requires extra effort. Sometimes this investment produces tangible benefits to the bedside nurse and the nursing administration when a family can take on care duties usually provided by a nurse, which may also result in a shorter stay. (4)Nevertheless, most of the time, working with families adds to a caregiver's responsibilities and time commitment. In addition, bedside providers are not usually trained to provide the type of family support provided by social workers, psychologists, and other support specialists, so hospitals are required to provide these individuals who may be able to help with barriers that families are experiencing that limit their ability to fully participate in their baby's care. It is often easier for a caregiver to complete their assigned tasks after which providing additional nurturing care to the infant or helping the family to do so can be seen as a burden. Other operational barriers may include challenges to family access because of arcane hospital rules such as parking fees or limited "visiting" hours.

"The trend toward single-family rooms has strengthened over the past 20 years, but even now, NICUs are being built with limited support for full family participation – some of these rooms do not have a bathroom or a comfortable sleep surface, for example, making it more difficult for families to commit to being fully engaged with the care of their baby."

Families: Sometimes families are unable to fully participate in the care of their infants, even when they desire to do so, because of lack of paid family leave from work or limitations in transportation and child care, all of these more significant challenges in the US than in most other developed countries. In other cases, parents are unwilling to participate fully in their baby's care, even when all other barriers have been removed. A more subtle but pervasive factor is that minority families who do not see many caregivers like themselves can feel alienated or judged.

"Every NICU team that aspires to be fully family-centered can use the items on this list to evaluate its current status and to plan future initiatives. (5)"

Initiatives to Consider when Implementing and Strengthening Family-Centered Care: Some of the barriers mentioned are far beyond an individual's or even a team's ability to influence – but many are not. This list will begin with those most easily addressed at the level of an individual NICU and finish with those we will need to advocate for as citizens and professionals. Every NICU team that aspires to be fully family-centered can use the items on this list to evaluate its current status and to plan future initiatives. (5)

- Choose a formal program of family-centered care to provide the framework for all subsequent efforts
  - There are many good programs available, several of which will be presented during the 2023 Gravens Conference – e.g., VON, FiCare, NIDCAP, Family Nurture Intervention, and more.

- Make developmental and family-centered care a measured and monitored expectation of every patient encounter.
    - Developmental and family support should be elements of each patient care encounter - i.e., of equal importance to vital signs and feedings. Regular audits are necessary to ensure these practices become part of the NICU culture.
- Remove barriers to a family's access to their baby
    - Allow 24/7 presence
    - Provide free parking
    - Include couplet care and single-family (as opposed to single-patient) rooms in all new construction or renovation
- Provide ongoing training for all staff on implicit bias in neonatal care
- Promote community efforts to increase training and employment of minority individuals in neonatal care
- Employ sufficient support personnel (e.g., social worker, psychologist, family advocate) to meet families' needs.
- Advocate for paid family leaves for all parents of newborns requiring NICU care.

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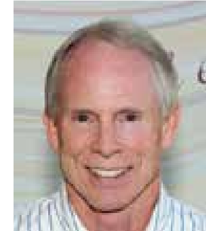

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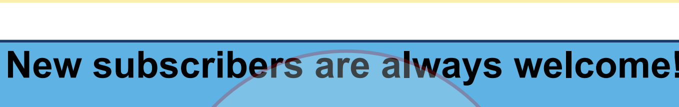

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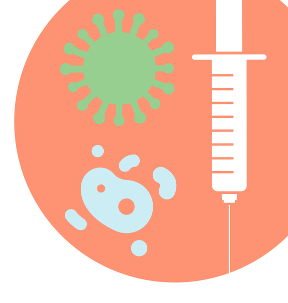
PROTECT YOUR FAMILY FROM

RESPIRATORY VIRUSES

flu coronavirus pertussis RSV

WASH YOUR HANDS

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



GET VACCINATED

for flu and pertussis. Ask about protective injections for RSV.

COVER COUGHS AND SNEEZES.

Sneeze and cough into your elbow.

USE A HAND SANITIZER THAT IS 60%+ ALCOHOL.

STAY AWAY FROM SICK PEOPLE

Stay at home to protect vulnerable babies and children. Avoid crouds when out.

nicuparentnetwork.org
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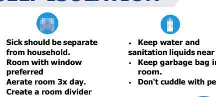
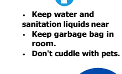
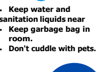
COVID-19

STOP THE SPREAD AT HOME

What to do when you or a loved one is infected.

HYGIENE TIPS

MOUTH
- Wear a face mask or face shield.
- If in car, wear mask & put windows down.
- NO cloth face masks for children younger than 2yrs.
- Avoid kissing

EYES
Wear protective eye gear (glasses)

HANDS
ALWAYS wash your hands

CLOTHING
- Wear a jacket when dealing with infected.
- DO NOT share clothing, sheets, or pillows.

BATHROOM

- Sanitize EVERYTHING.
- Clean after every use.
- Patient gargle Listerine every morning & night.

PROTECT

- If infected, notify everyone in contact from the past 10 days.
- Ask Dept. of Health for further assistant.
- Call 211 for FREE delivery services.

If you are feeling sicker, DON'T WAIT. Call your doctor immediately.

SELF ISOLATION

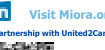
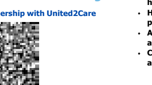
- Sick should be separate from household.
- Room with window preferred
- Aerate room 3x day.
- Create a room divider with sheet.

- Keep water and sanitation liquids near
- Keep garbage bag in room.
- Don't cuddle with pets.

6 FT

Practice social distancing

KITCHEN

- Use SEPARATE utensils.
- Clean utensils separately.
- If sick avoid the kitchen.

TRACK COVID-19 NEAR YOU BY VISITING COVIDNEARYOU.ORG

#STOPTHESPREAD

MIORA

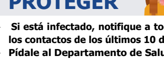
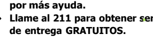
Visit Miora.org

Brought to by Miora in partnership with United2Care

COVID-19

DETENER LA PROPAGACIÓN EN CASA

Qué hacer cuando usted o un ser querido está infectado.

CONSEJOS DE HIGIENE

BOCA
- Use una mascarilla o careta
- Si está en el automóvil, use una máscara y baje las ventanas
- NO mascarillas de tela para niños menores de 2 años.
- Evitar besos

OJOS
Use equipo de protección para los ojos (lentes)

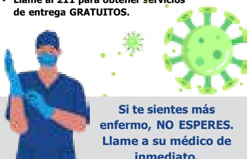
MANOS
SIEMPRE lávate las manos

ROPA
- Use una chaqueta cuando se trata de infectados.
- NO comparta ropa, sábanas o almohadas.

BAÑO

- Desinfecte TODO.
- Limpiar después de cada uso
- El paciente hace gárgaras con Listerine todas las mañanas y noches.

PROTEGER



- Si está infectado, notifique a todos los contactos de los últimos 10 días.
- Pídale al Departamento de Salud por más ayuda.
- Llame al 211 para obtener servicios de entrega GRATUITOS.

Si te sientes más enfermo, NO ESPERES. Llame a su médico de inmediato.

AISLAMIENTO

- Los enfermos deben estar separados del hogar.
- Habitación con ventana preferida
- Airear la habitación 3x al día
- Crea un separador de ambientes con sábana.

- Mantener agua y
- líquidos de saneamiento cerca
- Mantenga una bolsa de basura en la habitación.

6 FT

Practica el distanciamiento social

COCINA

- Use utensilios SEPARADOS.
- Limpie los utensilios por separado.
- Si está enfermo, evite la cocina.

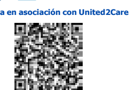
SIGUIR COVID-19 VISTAR COVIDNEARYOU.ORG

#STOPTHESPREAD

MIORA

Visitar Miora.org

Traído por Miora en asociación con United2Care



Ways to Manage Covid 19 @ Home

Household

1. Stay 6 feet apart from others at all times.
2. Wear protective covering over mouth and eyes (mask AND shield/goggles/glasses) when near others. (Do not put masks on children under 2 years old)
3. Gargle with antiseptic mouthwash in the morning and evening.
4. Wash hands 10-12x a day, before each meal for at least 20 seconds.
5. Keep good ventilation throughout home. (open windows/doors) where possible
6. Do not share towels, blankets, pillows with sick.
7. Call 211 for assistance/free delivery of services.
8. Wear protective clothing (jacket, gloves, mask) that can be removed after being around infected.

Stop the Spread at HOME

MIORA

Sick

1. Self-isolate by staying in separate room with separate bathroom where possible. Don't go into shared spaces.
2. Create a room divider with sheet, if shared space is unavoidable.
3. Ventilate room with fresh air at least 3x per day.
4. Keep water and sanitation products in room.
5. Keep plastic garbage bag in room.
6. Protect pets - don't cuddle.
7. Notify contacts in last 10 days.
8. Don't wait! Call doctor if symptoms get worse.

Maneras de manajer COVID-19 en casa

Hogar

1. Manténgase 6 pies de distancia de los demas en todo momento.
2. Use una cubierta protectora sobre la boca y la máscara para los ojos Y el protector / gafas / anteojos cuando esté cerca de otras personas. No ponga máscaras a niños menores de 2 años.
3. Hacer gárgaras todas las mañanas y noches con productos de enjuague bocal antiséptico que contienen alcohol.
4. Lavesé la manos 10-11 veces al dia, y antes de cada comida por lo menos 20 segundos.
5. Mantéga Buena ventilacion en toda la casa. Abra las ventanas y puertas cuando sea posible.
6. No compartá toallas, cobijas, y almohadas con personas que esten infectados.
7. Llame al 211 para obtener servicios de entrego gratuitos.
8. Use ropa protectora, chaqueta, guantes, máscara que se pueda quitar después de estar cerca de infectados.

Detén la propagacion en casa

MIORA

Enfermo

1. Aislese permanecindo en una habitación separada con baño separado. No vayas a espacios compartidos
2. Si no se puede aislarse crea un separador de ambiente con una sabana.
3. Ventile la habitacion con aire fresco por lo menos 3 veces al dia.
4. Mantenga agua y productos de saneamiento en la habitacion.
5. Mantenga una bolsa de basura en la habitación.
6. Proteja a las mascotas, no las abrace.
7. Notifique a todos los contactos de los últimos 10 días.
8. No espere! Si se siente peor llame a su medico.

WEAR A MASK

PROTECT PARENTS + BABIES

COVID-19

When we all wear masks...

We protect parents and babies.

Project Sweet Peas + National Perinatal Association

USA UNA MASCARILLA

PROTEGER A LOS PADRES Y BEBÉS

COVID-19

Cuando todos usamos mascarillas ...

Protegemos a los padres y los bebés.

Peer Reviewed

White Paper Executive Summary for the First Fragile Infant Forum for Integration of Standards (FIFI-S): Feeding, Eating, and Nutrition Delivery based on the Recommended Standards, Competencies, and Best Practices for Infant and Family-Centered Developmental Care in Intensive Care Monrovia, CA July 13-15, 2022

Joy V. Browne, PhD, PCNS, IMH-E, Carol Jaeger, DNP, RN, NNP-BC

"As the field of Infant and Family-Centered Developmental Care (IFCDC) has advanced, its principles have become integrated into current intensive care policies and procedures. In parallel, research has emerged to support a variety of practices to modify the caregiving environments for babies and their families in intensive care."

Overview of the FIFI-S White Paper Origins and Process:

As the field of Infant and Family-Centered Developmental Care (IFCDC) has advanced, its principles have become integrated into current intensive care policies and procedures. In parallel, research has emerged to support a variety of practices to modify the caregiving environments for babies and their families in intensive care. The evidence is strong enough for a Gravens interprofessional panel of leaders to converge and identify significant constructs represented in IFCDC and to gather evidence to support practice. However, once evidence is identified, implementation strategies in a systematic approach need to be articulated and disseminated. As they continue to accumulate evidence and further articulate standards, competencies, and best practices in intensive care, the Gravens IFCDC consensus panel has identified a need to disseminate information about implementing the standards.

As a result, a series of Fragile Infant Forums for the Implementation of Standards (FIFI-S) has been initiated to assist intensive care professionals in understanding the evidence available for IFCDC practice and knowing how to successfully integrate the standards into intensive care and hospital systems. Without systems integration, IFCDC practices and adherence to the standards cannot be successfully accomplished.

"The 2-day conference allowed participants to engage in dialog about how systems impact interventions at the bedside for the emphasis of this forum--feeding practices."

In July 2022, the FIFI-S hybrid conference provided an opportunity for interprofessional leaders, providers, caregivers, parents, and educators to focus on the Feeding Eating and Nutrition Delivery domain (FEND), and to learn, discuss, and plan implementation strategies. The 2-day conference allowed participants to engage in dialog about how systems impact interventions at the bedside for the emphasis of this forum--feeding practices. Evidence was reviewed, gaps in knowledge were identified, and there was an ensuing discussion of strategies for examining how best practices can be implemented. Using evidence-based continuous quality improvement (CQI) tools and change theory, implementation science helped participants outline how standards could be implemented in the Intensive Care Unit (ICU).

Implementation Science used to Integrate IFCDC Into Practice.

Implementation science uses methods to systematically integrate research and experiential clinical evidence to improve the quality

and effectiveness of health practice. To implement and operationalize the evidence, integration using systems thinking is essential.

"Systems thinking is an approach to guide the successful identification of the parts of the system, their relationship to each other, and the implication of change to one or more parts of the system."

Systems thinking is an approach to guide the successful identification of the parts of the system, their relationship to each other, and the implication of change to one or more parts of the system. Systems thinking is used to assess the components/parts of a whole, a human or an organizational system, and how they relate to each other to make the system function as intended.

Continuous Improvement as a Systems Thinking Approach uses systems thinking to guide assessment, planning, implementation, and evaluation. Systems thinking uses evidence and continuous improvement to address the advancement of healthcare, the rapid evolution of technology, and changing needs of babies, parents, and families. Essential tools of the Continuous Quality Improvement Process (CQI) include assessment of where and how to begin and measurement and metrics.

> *Gap analysis* helps to determine if there is a difference between the current practice and how it can be improved. Sometimes a gap analysis includes an evaluation or measurement of post-discharge activity to fully understand the evidence-based change that needs to be made to caregiving while the baby is in the ICU.
>
> Implementation of systematic *measurement and metrics* also are essential for continuous improvement. There are many ways to present data. Selection of the method that makes the most sense for the project, the organization, and the unit, including tools to display, monitor, and analyze measures and metrics.

"Exemplars of professionals who utilized the CQI process for FEND standards systems implementation provided a discussion of the strengths and challenges of the gap analysis process."

Exemplars of professionals who utilized the CQI process for FEND standards systems implementation provided a discussion of the strengths and challenges of the gap analysis process. Exemplars included a presentation from D Paul, OTR/L, the Children's Hospital Colorado, Aurora, on the implementation of a feeding policy, and a study by S Horner, et al., who identified adverse feeding behaviors exhibited by babies 3-5 months post-discharge as reported by parent feeders.

Process and Tools for Implementation of FEND Standards:

The forum faculty used step-by-step guidance to implement IFCDC standards for FEND using Continuous Quality Improvement (CQI), Operational Business Plans, Motivational Strategies for the Health Care Team, and Strategies to Measure Progress.

"The forum faculty used step-by-step guidance to implement IFCDC standards for FEND using Continuous Quality Improvement (CQI), Operational Business Plans, Motivational Strategies for the Health Care Team, and Strategies to Measure Progress."

The following process was then used by FIFI-S participants to allow for working through the systems thinking process related to FEND standard implementation. FIFI-S workgroups, guided by faculty, used implementation science tools for the initial identification of issues to be addressed, beginning implementation planning and the process of implementation.

Note: Examples of the workgroup process are detailed in the White Paper, and implementation tools are found in the White Paper Appendices.

Workgroup identification of gaps and/or FEND issues to be addressed using two evidence-based models:

"Workgroups used the Logic and/or the Fishbone Model approach to implement IFCDC Standards, Competencies, and Best Practices in Intensive Care Management of FEND of the newborn found at the website: https://nicudesign.nd.edu/nicu-care-standards/ "

Workgroups used the *Logic and/or the Fishbone Model* approach to implement IFCDC Standards, Competencies, and Best Practices in Intensive Care Management of FEND of the newborn found at the website: https://nicudesign.nd.edu/nicu-care-standards/ .

> *The Logic Model* utilizes a graphic illustration of how a program or intervention is expected to produce desired outcomes. The *Logic Model* is beneficial to better understand situations in complex and dynamic systems to highlight systems interactions/change, clarify aims and gaps, guide the development of measures, and track the progress of the intervention and changing needs. Because it provides a "big picture" overview, it must be combined with other tools to detail the steps and stages of the intervention and encour-

age creative thinking in change initiatives. (1)

The Fishbone Diagram determines the relationship between the cause and effect of the problem/situation. It can be used to determine possible causes and causal relationships of a problem or when a team's thinking tends to fall into ruts. (2,3) The diagram can be used when challenges, obstacles, or barriers hamper the progress of a change initiative.

Workgroup planning for implementation of FEND Standards using the PDSA and Key Driver approaches at the FIFI-S forum:

The *Plan-Do-Study-Act (PDSA) Rapid Cycle of Improvement* approach shows how to change an idea into action. It helps define the cycle(s)/initiative(s) of the change needed for implementation.

A *Key Driver diagram* shows the relationship between the project's overall aim, the primary drivers/key drivers that contribute to achieving the objective, the secondary drivers that are parts of the primary drivers, and change ideas to test for each secondary driver. It helps to visualize what drives the achievement of the aim/objective – steps, sequence, new knowledge, skills - needed to make a difference/change, as well as to know if the endpoint has been reached. (4)

"Throughout the implementation phase, caregivers and parents monitor the process, communicate openly, and share innovations with the team to maintain consistency of practice. "

Systems Implementation Strategies of the FEND Standards:

Execution, Monitoring, and Maintenance:

Throughout the implementation phase, caregivers and parents monitor the process, communicate openly, and share innovations with the team to maintain consistency of practice. The roll-out of each change idea/initiative can be managed using continuous improvement process tools. Consistent use of these tools helps to ensure that caregivers stay motivated.

Workgroups focused on the following strategies using continuous improvement strategies:

Monitoring the Implementation – Continuous monitoring is critical to know if the change has been implemented to achieve the desired outcome.

Maintenance – Although challenging, change must be maintained in any change process. When the change initiative is complete, the measures/metrics are documented, and the outcome evaluated, consider the spread of the initiative to the larger population of babies, like-ICUs, out-patient services, community outreach services

Evaluating and monitoring of FEND standards systems implementation:

Lessons Learned – There are always lessons learned from an experience. Asking what has been learned through the change process(s) and monitoring the data is helpful.

Playbook/Storybook – The development of a playbook/storybook records the products and process of the CQI improvement and subsequent improvements over time. (3)

Dissemination and Publication –Dissemination of the process and findings of the CQI initiative to share the experience and data with comparable systems constitutes a component of the evaluation.

Sustainment – Sustain the practice long term by continuously monitoring the education, competency, collaboration, and outcome(s). As science evolves, sustaining improvement and continuing to improve over time can be challenging, though it is paramount.

"As a summary of the FIFI-S initial forum, the White Paper describes how like-minded neonatal interprofessionals can engage in collaborative work using evidence-based implementation science strategies."

FIFI-S White Paper Executive Summary—Final Words

The first FIFI-S Forum White Paper has summarized evidence-based approaches that apply implementation science strategies for integrating IFCDC standards related to feeding, eating, and nutrition delivery. As a summary of the FIFI-S initial forum, the White Paper describes how like-minded neonatal interprofessionals can engage in collaborative work using evidence-based implementation science strategies. The White Paper describes strategies and tools for developing initiatives for the successful and ongoing implementation of IFCDC standards. It also provides guidance with specific process examples for interprofessionals committed to implementing evidence-based IFCDC standards, competencies, and best practices in intensive care.

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Disclosure: The author has no conflicts of interest

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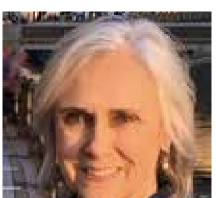

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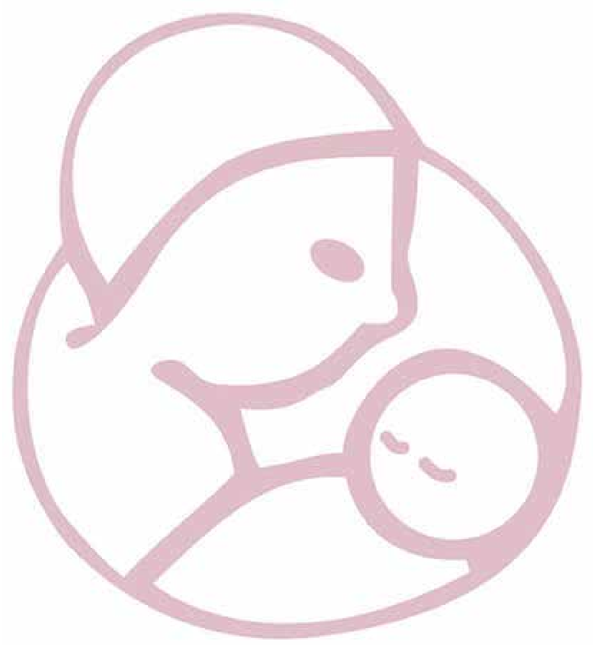

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Leadership

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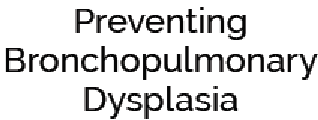

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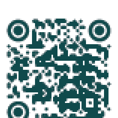

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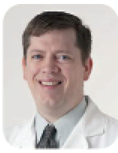

Jonathan R. Swanson, MD, MSc

Associate Professor of Pediatrics
University of Virginia
Children's Hospital
Charlottesville, VA

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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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.**

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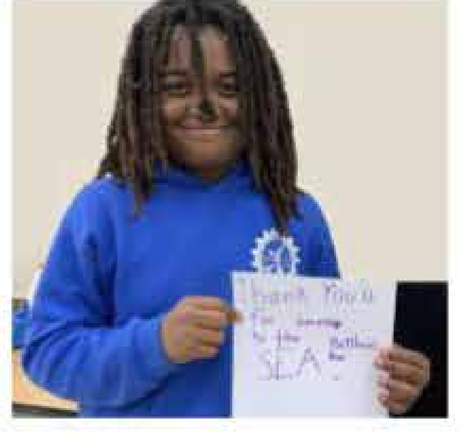

1 session	$15
1 week	$30
1 month	$120
1 semester	$540
1 year	$1,080
Middle School	$3,240

he Emily Shane Foundation is a 501(c)3 nonprofit charity, Tax id # 27-3789582. Our flagship SEA (Successful Educational Achievement) rogram 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.

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Respiratory Care Week: Essential Skills Exceptional Care

Bernadette Mercado BS RRT

Please celebrate with us that it is Respiratory Care week! Oct 23-29 is Respiratory care week. The theme this year, 2022, is Essential Skills Exceptional Work.

Take the time to pat your Respiratory Therapist on the back. Say how appreciative you are of each one of them. What is Respiratory Care week, and why do our RT have such a special week just for them? Do people in the hospital or patients know it is respiratory care week?

"Take the time to pat your Respiratory Therapist on the back. Say how appreciative you are of each one of them. What is Respiratory Care week, and why do our RT have such a special week just for them? Do people in the hospital or patients know it is respiratory care week?"

The AARC, or American Association of Respiratory Care, sets a date and theme for Respiratory care week. Usually, Respiratory Care week is around the last week of October. This is the opportunity for Respiratory Therapists to shine and let the community know more about the profession. This is also the best time of the year to praise your Respiratory Therapist for a job well done.

Respiratory Therapists are more than treatment-pushing and ventilator knob-turning health care professionals. Respiratory Therapists undergo extensive training for 2-4 years in college school, two board certification, and some RTs even take other certifications to broaden their scope of practice. They contribute to the most critical aspects of the hospital. Giving a baby their first breath is vital as giving an adult person a new lease on life by weaning them off ventilators and assisting them in rehabilitation to breathe on their own.

During the pandemic, RTs suddenly emerged from the depths of the hospital chain. Respiratory Therapists are also heroes who work hand in hand with doctors in the sickest rooms of patients and the most critical care units. They are in delivery rooms assisting premature babies to take that first breath of life.

The respiratory Therapist's role is evolving. RTS are present in-home care; they participate in the community. Asthma and COPD clinics and pulmonary rehabs are emerging even before the pandemic. More RTs are pursuing higher education and focusing on sharing the importance of treatment to support the pediatric and adult patient population living with chronic respiratory issues.

Knowledge is power. The more people who know their lungs are being damaged due to undiagnosed COPD, the greater the number of people who will be able to engage in activities, education, and treatments that will slow or halt the progression of the disease. (Rickards T, Kitts E., 2018) More understanding of what smoking can do to unborn children through education and early prevention from Respiratory professionals is essential. Asthma education can save the lives of young children and teenagers and have parents at ease knowing their children are knowledgeable and know the steps in preventing, monitoring, and medicating.

Funding Programs that provide opportunities for partnership to sustain long-term programs is essential, and having the Respiratory Therapist on the front-line working hand in hand with doctors

and RN will help in successful COPD or asthma programs for the community. The value of preventative health care programs is essential in promoting healthy and sustainable living.

" More understanding of what smoking can do to unborn children through education and early prevention from Respiratory professionals is essential. Asthma education can save the lives of young children and teenagers and have parents at ease knowing their children are knowledgeable and know the steps in preventing, monitoring, and medicating."

During Respiratory Care week, Food is the language of love in the hospital; the administration, managers of different units, and Vendors shower the Respiratory Department with love. In cooperation with Respiratory Managers, the administration makes it a point to recognize the Respiratory Therapist on this special week-long celebration. However, behind that Food, banners, and congratulations, let us remember that Respiratory care week has a deeper meaning. It is not just about the celebration but also about recognition and a demonstration of what RTs can bring to the healthcare system as a vital part of the multidisciplinary team. RTs have the essential skills to give exceptional care. #RCWEEK2022

References:

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Disclosures: The author has no conflicts noted.

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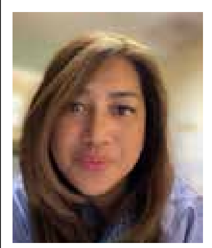

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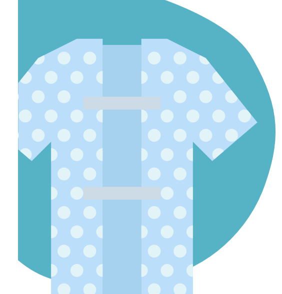

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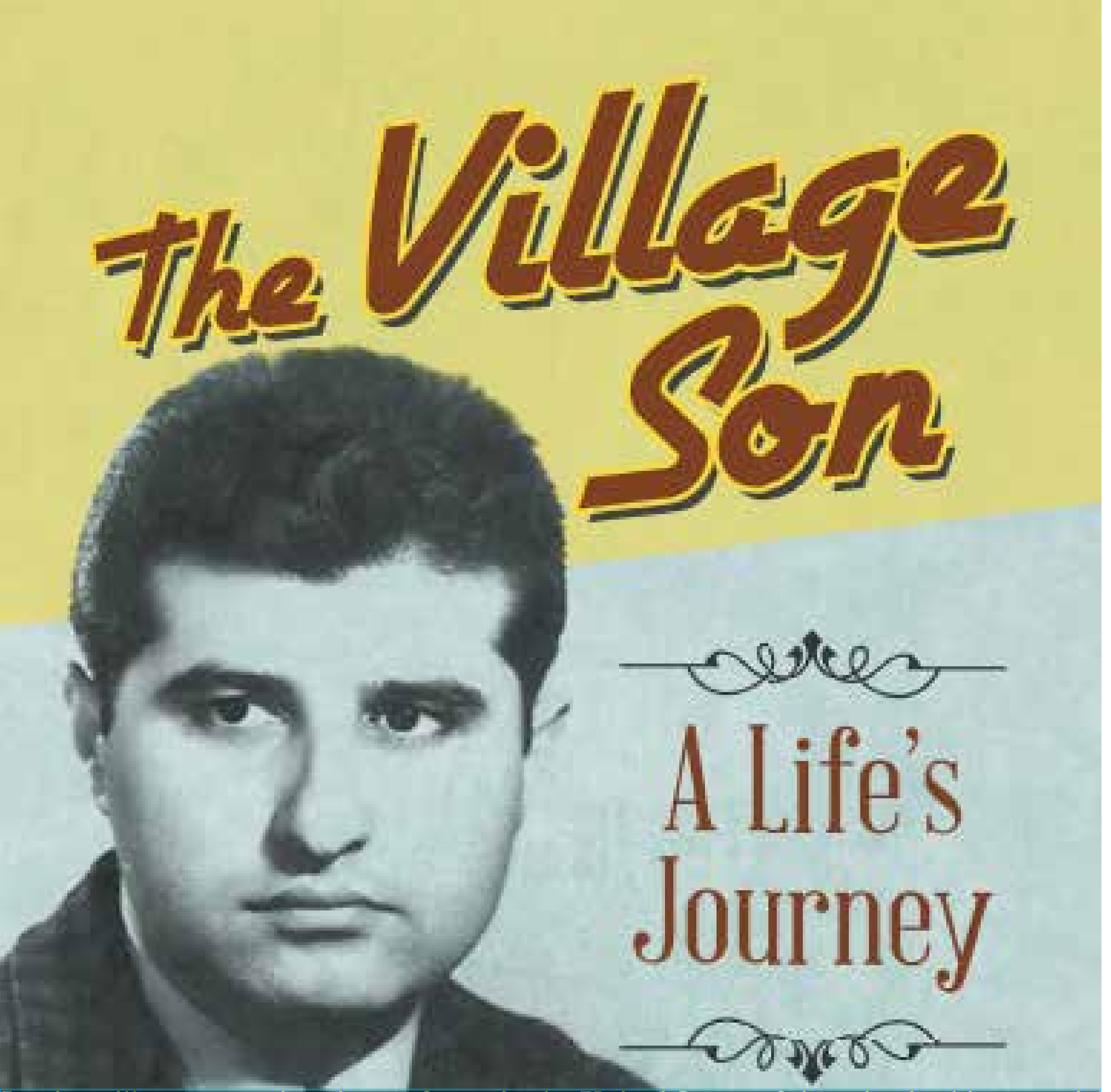

Iranian village to a university professor in the United States of America in this memoir. As a boy, his unruly behavior was sedated by scholastic challenges as a remedy. At age twelve, he left home for junior high school in a provincial capital. At first, a lack of self-esteem led him to stumble, but 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.

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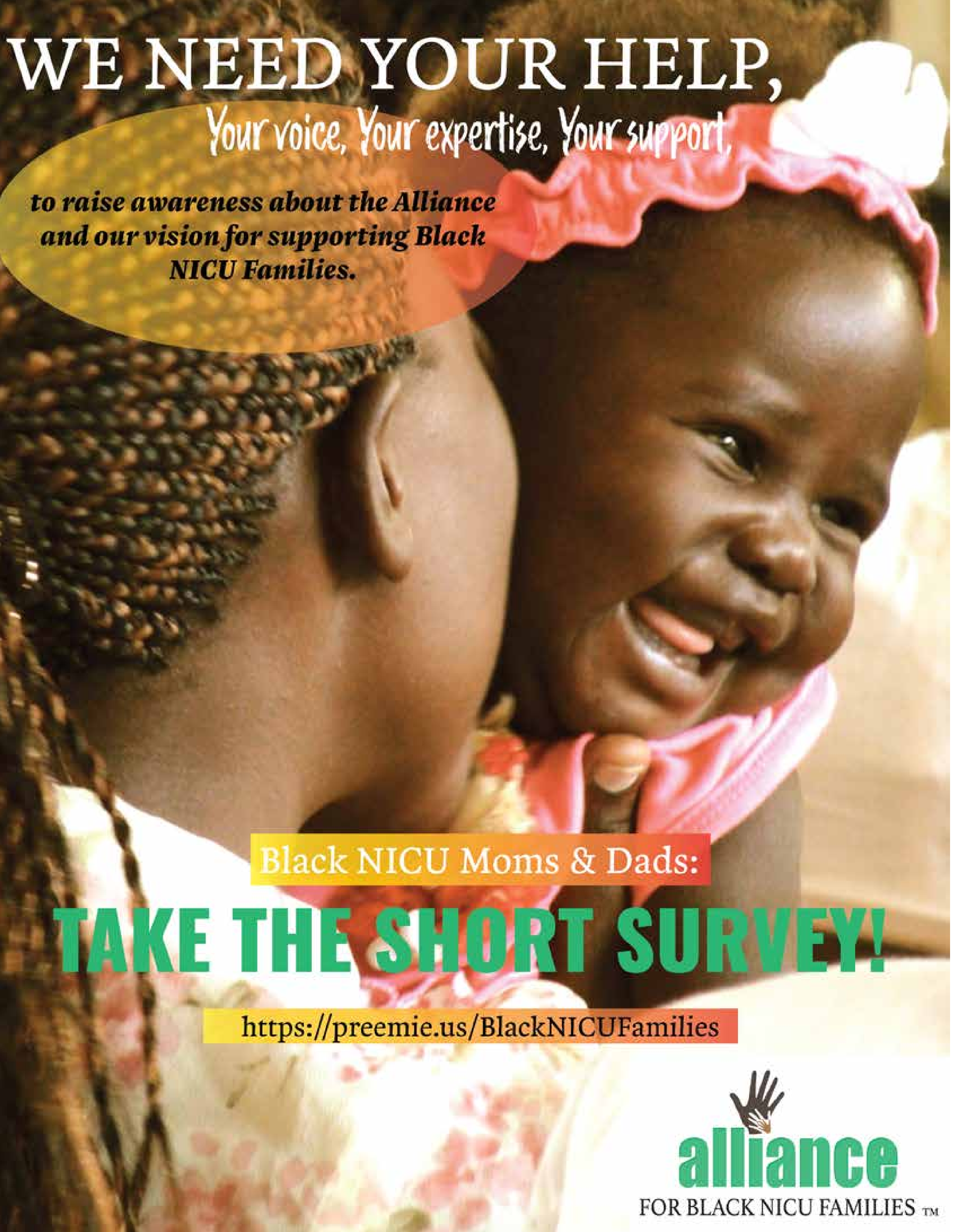
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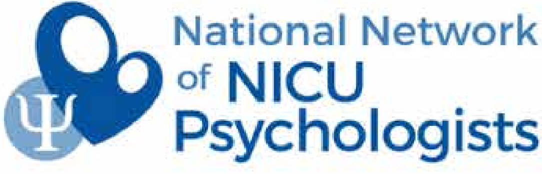

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- Bonding with Your Baby
- Caregivers Need Care Too

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The Importance of Infant-Safe Sleep Practices for Second Sleep

Barb Himes, CD

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

October marks Infant Safe Sleep Awareness Month and Sudden Infant Death Syndrome (SIDS) Awareness Month and is an excellent time to call attention to a risk that is likely overlooked in infant safe sleep education.

"October marks Infant Safe Sleep Awareness Month and Sudden Infant Death Syndrome (SIDS) Awareness Month and is an excellent time to call attention to a risk that is likely overlooked in infant safe sleep education."

In May 2022, the American Academy of Pediatricians (AAP) released a study (1) of safe sleep practices during infant second sleep among a 1,500 sample of White (65%), Black (12%), and Hispanic (17%) participants, nearly three-fourths of which were female (74%). Safe sleep criteria followed AAP infant safe sleep guidelines and were defined as supine position, sleep in a separate space, and a crib, bassinet, cradle, or playard.

The study also looked at parental age, race, and ethnicity; first-time parents; homes with smoke exposure; and infants born at 37 weeks.

"The results were sobering. While 44% met all three safe sleep practices at onset, it dropped to 39% reporting having a second-sleep practice, and, of those, 28% met the three criteria at sleep onset, but only 9% met them at both the first and second-time points."

The results were sobering. While 44% met all three safe sleep practices at onset, it dropped to 39% reporting having a second-sleep practice, and, of those, 28% met the three criteria at sleep onset, but only 9% met them at both the first and second-time points.

As the study authors point out, although nighttime waking is common with infants, less attention appears to be paid to infant second-sleep practices. This matters because sleep-related infant mortality claims 3,500 lives of babies in the United States each year, including sudden infant death syndrome (SIDS), accidental suffocation and strangulation in bed (ASSB), and deaths from unknown causes.

The advent of the public health campaign Back to Sleep (now known as Safe to Sleep®) in the 1990s resulted in a 50% drop in the mortality rate between 1994 and 1999 (2), but this rate has since stayed relatively level, and sleep-related Sudden Unexplained Infant Death (SUID) remains the leading cause of death for infants one month to one year of age.

At the core of the Back to Sleep and the subsequent campaigns are the AAP infant sleep guidelines, last updated in 2022, which also specify that in addition to placing infants sleep alone on their

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

At First Candle we're educating parents, grandparents and caregivers about safer sleep to make sure all babies reach their first birthday. Learn more at firstcandle.org

backs, the mattress is flat, firm, and level with no bedding, pillows or other items. Infants should share a room with adults during the first six months, but their sleep space should be separate.

"It matters that caregivers and health care providers counsel them to consider that the risks associated with not using safe sleep practices do not diminish from onset sleep to second sleep and may even increase. "

It matters that caregivers and health care providers counsel them to consider that the risks associated with not using safe sleep practices do not diminish from onset sleep to second sleep and may even increase. The study reported that 18% of infants who used a separate space at sleep onset slept with another person after nighttime waking, which can increase the risk of overlay and ASSB.

Understanding family situations, characteristics, and cultural practices also play a role in advancing infant-safe sleep practices. Every family is different, and coming to pre-conclusions about their perspectives on safe sleep can be misleading. The study indicated that parent characteristics, including being under 25, first-time parents, parents identifying as Black non-Hispanic or Hispanic ethnicity, parent education (four-year degree or higher), smoking, and infants born at less than 37 weeks were associated with second-sleep practices after nighttime waking.

"However, results also indicated that households with cigarette smoke exposure and babies born at less than 37 weeks had a lower prevalence of meeting all three safe sleep criteria at sleep onset, which is important because both are at higher risk of sleep-related death."

However, results also indicated that households with cigarette smoke exposure and babies born at less than 37 weeks had a lower prevalence of meeting all three safe sleep criteria at sleep onset, which is important because both are at higher risk of sleep-related death.

The study authors conclude that the findings "highlight that many parents may benefit from discussion with their pediatrician specifically focused on the importance of continued safe sleep practices after nighttime waking."

They also conclude, and we agree, that families and their healthcare providers should discuss nighttime wakings and the need for safe sleep practices every time. This is a component of our Straight Talk for Infant Safe Sleep workshops for healthcare providers, including nurses, agency workers, doulas, hospital staff, and others, and in our Let's Talk Community Chats with parents, extended family, and other caregivers.

The first, second, and all-time sleep preparation call for infant-safe sleep practices.

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2. *https://safetosleep.nichd.nih.gov/activities/SIDS/progress*

***Disclosure**: The author is a Certified Doula and the Director of Education and Bereavement Services of First Candle, Inc., a Connecticut-based not-for-profit 501(c)3 corporation.*

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About First Candle

First Candle, based in New Canaan, CT, is a 501c (3) committed to eliminating Sudden Infant Death Syndrome and other sleep-related infant deaths while providing bereavement support for families who have suffered a loss. Sudden unexpected infant death (SUID), which includes SIDS and accidental suffocation and strangulation in bed (ASSB), remains the leading cause of death for babies one month to one year of age, resulting in 3,600 infant deaths nationwide per year.

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 CrossRef 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.

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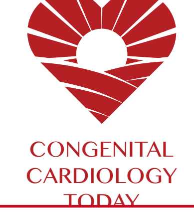

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Dermatologic Findings in Skin of Color for Life-Threatening Pediatric Diseases

Saba Saleem BS, Kristina Burger BS,

"The U.S. Census Bureau projects that by 2050 about half of all dermatologic patients who require treatment will have a skin of color. Skin conditions can present differently in patients with a darker complexion, but primary care physicians and dermatologists are not adequately trained to recognize this (1)."

Introduction

Dermatologic treatment disparities lead to inequitable health outcomes in vulnerable populations (3). Race, age, sex, education level, and health insurance status are all known contributing factors that magnify these disparities (2). The U.S. Census Bureau projects that by 2050 about half of all dermatologic patients who require treatment will have a skin of color. Skin conditions can present differently in patients with a darker complexion, but primary care physicians and dermatologists are not adequately trained to recognize this (1). This is because the current dermatologic literature does not describe pathology presentations in people of color.

"Furthermore, one study found that only 2% of teaching provided at meetings hosted by the American Academy of Dermatology addressed the issue (2). As a result, medical students have reduced accuracy in diagnosing skin conditions if shown an image of the disease on darker skin (6)."

Furthermore, one study found that only 2% of teaching provided at meetings hosted by the American Academy of Dermatology addressed the issue (2). As a result, medical students have reduced accuracy in diagnosing skin conditions if shown an image of the disease on darker skin (6). In this discussion, we will focus on the life-threatening complications of Kawasaki Disease and congenital measles and highlight the potential for their associated skin findings to go unrecognized in pediatric patients of color. The implication of this suggests that minority patients may receive delayed or less aggressive therapy compared to their white counterparts (3). Late or misdiagnosis can lead to a higher morbidity and mortality rate that disproportionately affects this population, which largely comprises Hispanic and African American patients (2). Consequently, patients and their families may mistrust physicians and the healthcare system, worsening their care outcomes (4).

"Kawasaki Disease is an acute, systemic vasculitis that predominantly affects infants and young children between the ages of 6 months to 2 years (7, 10). It is the most common cause of acquired heart disease in American children, with 76% of patients being younger than age five (8, 12)."

Kawasaki Disease

Kawasaki Disease is an acute, systemic vasculitis that predominantly affects infants and young children between the ages of 6 months to 2 years (7, 10). It is the most common cause of acquired heart disease in American children, with 76% of patients being younger than age five (8, 12). The median age of onset is about two years old. Thus, presentation in the neonatal period is considered extremely rare (8, 10). The highest disease incidence is in patients of Japanese descent, followed by black and non-Hispanic white individuals, respectively (8, 9). The diagnostic criteria for Kawasaki Disease include a high fever (greater than 102° F) for five or more days and the presence of at least 4 of the following: bilateral non-purulent conjunctivitis, oral mucosa abnormalities, polymorphous skin rash, peripheral extremity changes, and cervical lymphadenopathy (5). During the acute phase (1-2 weeks of onset), the most characteristic symptoms are a "strawberry red" tongue, cracked lips, and a maculopapular rash. Watchful waiting may be necessary to confirm the diagnosis in patients who do not display all these clinical features at once (8). However, if treatment is considerably delayed or not provided, it can lead to Coronary

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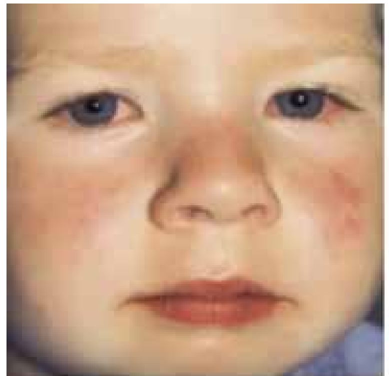
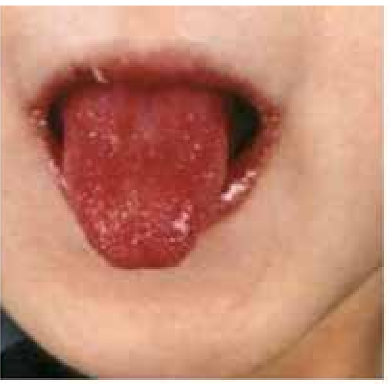

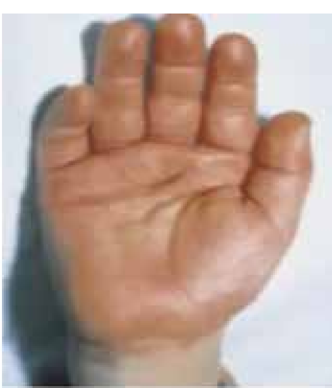

Figure 1: Kawasaki Disease symptoms (conjunctivitis, strawberry tongue, rash, palmar erythema) in a white child (13, 14).

Artery Aneurysm (CAA) formation (5). Lack of treatment can also cause sudden death in the subacute phase (2-8 weeks after onset) due to an increased risk of thrombosis. During this period, the patient may appear to be doing better because of the disappearance of fever and other physical symptoms. However, being left untreated results in an elevated platelet count, which creates a hypercoagulable state. Therefore, all children diagnosed with Kawasaki Disease require intravenous immunoglobulin (IVIG) in combination with high-dose aspirin within the first ten days of illness. The most efficacious period is within seven days from the onset of fever. Providing IVIG and aspirin decreases the risk of CAA development to less than 5% and inhibits platelet activation to prevent thrombus formation (8).

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Kawasaki Disease is an acute, systemic vasculitis that predominantly affects infants and young children between the ages of 6 months to 2 years (7, 10). It is the most common cause of acquired heart disease in American children, with 76% of patients being younger than age five (8, 12). However, it is important to note that even with prompt diagnosis and treatment initiation, the research suggests that there are also racial and ethnic discrepancies in treatment response. One study found that despite no racial difference in time to diagnose and provide treatment, black children with Kawasaki Disease still had worse outcomes than white children. Black patients had more severe inflammation and worse response to IVIG, requiring adjuvant medications such as Etanercept and longer hospitalizations. Providing the standard treatment of IVIG and aspirin within the recommended window did not reduce the risk of coronary artery abnormalities in black children to the same extent as in other demographics (9). This highlights the fact that recognition of physical exam findings of Kawasaki Disease in darker skin tones is only one part of the solution to improving treatment outcomes. There must also be an emphasis on individualizing therapy to the racial and ethnic background of the patient once the diagnosis is made.

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Congenital Measles

Measles (rubeola) is a highly contagious and potentially fatal disease caused by a viral respiratory infection. It is a vaccine-preventable disease and was almost completely eradicated in the United States (19). However, due to declining vaccination rates, there has been a worldwide resurgence between 2017-2019. Fortunately, between 2020-2021, the case numbers dropped again, which was attributed to social distancing with the COVID-19 pandemic (20). Despite this positive news, there is a growing concern that outbreaks will occur again as restrictions ease and the number of unvaccinated children increases (21). Measles

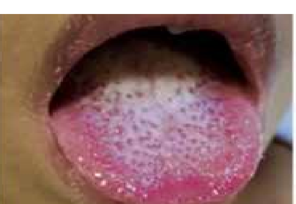

Figure 2: Kawasaki Disease symptoms in a Brazilian child with a medium-to-dark complexion (13, 15).

symptoms begin 7-14 days after exposure and include high fever (above 101° F), maculopapular rash, and at least one of the three C's: cough, coryza, conjunctivitis (19, 20). However, vaccinated individuals can have mild-to-no symptoms. Thus, diagnosis depends on detecting specific IgM antibodies in the serum, fluid, or viral RNA in bodily fluids (20). Acute management for measles includes vitamin A supplementation, a potent immune system enhancer that reduces the risk of blindness and death by 87% for children under two years (22, 23). It is also imperative to monitor and treat secondary bacterial infections with antibiotics. However, since there is no specific antiviral therapy, disease control largely depends on vaccine-driven prevention (21). Recognizing the measles rash and other characteristic symptoms is essential for early diagnosis and treatment (23). The rash begins on the face and spreads to the neck and upper trunk, followed by the lower trunk and extremities. The lesions on the face may become confluent, and the palms and soles are rarely involved. After 3-4 days, the rash changes to a purple-brown color and begins to fade with desquamation (24).

"The measles rash can be misdiagnosed in brown skin tones because it appears hyperpigmented and can resemble petechiae (See Figure 3). It may be missed entirely in black skin as it can be challenging to identify, except for its rough and textured surface (see Figure 4)."

The measles rash can be misdiagnosed in brown skin tones because it appears hyperpigmented and can resemble petechiae (See Figure 3). It may be missed entirely in black skin as it can be challenging to identify, except for its rough and textured surface (see Figure 4). In contrast, the rash is more distinctly visible on lighter skin and appears erythematous (25). The danger of a late diagnosis in the neonatal period is an increased risk of subacute sclerosing panencephalitis (SSPE), a degenerative neurological disease. Measles infection before one year of age can cause SSPE due to the immaturity of the brain (26). Thus, measles is often more deadly in infants and young children (28). Other complications include otitis media, laryngotracheobronchitis, and pneumonia, as the virus destroys epithelium, which favors bacterial superinfections (27). Pregnant women and infants under one year are among the highest-risk groups for these life-threatening complications because of their inability to receive the MMR vaccine (19). This is known as congenital measles, when an infected pregnant woman transmits the virus to her fetus. It is further defined as the presence of the measles rash at birth or within the first ten days of life. Mothers infected with measles late in pregnancy can also transmit the virus postpartum. Newborns with measles display a more severe and rapidly progressive form of SSPE (28). Regarding MMR vaccination before pregnancy, a study on maternal vaccine acceptance found that Black and Hispanic women are less confident in vaccine safety and efficacy and less likely to perceive the risk of acquiring vaccine-preventable diseases (29). These results suggest that congenital measles may be more prevalent in minority populations; however, further research is required.

"With these strategies in place, we can better address treatment disparities and improve health outcomes."

In summary, to correctly identify the measles rash when it presents in a patient of color, healthcare providers should have a high index of suspicion based on the patient history and vaccination status. Prevention is the most critical component of treatment, and it begins with communication. Providing families with evidence-based vaccine information will help them make informed decisions and clear misconceptions (19). Lastly, implementing a nationwide "catch-up vaccination campaign" would help alert parents to the urgency of resuming their child's immunization schedule as the pandemic disrupted it. With these strategies in place, we can better address treatment disparities and improve health outcomes.

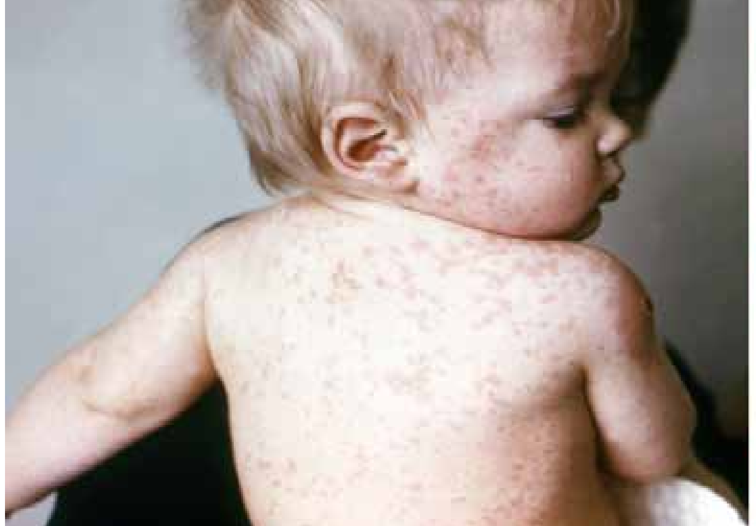

Figure 3: Comparison of measles rash in a white and Filipino infant (16, 17).

Figure 4: Nigerian child with measles rash covered by calamine lotion (18).

Conclusion:

Kawasaki Disease and congenital measles can be fatal in pediatric populations if left untreated. Both diseases share a characteristic maculopapular rash; however, this skin finding and other symptoms vary among racial and ethnic groups. Healthcare providers should be aware of potential treatment resistance to Kawasaki Disease in black children and the risk of congenital measles in black and Hispanic newborns with unvaccinated mothers. Physicians can use this information to help guide their diagnosis and management, which can be helpful in vague or unclear clinical presentations. The clinical course of these diseases, particularly in neonates, requires swift recognition and treatment within a certain timeframe; otherwise, there can be deadly consequences.

One way to address this issue is by incorporating health education, open dialogue, and family engagement in discussions about preventing the spread of highly infectious diseases. Another solution is to update dermatologic literature to include more images of skin conditions in patients with a darker complexion. This is especially necessary for diseases with a higher incidence in patients with brown or black skin. For instance, African American children with atopic dermatitis are more likely to develop eczema herpeticum, a medical emergency, than white children. The research shows that due to decreased healthcare utilization in black communities, the disease presentation becomes more advanced than what may be shown in textbooks. Increased disease severity also occurs because darker skin masks the associated erythema, further delaying care (30). An organization that aims to promote awareness of this problem is The Skin of Color Society, which educates providers and the public on dermatologic diseases in the skin of color to help achieve health equity. Better health outcomes will then translate into a stronger trust between the patient and their physician.

"One way to address this issue is by incorporating health education, open dialogue, and family engagement in discussions about preventing the spread of highly infectious diseases. Another solution is to update dermatologic literature to include more images of skin conditions in patients with a darker complexion."

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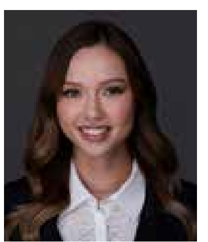

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Which Infants are More Vulnerable to Respiratory Syncytial Virus?

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 guidlines limit their access to RSV preventative treatment, increasing these babies' risk.

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Provide culturally-informed and respectful care.

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

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

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and

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NICU Parent Network

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

TOP 10

RECOMMENDATIONS FOR THE PSYCHOSOCIAL SUPPORT OF NICU PARENTS

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

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

1 PROMOTE PARTICIPATION

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

2 LEAD IN DEVELOPMENTAL CARE

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

3 FACILITATE PEER SUPPORT

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

4 ADDRESS MENTAL HEALTH

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

5 SCREEN EARLY AND OFTEN

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

6 OFFER PALLIATIVE & BEREAVEMENT CARE

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

7 PLAN FOR THE TRANSITION HOME

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

8 FOLLOW UP

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

9 SUPPORT NICU CARE GIVERS

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

10 HELP US HEAL

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

SUPPORT4NICUPARENTS.ORG

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

Take precautions & LIMIT INTERACTIONS.

6 FT

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

Keep prenatal APPOINTMENTS.

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

LEARN MORE ›

NCfIH National Coalition for Infant Health

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

nicuparentnetwork.org

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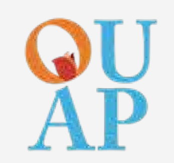

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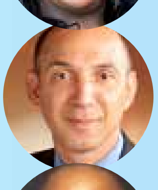
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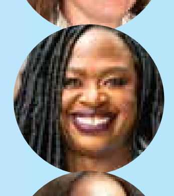
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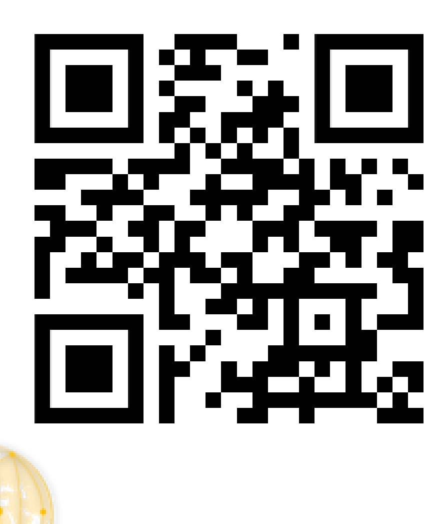
Raising Global Awareness of RSV

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.



The RSV awareness video was produced in collaboration with the Bill & Melinda Gates Foundation

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.**

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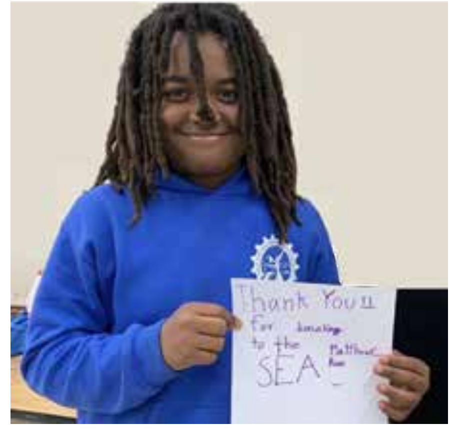
The average cost for the program to provide a mentor/ tutor for one child is listed below.



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.

Peer Reviewed

In Memory of Dr. Heidelise Als

Joy Browne, PhD, Shannon Hanson, PhD, Michael Hynan, PhD

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.

"Although Dr. Als was most well known for her developmental work, she was also a trained clinician and member of the National Network of NICU Psychologists (NNNP)."

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Dr. Heidi Als, founder of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) died last August. Although Dr. Als was most well known for her developmental work, she was also a trained clinician and member of the National Network of NICU Psychologists (NNNP). Members of the leadership of NNNP would like to express their appreciation of the propound impact of Dr. Als' work through a few remembrances expressed here. Dr. Als' influence on many members of NNNP can also be found in chapters of a recently published book, "Behavioral Health Services with High-risk Infants and Families: Meeting the Needs of Patients, Families, and Providers in Fetal, Neonatal Intensive Care Unit, and Neonatal Follow-up Settings." (1,2) Prior to the remembrances, we have reprinted a few paragraphs from Dr. Als' obituary."***Heidelise Als, PhD, 1940-2022,*** *Professor of Psychology, Department of Psychiatry, Emerita, Harvard Medical School, Director, Neurobehavioral Infant, and Child Studies, Boston Children's Hospital, Founder, NIDCAP Federation International, Inc*

Heidelise Als, PhD, of Boston, Massachusetts, and Tunbridge, Vermont, died suddenly on Thursday, August 18, 2022. She is survived by her husband, partner, and research colleague of 44 years Frank H. Duffy, MD (Neurologist at Boston Children's Hospital and Associate Professor of Neurology, Harvard Medical School and Department of Neurology, Boston Children's Hospital), and son Christopher Hopkins Als Duffy of Camphill Village (an anthroposophical community for adults with developmental disabilities in Copake, New York).

Heidelise (Heidi) was born in Krumbach, Germany in 1940, the daughter of Elizabeth Broicher and Heinrich Maria Als, a barrister. Heidi grew up in war-torn and post-World War II Germany. Her experiences during these formative years led her to question how people develop their emotions and inspired her to study how people are shaped by their environment.

During her graduate training and newly married to her first husband, Heidi gave birth in 1965 to her son, Christopher. He was a beautiful infant whose neurological and developmental differences shaped Heidi's career by teaching her to understand that babies communicate and participate in their care if adults would only listen. This understanding led her to create a theoretical model, the Synactive Theory, which became the foundation for the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) in 1982. This caregiving approach quickly became internationally recognized. During this year, Dr. Als established the National NIDCAP Training Center, affiliated with both Boston Children's Hospital and Brigham and Women's Hospital, which provided a formal structure for NICU professionals to become certified in the use of NIDCAP within their own NICUs.

"Dr. Als founded the NIDCAP Federation International, Inc., a non-profit organization (501c3) that ensures the quality of the NIDCAP model of developmental care education, training, and implementation and ultimately improves the future for infants in hospitals and their families around the world."

In 2001, to coordinate and support NIDCAP training and training center development, Dr. Als founded the NIDCAP Federation International, Inc., a non-profit organization (501c3) that ensures the quality of the NIDCAP model of developmental care education, training, and implementation and ultimately improves the future for infants in hospitals and their families around the world. Today there are 29 centers around the world training in individualized, developmental, family-centered, research-based NIDCAP care."

"She embodied the definition of resilience, using her personal experience of having a high-risk baby as the guide to create an innovative way to care for patients and families in the NICU. She was approachable and supportive, a true mentor."

From Dr. Shannon Hanson:

When I think of Dr. Heidi Als, the words that come immediately to mind are passionate, compassionate, committed, and tireless. She was a visionary and an inspiration. She embodied the definition of resilience, using her personal experience of having a high-risk baby as the guide to create an innovative way to care for patients and families in the NICU. She was approachable and supportive, a true mentor. Like the gardener she was at heart, she sowed the seeds of NIDCAP far and wide so that those who work in NICUs worldwide could bloom where we were planted.

"Later she worked with Dr. T Berry Brazelton to develop his Newborn Behavior Assessment Scale. In the consulting call, she said that Dr. Brazelton worried, "If you go into the NICU, I will lose you." Dr. Brazelton's loss meant an enormous gain for the world."

From Dr. Michael Hynan:

I heard Dr. Als speak at three conferences, and I was in awe of her knowledge and dedication. Years later, I contacted her with a request to serve as a consultant on one of the phone discussions of the growing group of NICU psychologists, now the NNNP. She agreed to explain her NIDCAP work to the group and answer questions. During our two or three conversations prior to the group call, I always addressed her as "Dr. Als." I got a very warm feeling when she asked me to call her "Heidi". The consulting call with Heidi set a record for the number of participants. Heidi described her early work as a graduate student observing preterm infants' behavior for countless hours. Later she worked with Dr. T Berry Brazelton to develop his Newborn Behavior Assessment Scale. In the consulting call, she said that Dr. Brazelton worried, "If you go into the NICU, I will lose you." Dr. Brazelton's loss meant an enormous gain for the world.

"On a chance trip to a meeting in Boston, I heard a presentation by Dr. Als, who was describing her new Assessment of Preterm Infant Behavior (APIB) and the promise of better medical and neurodevelopmental outcomes for babies such as those with BPD. I was immediately interested in getting trained in the APIB, which was available before NIDCAP was available or even had an acronym."

From Dr. Joy Browne:

In the early 1980s, I was the Director of a Pediatric Pulmonary Center in New Mexico. We were trying to support preterm infants who had developed bronchopulmonary dysplasia (BPD). Babies we cared for struggled to breathe and had many difficulties with fussing, interacting, sleeping and eating, and development. Most spent their first few months and even years in the intensive care unit. On a chance trip to a meeting in Boston, I heard a presentation by Dr. Als, who was describing her new Assessment of Preterm Infant Behavior (APIB) and the promise of better medical and neurodevelopmental outcomes for babies such as those with BPD. I was immediately interested in getting trained in the APIB, which was available before NIDCAP was available or even had an acronym. After the emergence of a more structured NIDCAP program, I was fortunate to be guided by Dr. Als to establish the first NIDCAP training center outside of the Boston "mothership."

The next decades were full of applications of the supportive NIDCAP approach in NICUs that were not readily accepting of this "soft science." The NIDCAP Federation International (NFI) was established, and the now global integration of Dr. Als's vision for professionals and parents to understand the newborn's voice. Integration of her vision into clinical practice has changed NICU policies, procedures, and outcomes for babies worldwide. There are currently 29 NIDCAP training centers in the United States, Europe, Asia, South America, Australia, and Japan. For more information, see https://nidcap.org

"Through thick and thin, her vision was to provide exemplary neurodevelopmental, evidence-based care for babies and their families and support staff caring for them."

Along the way, I developed a personal and professional relationship with Dr. Als. Her style was exacting, rigorous, and structured, yet warm and supportive simultaneously. Her "good enough" was typically not quite "good enough," leading the learner to continue striving to be a better observer and clinician. Through thick and thin, her vision was to provide exemplary neurodevelopmental, evidence-based care for babies and their families and support staff caring for them. Her focus was primarily on how babies communicate their needs and strengths and how the professional needs to recognize the goal striving of each and every individual baby. The result was the individualized intervention approach according to the baby's needs indicated through their behavior.

After days of rigorous NIDCAP or APIB training, Dr. Als morphed into the elegant ballroom dancer, the pony-riding cowgirl, the roaring 20s flapper, or the obstacle course ninja. She definitely knew how to play and always encouraged others to play along with her.

Few leaders in the field have been more committed to supporting babies and families, took on countless naysayers with grace and poise, or showed every person who interacted with her a personal and unforgettable experience.

The philosopher Thomas Kuhn in his groundbreaking "The Structure of Scientific Revolutions" (3), wrote that "scientific fields undergo periodic *paradigm shifts*" rather than solely progressing linearly and continuously and that these paradigm shifts open up new approaches to understanding what scientists would never have considered valid before". He further notes that the initial rejection of new concepts and approaches is often downplayed or even rejected by the scientific community until enough evidence and change in practice make people think that the initially rejected new practices are "the norm." His perspective describes Dr. Als' work succinctly. Her work and evidence were initially rejected as, at worst, detrimental to neonatal care and, at best, "soft" science. She provided a true "paradigm shift" to neonatal care, making neurodevelopmentally supportive care now the norm rather than the exception in global NICUs. Every NICU that practices developmental, family-centered care pays tribute to her dogged determination to provide babies and families with evidence-based, sensitive, and individualized developmental care.

Dr. Als' leadership, compassion, and personal integrity will be sorely missed. However, she leaves a cadre of committed professionals who join in promoting her vision to provide sensitive, individualized care to every newborn, family, and intensive care professional.

"Dr. Als' leadership, compassion, and personal integrity will be sorely missed. However, she leaves a cadre of committed professionals who join in promoting her vision to provide sensitive, individualized care to every newborn, family, and intensive care professional."

In summary, we are very saddened by Dr. Als death but very appreciative of how her work has changed newborn intensive care. Members of NNNP have made a financial contribution to Camphill Village for the care of Dr. Als son, Christopher.

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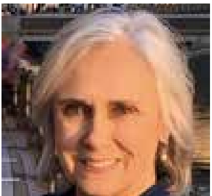
3. Kuhn, T. S. The Structure of Scientific Revolutions. Chicago: University of Chicago Press, 1962.

Disclosure: The National Perinatal Association www.nationalperinatal.org is a 501c3 organization that provides education and advocacy around issues affecting the health of mothers, babies, and families.

Corresponding Author



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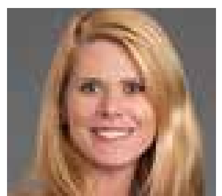

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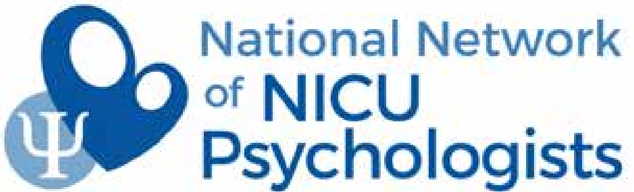
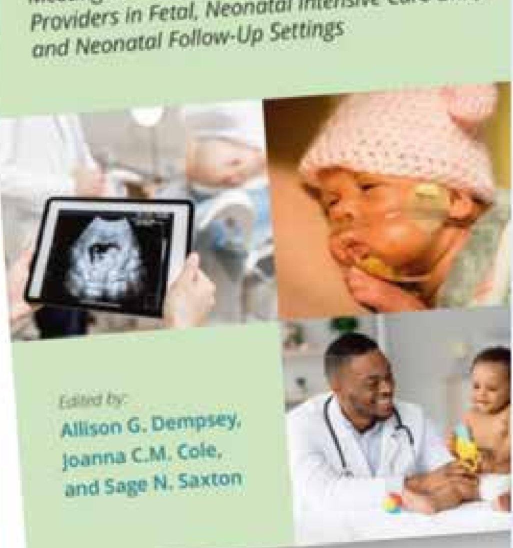


Education, Resources, and Support for Perinatal Mental Health Professionals



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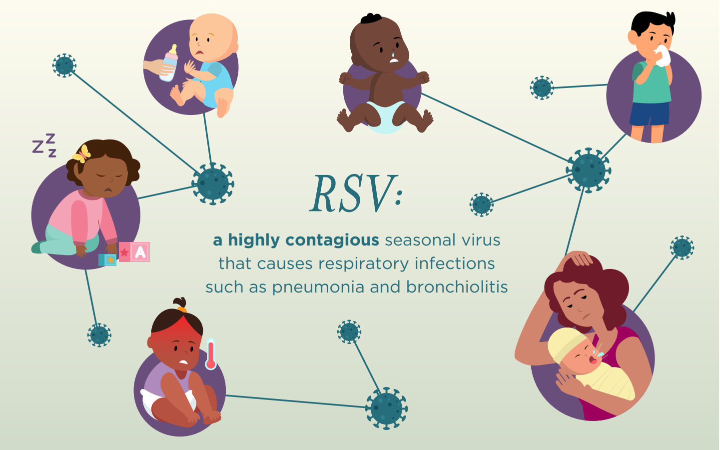

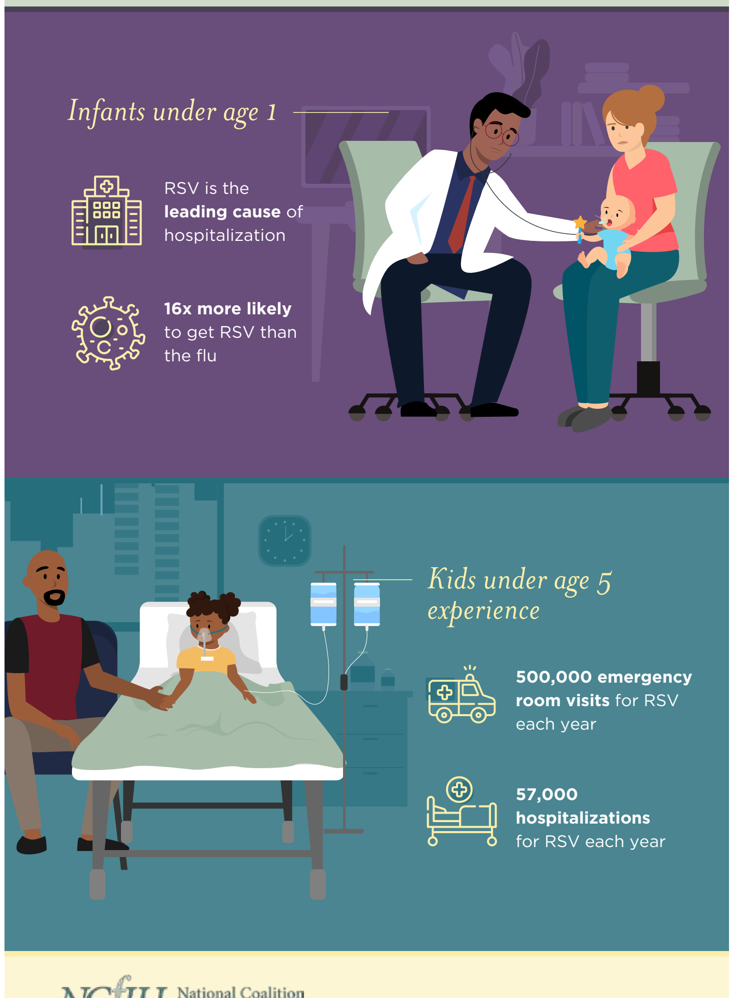

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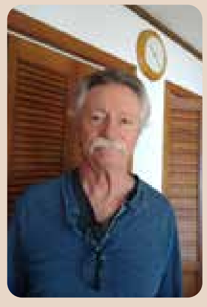
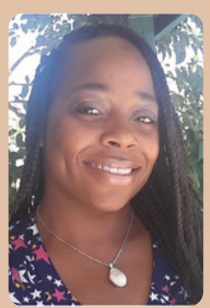


Mike Hynan, PhD
he/him
Emeritus Board Member, National Perinatal Association



Necole McRae
she/her
VP, GloPreemies
Exec. Director, Free2Read Education Recovery Services

Ways to Support Parents at Local NICU

PRESENTERS:

Michelle Wrench, RN, CCRN
she/her
CPQCC Family Advisory Council Chair

Dharshi Sivakumar, MD
she/her
Clinical Professor, Stanford University
Medical Director, El Camino Health NICU

The Power of Peer Support at the National Level

PRESENTERS:

Meegan Snyder
she/her
Director, Preemie Parent Mentor Program Graham's Foundation

Keira Sorrells
she/her
Founder and Exec. Director, NICU Parent Network

Peer Reviewed

Family Centered Care (FCC) Taskforce: How to build a Family Advisory Council in your local NICU

Marybeth Fry, Jennifer Johnson, Molly Fraust-Wylie, MA

This is the second of a series of Webinars from the Family Centered Taskforce. In this first interview, Mary Coughlin, MS, NNP, RNC-E described responding to " The Biological Urgency of Families in NICU Based on our Understanding of Trauma."

MaryBeth Fry:

Good afternoon, everyone. Thank you so much for that nice introduction. Good morning also on the West Coast. So sorry for that. I'm in Ohio, so Eastern for me. I'm going to be one of our three speakers today, talking about creating and strengthening your family advisory partnership councils in the NICU. Molly and I were consulting just a little bit at the VON conference this last week. So there may be some repetition in our presentations because we're all doing similar work but at all different sites. So please take away whatever it is that's beneficial to you as you're doing this work at your own site

"I'm going to be one of our three speakers today, talking about creating and strengthening your family advisory partnership councils in the NICU."

So just a little bit about my site and where we're located. I am with Akron Children's Hospital, Ohio. We are a Level IV regional transport NICU. I do find that that makes us a little bit unique sometimes in the work that we do regarding patients and families because all the babies that we treat here in our unit have mamas who are at other sites at the time of their initial admissions.

We are a seventy-five-bed, single-patient room unit that is divided into two floors and three wings. In that photo, we are [on] the top two floors, seven and six, and we do have three wings on those two floors. Our patient population includes premature babies and babies requiring many of our surgical services and NAS. Another eight sites within our region are Akron Children's Hospital NICUs or SCNs, and then we also take care of babies born anywhere within the region. I share all that information demographically with you because some of our patients come from an hour to two hours away, which sometimes can create challenges for families as they come to stay with their babies here in my unit. This is a picture of one of our single-patient rooms. I'm the NICU Family Care Coordinator here, and I have the good fortune to be able to offer support programming for families who are here with their babies.

" I share all that information demographically with you because some of our patients come from an hour to two hours away, which sometimes can create challenges for families as they come to stay with their babies here in my unit."

I did start that work as a volunteer back in 2009. My NICU experience was [in] 2004. So some of you may be thinking, Oh, wow! That's seventeen years, you're right. I have a high school senior this year. That was seventeen years ago when my actual make-you experience occurred. How do I stay relevant? Believe it or not, and I'm sure you'll hear this from others as we continue our webinar today. That experience never leaves you, but the pain and trauma of the experience here, so you can help other families as they continue the journey.

"There are those of us who work in paid roles and those of us who work in volunteer positions. I can't emphasize enough the importance of really pushing and furthering that paid position for consistency."

I did start as a volunteer and honestly didn't start until two years after I had my term baby, my son, who helped me to realize what a traumatic experience I had in the NICU. It really propelled me to want to help other families and support them, so over time, that volunteerism to become a paid parent position here in my unit as NICU Family Care Coordinator. There are those of us who work in paid roles and those of us who work in volunteer positions. I can't emphasize enough the importance of really pushing and furthering that paid position for consistency. Volunteers are phenomenal, generous folks who offer their time to make the experience better for families and who make the outcomes better for physicians and families. But it's just so important to really push for that consis-

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tency that can come with a paid position.

At Children's, our family advisory council is set up in this structure. We do have a hospital-wide council across all departments within our Children's Hospital. Then underneath our Family Advisory Council umbrella, we have smaller FACTs. A FACT is a family action collaborative team or a unit-based council. We have PICU, NICU, and hematology FACT groups.

We are fortunate in the NICU that this has been a long-standing group formed in 2005 by a group of really motivated NICU graduate families. They worked hard as volunteers with the Peer Mentor Coordinator to establish this group, and they have kind of taken on different roles. Some of our NICU FACT volunteers serve just on that group, while others are also peer mentors. Some volunteer members have served on QI teams. We also had a hospital employee serve as the go-between for our volunteers and the clinical team. Our NICU FACT does still, at this time, report to our larger hospital-wide FAC.

" We are fortunate in the NICU that this has been a long-standing group formed in 2005 by a group of really motivated NICU graduate families. They worked hard as volunteers with the Peer Mentor Coordinator to establish this group, and they have kind of taken on different roles. Some of our NICU FACT volunteers serve just on that group, while others are also peer mentors."

I share that timeline that really brief timeline with you because NICU FACT has had a long timeline of establishment, and along with that comes a lot of opportunities for projects and advancement. We must also talk a bit about the ebb and flow that comes with having a long-standing committee, right? At the very inception of the group, there was a great deal of motivation and excitement over supporting families, and at the time, we were a 59-bed pod-style unit. Today, we've been seven years in our current space of 75 single-patient bedrooms. So you know, those changes over time have affected our FAC population.

We had financial support from the March of Dimes at one time. We no longer have that. We now rely on donor funds and assistance from our capital budgets.

We have and do review and developed educational materials that go out to families. We do continue to try to have those celebration and support dinners. We'll talk about Covid in a little bit, because that definitely had an impact on some of the work that we've done. Being mentors, we are really fortunate enough for Children's to have an online parent mentor model. And so, if you were to go to our Admin Children's Hospital website and go under our volunteer tab, you would find a list of all our parent mentors that are available to families. We do find that it's a really nice way for families to reach out and get the support that they need at any given time as opposed to going through a coordinator. All the parent mentor profiles are uploaded and available online. We do really encourage a lot of our FAC members to become parent mentors as well. That way, we can encourage group and individual mentorship. Face-to-face meetings, as well as phone calls and email communication. Again, Covid had a bit of an impact on that because some of our parent mentors are not vaccinated. Currently, we require all volunteers to be vaccinated if they're going to come to the hospital. That said, it's just kind of propelled us to make sure that we're using other modes of communication, such as phone calls, email, and online platforms.

I was asked to talk a little bit about the challenges and solutions to maintaining a FAC in the unit. Families are growing and changing and relocating over time. As I said, this group was formed back in 2005. Many of the founding members of our group are no longer involved.

Your volunteer time changes and maybe, repurposed from providing feedback to NICU to serving on PTOs at elementary school or coaching on teams as children get older, so changes in families over time can affect your membership. It's really important to have active and ongoing recruitment and really clear terms of service. It's important for families to know what they're signing up for. What is the duration of time that they're going to be serving? Is it a year or 3 years? How do those cycles work with your FACs? In terms of service, what is involved in your FAC? Are folks going to be required to come to in-person meetings? Is there going to be an online platform? Are they going to be reviewing and developing education? What are the QI needs of the team? So those things are really important to be upfront with families as they're signing up. Leadership changes can also be a big impact on FACs. Your physician and provider leaders, and your nursing leaders all impact the work of the FAC. When leadership changes occur, the FAC should remain, and parent participation should still be meaningful in projects.

" Your physician and provider leaders, and your nursing leaders all impact the work of the FAC. When leadership changes occur, the FAC should remain, and parent participation should still be meaningful in projects."

Sometimes with leadership changes, perspectives change, and it's just still really important for your FAC to continue to have meaningful and meaningful quality Improvement projects to participate in and parent support opportunities as folks are volunteering their time. It's important for them to be able to see the impact that they're making in the unit so that they have that satisfaction and they know that the time is well spent in helping families. That's really what they're there for.

Covid.

Unfortunately, the negative impact that Covid has had on everything with regard to families as partners and family-centered care is great. I think it's also been a real opportunity for us to be able to leverage online platforms to continue the work. There are some FACs who transitioned wonderfully from being in person to being online. They were able to offer support to families online, and that was really important.

"Whatever the lasting impact of Covid is on your institution, it's really important to continue to use online platforms to continue engaging families in the work. For families who may have children at home with long-term needs or families who have recently transitioned home and [are] not comfortable taking their babies out in public, this is a great opportunity to leverage online platforms."

Whatever the lasting impact of Covid is on your institution, it's really important to continue to use online platforms to continue engaging families in the work. For families who may have children at home with long-term needs or families who have recently transitioned home and [are] not comfortable taking their babies out in public, this is a great opportunity to leverage online platforms. I often hear in work with families as partners. "Well, you know, we can't get families to participate in our FAC or in quality improvement. They're just not interested. I respectfully disagree. I promise there is always a family that is out there that wants to make the experience better for the next family. It's on us to make sure that we are extending the offer to engage them in that work. So I challenge all of you. Talk to your bedside staff and those frontline folks who are there day in and day out with families. They can be your point people, and they can give you a list of people to consider recruiting. Setting up tables at any of your hospital events promoting your FAC is another way to recruit members. Within your unit, promote the work of the FAC so current NICU families can see the impact of giving back to the unit. This may motivate them to seek FAC membership once they are transitioned home. Please ensure that the membership of FAC is reflective of your unit. I will be very transparent and say many units have yet to crack that nut. Many have a patient population where there are a lot of single-parent families who may not have additional support at home to take care of children or to come to meetings. It's up to us to continue to recruit families and leverage technology to gain their participation. We particularly need to be better at recruiting with a lens of equity. We need to really reach out to family members who have incredible insights in the work that we do.

Jennifer Johnson's Talk :

I just want to thank you for dedicating this talk to our NICU kids. That was really beautiful. Grace will be turning eleven this coming Monday. So any opportunity to see her voice and see her name on the screen is welcomed. So, thank you.

As Colby mentioned, I'm the Director of Family and Community Outreach, and I want to stress that there is no mention of NICU in my title. I am not NICU-specific, and quite honestly, I wondered if I was really right for this talk since my approach is very, very different. Then I kind of thought: you know what? Maybe someone will benefit from a very different approach. So bear with me. Here we go. My responsibilities in this job are really threefold, including growing an army of diverse families to give feedback and input... and of course, that's what I'll be talking about today. But I'm also out in the community representing the hospital through speaking engagements, community engagement, events, and fundraisers. And again, having been a journalist for twenty years, I still love to tell stories. I still embrace the media, and so I also work with our medical staff to help them feel comfortable working with the media and social media because, you know, we need educated voices on those platforms now more than ever. I also work with our staff to create medical education videos like the one in the lower part of your screen there on the right. This is on our NICU website about how to fortify breast milk at home, which was identified by our NICU families through discharge surveys that Dr. Jeff Meyers helped create, who, I believe, is on this call today! When we identified that families lacked confidence in this area on the surveys, we thought, well, let's do something about that. And so we created this, You know, simple video. It's about five minutes long, and families can watch it before they leave, and then they can access it on our website once they're home. So that's some of what I do. Again, some of the work that I'm talking about today is actually just a third of what I do.

"As Colby mentioned, I'm the Director of Family and Community Outreach, and I want to stress that there is no mention of NICU in my title. I am not NICU-specific, and quite honestly, I wondered if I was really right for this talk since my approach is very, very different. Then I kind of thought: you know what? Maybe someone will benefit from a very different approach."

So about our hospital, we're a part of the University of Rochester Medical Center in Rochester, New York. Our Children's Hospital is an eight-story tower. It connects in a few places to our adult hospital. It used to be stuffed into the adult hospital, and then, seven years ago, we built this beautiful tower. As for the NICU, it is our largest unit, [with] forty-four private NICU beds in our tower, as well as twenty-four beds in the adult hospital. That's like a NICU step-down unit. Most of those are individual family rooms also. We're often at one hundred percent capacity or more, and it's the only level-one NICU in our region.

So how did you build the Family Advisory Council or Family Partnership Council Programs in your local NICU? Well, I didn't. Maybe I'm helping to rebuild them. I want to give a huge shout-out to our social work clinical manager, Carla LeVant, who, I believe,

is on this call today! She is a family-centered care pioneer and champion at our institution, especially in the NICU. In fact, what you're seeing on the left here is a poster that she presented in 2012.

Carla and her small team – some of them are on this call, and if I'm leaving you out, forgive me. But they really moved mountains to get things going at our Children's Hospital, and by 2009 they had created a family advisory council to gain parental input on many policies and procedures. Here are some of their successes. Yes, I agree; she is amazing. Some of their successes include expanding parent visiting hours and allowing parents to stay in [the] unit during rounds and shift changes. Establishment of a parent advocate/peer support volunteer position. Yes, volunteer. We rely heavily on those at our hospital I am paid, but so many of the people that we rely on for this work are volunteers. Improvements in discharge planning and follow-up and parent participation on hospital committees for planning and quality.

"So Carla and the small team built this great foundation for this work at our Children's hospital, even bringing in Beverly Johnson, who, we just mentioned from the Institute for Patient and Family Centered Care to really take their work to the next level, and they were off to an incredible start."

So Carla and the small team built this great foundation for this work at our Children's hospital, even bringing in Beverly Johnson, who, we just mentioned from the Institute for Patient and Family Centered Care to really take their work to the next level, and they were off to an incredible start. The momentum for this work kind of hit a little bit of a pause, just a little bit, when our larger hospital system that we're a part of, really seeing the importance of family-centered care, wanted to take over that care and sort of bring it system-wide. Don't get me wrong: a ton of the work that Carla and her team established continues and [is] carried on like a family advisory council that continues to have representation from all across the Children's Hospital, including the NICU Advisory Council. But to be honest, in my role, I don't know as much about that. I know Dr. Meyers is on here, and I think Morgan Kowalski is here as well, and they can probably answer a lot more about the status of the NICU Advisory Council. But another thing that Carla inspired is a strong, strong core of parents who have that lived NICU experience. They remain so dedicated to our Hospital Pre-covid. They would come to the unit in person and cold call visiting with families, host family dinners once a month, and host scrapbook nights on the unit. It really is a robust effort, and my hat is off to Carla and her team. Everyone helped build this great foundation that I got to help build on top of. But that time that I mentioned when the leadership of the effort was a little bit in limbo sort of allowed some of this work to grow, organically, if you will, which is really impressive but not necessarily structured. Some pockets grew much better than others, so to try to get a snapshot of what was happening in this realm across the Children's Hospital. That was kind of hard, and we know that tracking this work and producing data on it to measure its impact is important, you know, keeping track of the parents involved in this work. In case, for example, the Joint Commission ever comes and says, Hey, what are the qualifications of these folks? You know? That's quite important, which actually happened this week to us! And we also know that keeping track of the parents and how they're feeling about this work again and it can bring up a lot of feelings about their own time there. Keeping track of them and seeing how they're doing because we know that they're such valuable resources, and we're really trying to tap into their input now more than ever!

All that is easily said to track all of this, but not easily done, especially with limited resources. So if we can go ahead and change the slide, please.

I had actually no idea about any of this internal history that I've just shared with you. I didn't join the hospital staff until 2019, so yes, I'm experiencing a little bit of imposter syndrome right now, having just heard our last two speakers. But what I knew was after having a baby in the NICU in 2011 for seventy-two days, and bringing her home on all sorts of medical equipment, and managing her around [the] clock care at home, and then having her pass away at a year and a half was really very hard. I say that as someone who is so privileged to have, you know, a very supportive and dedicated spouse, a safe home, reliable transportation, et cetera, et cetera, and all of those supports. I say that as someone who is privileged to be able to call up the head of our hospital at the time and tell her my thoughts on what went well with our care and what didn't go well with our care, and actually to see some changes happen as a result of that conversation. And I say that as someone who is privileged to have gotten to know a lot of our hospital families and hear their ideas for change all across the hospital, and not just the NICU. And honestly, I was happy in my other job as a journalist. But I had such an urge to do something with all of this information, and I was able to brainstorm this all into a full-time job and work with the head of our hospital (A new head of our hospital came in 2018), I was able to put this job together in part because he's very encouraging family-centered care. By the fall of 2019, I was actually in place doing that job that we created, and that was actually the first time I was hearing the term "family center care." I didn't realize that there was a term for something that I was finding was my passion.

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What were the next steps, and what were the challenges for all of this? Well, after I started in this newly dreamed up, Job Carla and I connected and tried to regain some of that momentum that she and her team had really planted the seeds for and really re-energized the effort. We identified that it'd be great to get more family advisors on the overall Family Advisory Council, you know,

and quality improvement teams, and identified it would be great to get more families on QI committees that already existed or were on a list to get started. Same for our Public Relations group, marketing group, and advancement teams, who wanted more families who'd be willing to show up and share their stories. And the same [happened] for our new bereavement coordinator, who wanted to introduce more parents to the work that she was doing. So we can go to the next slide, please.

"We named this effort to incorporate more families into our work the family connection program, and in late January of 2020, we brought a bunch of families together and told them all the ways that they could engage, and many of them signed it to engage in multiple ways."

We named this effort to incorporate more families into our work the family connection program, and in late January of 2020, we brought a bunch of families together and told them all the ways that they could engage, and many of them signed it to engage in multiple ways. And this was really a dream come true for me to harness the power and insight of families. And then, of course, you all know what happened next. Right?

Covid was like, Yeah, not so fast, right? So many of the engagement Opportunities, of course, were put on hold. Families couldn't necessarily come in, and our staff was so busy, especially those NICU nurses, that Melanie gave a shout-out to [them] earlier.

As devastating as Covid has been, it really gave us the wake-up call and, honestly, the time to realize that we needed to build this program in a way that it could exist virtually and actually, a few other ways that have been important to me as well, and I'm going to talk more about that in just a moment. But first, I want to go over our engagement opportunities as they currently exist, and are presented to all of our families, including our NICU families, so we can go ahead and change the slide, please.

So It might be kind of hard to read on this screen, but I put together this chart, and actually, there are a few other pages to it. Not only this description of the opportunity but the paperwork that's required and the training that is required. The time commitment that's involved, and who are the contacts for a lot of this work. For example, a quality improvement family advisor. We have a CLABSI committee, NICU handoffs committee going, employee safety, and patient behavior that we have parents actively on right now, and I think they're seeing the benefits of having families involved. If we go to the next section, There are our buddy programs! We actually built this during Covid as a way for families with lived NICU experience who were at least two years out from that experience to be matched with a family that was currently in the NICU, and these connections were meant to be virtual. So we said, you know, connect by text, phone, email or a platform like zoom, kind of like whatever works for you guys. And this has been a really big lift. We have now a 19-page handbook for our Buddy Mentors to follow as they onboard. But it has really caught on and is being replicated by our trach and ventilator program, as well as our g-tube program, with many more units interested in starting a buddy program, including our bereavement coordinator, who i'll talk about in just a moment. But our third graph there, sharing with the public, you know, whether it is again speaking at a fundraiser like a golf tournament, or a gala, or simply sharing a picture of your child who has a g-tube on our hospital's social media, as we celebrate g-tube awareness month or something like that. A lot of families are wanting to share their stories to help promote the good that happens at our hospital, so that's an opportunity for families to engage. Bereavement advisors: I mentioned the future bereavement buddy program… our advisors are doing things like reviewing and standardizing what units give to families when a child passes away in the hospital, like a memorial box, like If there's a child in the NICU versus the PICU there might be different things that families get. So they're looking at standardizing those things. We have our Family Advisory Council and Family Support there on the right that I mentioned - that strong core of making parents cold calling on the unit and host those monthly dinners and scrapbooking events before Covid. They've missed this work. They are itching to get back in our hospital physically, and I think you're just getting the green right now. We want to really expand this concept of support out of the NICU into other units. For example, in our hospital, a lot of our oncology patients have great community supports, our cardiac patients have great community support, but maybe other patients like burn patients or orthopedic patients - maybe there aren't as many community supports, so maybe we could create those supports for them through involving families.

So those are the engagement opportunities, and we're in the process right now, literally right now, of adding this chart to our website so that everyone is aware of what these opportunities are and what it takes to be involved. If we can go to the next slide, please.

"So what did Covid teach us about how we should build and run this program? I think that they should exist in these ways. Really, what's important to me is that so much of this can run virtually, and that's both internally and externally."

So what did Covid teach us about how we should build and run this program? I think that they should exist in these ways. Really, what's important to me is that so much of this can run virtually, and that's both internally and externally. And what I mean by that is, you know, externally, even after this pandemic is hopefully over connecting virtually instead of in person may be easier for families with medically complex kids or medically fragile kids, of course, for families who live far away and can't make that drive into the hospital for a meeting., Internally, many of us doing this work, myself included, are working from home. Space is at a real premium at our hospital. So the office that I used to have - I don't have any more at the hospital. I'm talking to you from my basement. So it's kind of hard to stay on the same page, being in a lot of different places when we really do cross-disciplinary work! And so this has been a huge challenge because we already have a

focus on meeting industry standards for the training and paperwork required of our families while at the same time making it not too much of burden that it is a barrier for them to participate. It's figuring out how that whole system can work, and then how it can actually all work virtually -it's been a big lift, but I think one that is important to gather more voices of more families. This program, of course, needs to be HIPAA compliant as we talk about all of these, you know, paperwork papers flying back and forth. It needs to exist in an equitable fashion, and it needs to reflect and meet our values. For example, diversity, equity, and inclusion training. So a little bit more kind of about what that means. The whole process of getting family advisors into our system will soon start online. So yes, we do definitely want recommendations from staff, but we also don't want it to be a barrier. We want anyone to be able to find us and be able to say, Hey, I want to be a part of this. So this is a Redcap form that gives us their basic information, their lived experience, and how they are actually interested in engaging in our system. And this also allows us to track them in our system, and shout out to Dr. Meyers, who helped me create this a long time ago because that Redcap can be a beast!

"The Canadian Premature Baby Foundation - it has this introduction to NICU Peer support training that is online and in video form, and it is absolutely great. Again, Dr. Meyers found this as well. You can access it anytime, and it covers empathetic listening and the importance of HIPPA, which are hallmarks of our program."

The Canadian Premature Baby Foundation - it has this introduction to NICU Peer support training that is online and in video form, and it is absolutely great. Again, Dr. Meyers found this as well. You can access it anytime, and it covers empathetic listening and the importance of HIPPA, which are hallmarks of our program. We have a HIPAA document advisors signed to go along with that as well. And what do I mean by existing in an equitable fashion? Well, not everyone you know working from home, like has access to a printer, for example. So someone sending someone an attachment to print and fill out and then send back by snail mail may exclude some people. It's also extra steps for already busy families to print it. Fill it out. Find a stamp and put it in the mailbox, right? So we're trying to create forms that can be filled out online instead. You know, for example, our public relations team. They need parents and guardians to sign this very specific HIPAA form before they do an interview with the media sharing their child's health journey, or sharing a picture on our social media pages. So we're working on making this form electronic and looking to see if Docusign might be an option that checks all the privacy boxes.

How about diversity, equity, and inclusion training? Many workplaces, mine included, required DEI training for employees, and we think it's important to bring this to our family advisors in a form that is tailored to them. A lot of us have to sit down and do those hours-long trainings where volunteers don't have time for hours-long stuff. So we created our own by working with our office of equity and inclusion, as well as a grateful mom who is also a DEI consultant, and our hope is that this one-hour virtual, authentic advocacy and unconscious bias training are helpful, as our advisors support a family that may be very different from them, or they may be advocating for the diverse and beautiful families of our hospital through a place on a committee, for example. I'll be honest. Not everyone embraced this unconscious bias training at first, but I'm happy to report that our first training session over the summer was a real success, and we actually have our second session happening next week.

Finally, setting up a system to track all of these trainings and all of this paperwork -- and honestly, right now, I kind of feel more like a virtual structural architect than someone who is actually connecting with humans on a day-to-day basis. So I'm excited to finally get all of this done and transition to, you know, connecting with other parents and seeing how we can support parents. So if we could go to the next slide, please.

Did you have financial support? And how are you planning to sustain this? Well, I'm calling for backup. Carla is my partner in crime on a lot of this, and we rely heavily on a former NICU Mom as a volunteer to help with the day-to-day logistics and keeping track of all that paperwork I talked about. I have asked for a Family Connection Program Coordinator to be funded through our hospital's budget, which my boss, who is the head of the hospital, supports, but we're currently in a hiring freeze. So that's not an option right now. Another approach, our NICU, which has a lot of representatives on this call, is really looking to kick our family-centered care into high gear, so we've asked a NICU-focused donor to fund a position that would head up the NICU-focused components of the Family Connection Program that I've talked about, and many other NICU focused projects. We're hoping we'll hear back on that very soon. As far as logistical support, we connected with an office that tracks our on-site volunteers like our in-person volunteers. Even though most of our Family Connection Program advisors are engaging virtually, that office still has the capacity to track people. So we were able to rope them in to get some help with some of this paperwork.

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How do you get buy-in from staff and physicians to engage in family-centered care?... that's a good question. We have some

staff that are all about family involvement, like Dr. Day, for example. Dr. Meyers and Dr. Day - thank you for the invite to talk today. But we do have other staff that I worry about when it comes to engage with families. As mentioned, quality improvement can mean looking at where your strengths aren't, which isn't necessarily easy to hear. So human nature may mean that we become defensive. I worry about that when it comes to staff and parent adviser interactions because it takes a lot for a parent or guardian who maybe has been hurt by the system or doesn't trust the health care system to choose to engage back into the system. We really need those voices now more than ever. So, we need to make sure that everyone's on the same page about the importance of this family-centered care and family-centered care for all types of families. We're also working on having Bev Johnson come back to do a grand round and talk about why is it important to have diverse voices? Why do we need to hear this feedback? And where does our hospital stand in regard to this work? And hopefully, by then, in November, it'll be our chance to highlight this Family Connection Program, which will hopefully be all online by then so that everyone knows it as the one place to go for families to start their engagement journey in our hospital.

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And finally, on my last slide, like Molly, I just want to highlight the kids in our hospital and say thank you because, yes, like you, this slide brings me joy.

<u>*Molly's Talk:*</u>

I always like to center my talk around my son Max. Max is why I am here. ! This is my son Max. This is the very first time I met him. He was born at thirty-two weeks after I was on bed rest for six weeks. .. I always like to use this photo because I don't remember this moment. I don't remember this photo being taken at all, but a very amazing nurse told my husband to take this picture, and on my son's first birthday, my husband gave it to me, and I just love it. . Look at my smile. I finally got to touch him. I didn't get to hold him for quite some time. This photo means the world to me, so I always like to share it, and here are some pictures of us during our NICU stay, Max doing skin-to-skin with my husband and, of course, making our way out of the NICU in front of the exit doors.

Max is now nine and a half. He's in fourth grade. He's healthy. He's doing beautifully. He's the big brother to a younger brother, Renzo, but our NICU experience changed our lives. Now I work with families like ours to try and make the experience a little gentler.

I want to center this talk around our NICU family advisory and how we approach family engagement with our philosophy of care. So in my unit, several years ago, right before the pandemic, we came up with a philosophy of care, and I actually learned about philosophies of care through similar networks like this one. Ours was co-created by NICU families for NICU families, and the goal is to just really show our parents our commitment to them being a part of the care team.

"Our philosophy of care reads: Welcome to the Klarman Family NICU. Your family is part of the care team. Here, we value families and all the love and knowledge they bring and support the uniqueness of all families and cultures."

Our philosophy of care reads: Welcome to the Klarman Family NICU. Your family is part of the care team. Here, we value families and all the love and knowledge they bring and support the uniqueness of all families and cultures. The BI (Beth Israel Deaconess Medical Center) is a sixty-three-bed level three NICU in Boston. We are not a surgical unit. Our rooms are semi-private. We have a main unit, and then we have a step-down special care unit as well, and we are part of a network hospital system, and we are the main level three unit. We get outborn and retro transfers to about seven different area hospitals.

Our NICU family Advisory committee has about twenty-five members, and they inform all aspects of what we call our NICU Cares program. So I'm going to talk a bit about our NICU Cares program today and the work that I do with the support of the NICU Family Advisory Committee and talk a little bit more about sort of how those roles intersect.

"These are some examples of the day-to-day work and really what we care about. So some of our alumni events, some of our support documents. The bereavement work and memorial service work, which is such an important piece of our NICU sibling work, on the bottom, you'll see all sorts of roadblocks, and this is sort of a painful reminder. "

It's incredible how much the NICU world loves acronyms. That's something that I've learned in my almost eight years in this field… you guys really love acronyms! So, of course, NICU Cares is an acronym. These are some examples of the day-to-day work and really what we care about. So some of our alumni events, some of our support documents. The bereavement work and memorial

service work, which is such an important piece of our NICU sibling work, on the bottom, you'll see all sorts of roadblocks, and this is sort of a painful reminder. During the pandemic, when our resources were very limited, we were not able to have our families in some of our shared family spaces. My co-worker and I met very regularly to pack brown snap bags for our families, so they had a little nutrition and a little bit of, you know, just a little bit of sugar, a little bit of salt so that they could, you know, have help for that long day, and then some of the fun events. We do like photography.

Our acronym stands for compassion, advocacy, respect, empathy, and support.

But what does that really look like? It looks like remembering to celebrate all the little things that happen in the NICU. All these beautiful, incredible milestones for these families that we get to be a part of. We have front-row seats to the best and the worst days of some of these families' lives, and it's really important to honor that.

"So our NICUCares program was developed to coordinate social and informational programs, and it's meant to help families during their baby's hospitalization. But additionally, NICU Cares program helps families connect with other parents during and after their hospital day and to stay in touch with us at the hospital."

So our NICUCares program was developed to coordinate social and informational programs, and it's meant to help families during their baby's hospitalization. But additionally, NICU Cares program helps families connect with other parents during and after their hospital day and to stay in touch with us at the hospital.

We involve our parents during and after their NICU stay in a lot of different ways. This is just kind of wanted, you know, one slide that shows all the different ways, but things from parents at grounds for an if you family advisory committee Uh, with your parents on our subcommittees graph. We have an online support community for our needs to graduate families. We have different documents to help them be more involved in the day-to-day care of their infants, you know, not. Everybody is ready to be hands-on [with] it, so it gives them some very focused things that they can do every day to help care for their infants. ! We have a family integrated, terrified here uh curriculum and program on our special care and unit that we're about to roll out to our main unit. ! A lot of us just came back from VON. We have ongoing and active bond collaborations, and we typically have anywhere between twelve and fifteen parent advisors. This year, I was the only parent who came, and in past years we brought some of our families with us to bond. We do one-to-one virtual.

We have a NICU app that is beautiful. We have a music therapy program that I'm very hopeful will restart soon. During the pandemic, Of course, we had to get really creative and flexible about how we engaged our families. Through a donor program, we were able to secure some iPads and kindles. We have a reading and literacy program. We have support documents and alumni events. A beautiful meditation and relaxation program for our families through our pastoral care services. . And we have a bi-annual Memorial Service.

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Our NICU family Advisory committee is the oldest patient and family advisory committee in our hospital, and it was created to increase programs for NICU Families and create more opportunities to support NICU Caregivers. It was also created based on our family satisfaction surveys. I'm sure all of you are collecting data and doing longitudinal studies at discharge about your patient and family satisfaction. And So this was in direct response to some of the feedback from families. We saw there was a growing demand for parent involvement. Parents really wanted to give back.

Thanks to our amazing NICU Leadership team, There was a really high value placed on that unique parent perspective and also a need for funding. The inception of our family advisory committee was about finding opportunities for grateful families to be philanthropic and give back. Our family advisory committee has grown substantially since two thousand five. We now have anywhere between twenty and twenty-five members who attend our meetings, and I want to highlight that one of the most significant things about our family advisory is we have seven different bereaved families who also participate. I think it really speaks to the level of care that we're providing even in the most difficult of circumstances that our families want to stay involved and stay connected and improve the hospital experience for families that come after them.

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So the mission of our NICU Family Advisory Council is to touch the lives of each NICU family in a positive and lasting way. Our goal is to complement a NICU's outstanding clinical care and embrace the hospital's commitment to family-centered care with programs and initiatives that acknowledge and support the family and the time of crisis and extend the relationship between the family

and the hospital well beyond making your discharge.

So the NICU, in fact, supports this mission through representative feedback on existing and future programming, facility and policy enhancements, redesign and renovation, staff and family relations, development/ fundraising, and other issues related to the needs of NICU families.

We also have eighteen different subcommittees from our NICU leadership team. So we have three to four parents on most of our subcommittees. So this is another way for our families to be involved. They're not able to join our advisory committee. We often find opportunities for them to join these sorts of subcommittees, which are more of a working group, roll up your sleeves type of opportunity. They meet monthly. But we only ask our parents to join about two to three meetings.

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They're now virtual, for the most part, though they were in person before the pandemic, in person. Generally, we start talking to parents about their involvement a year post-discharge, and we talk to all the staff who have worked for the family or who have been exposed to the family to see if they might be a great fit. We connect with anyone from their bedside team to their neonatologist, respiratory therapist, as well as their social workers to see

If they think a family or individual would be a good fit. We do this thoughtfully and carefully because we are certainly surfacing some complicated issues in some of these subcommittees and in some of our meetings. It's delicate, and we want to make sure that we're not traumatizing our families but also that they're ready to share their experience. And if they're able to take that expertise and that experience, and to build better programming and to improve care for other NICU Families.

But how are we getting these folks involved? So that's sort of the meat of this, right? So we use a lot of different channels to connect with our families. , everything from emails and phone calls. We have an alumni group online and on Facebook. ! We have a discharge nurse who calls families and specifically says, Hey, do you want to stay in touch. And then we're given those emails, and we're able to communicate with our families and figure out what level of involvement they'd like.

I'm in a paid family position. I know I've seen some questions in the chat about that, and I'd be happy to talk about that a bit more. But I'm paid part-time. The hospital employed a program manager within my hospital. So that's another way that I engage because I'm able to be present at the bedside and build relationships with these families. So we cast a really wide net because we know a lot of families will express interest, right? But you know, things like a pandemic happen. . And also we know, as NICU providers, that sometimes a NICU Baby is not the most critical thing happening in a family's life. There are so many different things that happen to our families at any given time. So we really want to figure out ways that we can engage our families but not add to their stress.

"One of the things that I think is most effective. Some of you may have heard me say this earlier this year when I gave a similar talk at the Gravens Conference earlier this year if you don't have a stay-in-touch document or someone reaching out to your graduate families to check in and to see if they want to stay in touch, start there."

One of the things that I think is most effective. Some of you may have heard me say this earlier this year when I gave a similar talk at the Gravens Conference earlier this year if you don't have a stay-in-touch document or someone reaching out to your graduate families to check in and to see if they want to stay in touch, start there. That's a really low-lift thing that you can do to help you understand what their interests are, and also to what degree they want to be involved. If you're keeping something like that active and updated, and if you can find a way to just get in touch with your families and ask what they want to stay in touch with you. That's a good starting point. We know that our families want to be really a part of things. They want to be involved in our Qi work coming off of the heels of a bond. It's amazing to see what families can add to our quality, improvement, and to our advising. So you're giving them a really great way to help future families and give back after their experience.

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But it's all about relationships, right? Because if we're inviting families to come back and share in a vulnerable way. We really need to build trust and establish connections and relationships. So this starts at the bedside during their NICU day, and it lasts for many, many years, or in some cases, a lifetime. They've been sitting on our advisory committee since its inception more than twenty years ago. You know they Really,

This is such a critical part of their lives, and it was such a touch-

stone for them that they want to be involved. The NICU has changed wildly. I know, even for myself. My NICU stay was almost ten years ago, and the way that we provide care has dramatically changed. So it's really beautiful to see those changes over time and to see how things are moving forward and how your feedback is being used.

"But in order to get that feedback right. It's really important to have trust. Families need to feel safe in sharing the good and the bad about their NICUexperiences. It's not easy to tell the people who have taken care of your infant that while everything was beautiful, there were some things that could have been better."

But in order to get that feedback right. It's really important to have trust. Families need to feel safe in sharing the good and the bad about their NICUexperiences. It's not easy to tell the people who have taken care of your infant that while everything was beautiful, there were some things that could have been better. So when we're talking about,

Sometimes it's really hard to hear about your child as a data point, right? Or when we talk about some of the more difficult topics, we need to make sure we're always using content warnings when they're appropriate. We always need to make sure that we're giving families a heads-up. We're going to talk about something that may bring up some feelings and emotions for them. So we need to really think about the clinical language that we're using in our NICU settings when we're bringing parents into this type of work., it's really important to talk to NICU Staff, and the nurses, especially about what projects you've got going on, so they can see if they can think of any families that might be a good fit, and a lot of our families are still in touch with their day to day nurses. Right? They are updating them, and you know how to their homes. So that's great, that's a great starting point, and then we also need to be really flexible. ! A lot of our working families may not be able to be regular at all soon. Zoom has been an incredible option for engaging families, getting them involved in the day today, and sort of making sure that they're once a month, and then is it too much? ! something that we're trying to do in our hospital that we haven't had much success with, but I know that it works at other units is some night meetings. Not everybody is able to meet and burn during the day. But could you do, you know, even if it's one or two night meetings a year or a night zoom meeting. Is that something that can happen? ! Also? Are there opportunities for you to involve families over email? , we're gonna work online. So just be flexible and be upfront about the task. So what is the time commitment looks like? What staff are going to be involved in? Do you want to be forthcoming about that? And also, will they have a chance to connect with other nations' families, and do they want to do that?

Compensate if you can? I know this is, you know this is hard, right. Not a lot of our units even have a paid parent advisor role. But, you know, we need to be paying people for the time that they're giving us, and if you're writing a budget for a grant, or you're putting a proposal together, add some time for parent participation, for their time and for their expertise. We're not currently compensating our NICUfamily advisory committee, but we do offer them free parking and meals when they call in person for things and for NICU projects like ours. You know our co-creation of our family integrated care program. We had two co-eds who were to keep graduate families, and we offered them a stipend, even if it's just some hospitals. Why [do] you just really want to show your appreciation for the expertise and for the time commitment because a lot of these things can be very time-intensive.

We know that it's really important to bring in all aspects of NICU families. So if you have families who are limited in efficiency, or who do not speak English or are limited, using interpreters, having staff involved who speak those languages is really important to engage those families. And then transportation. I'm not. You know some of you may have closer units, but we're a main level, and some of our families live hours away. Different states. So providing transportation, parking, and child care, if possible, is really helpful,

and we know, as Mary vested, and I want to echo the importance like we need to be recruiting in ways that represent and reflect our patient population. So we need to be prioritizing welcoming people from all different backgrounds, so races, and ethnicity. But not only that, sexual orientation, family structures, gender financial situations, and physical and mental abilities, Right? The experience of disabled parents is very different in the making. So are we. Are we doing what we can to listen to their experience,and also education, level, diversity, and family structures. So are you engaging LGTQI, headed families? Are you teaching single parents and then culture and adversity. So again, families who are not speaking the dominant language in your unit reach out to them and find ways to connect with them. We have some incredible family advisors in our bond who work and speak different languages. So it's always great to sort of tap an expert and see and see how they can help you engage.

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So, of course, one of the things we were asked to talk about was the impact of our family advisory and Covid and parent participation. And you know something that has sat with me the uh at the Gravens Conference earlier in March. Someone, I believe, from

the IPCC in the Institute for patients, and I'm getting all my acronyms to use. Anyways, there is a really powerful quote that said something along the lines of the pandemic detainee parents.

"What the pandemic did to make your parents want the asteroid to design a source. I think a lot of families are really feeling like we have a lot to come back from, and that, I think, resonated with a lot of us, like your families and people in roles like mine. You know everything moved virtual, so you know, on the fortunate side, at least for our family advisory committee."

What the pandemic did to make your parents want the asteroid to design a source. I think a lot of families are really feeling like we have a lot to come back from, and that, I think, resonated with a lot of us, like your families and people in roles like mine. You know everything moved virtual, so you know, on the fortunate side, at least for our family advisory committee. We moved to virtual quarterly zoom calls, and surprisingly we found there was increased participation. Our family provides feedback and hears updates about Indicators and Covid in an increased way. But our subcommittee sort of our working groups that were regularly. We saw that participation sort of dropped off, so less parents are available to join the monthly calls. We saw a lot of zoom fatigue. I'm: Sure, we're all experiencing the same. And we, you know, we really had to do things like, get really creative emailing for feedback, for documents and engaging them in different ways. And we're still working our way out of that, you know, transparent. I think you know what that was saying. Sort of similar. It's. This is hard work, and it's not easy, and when it works for a little while, something may happen, and you'll have to kind of start over again at the ground. But, I'm able to have a community of family advisors who are more like one to pick their brains. So know that if you don't have questions and they're building a family advisory, you don't have to do it alone. There's ten of us who are doing it, too, who, you know. We may not have all the answers, but we can hopefully find you a way to work together to build this. So that's what I've got for today. I just wanted to say, Thank you again. Here's my contact information. And here are some pictures that bring me some joy. It's not easy. , but I think it's so important, and you know I think our families appreciate this work. So much so. Thank you for your time.

Disclosures: No conflicts have been identified. .

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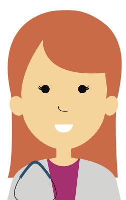
Marybeth Fry *is the NICU Family Care Coordinator at Akron Children's Hospital in Akron, Ohio. In her role, she mentors and coordinates programming to support current NICU families. Additionally, she serves on a number of unit and hospital based committees as the parent voice in quality improvement projects. Ms. Fry is Vermont Oxford Network faculty as the lead Family Partner of their NICQ and iNICQ collaboratives, and Experience Based Co-Design program.*

Jennifer Jones *is Director of Family and Community Outreach at UR Medicine Golisano Children's Hospital. Her child Grace was in the NICU. When you report the news for 17 years in one city the name "TV news lady" is hard to shake but it's one Jennifer Johnson embraces after a career as a television news anchor. Journalism is what brought Jennifer to Rochester, New York but three years ago she started a new career inspired by her late daughter Grace. Grace was born very sick in 2011 and was not expected to survive but because of the exceptional care she received Grace lived almost 17 months. You learn a lot being the parent of a medically-fragile child. Jennifer began advocating on behalf of patients and families and soon realized there was so much work to be done in this area that it could be a full-time job. Now, as the Director of Family and Community Outreach at the children's hospital that cared for Grace (UR Medicine Golisano Children's Hospital), Jennifer is working to bring the voices of families with diverse backgrounds, diagnoses, outcomes and experiences into the decision-making process at the hospital. She is often out in the community speaking about the hospital and also works with medical teams in Rochester and across the county to help them feel more comfortable with the media and social media.*

Molly Fraust-Wylie *is a NICU Parent and a NICU Family Program Manager at Beth Israel Deaconess Medical Center in Boston. As a direct result of her experience both on bed rest for 6 weeks with her son, to being in the NICU with her premature infant, Molly believes in the importance of community support and shared experience for NICU families. Molly provides the unique parent voice on multidisciplinary teams with the aim of improving the overall experience for families with infants in the hospital. From developing materials and running educational programing on the unit, to leading quality improvement efforts and collaborating on family engagement, to bedside support and advocacy both locally and nationally, her focus is empowering NICU Families and integrating NICU parents into all aspects of decision making and caretaking. Molly is the Chair of the Family Advisory Leadership Committee for the Neonatal Quality Improvement Collaborative of Massachusetts Family Engagement Collaborative and serves as a Board Advisor to Project Sweet Peas, a national nonprofit that supports families of hospitalized infants and those who have been affected by pregnancy and infant loss. Molly holds an MA from Emerson College in Integrated Marketing Communication and is a graduate of Dickinson College.*

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

www.perinatalharmreduction.org | www.nationalperinatal.org

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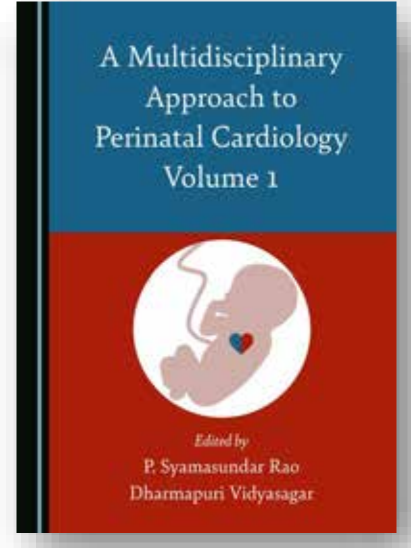
A Multidisciplinary Approach to Perinatal Cardiology *Volume 1*

Edited by P. Syamasundar Rao and Dharmapuri Vidyasagar



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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 PPROM 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 PPROM 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 PPROM 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 Contributers:

Brittany Boet
Founder, Bryce's NICU Project, San Antonio, TX.

Angela Davids
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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 Providership 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)TM*. 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

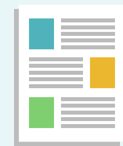
www.myperinatalnetwork.org Phone: 805-372-1730

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** SSESS PREFERENCES
- **R** EACH A DECISION
- **E** VALUATE THE DECISION

TRAUMA-INFORMED

Both parents and providers are confronting significant...

- FEAR
- GRIEF
- UNCERTAINTY

LONGITUDINAL DATA

We need to understand more about outcomes for mothers and infants exposed to COVID-19, with special attention to:

- MENTAL HEALTH
- POSTPARTUM CARE DELIVERY

NEW DATA EMERGE DAILY. NANN AND NPA ENCOURAGE PERINATAL CARE PROVIDERS TO ENGAGE IN CANDID CONVERSATIONS WITH PREGNANT PARENTS PRIOR TO DELIVERY REGARDING RISKS, BENEFITS, LIMITATIONS, AND REALISTIC EXPECTATIONS.

Partnering for patient-centered care when it matters most.

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Coping with COVID-19

A viral pandemic

A racial pandemic within a viral pandemic

Will mental illness be the next inevitable pandemic?

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National Perinatal Association
NICU Parent Network

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COVID-19

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Peer Reviewed

Enhanced Pregnancy-Related Death Data Elucidates Opportunities for Intervention

Michelle Winokur, DrPH

The Alliance for Patient Access, founded in 2006, is a national network of physicians dedicated to ensuring patient access to approved therapies and appropriate clinical care. AfPA accomplishes this mission by recruiting, training and mobilizing policy-minded physicians to be effective advocates for patient access. AfPA is organized as a non-profit 501(c)(4) corporation and headed by an independent board of di[1]rectors. Its physician leadership is supported by policy advocacy management and public affairs consultants.

In 2012, AfPA established the Institute for Patient Access, a related 501(c)(3) non-profit corporation. The Institute for Patient Access is a physician-led policy research organization dedicated to maintaining the primacy of the physician-patient relationship in the provision of quality health care. In furtherance of its mission, IfPA produces educational materials and programming designed to promote informed discussion about patient access to approved therapies and appropriate clinical care.

Visit allianceforpatientaccess.org and instituteforpatientaccess.org to learn more about each organization.

According to newly released data, nearly one in four pregnancy-related deaths were caused by a mental health condition, including suicide and drug overdose. (1) Maternal deaths that occur during pregnancy through one year postpartum are included in the compilation of data from 36 states.

Leading Causes of Maternal Mortality

After mental illness, excessive bleeding claimed the most maternal lives, 14%, while cardiac and coronary conditions accounted for 13%. Infection, thrombotic embolism, and cardiomyopathy were each linked to 9% of deaths.

More than half of deaths, 53%, occurred between seven days and one year after pregnancy. Furthermore, according to the Centers for Disease Control and Prevention, four in five deaths were preventable.

Enhanced Data Program

These are the first data to be released through ERASE Maternal Mortality, (2) a program that aims to support more robust data collection about the causes of pregnancy-related death. The CDC launched Enhancing Reviews and Surveillance to Eliminate Maternal Mortality in 2019 in response to increasing maternal mortality rates and deepening disparities in deaths between women from communities of color and white women.

> ***"The CDC launched Enhancing Reviews and Surveillance to Eliminate Maternal Mortality in 2019 in response to increasing maternal mortality rates and deepening disparities in deaths between women from communities of color and white women"***

Since then, the federal government has awarded 39 states and one U.S. territory additional funding to enhance the work of Maternal Mortality Review Committees. (3) These multidisciplinary committees convene to identify, review, and characterize pregnancy-associated death data, which include representatives from public health, obstetrics and gynecology, mental and behavioral health, forensic pathology, and other stakeholders.

Improving Prevention Efforts

A more comprehensive understanding of drivers of maternal mortality can better inform prevention efforts. Given the complexity of interrelated factors, intervention opportunities exist at the patient, provider, facility, system, and community levels. Federal officials suggest that "everyone can help prevent pregnancy-related deaths." (3)

> ***" Likewise, listening to new moms' physical and mental health concerns is critical to linking them to the most appropriate care. Finally, expanding access to comprehensive insurance coverage can improve prenatal and postpartum care, enhancing the opportunity to identify and mitigate risk factors before they become deadly."***

Asking female patients if they are or have recently been pregnant can help inform healthcare providers' diagnoses and treatment decisions. Likewise, listening to new moms' physical and mental health concerns is critical to linking them to the most appropriate care. Finally, expanding access to comprehensive insurance coverage can improve prenatal and postpartum care, enhancing the opportunity to identify and mitigate risk factors before they become deadly.

The newly available data elucidate the causes of pregnancy-related mortality in America. It is up to policymakers and healthcare providers everywhere to make more informed decisions and implement interventions to improve outcomes for pregnant women and new moms.

References:

1. *https://www.cdc.gov/media/releases/2022/p0919-pregnancy-related-deaths.html*
2. *https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/index.html*
3. *https://www.cdc.gov/media/releases/2022/p0919-pregnancy-related-deaths.html*

Michelle Winokur, DrPH, is the Executive Director of the Institute for Patient Access. This article was also published at healthpolicytoday.org.

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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

Peer Reviewed

I CAN Digitally Involved (I CANDI): iCANDI National Work and Family Month

Amy Ohmer

"October is National Work and Family Month! This month is a time designated to supporting parents and families to create a healthy balance in daily life. For many chapters, this means a balance in work and the endless array of medical appointments and well-child visits. "

October is National Work and Family Month! This month is a time designated to supporting parents and families to create a healthy balance in daily life. For many chapters, this means a balance in work and the endless array of medical appointments and well-child visits. To do this, we have an exceptional support network to provide an outlet to create a better family community. Did you know that the International Children's Advisory Network, Inc. (iCAN) has a Parent Council?

Through our 'iCAN Parents', iCAN supports parents and families in various ways to ensure that parents are connected to community support and parenting information that they can use.

Since forming in 2014, iCAN has remained a proud partner of the American Academy of Pediatrics (AAP). Through our partnership, we have important pediatrician-supported information on the following:

* media and internet safety
* mental health wellness
* hurricanes and floods
* holidays and food allergies
* and more topics available at www.healthychildren.org

If you have not signed up for the iCAN Parent Council, please visit: https://www.icanresearch.org/parents-families or to learn more and to connect with our parent chairs, Deb Discenza and Jen Degl, please send an email to icanparent@icanresearch.org.

Through the collaboration of multi-stakeholder organizations, iCAN supports the ongoing effort to help spotlight the need for acceleration of Pediatric Drug Development through sharing the voice of our youth members, parents, and other community stakeholders. During September, iCAN met with several groups from Syneos, Pfizer, Lilly, and AbbVie to share the support of pediatric clinical research projects.

"Through the collaboration of multi-stakeholder organizations, iCAN supports the ongoing effort to help spotlight the need for acceleration of Pediatric Drug Development through sharing the voice of our youth members, parents, and other community stakeholders."

On October 21st, 2022, iCAN is participating in a panel discussion in partnership with MRCT for pediatric patient engagement in the Caribbean. Leanne West, President of iCAN will be on hand, along with an iCAN youth member, to share their experiences within clinical research to spotlight the need for patient inclusion at all ages. To learn more, visit MRCT.org to register.

Additionally, iCAN is working with the FDA to share the youth member voice at an upcoming November 7th Patient Panel: "Health Effects and Daily Impacts of Opioid Use on Patients." The panel will take place at approximately 11:00 a.m. – 12:15 p.m. EST. on the first day of the National Institutes of Health/National Institute on Drug Abuse (NIDA) and U.S. Food and Drug Administration (FDA)/Center for Devices and Radiological Health (CDRH), Public Workshops.

Two friends of iCAN, Dr. Susan McCune and Dr. Ron Portman wrote an article entitled "Accelerating Pediatric Drug Development" for a 2022 Special Issue of *Therapeutic Innovation & Regulatory Science*. Published September 14th, 2022, the authors

review the progress made and discuss the ability to accelerate the availability of medicines for children. They present a historical framework starting with a period of acknowledgment, followed by a period of suggested activities and required action, leading to the current period of refinement. To read the article and others, please visit: https://link.springer.com/collections/bcgbbhbggh

Concluding the series of pediatric patient learning modules, MRCT released the last of the collaborative guides for young people in September. To see all of the exciting and helpful learning tools, visit iCAN at https://www.icanresearch.org/educational-materials. Each learning resource has been given the iCAN Seal of Approval to ensure that the materials were 'Kid Reviewed. Kid Approved.' If you would like to include the iCAN Seal of Approval in your work, visit us at nhttps://www.icanresearch.org/work-with-our-youth

and opportunities provide a unique way to connect with the pediatric medical community.

In case you missed it If you have patients or parents that would also like to share in the "What I Wish Doctors Knew" survey, please join in using the link and the survey code below. https://uconn.co1.qualtrics.com/jfe/form/SV_cvxUkzQs0jLvyNE

If needed, the code to access the survey is 06019.

This week, iCAN heads to the American Academy of Pediatrics National Conference and Exhibition (AAP NCE) from October 7th - 11th, 2022, in Anaheim, California. For 2022, iCAN will be exhibiting at booth #2034. If you are able, please stop by to say hello. SAVE THE DATE: For next year, iCAN will be at the AAP NCE in Washington, D.C., in booth #1841 from October 20th - 24th, 2023.

Communication & Digital Design Coordinator

Abby Clark

Abby Clark earned her Bachelor of Science degree in Literature, Media, and Communication from Georgia Institute of Technology with a concentration in interactive media and design. Prior to joining iCAN, she worked with Georgia Tech's Center for Health Analytics and Informatics as a digital communications and graphic design intern.

Abby enjoys the challenge of marrying technology with creativity. Through her work, Abby strives to inspire others and change the world using creativity, innovation, and imagination. In her free time, she loves to read, paddleboard, and drink coffee alongside her adorable cock-a-poo, Magnolia. She is excited to join the iCAN Research team and cannot wait to help showcase what a wonderful organization it is.

At the KIDS Walter-Payton Chapter in Chicago, Illinois, KIDS leader Stefanie McCormick welcomed a new class of medical seminar students to start the new school year at iCAN. Stefanie invited iCAN's newest colleague, Abby Clark, as a virtual guest speaker to meet with youth members to share their voices as active collaborators; youth members participating in iCAN projects

For all interested doctors, iCAN is collecting quotes to be included in the collaborative project held in conjunction with the Pediatric Trials Network (PTN) and Duke Clinical Research Institute (DCRI). Scan the QR code to send in a quote or contact info@icanresearch.org to leave a message of "Why is Clinical Research Important?".

The survey was designed by medical students from UCONN under the guidance of Dr. Sharon Smith, Connecticut Children's Hospital *(Dr. Smith is shown on the right with KIDS France Chapter Leader Segolene Gaillard on the left)* and is another excellent example of the collaboration iCAN relies upon to support patient needs. If you want to create a project or initiate a new chapter, please reach out to Amy Ohmer at amyohmer@icanresearch.org to get started today. Chapter groups can be as small or large - with the emphasis on helping to spotlight the youth voice. To learn more, check out https://www.icanresearch.org/chapters.

iCAN Youth Council: This is the next leadership level for youth members interested in supporting iCAN in a more significant way. The iCAN Youth Council is active in creating, overseeing, executing, and disseminating pediatric issues/topics through the unique perspective of youth throughout research, science, advocacy, technology, and medicine. Interested young people can learn more at https://www.icanresearch.org/our-youth.

iCAN YoungAdultProfessionals

iCAN Young Adult Professionals: This dedicated group of young adults ages 18+ helps to support iCAN at a professional and higher educational level. iCAN offers internships and more significant leadership roles in helping retain and engage young adults as they begin their careers. To learn more about this group, head over to https://www.icanresearch.org/ican-young-adult-professionals.

iCAN Parents: All parents (and family members) are welcome to join iCAN to participate as advisors for the littlest patients (0-7 years old). Joining is free and can be done by either visiting www.icanresearch.org or sending an email to iCANparent@icanresearch.org. To learn more, check out this page at https://www.icanresearch.org/parents-families.

NEW! iCAN Siblings:

Starting this month, iCAN is launching a brand-new chapter for Siblings! This special group will meet to share their unique perspective about sibling viewpoints within pediatric clinical research, medicine, innovation, and science. To sign up, visit: https://www.icanresearch.org/siblings-chapter

SAVE THE DATE:

- iCAN's unique youth series **'Ask the Experts'** has a new session planned for **October 15th, 2022, at 10:00 a.m.EST.** To join this fun and free event, please register at www.icanresearch.org/events. All are welcome to attend, and kids of all ages are invited to join. Additional sessions are open for registration, and we welcome all doctors, researchers, and community leaders to join us. For this month, we will have multiple special speakers joining to share their voices as they discuss career pathing and how to navigate many educational pathways to learning. Sign up for this session, as you will not want to miss it.

- **Join iCAN and the American Academy of Pediatrics National Conference and Exhibition from October 7th - 11th, 2022,** at the Anaheim Convention Center, Anaheim, California. We cannot wait to see you at our booth #2034! Look for the iCAN colors and stop by and say hello!

2023 iCAN SUMMIT

to be held July 10-14th in Southern California

Join Us In-Person for 2023

Kids - Make Your Summer Count!

- Travel to California
- Share your expert voice
- Shape the future of clinical research
- Support new pediatric innovation
- Learn about careers in healthcare
- Engage with global leaders
- Meet friends from around the world
- Make a positive impact in healthcare

iCAN
International Children's Advisory Network
Learn more:
www.iCANResearch.org

Registration opens March 1st, 2023

iCAN is not responsible or liable for any and all travel arrangements (including but not limited to flights, trains, cars, transport of any kind, accommodations, meals, reservations or other rental / vacation services acquired) by/for participants for any reason. iCAN is not responsible for any attendee medical needs. iCAN advises attendees to purchase travel insurance for the iCAN Summit.

- **iCAN 2023 Summit Information -**The summit next year will be held in Southern California from July 10th - July 14th, 2023. You can stay up to date on all the coming information and updates by bookmarking www.icanresearch.org/2023-summit. We need sponsors, speakers, and donations. To join in, email us at amyohmer@icanresearch.org. In case you missed the week-long International Children's Advisory Network, Inc. (iCAN) is pleased to share our excitement from the 2022 iCAN Summit presented by Jumo Health in a video highlighting the fantastic event. Check it out at: https://youtu.be/5faoza6ONFA.

Disclosure: *The author has no conflicts of interests to disclose.*

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2022

Ask the Experts

With Anthony Chang, MD

International Children's Advisory Network
www.icanresearch.org

iCAN

Hosted by:
Dr. Anthony Chang, MD

2022 Sessions Presented by iCAN and Dr. Anthony Chang:

January 15:	Kids and Covid-19
February 19:	Leadership
March 19:	Insight Into Pediatric Heart Disease
April 16::	Innovation in Pediatrics
May 21:	Advisors vs. Advocates
June 18:	What does it mean to be Rare?
July 11:	2022 iCAN Summit Week
August 20:	What Can Kids do to Help?
September 17:	Insight into Pediatric Cancer
October 15:	Specialty Careers in Medicine
November 19:	Patient Rights
December 17:	Hot Topics in Pediatrics

www.icanresearch.org
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International Children's Advisory Network

Register Today
iCANResearch.org/events

READ NPA's statement: BLACK LIVES MATTER

Respiratory Syncytial Virus is a

Really Serious Virus

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

Coughing that gets worse and worse

Breathing that causes their ribcage to "cave-in"

Rapid breathing and wheezing

Bluish skin, lips, or fingertips

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

Call your doctor and meet them at the hospital.

If you baby isn't breathing call 911.

Thick yellow, green, or grey mucus

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

Fever that is higher than 101° Fahrenheit

which is especially dangerous for babies younger that 3 months

www.nationalperinatal.org/rsv

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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.

ONCE UPON A PREEMIE INC. PRESENTS

OUAP

1ST ANNUAL CONFERENCE:
ACCELERATING HEALTH AND RACIAL EQUITY IN BLACK MATERNAL AND NEONATAL CARE

THURSDAY,
NOVEMBER 17TH
2022
8AM - 4PM

SAVE THE DATE

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Caring for Babies and their Families:
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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

FREE RESOURCES FOR YOUR NICU

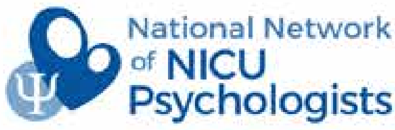
Coping During COVID-19

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



nationalperinatal.org/psychologists

Respiratory Syncytial Virus:

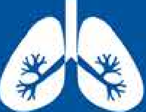
How you can advocate for babies this RSV season

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 *

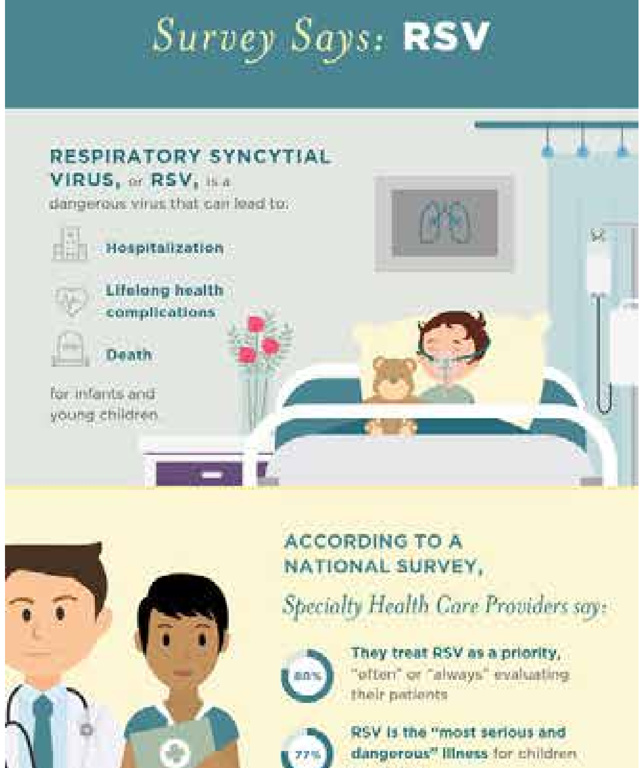
Use your best clinical judgement

when prescribing RSV prophylaxis

Tell insurers what families need

and provide the supporting evidence

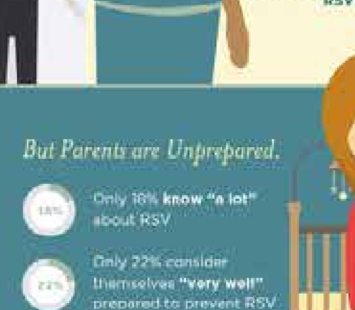
*See the NPA's evidence-based guidelines at www.nationalperinatal.org/rsv



ACCORDING TO A NATIONAL SURVEY,

Specialty Health Care Providers say:

- 80% — **They treat RSV as a priority,** "often" or "always" evaluating their patients
- 77% — **RSV is the "most serious and dangerous" illness** for children under four
- 77% — Barriers to access and denials from insurance companies **limit patients' ability to get preventive RSV treatment**



But Parents are Unprepared.

- 18% — Only 18% **know "a lot"** about RSV
- 22% — Only 22% consider themselves **"very well"** prepared to prevent RSV

RSV EDUCATION & AWARENESS CAN HELP

After parents learned more about RSV, they were:

- 65% — **"More concerned"** about their child contracting the disease
- 67% — **Likely to ask their doctor** about RSV

NCfIH National Coalition for Infant Health

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

Peer Reviewed

Regulating donor milk will protect infant health

Jennifer Carroll Foy, JD

"We are facing an inflection point regarding what we feed our children and how we ensure their safety. Recent years have shown severe gaps in child food and nutrition oversight, from heavy metals found in toddler pouches to infant formula recalls and shortages."

We are facing an inflection point regarding what we feed our children and how we ensure their safety. Recent years have shown severe gaps in child food and nutrition oversight, from heavy metals found in toddler pouches to infant formula recalls and shortages.

Following my twin sons' traumatic and severely premature birth, I saw firsthand how our healthcare system failed me as a mother and my sons as vulnerable babies. After giving birth to Xander and Alex, my body was initially not ready to produce breast milk, which is universally accepted as the best food for all infants up to 6 months. I was fortunate that my preemies had access to donor breast milk. Not all babies are as lucky as mine.

While breast milk is best, providing it is an impossibility for many parents. Whether due to adoption, surrogacy, difficult births, a baby's inability to latch onto their mother's breast, or insufficient work policies allowing mothers to breastfeed and pump, it can be difficult, if not impossible, for parents to feed their children. Donor milk often helps in these situations.

But imagine my shock upon learning that the donor milk the Neo-

Pasteurized donor human milk sits in a refrigerator at the University of California Health Milk Bank on May 13 in San Diego. The U.S. baby formula shortage has sparked a surge of interest among moms who want to donate breast milk to help bridge the supply gap as well as those seeking to keep their babies fed. (AP Photo/Gregory Bull) (Gregory Bull/AP)

natal Intensive Care Unit doctors were feeding my tiny, vulnerable babies through a tube in their nose was essentially unregulated and had no safety or quality assurances from the FDA or Virginia Department of Health. Would you feel comfortable giving your fragile, hospitalized, 8-ounce newborn food from an unverified source containing potential contaminants with unknown side effects?

"But imagine my shock upon learning that the donor milk the Neonatal Intensive Care Unit doctors were feeding my tiny, vulnerable babies through a tube in their nose was essentially unregulated and had no safety or quality assurances from the FDA or Virginia Department of Health."

As I spent months running back and forth between the NICU, the Virginia House of Delegates, and my full-time public defender job, I knew I needed to draw on my own personal experiences — shared by thousands across Virginia and the nation — to fight for our children. In the Virginia House, I introduced legislation providing paid family leave, so families could care for their sick children without worrying about losing their jobs or homes, and passed bills to end pregnancy discrimination and force employers to provide reasonable accommodations to pregnant and breastfeeding people and to reduce the Black maternal mortality rate by covering doula services under Medicaid. I also introduced a bill to create safety standards and reimbursement of donor human milk and human milk derived-fortifier — which saved my boys' lives in the NICU. Improving the safety of and access to donor breast milk is a personal crusade for me.

"Currently, donor milk is considered mere food by the FDA, meaning there is no requirement for FDA inspectors to scrutinize the milk banks manufacturing and distributing donor milk for infants. Similarly, there is no requirement for milk banks to meet universal quality standards or report adverse events that may arise in donor milk batches. "

Currently, donor milk is considered mere food by the FDA, meaning there is no requirement for FDA inspectors to scrutinize the milk banks manufacturing and distributing donor milk for infants. Similarly, there is no requirement for milk banks to meet universal quality standards or report adverse events that may arise in donor milk batches. Adverse events happen at even the most careful milk banks. Without reporting these incidents, we would never have known about the bacterial outbreak at the Abbott Sturgis plant. In short, there are unacceptable, and frankly appalling, gaps in the regulation and safety of donor breast milk, a growing industry.

The U.S. Senate recently released its draft FY23 Agriculture/FDA appropriations bill directing the FDA to regulate donor breast milk banks and manufacturers. This is Congress' most direct action to date in favor of donor breast milk regulation and builds on the Donor Milk Safety Act introduced earlier this year. I am encouraged by this development and commend the Senate for its directive.

"The U.S. Senate recently released its draft FY23 Agriculture/FDA appropriations bill directing the FDA to regulate donor breast milk banks and manufacturers. This is Congress' most direct action to date in favor of donor breast milk regulation and builds on the Donor Milk Safety Act introduced earlier this year."

As both a mom and a legislator, I hope the FDA will act in the best interest of our children. It is past time for the federal government to address the issues of safety and access to donor milk and donor milk products. Improving oversight of the infant formula industry without addressing donor milk would be a devastatingly short-sighted move, leaving us at risk of another Abbott-style tragedy. We have all been warned.

Disclosures: No disclosures noted.

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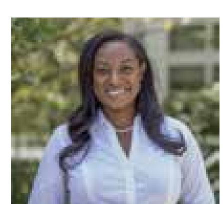
Corresponding Author



Jennifer Carroll Foy, JD
Former Public Defender, Prince William County, VA
Former Delegate
Virginia's 2nd House District
Candidate
State Senate
33rd District Virginia
Email: info@jennifercarrollfoy.com

Peer Reviewed

The Delivery Room

Scott D. Duncan, MD, MHA

"Within the delivery room, differences exist between the CPT® code sets, 99464 (attendance at delivery) and 99465 (the code for delivery or birthing room resuscitation, provision of positive pressure ventilation and/or chest compressions in the presence of acute inadequate ventilation and/or cardiac output)."

A 2020 article titled "The Bundled Neonate" reviewed the concept of "bundled" procedures within the global daily codes and highlighted the differences within the Current Procedural Terminology (CPT®) codes for delivery room management. Within the delivery room, differences exist between the CPT® code sets, 99464 (attendance at delivery) and 99465 (the code for delivery or birthing room resuscitation, provision of positive pressure ventilation and/or chest compressions in the presence of acute inadequate ventilation and/or cardiac output). Ultimately, reimbursement requires proper documentation supporting the CPT® code and International Classification of Disease, Tenth Revision, and Clinical Modification (ICD-10) diagnosis codes.

Proper documentation found in a delivery room note should include the following:

- Request for attendance at delivery
- Known maternal-fetal conditions impacting the delivery
- Attendance at delivery and/or resuscitation
- Focused physical examination
- Disposition of the patient

"The encounter should be initiated by the delivery physician's request for attendance at delivery. A hospital policy that requires a neonatologist to attend select deliveries (ex. - all cesarean sections) will not suffice for reimbursement purposes as a medical indication for attending the delivery."

The encounter should be initiated by the delivery physician's request for attendance at delivery. A hospital policy that requires a neonatologist to attend select deliveries (ex. - all cesarean sections) will not suffice for reimbursement purposes as a medical indication for attending the delivery. Preferably, the documentation should note the name of the delivery physician who requested the care provider to attend the delivery.

The neonatologist and/or advanced practice provider (APP) should be aware of known maternal-fetal conditions impacting the delivery. Note that maternal diagnosis found within the "O" Chapter, Pregnancy, Childbirth, and the Puerperium (O00 – O9A) is for use only on the maternal record! Further, the ICD-10 codes found within Z37 (Outcome of delivery) are used exclusively on the maternal record.

As noted above, there is a difference between CPT® codes 99464 (attendance at delivery) and 99465 (the code for delivery or birthing room resuscitation, positive pressure ventilation and/or chest compressions in the presence of acute inadequate ventilation and/or cardiac output). It is important to note that the application of continuous positive airway pressure (CPAP) is not considered resuscitation.

"As noted above, there is a difference between CPT® codes 99464 (attendance at delivery) and 99465 (the code for delivery or birthing room resuscitation, positive pressure ventilation and/or chest compressions in the presence of acute inadequate ventilation and/or cardiac output)."

If the infant requires additional resuscitative efforts, including intubation, surfactant administration, thoracentesis, paracentesis, and umbilical artery and/or vein catheterization, they should be reported separately. However, the procedure must be an essential component of resuscitation. Examples of CPT® procedure codes include emergency endotracheal intubation (31500), catheterization of the umbilical vein (36510), catheterization of the umbilical artery (36660), and surfactant administration (34610). Documentation of the procedure(s) should be included as part of the delivery room note.

The care provider should perform a focused physical examination of the infant prior to disposition. Note that this examination should not be construed as the initial examination upon admission to the newborn nursery or NICU, which represent separate encounters. Once disposition has been determined, the parent should be up-

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dated as to the condition and ongoing care of the infant.

Question

Dr. Smith asked you to attend an emergency cesarean delivery of a 28-week estimated gestational age neonate. The mother presents with chronic hypertension and a placenta previa with bleeding. Upon reviewing her prenatal labs, she is noted to have had a Group B Strep UTI during the pregnancy. The neonate is born limp, with poor respiratory effort, low heart rate, and cyanosis. Following NRP guidelines, you provide bag-mask ventilation. Subsequently, the neonate requires intubation and positive-pressure ventilation. The heart rate was initially less than 60 beats per minute and accelerated once the airway was secured. The physical examination demonstrates respiratory distress, with findings consistent with 28 weeks gestation and birthweight of 720 g. You discuss the findings with the parents and obstetrician and note the need for ongoing care. The infant is moved to the NICU. CXR confirms RDS. The infant is placed on assisted ventilation, an umbilical arterial catheter is placed, and surfactant is given. What is the correct CPT® code(s) for the delivery room?

A. 99465

B. 99465, 31500

C. 99465, 31500, 36660

The correct answer is B.

99465 represents the code for delivery or birthing room resuscitation, provision of positive pressure ventilation and/or chest compressions in the presence of acute inadequate ventilation and/or cardiac output.

31500 represents the code for endotracheal intubation, an emergency procedure.

36660 represents the code for catheterization of the umbilical artery for diagnosis or therapy in the newborn. As this procedure was performed in the NICU, this procedure is not billable as part of the resuscitation nor as part of the initial day of critical care.

Question

Correct ICD-10 Codes include all the following except:

A. Z38.01 Single liveborn infant, delivered by cesarean

B. P07.31 Preterm newborn, gestational age 28 completed weeks

C. P05.13 Disorders of newborn related to slow fetal growth and fetal malnutrition, small for gestational age, 500-749 g

D. P00.0 Newborn affected by maternal hypertensive disorders

E. O69.4 Labor and delivery complicated by vasa previa

F. P00.82 Newborn affected by maternal group B Streptococcus (GBS) colonization

G. P22.0 Respiratory distress syndrome of the newborn

The correct answer is **E**. Codes from the "O" chapter are exclusive to the maternal chart. The correct code for placenta previa affecting the newborn is P02.0.

Proper documentation may be similar to the following:

Dr. Smith asked me to attend a cesarean section for an EGA 28-week infant. The maternal history is significant for chronic hypertension and a GBS UTI during the pregnancy. She presents with placenta previa and vaginal bleeding. The infant was delivered by emergency cesarean section, which produced a live/viable female infant. Delayed cord clamping was not performed as the infant was limp with no respiratory effort. The infant was dried, the OP was suctioned, and the infant was stimulated. HR was approximately 60 bpm. PPV was applied via bag and mask. The infant was subsequently intubated with a 2.5 ETT via direct laryngoscopy with a 00 Miller blade and demonstrated increased HR, respiratory effort, and tone. PE was consistent with a symmetrically SGA 28-week infant. There continue to be significant intercostal and subcostal retractions and an increase in WOB with bilateral rales. HR is regular w/o murmur. The abdomen reveals a 3-vessel umbilical cord. There is no HSM Normal preterm female genitalia. The anus is patent. The infant is to be transferred to the NICU. The parents were updated following the delivery. Dr. Smith is aware and updated.

Disclosure: The author has no disclosures.

NT

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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.

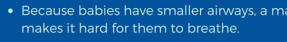
Take Care of Yourself

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

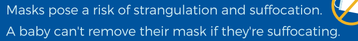
Immunizations Vaccinations save lives. Protecting your baby from flu and pertussis lowers their risks for complications from coronavirus.

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

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

Position available for Neonatal Nurse Pretensioner (NNP)

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

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PREEMIE BOOK ON SALE

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BY JENNÉ JOHNS

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MATERNITY CARE COALITION ADVOCACY DAY

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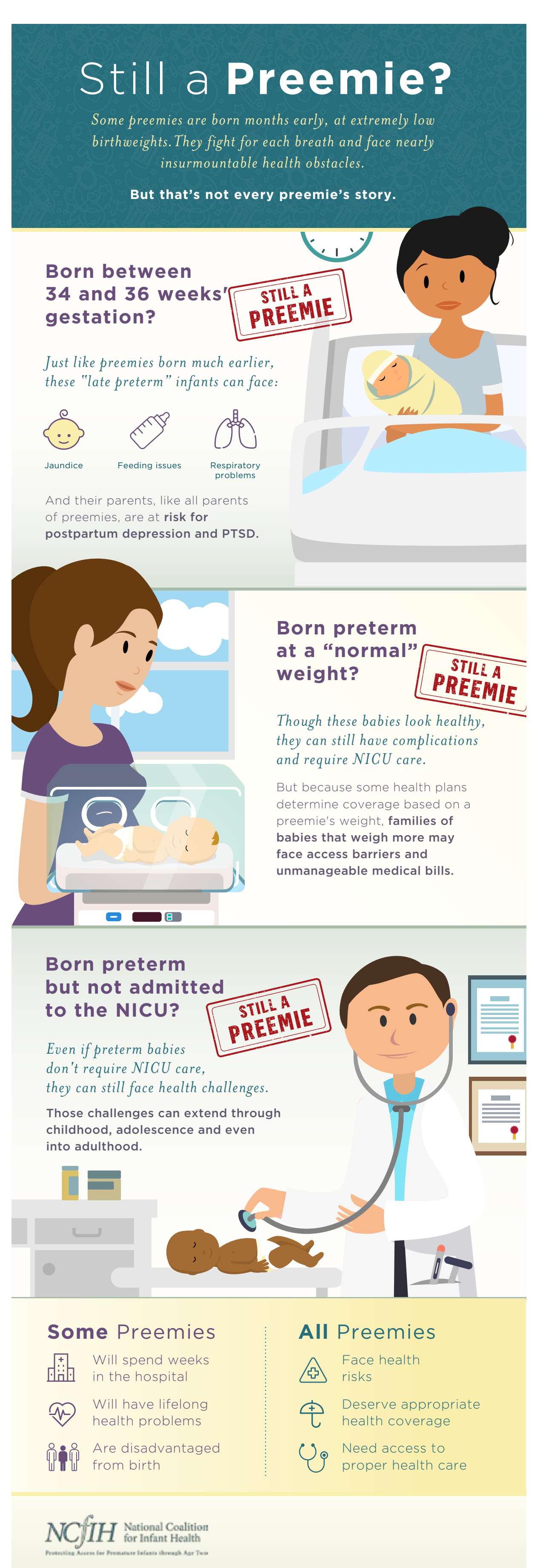


OPIOIDS and NAS

When reporting on mothers, babies, and substance use

LANGUAGE MATTERS

I am not an addict.

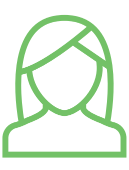
I was exposed to substances in utero. I am not addicted. Addiction is a set of behaviors associated with having a Substance Use Disorder (SUD).

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.

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

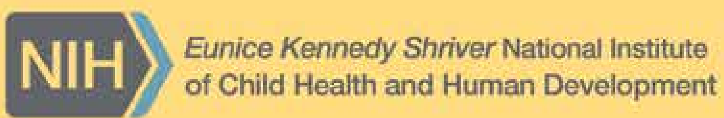
FREE Online CE Activity

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.



Compiled and Reviewed by Saba Saleem, BS, OMS 4

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New Peer-Reviewed Study Finds Vat Pasteurization Retains Molecular Structure of Naturally Occurring Bioactive Proteins in Human Donor Milk, Similar to Raw Breast Milk

NEWS PROVIDED BY

Prolacta Bioscience

Oct 04, 2022, 09:07 ET

Vat pasteurization preserved more of the bioactive proteins than ultra-high-temperature or retort sterilization, especially immunoglobulins, lactoferrin, and caseins

DUARTE, Calif., Oct. 4, 2022 /PRNewswire/ -- Prolacta Bioscience®, the world›s leading hospital provider of 100% human milk-based nutritional products for critically ill, premature infants, announced today the publication of a journal article that compares the effects of various manufacturing methods on bioactive proteins in donor human milk.

The naturally occurring bioactive proteins in human milk play a vital role in infant nutrition. In addition to providing key nutrients like amino acids, calcium, and phosphorus,1 bioactive proteins also protect against bacterial and viral infections and contain anti-inflammatory properties.2

The peer-reviewed article, which focuses on structural and functional changes of bioactive proteins, found that the molecular structure of bioactive proteins in donor human milk that had been vat pasteurized most closely resembled those in raw milk controls, compared with other human milk processing methods, including ultra-high-temperature (UHT) sterilization and retort sterilization.2

Authored by Ningjian Liang, PhD; David C. Dallas, PhD; and colleagues at Oregon State University and the University of California, Davis, «Structural and Functional Changes of Bioactive Proteins in Donor Human Milk Treated by Vat-Pasteurization, Retort Sterilization, Ultra-High-Temperature Sterilization, Freeze-Thawing and Homogenization» was published in September in the peer-reviewed journal Frontiers in Nutrition.2 The study compared the effects on human milk when treated by commonly used processing methods.

The researchers concluded that different bioactive proteins have different sensitivity to the treatments tested. Overall, vat pasteurization preserved more of the bioactive proteins than UHT sterilization or retort sterilization did. This was especially true of three bioactive proteins: immunoglobulins, lactoferrin, and caseins.2

Intake of human milk is especially critical for babies born prematurely, with mother's own milk (MOM) being the best feeding option. When an adequate amount of MOM is not available, the American Academy of Pediatrics recommends the use of donor human milk.3

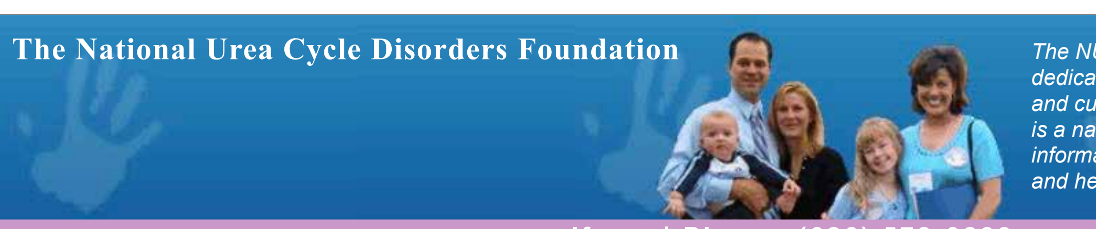
Donor human milk must be processed to eliminate the possibility of pathogen contamination before being given to infants in the neonatal intensive care unit (NICU).4,5 Once the milk is processed and/or pasteurized to ensure safety, bioactivity is impacted.6,7 But prior to this study, the extent of those changes based on each processing method were unknown.

"Currently, donor milk processors lack information about the extent to which different processing techniques degrade or preserve bioactive milk proteins. Our study addresses this critical research gap as we examined the extent to which various treatments can preserve bioactive proteins," wrote Liang, a postdoctoral researcher in the laboratory of David Dallas, an assistant professor in the College of Public Health and Human Sciences at Oregon State University. "This information will support milk processors in determining how to optimally process donor milk to preserve specific milk proteins."

Liang et al. tested processed milk samples using the SDS-PAGE method, which separates proteins based on their molecular weight. They then tested the milk samples using the enzyme-linked immunoabsorbent assay (ELISA), a widely used laboratory technique that measures proteins and other substances.

"The more we learn about the importance of bioactivity in human milk, the more important it is that we understand how processing affects the milk we rely on to provide optimal nutrition to our patients," said Melinda Elliott, chief medical officer of Prolacta and a practicing neonatologist. "This study reinforces that how human milk is processed matters. Prolacta's human milk-based products are vat pasteurized to preserve as much of the natural bioactivity of the milk as possible."

Human donor milk providers use several methods to process human milk, including:



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

- **Vat and Holder pasteurization**: Heating milk to a set temperature to inactivate contaminants including bacteria and viruses. The process may reduce the activity and concentration of milk enzymes and some bioactive proteins.6
- **Retort sterilization**: Commercial canning method that exposes milk to high temperature and pressure. This method inactivates bacteria and viruses and is shown to result in greater damage to bioactive proteins when compared to vat and Holder pasteurization.2,6
- **Ultra-high temperature (UHT) processing, with or without homogenization**: Heating milk to high temperatures and homogenization, a process that evenly disperses two liquids to create a single uniform mixture, cause structural and compositional changes to the milk fat globule membrane (MFGM). Separately or in combination, these processes may play an important role in the decrease of MFGM bioactivity.8,9

About Human Milk-Based Nutritional Products

The major difference between cow milk-based and human milk-based nutritional products is the composition — notably, the bioactive components that are unique to human milk. These include immunoglobulins, lactoferrin, milk fat globule membrane, and the wide spectrum of prebiotics known as human milk oligosaccharides (HMOs), which are not easily manufactured and thus are greatly decreased or missing from cow milk-based nutritional products.10 Bioactivity is thought to support infants' immunity, development, growth, and long-term health.11

Prolacta's 100% human milk-based nutritional products have the highest bioactivity in the human milk industry.12 Prolacta's nutritional products are vat pasteurized using temperature profiles defined by the U.S. Food and Drug Administration (FDA) to ensure pathogen inactivation and the highest level of safety while retaining as much of the natural bioactivity of the milk as possible.12 Prolacta's vat pasteurized products retain higher bioactivity than products processed using other methods, including retort sterilization and UHT processing.2,6,7

About Prolacta Bioscience

Prolacta Bioscience® Inc. is a privately held, global life sciences company dedicated to Advancing the Science of Human Milk® to improve the health of critically ill, premature infants. Prolacta's 100% human milk-based nutritional products have been evaluated in more than 20 clinical studies published in peer-reviewed journals. More than 80,000 premature infants have benefited from Prolacta's nutritional products worldwide to date.13 Established in 1999, Prolacta is the world's leading provider of human milk-based nutritional products for hospital use and is also exploring the therapeutic potential of human milk across a wide spectrum of diseases. Prolacta maintains the industry's strictest quality and safety standards for screening, testing, and processing donor human milk. Operating the world's first pharmaceutical-grade human milk processing facilities, Prolacta uses vat pasteurization and a patented, FDA-reviewed manufacturing process to ensure pathogen inactivation while protecting the nutritional composition and bioactivity of its human milk-based products. Prolacta is a global company with headquarters in Duarte, California, and can be found online at www.prolacta.com, on Twitter, Instagram, Facebook, and LinkedIn.

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310-721-9444

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www.mynicunetwork.org

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13. *Estimated number of premature infants fed Prolacta's products from January 2007 to May 2021; data on file.*

SOURCE Prolacta Bioscience

NT

Children's Hospital Los Angeles: Time to Extubate Varies Widely After Mandibular Distraction Osteogenesis

October 11, 2022

Study finds no significant risk of reintubation at hospitals that extubate infants earlier.

Nearly two decades ago, Children's Hospital Los Angeles was among a handful of centers that pioneered mandibular distraction osteogenesis (MDO) for infants with airway obstructions due to micrognathia (undersized jaw).

But while MDO is now the mainstream surgical treatment for these babies, there are no standard guidelines for how to care for these complex patients. One key question: How long should these babies stay on a ventilator after surgery?

Kuan-Chi Lai, MD, MPH, a neonatologist in the Fetal and Neonatal Institute at Children's Hospital Los Angeles, recently led a study comparing postoperative extubation times—and their impact on patients' length of stay—at pediatric hospitals across the country. He presented his findings in a poster presentation at the Pediatric Academic Societies Annual Meeting in April.

"We found large variations between hospitals in how quickly these patients are extubated," Dr. Lai says. "And those differences have a significant impact on how long babies need to stay in the hospital."

Key findings

Using the national Pediatric Health Information System database—an administrative database of more than 45 pediatric hospitals—Dr. Lai and the team looked at infants with micrognathia who underwent the MDO procedure in the first six months of life, from 2011 to 2020.

Because this complex craniofacial anomaly—part of Pierre Robin syndrome—is rare, he focused only on hospitals treating more than 20 patients in that 10-year period. In all, the study included 842 infants across 21 centers.

The team found that:

- Time to extubate varied widely among hospitals—from five days or less at a few centers to 10 days or more at others.
- Patient severity did not explain differences in extubation practices. Hospitals with later extubation times did not have more patients with such risk factors as lower birth weight, premature birth, syndromic micrognathia or being intubated prior to surgery.
- There was no significant risk of reintubation at hospitals that extubated patients earlier.

That last finding is particularly important because the main reason why patients have traditionally been left intubated for

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longer times is to prevent the risk of reintubation.

"The risk for reintubation is low, but it's not zero," says Dr. Lai. "There's always fear for that one case. But what this data shows is that earlier extubation is not associated with increased adverse events."

Impact on length of stay

For centers with the shortest time to extubate (five days or less), the median postoperative length of stay was 19 days. At hospitals with the longest times, babies were discharged a full week later, at 26.5 days.

It's not just time on a ventilator that creates these longer lengths of stay. Even after the breathing tube is removed, those patients take longer to go home, Dr. Lai says. The study found that every additional day on a ventilator led to a delay in discharge of 1.33 days.

"It's not one-to-one," he notes. "The longer these patients are on a ventilator, the longer it takes to later wean them off of the sedation medicines and to initiate oral feeding.

"Our conclusion was that hospitals with later extubation times should consider adopting a standardized protocol for expediting extubation in clinically appropriate patients," he adds. "There are clear benefits to earlier extubation for these children, but it needs to be done safely."

Katie Sweeney

NT

Study highlights the importance of earlier contact between mothers and premature babies

Babies who are born two to three months early are usually separated from their mother in the first hours after birth.

By Magnus Nødland Skogedal

September 21, 2022

"The fact that skin-to-skin contact between the newborn and the mother is important is nothing new. And new research shows that early skin-to-skin contact has many psychological and physical benefits", says Pediatric Nurse and Associate Professor Anne Marit Føreland at the Department of Health and Nursing Sciences at the University of Agder.

The World Health Organisation has provided guidelines to promote early skin-to-skin contact between mother and baby. The organisation has nevertheless been hesitant to recommend this for babies who are born very prematurely, partly because there is uncertainty about whether the babies' condition is stable enough, and also because a lot of equipment is required to make this happen.

Mothers' experiences

Føreland and her colleagues are involved in a large research project, coordinated by St. Olav's Hospital, where the aim is to explore the effect of early skin-to-skin contact between mother and prematurely born baby immediately after birth. The babies' oxygen saturation, body temperature and the like were measured. However, they understood that not all answers could be obtained from the quantitative data.

"We also wanted to conduct a qualitative study on the mothers' experiences of skin-to-skin contact in such a situation. After all, there are two parties involved here, and the large study was enriched by also shedding light on the mothers' experiences", Føreland says.

They looked at births that occur from week 28 to 32 of pregnancy, which is two to three months early. A birth like that is a great strain, and very stressful for both mother and baby.

Many such births occur by caesarean section, and common practice is to put the baby in an incubator after being stabilised. It can take a long time before mother and baby are reunited, as an early birth is often due to illness in the mother.

Their qualitative study involved ten births, where one group received traditional care and the other was offered skin-to-skin contact with their baby within an hour after birth.

In the control group Føreland and her colleagues examined, it took from 2 to 30 hours before mother and baby were reunited.

Skin-to-skin contact best

After the births, the mothers were interviewed about their experiences. These interviews form the basis for the qualitative study.

"Both groups of mothers had a deep need to know that their baby was doing well. It was also clear that being able to have the baby placed skin to skin provided the best affirmation that the baby was doing well. Being able to use all of your senses makes a huge difference. The mothers felt that early skin-to-skin contact promoted bonding and a feeling of well-being", Føreland says.

There are several practical obstacles to offering skin-to-skin-to-skin contact between mothers and very preterm babies. The separation that is currently practiced in Norwegian hospitals is done for practical reasons, and this is where Føreland hopes that their research can lead to changes.

Photos and information help

"All the mothers who had been separated from their babies found it difficult. Seeing photos from the neonatal intensive care unit and getting information helped, but it was best to be able to hold their baby early on. The father's presence with the mother and the newborn baby was also important, both for those who were allowed to stay together and those who had to be separated", Føreland says.

Early skin-to-skin contact is an important research area internationally, and Føreland and her colleagues will present their findings at a conference in Spain in November.

In addition to changing hospital practice, the research may also have implications for how hospitals are built in the future.

"There is a long distance between the maternity ward and the neonatal intensive care unit in many hospitals today. That makes it more difficult to introduce the changes we are studying. They must be practically possible to achieve. We hope that our research can help inspire others", Føreland says.

Read the research article here: https://journals.sagepub.com/doi/10.1177/23333936221097116

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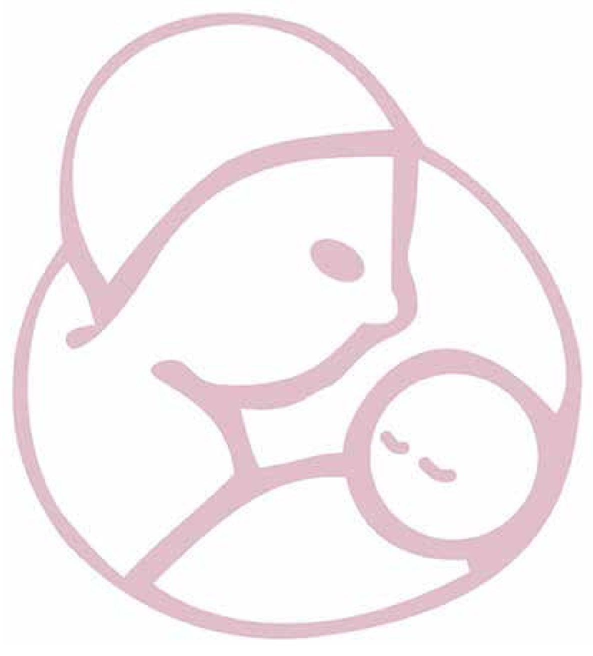

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University of Agder News

NT

World's first stem cell treatment for spina bifida delivered during fetal surgery

October 6, 2022

Groundbreaking trial aims to reverse the paralysis and other abnormal functions of spina bifida before birth

Three babies have been born after receiving the world's first spina bifida treatment combining surgery with stem cells. This was made possible by a landmark clinical trial at UC Davis Health.

The one-of-a-kind treatment, delivered while a fetus is still developing in the mother's womb, could improve outcomes for children with this birth defect.

Launched in the spring of 2021, the clinical trial is known formally as the "CuRe Trial: Cellular Therapy for In Utero Repair of Myelomeningocele." Thirty-five patients will be treated in total.

The three babies from the trial that have been born so far will be monitored by the research team until 30 months of age to fully assess the procedure's safety and effectiveness.

The first phase of the trial is funded by a $9 million state grant from the state's stem cell agency, the California Institute for Regenerative Medicine (CIRM).

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"This clinical trial could enhance the quality of life for so many patients to come," said Emily, the first clinical trial participant who traveled from Austin, Tex. to participate. Her daughter Robbie was born last October. "We didn't know about spina bifida until the diagnosis. We are so thankful that we got to be a part of this. We are giving our daughter the very best chance at a bright future."

Spina bifida, also known as myelomeningocele, occurs when spinal tissue fails to fuse properly during the early stages of pregnancy. The birth defect can lead to a range of lifelong cognitive, mobility, urinary and bowel disabilities. It affects 1,500 to 2,000 children in the U.S. every year. It is often diagnosed through ultrasound.

While surgery performed after birth can help reduce some of the effects, surgery before birth can prevent or lessen the severity of the fetus's spinal damage, which worsens over the course of pregnancy.

"I've been working toward this day for almost 25 years now," said Diana Farmer, the world's first woman fetal surgeon, professor and chair of surgery at UC Davis Health and principal investigator on the study.

The path to a future cure

As a leader of the Management of Myelomeningocele Study (MOMS) clinical trial in the early 2000s, Farmer had previously helped to prove that fetal surgery reduced neurological deficits from spina bifida. Many children in that study showed improvement but still required wheelchairs or leg braces.

Farmer recruited bioengineer Aijun Wang specifically to help take that work to the next level. Together, they launched the UC Davis Health Surgical Bioengineering Laboratory to find ways to use stem cells and bioengineering to advance surgical effectiveness and improve outcomes. Farmer also launched the UC Davis Fetal Care and Treatment Center with fetal surgeon Shinjiro Hirose and the UC Davis Children's Surgery Center several years ago.

Farmer, Wang and their research team have been working on their novel approach using stem cells in fetal surgery for more than 10 years. Over that time, animal modeling has shown it is capable of preventing the paralysis associated with spina bifida.

It's believed that the stem cells work to repair and restore damaged spinal tissue, beyond what surgery can accomplish alone.

Preliminary work by Farmer and Wang proved that prenatal surgery combined with human placenta-derived mesenchymal stromal cells, held in place with a biomaterial scaffold to form a "patch," helped lambs with spina bifida walk without noticeable disability.

"When the baby sheep who received stem cells were born, they were able to stand at birth and they were able to run around almost normally. It was amazing," Wang said.

When the team refined their surgery and stem cells technique for canines, the treatment also improved the mobility of dogs with naturally occurring spina bifida.

A pair of English bulldogs named Darla and Spanky were the world's first dogs to be successfully treated with surgery and stem cells. Spina bifida, a common birth defect in this breed, frequently leaves them with little function in their hindquarters.

By their post-surgery re-check at 4 months old, Darla and Spanky were able to walk, run and play.

The world's first human trial

When Emily and her husband Harry learned that they would be first-time parents, they never expected any pregnancy complications. But the day that Emily learned that her developing child had spina bifida was also the day she first heard about the CuRe trial.

For Emily, it was a lifeline that they couldn't refuse.

Participating in the trial would mean that she would need to temporarily move to Sacramento for the fetal surgery and then for weekly follow-up visits during her pregnancy.

After screenings, MRI scans and interviews, Emily received the life-changing news that she was accepted into the trial. Her fetal surgery was scheduled for July 12, 2021, at 25 weeks and five days gesta-

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tion.

Farmer and Wang's team manufactures clinical grade stem cells – mesenchymal stem cells – from placental tissue in the UC Davis Health's CIRM-funded Institute for Regenerative Cures. The cells are known to be among the most promising type of cells in regenerative medicine.

The lab is a Good Manufacturing Practice (GMP) Laboratory for safe use in humans. It is here that they made the stem cell patch for Emily's fetal surgery.

"It's a four-day process to make the stem cell patch," said Priya Kumar, the scientist at the Center for Surgical Bioengineering in the Department of Surgery, who leads the team that creates the stem cell patches and delivers them to the operating room. "The time we pull out the cells, the time we seed on the scaffold, and the time we deliver, is all critical."

A first in medical history

During Emily's historic procedure, a 40-person operating and cell preparation team did the careful dance that they had been long preparing for.

After Emily was placed under general anesthetic, a small opening was made in her uterus and they floated the fetus up to that incision point so they could expose its spine and the spina bifida defect. The surgeons used a microscope to carefully begin the repair.

Then the moment of truth: The stem cell patch was placed directly over the exposed spinal cord of the fetus. The fetal surgeons then closed the incision to allow the tissue to regenerate.

"The placement of the stem cell patch went off without a hitch. Mother and fetus did great!" Farmer said.

The team declared the first-of-its-kind surgery a success.

Delivery day

On Sept. 20, 2021, at 35 weeks and five days gestation, Robbie was born at 5 pounds, 10 ounces, 19 inches long via C-section.

"One of my first fears was that I wouldn't be able to see her, but they brought her over to me. I got to see her toes wiggle for the first time. It was so reassuring and a little bit out of this world," Emily said.

For Farmer, this day is what she had long hoped for, and it came with surprises. If Robbie had remained untreated, she was expected to be born with leg paralysis.

"It was very clear the minute she was born that she was kicking her legs and I remember very clearly saying, 'Oh my God, I think she's wiggling her toes!'" said Farmer, who noted that the observation was not an official confirmation, but it was promising. "It was amazing. We kept saying, 'Am I seeing that? Is that real?'"

Both mom and baby are at home and in good health. Robbie just celebrated her first birthday.

The CuRe team is cautious about drawing conclusions and says a lot is still to be learned during this safety phase of the trial. The team will continue to monitor Robbie and the other babies in the trial until they are 6 years old, with a key checkup happening at 30 months to see if they are walking and potty training.

"This experience has been larger than life and has exceeded every expectation. I hope this trial will enhance the quality of life for so many patients to come," Emily said. "We are honored to be part of history in the making."

By Tricia Tomiyoshi

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UC Davis Children's Health

NT

How the mother's mood influences her baby's ability to speak

October 07, 2022

Communicating with babies in infant-directed-speech is considered an essential prerequisite for successful language development of the little ones. Researchers at the Max Planck Institute for Human Cognitive and Brain Sciences have now investigated how the mood of mothers in the postpartum period affects their child's development. They found that even children whose mothers suffer from mild depressive mood that do not yet require medical treatment show early signs of delayed language development. The reason for this could be the way the women talk to the newborns. The findings could help prevent potential deficits early on.

Up to 70 percent of mothers develop postnatal depressive mood, also known as baby blues, after their baby is born. Analyses show that this can also affect the development of the children themselves and their speech. Until now, however, it was unclear exactly how this impairment manifests itself in early language development in infants.

In a study, scientists at the Max Planck Institute for Human Cognitive and Brain Sciences in Leipzig have now investigated how well babies can distinguish speech sounds from one another depending on their mother's mood. This ability is considered an important prerequisite for the further steps towards a well-developed language. If sounds can be distinguished from one another, individual words can also be distinguished from one another. It became clear that if mothers indicate a more negative mood two months after birth, their children show on average a less mature processing of speech sounds at the age of six months. The infants found it particularly difficult to distinguish between syllable-pitches. Specifically, they showed that the development of their so-called Mismatch Response was delayed than in those whose mothers were in a more positive mood. This Mismatch Response in turn serves as a measure of how well someone can separate sounds from one another. If this development towards a pronounced mismatch reaction is delayed, this is considered an indication of an increased risk of suffering from a speech disorder later in life.

"We suspect that the affected mothers use less infant-directed-speech," explains Gesa Schaadt, postdoc at MPI CBS, professor of development in childhood and adolescence at FU Berlin and first author of the study, which has now appeared in the journal JAMA Network Open. "They probably use less pitch variation when directing speech to their infants." This also leads to a more limited perception of different pitches in the children, she said. This perception, in turn, is considered a prerequisite for further language development.

The results show how important it is that parents use infant-directed speech for the further language development of their children. Infant-directed speech that varies greatly in pitch, emphasizes certain parts of words more clearly - and thus focuses the little ones' attention on what is being said - is considered appropriate for children. Mothers, in turn, who suffer from depressive mood, often use more monotonous, less infant-directed speech. "To ensure the proper development of young children, appropriate support is also needed for mothers who suffer from mild upsets that often do not yet require treatment," Schaadt says. That doesn't necessarily have to be organized intervention measures. "Sometimes it just takes the fathers to be more involved."

The researchers investigated these relationships with the help of 46 mothers who reported different moods after giving birth. Their moods were measured using a standardized questionnaire typically used to diagnose postnatal upset. They also used electroencephalography (EEG), which helps to measure how well babies can distinguish speech sounds from one another. The so-called Mismatch Response is used for this purpose, in which a specific EEG signal shows how well the brain processes and distinguishes between different speech sounds. The researchers recorded this reaction in the babies at the ages of two and six months while they were presented with various syllables such as "ba," "ga" and "bu.

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Original publication

Gesa Schaadt, Rachel G. Zsido, Arno Villringer et al

Association of Postpartum Maternal Mood With Infant Speech Perception at 2 and 6.5 Months of Age

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Prenatal cannabis exposure associated with mental disorders in children that persist into early adolescence

The New England Journal of Medicine Correspondence

Neonatal Monkeypox Virus Infection

October 12, 2022

To the Editor:

The ongoing monkeypox outbreak was recently declared to be a Public Health Emergency of International Concern by the World Health Organization.1 Young children are at risk for severe disease; therefore, early recognition and prompt treatment are important.2 We report a case of perinatally acquired monkeypox virus infection and adenovirus coinfection in a 10-day-old infant. After the infant's uneventful birth in late April 2022, a rash developed on day 9 of life. The rash was initially vesicular, starting on the palms and soles and subsequently spreading to the face and trunk, and gradually became pustular (Fig. 1). Nine days before the birth, the infant's father had had a febrile illness, followed by a widespread rash; the rash resolved before the infant's birth. Four days after the infant's delivery, a similar rash developed in the mother. The family lived in the United Kingdom, and there was no history of travel to Africa or of contact with any travelers. The infant was transferred to the regional pediatric intensive care unit on day 15 of life owing to evolving hypoxemic respiratory failure (Fig. S1 in the Supplementary Appendix, available with the full text of this letter at NEJM.org). A number of diagnoses (neonatal varicella, herpes simplex virus infection, coxsackievirus or enterovirus infection, staphylococcal skin infection, scabies, syphilis, and gonorrhea) were considered. The presence of axillary lymphadenopathy, the nature of the skin lesions, and the atypical timeline of intrafamilial infection aroused concern regarding human monkeypox. Polymerasechain-reaction testing of blood, urine, vesicularfluid, and throat-swab samples obtained from the infant and mother led to a diagnosis of monkeypox virus infection (clade IIb). Adenovirus was also identified in the infant's respiratory secretions and blood. The infant's condition worsened, and invasive ventilation was initiated. A 2-week course of enteral tecovirimat (at a dose of 50 mg twice a day) was commenced in combination with intravenous cidofovir. After 4 weeks in intensive care, including 14 days of invasive ventilation, the infant recovered and was discharged home. The timeline of intrafamilial infection and test results is shown in Figure S2. Reports of neonatal monkeypox virus infection are rare.3 This was a case of neonatal monkeypox virus infection after peripartum transmission within a family cluster; transplacental transmission could not be ruled out.4 Because this was a single case, it is not possible to attribute the clinical illness to either pathogen (monkeypox virus or adenovirus) directly, nor is it possible to attribute the improvement in the infant's clinical condition to the use of tecovirimat or cidofovir.5 Monkeypox virus infection should be considered in the differential diagnosis of a neonatal vesicular rash.

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*A list of the members of the NHS England High Consequence Infectious Diseases (Airborne) Network is provided in the Supplementary Appendix, available at NEJM.org.

Disclosure forms provided by the authors are available with the full text of this letter at NEJM.org.

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NT

American Academy of Pediatrics, Section on Advancement in Therapeutics and Technology

Released: Thursday 12/13/2018 12:32 PM, updated Saturday 3/16/2019 08:38, Sunday 11/17/2019 and Friday 11/20/2020

The American Academy of Pediatrics' Section on Advances in Therapeutics and Technology (SOATT) invites you to join our ranks! SOATT creates a unique community of pediatric professionals who share a passion for optimizing the discovery, development and approval of high quality, evidence-based medical and surgical breakthroughs that will improve the health of children. You will receive many important benefits:

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Thank you for all that you do on behalf of children. If you have any questions, please feel free to contact:

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NT

UCSF Researchers Discover How Vascular Cells Develop in Prenatal Brain

Findings Open Door to Precision Therapeutics for Neonatal Hemorrhage

With a new study, UC San Francisco researchers are the first to show how blood vessel cells develop in the prenatal human brain, paving the way to fully understand the role of these cells in healthy brain development and disease.

Recent research into vascular cells shows they are important players in many organs, going beyond delivering blood and nutrients to function as key signaling hubs that regulate organ physiology and pathophysiology. In this study, publishing September 29 in Cell, the researchers investigated the area in the prenatal human brain where nascent blood vessels interact with neural stem cells and newly born neurons.

Their findings have important implications for addressing neonatal neurovascular disease, said Elizabeth Crouch, MD, PhD, the study's first author and an assistant adjunct professor of Pediatrics and Stem Cell Biology at UCSF.

"Even in the middle of taking this course, I could see myself changing the way that I spoke to parents. After taking this course, I am much better at emotionally supporting our NICU families."

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"As a neonatologist, I work with babies who experience brain hemorrhage. There are currently no therapeutics in this area and neonatal hemorrhages can cause lifelong disability," said Crouch, who is also a researcher with UCSF's Eli and Edythe Broad Center of Regeneration Medicine and Stem Cell Research. "I'm excited that our work opens the door to precision therapeutics for our youngest and most vulnerable patients."

Crouch cited as an example of potential therapeutic application those infants who have a mutation in collagen gene COL4A1, which causes detrimental brain hemorrhages that are typically fatal at a young age. This study showed that COL4A1 is indeed one of the most active signaling pathways that regulate vascular cell development in the human brain during the second trimester.

"So now we have an answer as to why mutations in this gene are so detrimental so early on," said Crouch. "With this understanding, we can now envision cellular therapies to replace COL4A1 in vascular cells, particularly in mural cells which make most of this protein. Alternatively, we could activate this signaling pathway with small molecules. Either way, this discovery now allows us to envision therapies where previously the targets were unknown."

New Strategies to Isolate Vascular Cells

Vascular cells comprise about 10% of all cell types in the human brain. In this new study, researchers not only identified stages of vascular cell development, but were able to define subtypes of vascular cells in the prenatal brain.

"A lot of what we had understood about vascular cells was from the postnatal mouse brain, or models like the zebrafish," said Eric Huang, MD, PhD, professor of pathology in the UCSF School of Medicine, senior study author, and researcher with UCSF's Broad Center. "What is innovative here is that we used prenatal human tissue entirely, and that gave an insight and innovation that no one has had before."

UCSF researchers were able to work with human vascular cells for two reasons: they had access to donated human prenatal tissue—mostly from the second trimester—and they developed new strategies to isolate vascular cells from other cells in the brain.

"Other studies have looked at blood vessel cells, but they were diluted because of an inability to enrich them," Huang said. "Having the ability to isolate and enrich the cells was a major breakthrough that pushed the project forward. This is by far the largest database out there of human brain vascular cells."

As part of their work, the researchers created a web site with their data for other scientists to use in their own research on vascular cell subtypes and therapeutic strategies to facilitate mature brain vasculature in premature infants.

"Our results provide an important blueprint for additional studies that focus on vascular development in the third trimester, perinatal and early postnatal stages," the researchers stated in their paper. "These results will progress to a more complete model of vascular cell changes and environmental influences in other critical periods."

Together with UCSF researchers who recently published studies on the role of adult vascular cells in neurodegeneration in Hunter syndrome and Alzheimer's disease, Crouch and Huang are working to build a Center for Neurovascular Excellence at UCSF.

"It takes a village to execute a study like this, and we are fortunate to have collaborators at UCSF who helped us push the project to a level that we wanted it to be at," Huang said. "The study wouldn't have been possible without the collegial environment at UCSF."

Co-authors and funding: Please see paper for additional co-authors and funding disclosures.

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NT

Four in 5 pregnancy-related deaths in the U.S. are preventable

Data highlight opportunities to better protect moms

More than 80% of pregnancy-related deaths were preventable, according to 2017-2019 data from Maternal Mortality Review Committees (MMRCs), which are representatives of diverse clinical and non-clinical backgrounds who review the circumstances around pregnancy-related deaths to identify recommendations to prevent future deaths. Information from MMRCs in 36 U.S. states on leading causes of death by race and ethnicity can be used to prioritize interventions that can save lives and reduce health disparities.

"The report paints a much clearer picture of pregnancy-related deaths in this country," said Wanda Barfield, M.D., M.P.H., director of CDC's Division of Reproductive Health at the National Center for Chronic Disease Prevention and Health Promotion. "The majority of pregnancy-related deaths were preventable, highlighting the need for quality improvement initiatives in states, hospitals, and communities that ensure all people who are pregnant or postpartum get the right care at the right time."

Key Findings:

Among pregnancy-related deaths with information on timing, 22% of deaths occurred during pregnancy, 25% occurred on the day of delivery or within 7 days after, and 53% occurred between 7 days to 1 year after pregnancy.

The leading underlying causes of pregnancy-related death include:

- Mental health conditions (including deaths to suicide and over-

dose/poisoning related to substance use disorder) (23%)

- Excessive bleeding (hemorrhage) (14%)
- Cardiac and coronary conditions (relating to the heart) (13%)
- Infection (9%)
- Thrombotic embolism (a type of blood clot) (9%)
- Cardiomyopathy (a disease of the heart muscle) (9%)
- Hypertensive disorders of pregnancy (relating to high blood pressure) (7%)

The leading underlying cause of death varied by race and ethnicity. Cardiac and coronary conditions were the leading underlying cause of pregnancy-related deaths among non-Hispanic Black people, mental health conditions were the leading underlying cause for Hispanic and non-Hispanic White people, and hemorrhage was the leading underlying cause for non-Hispanic Asian people.

American Indian or Alaska Native data highlighted

American Indian or Alaska Native (AI/AN) people are disproportionally impacted by pregnancy-related deaths. A second report uses an approach for classifying AI/AN populations that includes those who also identify as multi-racial or of Hispanic ethnicity.

Based on a review of pregnancy-related deaths among AI/AN people, mental health conditions and hemorrhage were the most common underlying causes of death, accounting for 50% of deaths with a known underlying cause. Most pregnancy-related deaths of AI/AN people (93%) were determined to be preventable. About 64% of deaths occurred between 7 days to 1 year after pregnancy.

Everyone can help prevent pregnancy-related deaths

More than half (53%) of pregnancy-related deaths happen up to one year after delivery. It is critical for all healthcare professionals to ask whether their patient is pregnant or has been pregnant in the last year to inform diagnosis and treatment decisions. Healthcare systems, communities, families, and other support systems need to be aware of the serious pregnancy-related complications that can happen during and after pregnancy. Listen to the concerns of people who are pregnant and have been pregnant during the last year and help them get the care they need.

Examples of prevention recommendations from MMRCs include wider access to insurance coverage to improve prenatal care initiation and follow-up after pregnancy, providing opportunities to prevent barriers to transportation to care, and the need for systems of referral and coordination.

Maternal Mortality Review Committees are the best source for prevention strategies

MMRCs are multidisciplinary committees that convene at the state or local level to comprehensively review deaths during or within one year of pregnancy. Their goal is to understand circumstances surrounding each death and develop recommendations for action to prevent deaths in the future.

This is the first information to be released under the Enhancing Reviews and Surveillance to Eliminate Maternal Mortality, a CDC-funded program to support agencies and organizations that manage MMRCs. CDC also supports the Maternal Mortality Review Information Application (MMRIA) to standardize reporting of data from MMRCs. This report reflects efforts undertaken by jurisdictions to improve their MMRC processes and use MMRIA to document and disseminate information.

Recently, CDC significantly expanded its investment in efforts to eliminate preventable pregnancy-related deaths, with new awards totaling $2.8 million to support additional MMRCs in nine jurisdictions. CDC now supports MMRCs in 39 states and one U.S. Territory. Building this important infrastructure will help better understand and prevent pregnancy-related deaths in the U.S.

Additional information:

State Strategies for Preventing Pregnancy-Related Deaths: A Guide for MMRC Data to Action provides MMRCs and their partners with a guide to help facilitate implementation of data-informed strategies to prevent pregnancy-related deaths.

For information on ways to support people who are pregnant and postpartum, visit CDC's Hear Her campaign.

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Press Release

For Immediate Release: Monday, September 19, 2022

Contact: Media Relations

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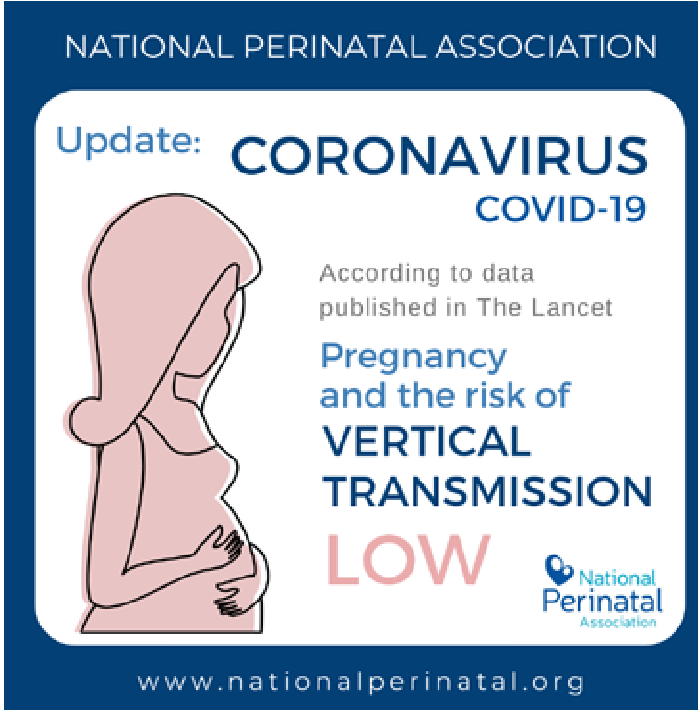

PROTECT YOUR FAMILY FROM

RESPIRATORY VIRUSES

flu coronavirus pertussis

SOAP

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

Peer Reviewed

Genetics Corner: Clinical Implementation and Improved Access of Whole-Genome Sequencing in the NICU: Learnings from a Virtual Educational Event

Holly L. Snyder, MS, LCGC

Illumina, a genomic sequencing company (San Diego, CA), hosted a virtual educational event for neonatal providers interested in learning more about WGS and sharing best practices for attendees interested in driving legislation and reimbursement in their states. The event format allowed formal presentations and open discussion through roundtable sessions.

"Illumina, a genomic sequencing company (San Diego, CA), hosted a virtual educational event for neonatal providers interested in learning more about WGS and sharing best practices for attendees interested in driving legislation and reimbursement in their states."

An estimated 30-50% of neonatal and pediatric intensive care unit (NICU/PICU) admissions are secondary to birth defects or genetic conditions, which result in death in approximately 40% of neonates. (1-4) Whole-genome sequencing (WGS) in acutely ill infants has become essential in the neonatologists' toolkit. Over the past five years, published evidence has demonstrated the diagnostic, clinical, and economic utility of rapid WGS in the NICU setting. (5-10) The NICUSeq randomized-controlled trial, published last year, showed that a change in management is twice as likely when WGS is introduced as a first-tier test compared to infants who undergo usual care testing. (5) Genomic sequencing results that do not yield a diagnosis may also be medically actionable and add value to shared decision-making. (5-7,11)These findings support WGS adoption and implementation in acutely ill infants.

Even though the diagnostic yield is superior with WGS compared to standard testing in acutely ill infants, implementation as a first-tier test remains limited.(5,8-10) Several states, including California and Michigan, have worked towards legislation and Medicaid reimbursement to improve access. In addition to reimbursement limitations, there remains a gap in knowledge about WGS and comfort with clinical implementation. (12) The limited availability of geneticists and genetic counselors at many institutions may also preclude test utilization.

"In addition to reimbursement limitations, there remains a gap in knowledge about WGS and comfort with clinical implementation. (12) The limited availability of geneticists and genetic counselors at many institutions may also preclude test utilization."

Salient topics covered in this virtual event include clinical utility, management of WGS reports, result communication, economic utility, clinical implementation, and impact on precision medicine. Experts from Rady Children's Institute of Genomic Medicine (RCIGM), Helen DeVos Children's Hospital, HudsonAlpha Institute of Biotechnology, the University of California San Francisco (UCSF), and Illumina presented. Representatives from Project Baby programs in California, Michigan, and Minnesota shared different perspectives on their state successes. The event culminated in a discussion with a patient advocate, Amber Freed, Founder of SLC6A1 Connect, who has deep experience using her voice to raise money and drive meaningful change for rare diseases.

The following aims to summarize key takeaways from the different presentations.

Clinical utility – *Kristen Wigby, MD, Rady Children's Hospital*

- There is strong evidence that early diagnosis can have significant impacts on the management of acutely ill infants
- WGS may help distinguish between disorders with overlapping phenotypes or remove clinical bias in test selection
- Acutely ill infants or children may be good candidates for GS if:

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- o There is no unifying diagnosis, or a rapid diagnosis may inform medical management
- o There is a suspected genetic disorder
- o A diagnosis has not been confirmed previously despite an extensive workup, previous testing
- o There is a history of multiple hospitalizations or prolonged stays

"First-line use of WGS in the NICU diagnostic workup is the most cost-effective approach and can bring potential savings to the payor, provider, and patient. (6,8,13)"

The current state of economic utility – *Audrey Ozuls, MBA, Illumina*

- Coverage of WGS, including rapid WGS, exists in several states across the US (see map)
- First-line use of WGS in the NICU diagnostic workup is the most cost-effective approach and can bring potential savings to the payor, provider, and patient. (6,8,13)

Experiences from Project Baby Programs in California, Michigan, and Minnesota - *Russell Nofsinger, Ph.D., Rady Children's Institute of Genomic Medicine; Andrea Scheurer-Monaghan, MD, Bronson Children's Hospital; Laura Appel, MS, Michigan Hospital Association; Jessica Aguilar, MHA, Sanford Health*https://www.mha.org/issues-advocacy/project-baby-deer/

- California: Project Baby Bear was a pilot project supported by a $2 million state appropriation and involved five hospitals throughout California. In total, 178 infants received rapid WGS with a diagnostic rate of 42%, and clinical management changes were noted in 31%. This project led to a legislative mandate and coverage of rapid WGS by Medi-Cal. (6)
- Michigan: Project Baby Deer was a collaboration between Michigan Health and Hospital Administration, Michigan clinical champions, and Rady Children's Institute for Genomic Medicine. Seven hospitals recruited 89 infants leading to a diagnosis in 39% and a change of management in 27%. This effort resulted in a net benefit totaling $252,938 and led to rWGS coverage through a 'carve out' payment by Michigan Medicaid.
- Minnesota: Project Baby Loon was initiated to emulate other projects' successes. In this instance, the Minnesota Sanford Children's Genomic Medicine Consortium formed by Sanford Health aimed to promote the implementation of precision medicine in pediatric practice. Before proposing a bill, their collaborative efforts led to the Minnesota Department of Human Services' decision to add coverage of rapid WGS to their Medical Assistance without additional research or legislative processes.

Successful Implementation - *Linda Franck, RN, PhD, FAAN, University of California San Francisco*

- Studies were performed as part of both the California and Michigan projects to assess knowledge, opinions and implementation barriers with rapid WGS
- Successful clinical implementation depends upon identifying champions, engaging all stakeholders, learning as a team, assessing interdepartmental relationships and unit culture, developing process maps, and defining metrics for success
- Tools were provided to map the clinical implementation process and assess team knowledge, attitudes and practices. (12,14)

"Successful clinical implementation depends upon identifying champions, engaging all stakeholders, learning as a team, assessing interdepartmental relationships and unit culture, developing process maps, and defining metrics for success"

Managing the WGS Report – *Becky Milewski, MS, CGC, Illumina*

- WGS test reports can be long and overwhelming for some providers
- WGS is a phenotype-driven analysis, and all relevant phenotypic information must be provided to the lab
- There are several reasons a report may be negative, including lack of phenotypic presentation, limitations in WGS technology, or unknown/undiscovered genetic cause
- Clinicians should be aware of additional findings that may be reported, including secondary or incidental findings

Impact of WGS on Treatment – Caleb Bupp, MD, FACMG, Spectrum Health Helen DeVos Children's Hospital

- Acceleration of comprehensive WGS and downstream precision medicine tools have enabled improvements in rare disease diagnosis and clinical utility
- Findings from DNA sequencing can be combined with transcriptomics, proteomics, and epigenomics to help further define the underlying etiology and potential impact
- With knowledge of genomic pathways for rare diseases, new and existing treatments can be repurposed to treat rare and ultra-rare conditions

Result Communication – *Kelly East, MS, CGC, HudsonAlpha Institute of Biotechnology*

- SouthSeq evaluated first-tier WGS in NICUs across the Southeast. Non-genetic NICU providers were trained to disclose results(15)
- Error rates in result disclosure compared between non-ge-

netic providers and genetic counselors

- Non-genetic providers could return genomic results with no significant errors in 92% of cases. The most common significant errors were over-interpreted negative results, omitted critical information, and misquoted recurrence risk.
- With appropriate training, non-genetic providers can successfully manage WGS result disclosure.

" While solid evidence supports the utility of rapid WGS in acutely ill infants, under-utilization of testing for clinical indications demonstrates that challenges remain to realize the potential impact in this population. There is an interest to continue building pathways for adequate reimbursement and tools to support education and successful implementation."

Overall, this event sparked discussion among providers with variable experience implementing WGS. While solid evidence supports the utility of rapid WGS in acutely ill infants, under-utilization of testing for clinical indications demonstrates that challenges remain to realize the potential impact in this population. There is an interest to continue building pathways for adequate reimbursement and tools to support education and successful implementation.

For more information or to be included in email lists for future events, please email: hsnyder@illumina.com

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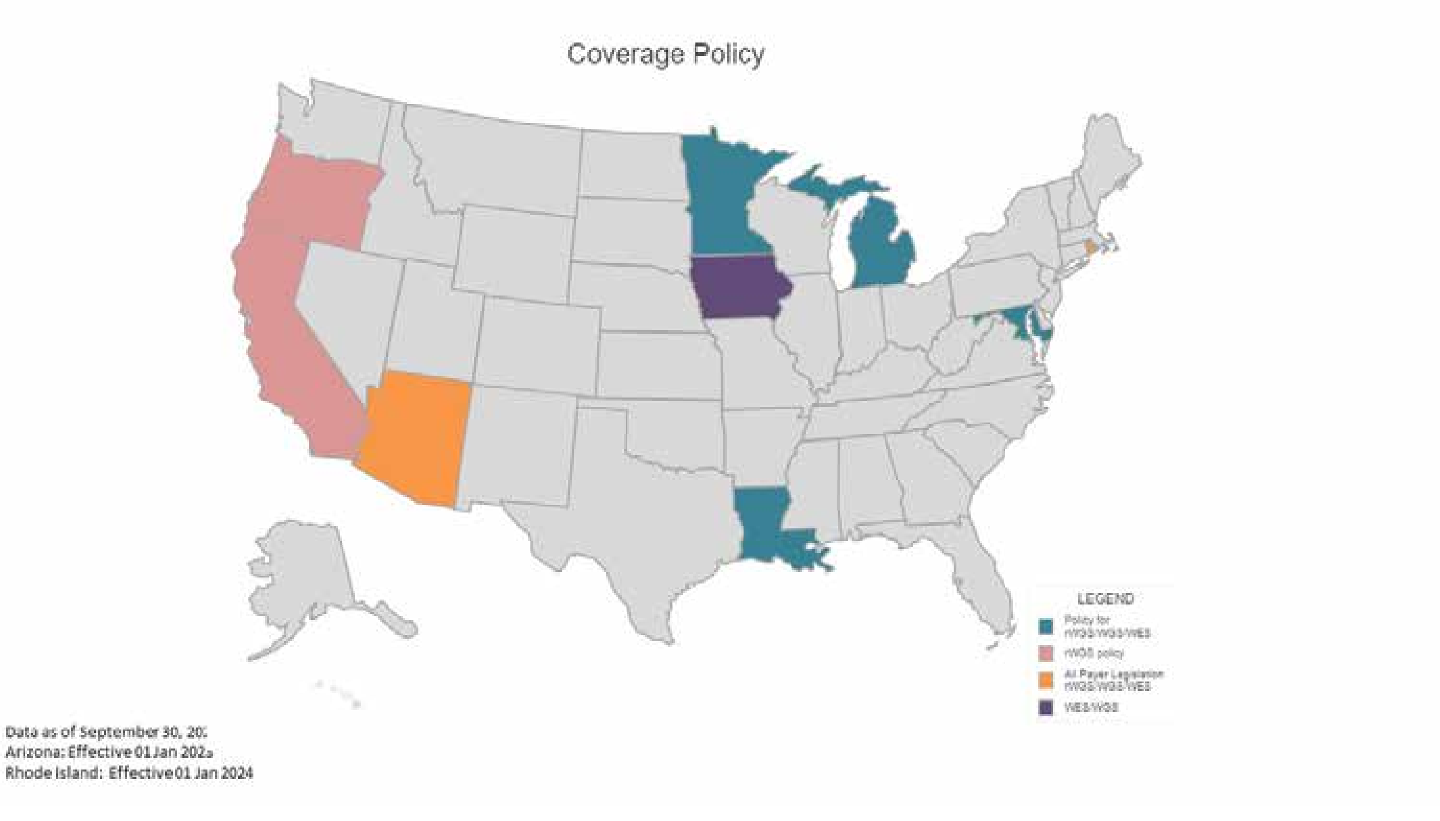

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Why PREMATURE INFANTS *Need Access to an* EXCLUSIVE HUMAN MILK DIET

In the United States, more than **1** IN **10** BABIES ARE BORN PREMATURE. *Micro preemies are born severely premature, weighing less than 1,250 grams.*

MICRO PREEMIES are at risk for Necrotizing Entercolitis (NEC), which:

- *Damages intestinal tissue*
- *Causes distended abdomen, infection, low blood pressure and shock*
- *Threatens infants' lives*

NEC occurrence increases when a preemie consumes non-human milk products.

When that happens:

5%
1%
17%
12%
on Exclusive Human Milk Diet[2]
on Non-Human Milk Products
Micro preemies who get NEC
Micro preemies requiring surgery to treat NEC

30% of micro preemies needing surgery will die from NEC[3]

HOW TO HELP PREVENT NEC:
EXCLUSIVE HUMAN MILK DIET

What is an Exclusive Human Milk Diet?

NO cow's milk
NO sheep's milk
NO goat's milk
NO formula

✓ mother's milk
✓ human donor milk
✓ human milk-based fortifier

Why Is An **Exclusive Human Milk Diet** Important?

An Exclusive Human Milk Diet gives vulnerable infants the best chance to be healthy and reduces the risk of NEC and other complications.

When a micro preemie can access an EXCLUSIVE HUMAN MILK DIET:

Mortality is reduced by **75%**[2]
Feeding intolerance decreases[4]
Chances of NEC are reduced by **77%**[2]

HUMAN MILK = **MEDICINE**

LEARN MORE ▸

NCfIH National Coalition for Infant Health

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Why Pregnant and Nursing Women Need Clear Guidance on

THE NET BENEFITS OF EATING FISH

2 to **3** servings per week of properly cooked fish can provide health benefits for pregnant women and babies alike:

Iron

Omega 3 fatty acids

Earlier Milestones for Babies

shrimp
canned light tuna
cod
catfish
salmon
pollock
tilapia

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.

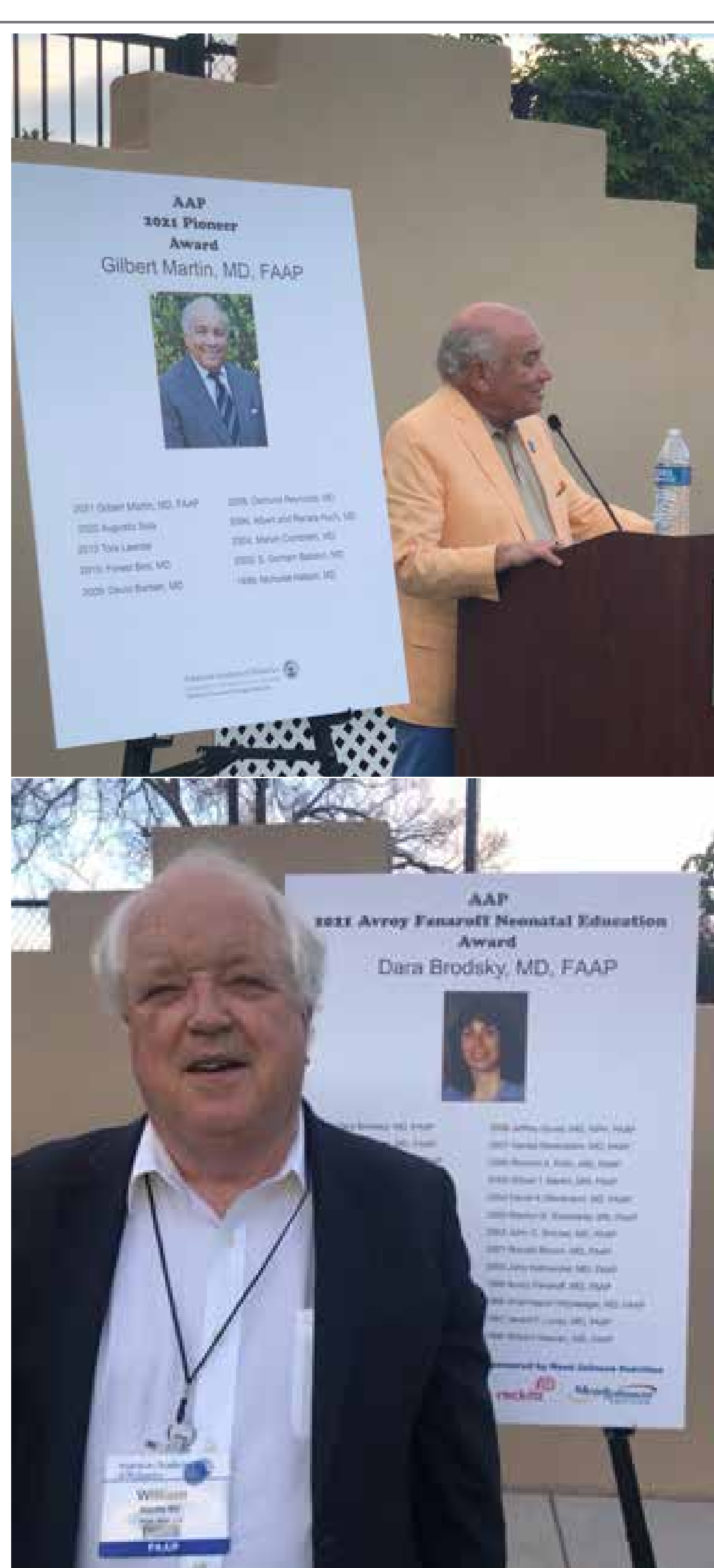
NCfIH National Coalition for Infant Health

LEARN MORE ▸

Awards Gala, Neonatology Hall of Honor, & Our History in Group Photos

Lily J. Lou, MD, FAAP

Aside from the joyful fellowship of gathering in person once again, the 2022 Scottsdale Workshop on Perinatal Practice Strategies included a special SONPM Awards Gala. On a balmy southwest evening, we recognized and celebrated our honorees for the 2020 and 2021 section awards in person.



We also made two significant announcements: Firstly, a SONPM Hall of Honor will be installed in the Itasca, IL AAP Headquarters building, within the 2nd floor west conference center that bears our sponsorship acknowledgment.

Secondly, a wonderful project was unveiled—to celebrate 50 years of collaboration in hosting the Neonatology Fellows Conferences; the AAP worked with Reckitt Mead Johnson to create a beautiful book showcasing five decades of group photos from the MJN-sponsored national conferences, highlighting half a century of scientific advances in our field. So many giants and trailblazers in neonatology are pictured in these photos! You can view a digital copy or get your own beautiful hardback book by clicking on the graphic below or through the QR link in the following page.

https://www.hcp.meadjohnson.com/s/commemorative-book-landing-page

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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

Peer Reviewed

Top 10 Reasons to attend 2023 American Academy of Pediatrics Section on Neonatal Perinatal Medicine Scottsdale Workshop February 3-5, 2023

Dena K. Hubbard, MD, FAAP

"The Workshop on Neonatal-Perinatal Practice Strategies is a great forum to learn, network, and get involved in your professional organization. Any pediatric professional caring for the fetus and newborn is welcome to attend."

While climate change has affected many things for our planet, it is not responsible for the change in Scottsdale Workshop dates (hotel availability)! Scottsdale has been great in March, but you "**can't touch this**" Scottsdale workshop in February 2023! The Workshop on Neonatal-Perinatal Practice Strategies is a great forum to learn, network, and get involved in your professional organization. Any pediatric professional caring for the fetus and newborn is welcome to attend. Regardless of practice type - community, university, Children's hospital-based practice, and beyond; regardless of career stage - trainee and early career, mid-career, or well-established neonatologists - you do not want to miss this fan**CACTUS** workshop!

"Register today! Visit: https://shop.aap.org/2023-workshop-on-neonatal-perinatal-practice-strategies-scottsdale-az/ or Contact AAP Registration Toll Free: (800) 433-9016, Option 3"

Register today! Visit: https://shop.aap.org/2023-workshop-on-neonatal-perinatal-practice-strategies-scottsdale-az/ or Contact AAP Registration Toll Free: (800) 433-9016, Option 3

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Top 10 reasons not to miss Scottsdale Workshop in 2023 (with a **Cactus** theme)

1. **Be a cactus in a world of delicate flowers. Stand out** with skills learned at the Point-of-Care Ultrasound procedure workshop. Limited to the 40 attendees, first-come, first-served, to provide plenty of hands-on introduction to POCUS! This will also coincide with the publication of the COFN POCUS clinical and technical reports. Two authors, Maria Fraga, and Shazia Bhombal, et al., will lead two groups of 20 Saturday afternoon, February 4th.
2. **Don't make me hurt you** (utilization review, insurance companies). Coding and billing, NOT of interest to anyone? Join Scott Duncan and the section coding committee to learn and share current information in the Neonatal Coding Seminar Friday morning, February 3rd. (Additional cost)
3. **Standing tall and looking sharp!** - Celebrate with us as we honor Wanda Barfield, recipient of the Apgar Award, who will be presenting the L. Joseph Butterfield Lecture.
4. **Grow** your knowledge, ask questions, and provide feedback on revising the COFN statement on neonatal hypoglycemia presented by Cami Martin.
5. **Thorny but beautiful** – Just like a cactus, RVUs and clinical FTEs are a point of contention amongst physicians, hospital administrators, and payors. Come learn from neonatologist and illustrator Satyan Lakshminrusimha.
6. Tempted to tell someone to "**Go sit on a cactus?**" AAP CEO Mark Del Monte will present on how to navigate the practice of neonatology in the current political and legal environment.
7. **Stick with kindness.** Hear lessons learned from AAP TECaN National Advocacy Campaign: Carousel Care – A New Standard of Excellence for NICU Family and Staff Well-being presented by TECaN leader Katie Hoge.
8. **Cacti** come in a variety of types, growth rates, and environments. 2023 Workshop Faculty represent a diversity of neonatology practice types, career stages, and experiences!
9. Don't be **prickly** when you attend sessions related to controversies related to feeding in patients with BPD, the utility of car seat screens by Erik Jensen; neonatal nutrition and hypoglycemia by Cami Martin; research in non-traditional settings by Dr. Kaashif Ahmad; and controversies TBD by Keith Barrington. Cheer on the debates, and let's learn together!
10. We "**stick** together," and this is the perfect way to connect with neonatology friends, old and new, while earning a maximum of 19.50 AMA PRA Category 1 Credits TM and 10 MOC Part 2 Points.

Disclosure: There are no reported conflicts.

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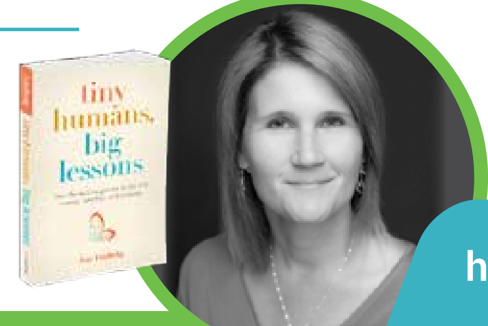
NICU Parents as Partners Nov 2-4

Redefining how professionals & parents can help create a healthier beginning for NICU families together.

There is a critical need for increased attention to these fragile families and the professionals who support them. Join the 2nd annual Hand to Hold NICU Community Conference, and be part of unlocking change for the NICU families of today and tomorrow.

Featuring
SUE LUDWIG
Author of Tiny Humans, Big Lessons



This program is provided in partnership with

handtohold.org/conference

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

At First Candle we're educating parents, grandparents and caregivers about safer sleep to make sure all babies reach their first birthday. Learn more at firstcandle.org

"Even in the middle of taking this course, I could see myself changing the way that I spoke to parents. After taking this course, I am much better at emotionally supporting our NICU families."

COURSE PARTICIPANT

Learn How Now

validated online NICU staff education

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My NICU Network
My Perinatal Network

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/5523fcf7e4b0fef011e668e6/t/62445afd0134140ff954f3f6/1648646910485/NCfIH_Monoclonal+Antibodies+Inclusion+in+the+VFC+Program_Position+Paper_Mar+2022.pdf

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.	**How does it work?**	Instead of teaching the body to create antibodies and defenses, they provide antibodies that are readily available.

Both support the immune system's defenses.

VACCINES		PREVENTIVE MONOCLONAL ANTIBODIES
Many vaccines are readily and easily available. The technology behind vaccines has been around for decades.	**What are the benefits?**	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.

VACCINES		PREVENTIVE MONOCLONAL ANTIBODIES
Polio Measles COVID-19 And more	**What can this immunization protect against?**	RSV COVID-19

Both can provide tailored protection from a variety of diseases.

VACCINES		PREVENTIVE MONOCLONAL ANTIBODIES
Yes	**Is it safe?**	Yes

Both vaccines and preventive monoclonal antibodies undergo extensive testing for safety and efficacy.

READ

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

Peer Reviewed

Vaccines and Preventive Monoclonal Antibodies: What is the Difference?

Mitchell Goldstein, MD, MBA, CML, Susan Hepwoth

The National Coalition for Infant Health is a collaborative of more than 200 professional, clinical, community health, and family support organizations focused on improving the lives of premature infants through age two and their families. NCfIH's mission is to promote lifelong clinical, health, education, and supportive services needed by premature infants and their families. NCfIH prioritizes safety of this vulnerable population and access to approved therapies.

"The importance of immunization cannot be sufficiently emphasized. Vaccines and preventive monoclonal antibodies introduce two different types of immunization. While they function differently, they both serve a similar purpose: protecting people from serious illnesses and diseases."

The importance of immunization cannot be sufficiently emphasized. Vaccines and preventive monoclonal antibodies introduce two different types of immunization. While they function differently, they both serve a similar purpose: protecting people from serious illnesses and diseases. Although many different technologies are applied in creating these essential defense mechanisms, both have similar protective values. Both support the immune system's defenses and protect again disease, providing a public health benefit by decreasing disease burden. Both can provide tailored protection from a variety of diseases. Despite social media blogs and posts to the contrary, both are generally regarded as safe.

Vaccines teach the body to create antibodies that fight off a specific disease or infection. Many vaccines are readily and easily available. Some have demonstrated effectiveness that goes back hundreds of years. The technology used to produce vaccines has been understood for decades. Polio, measles, and COVID-19 are amendable to vaccine creation and can protect most of the population from significant diseases. Although some have expressed concern over the newness of the COVID vaccines, this vaccine uses technologies similar to traditional vaccines that have been used to protect against other viruses.

Preventive monoclonal antibodies work by introducing antibodies that are ready to ward off disease in the body. Instead of teaching the body how to create antibodies and defenses, they provide the antibodies that are readily available. Preventive monoclonal antibodies can fight a disease that does not have an existing vaccine or where certain patient groups cannot use certain vaccine products because of intercurrent illnesses such as cancer. Both RSV and COVI-19 monoclonal antibodies have been used to protect certain at-risk groups. Although these are new technologies, RSV monoclonal therapy has been used for decades to protect at-risk premature babies.

"Both RSV and COVI-19 monoclonal antibodies have been used to protect certain at-risk groups. Although these are new technologies, RSV monoclonal therapy has been used for decades to protect at-risk premature babies."

Both vaccines and preventive monoclonal antibodies undergo extensive testing by the FDA for safety and efficacy.

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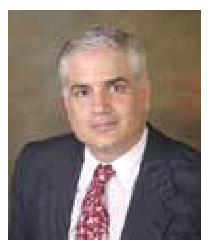

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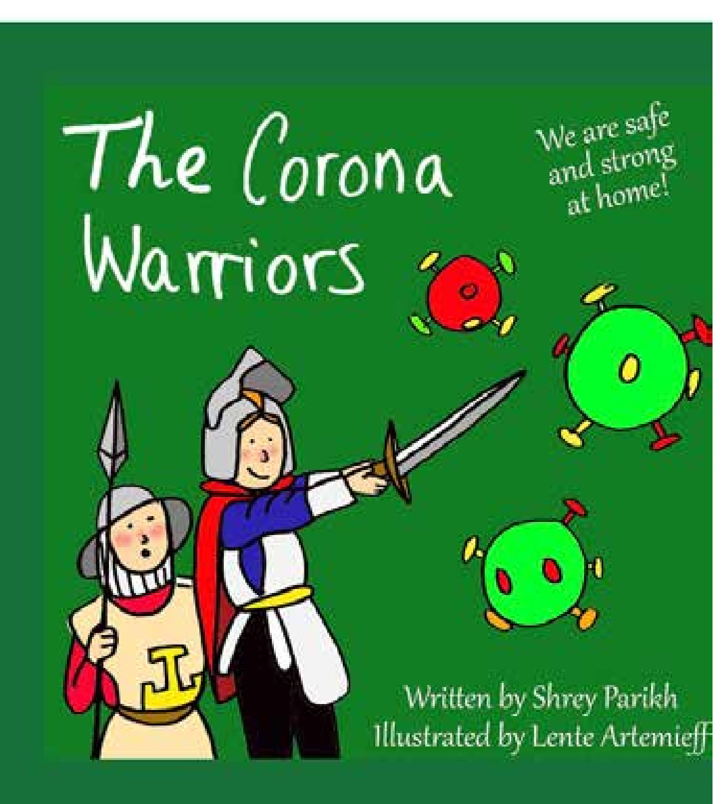
National Coalition for Infant Health Values (SANE)

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.



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

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FRESH CLOTHES

change into a clean gown or shirt.

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

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The Signs & Symptoms of RSV

RESPIRATORY SYNCYTIAL VIRUS

Know the Signs & Symptoms of RSV

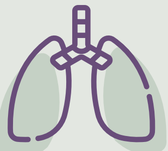
Cough

Runny Nose

Struggling to Breathe
(breastbone sinks inward when breathing)

Difficulty Eating

Lethargy



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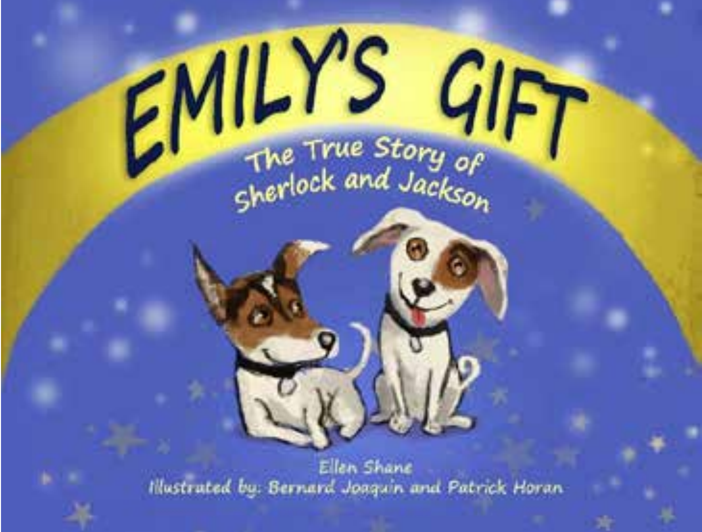

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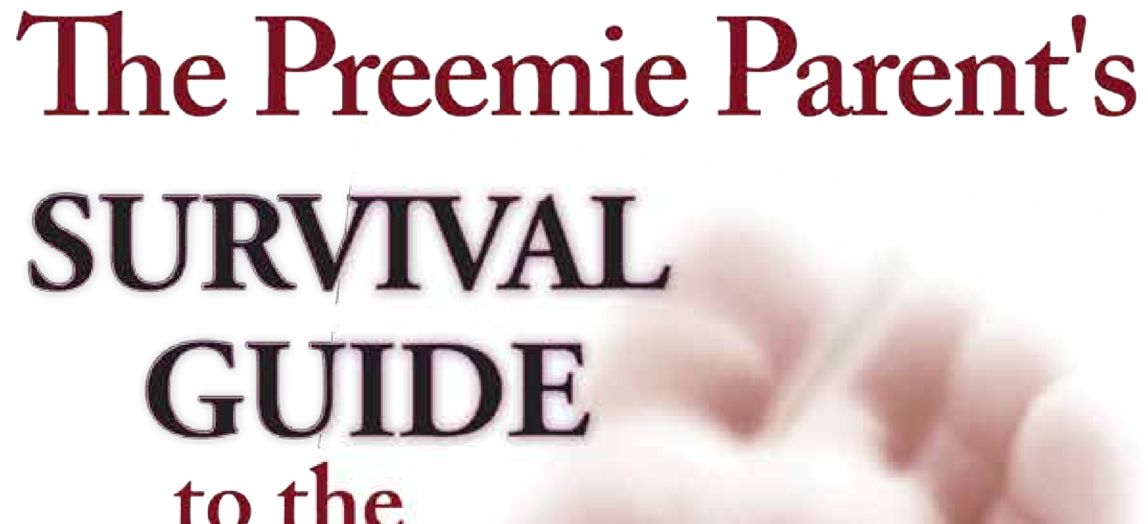

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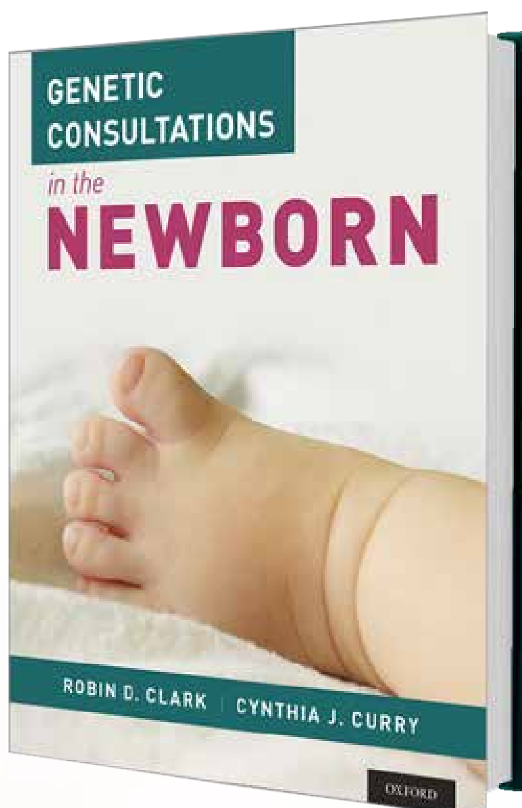

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Clinical Pearl: The Long-Term Effects of Neonatal Hypoglycemia in At-Risk Infants

Joseph R. Hageman, MD

"The diagnosis and long-term effects of neonatal hypoglycemia continue to be controversial. In a recent prospective study by Shah and colleagues of the long-term effects of neonatal hypoglycemia and its treatment in children at the corrected age of 9 to 10 years, the authors' definition was < 47 mg/dl (1)."

The diagnosis and long-term effects of neonatal hypoglycemia continue to be controversial. In a recent prospective study by Shah and colleagues of the long-term effects of neonatal hypoglycemia and its treatment in children at the corrected age of 9 to 10 years, the authors' definition was < 47 mg/dl (1). Severe hypoglycemia in this study was 36-46 mg/dl (1). In the 480 children ages 9-10 years of age who were tested, there were no statistically significant differences in educational achievement in the children who experienced hypoglycemia (173) which was diagnosed and treated, compared with the group that did not experience neonatal hypoglycemia (299) (1).In addition, in this study, at-risk newborns included late preterm, infants of diabetic mothers, and term infants: small or large for gestational age (1). Newborns with hyperinsulinism were not included(1).

" It was demonstrated that in the 681 babies who were randomized to dextrose gel and 678 randomized to placebo at 1 hour of age (2), at two years of age corrected, there was no significant difference in neurosensory impairment, although the study could have been underpowered to detect a small but clinically significant difference in risk (2)."

Another study of prophylactic oral dextrose gel from New Zealand by Edwards and colleagues of 1359 newborns was placebo-controlled and randomized. Plasma glucose levels were monitored. It was demonstrated that in the 681 babies who were randomized to dextrose gel and 678 randomized to placebo at 1 hour of age (2), at two years of age corrected, there was no significant difference in neurosensory impairment, although the study could have been underpowered to detect a small but clinically significant difference in risk (2).

What is also interesting is that there have been previous clinical studies, such as the one by Kaiser et al., that demonstrated that at-risk newborns who were also studied at a corrected age of 10 years had an association between early transient hypoglycemia and lower academic achievement (3, 4).

In the editorial by Rozance, the controversy continues to be discussed (3).

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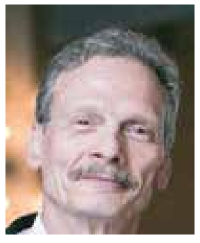

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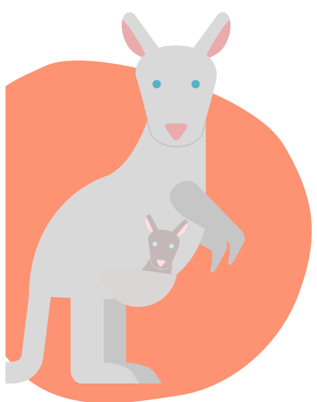

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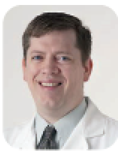

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Peer Reviewed

Mental Health of Children in Ukraine During War

Akshaya Ramakrishnan

"If we are to teach real peace in this world, and if we are to carry on a real war against war, we shall have to begin with the children …. You must be the change you wish to see in the world."
— **Mahatma Gandhi**

"There can be no keener revelation of a society's soul than the way in which it treats its children."

— **Nelson Mandela**

"Russia's invasion of Ukraine has taken the news world by storm. The world is constantly kept up to date about the mass devastation, damage, and deaths of thousands of innocent citizens. According to UNICEF, 90% of displaced Ukrainian refugees are women and children."

Russia's invasion of Ukraine has taken the news world by storm. The world is constantly kept up to date about the mass devastation, damage, and deaths of thousands of innocent citizens. According to UNICEF, 90% of displaced Ukrainian refugees are women and children. Unaccompanied and separated children are vulnerable to child abuse, violence, trafficking, and exploitation. Their lives are totally disrupted. The physical wreckage is horror enough, but what about the emotional damage? An important topic that often goes unnoticed is children's mental health in Ukraine. Being caught in the middle of a war is traumatizing for adults, but what toll does it take on young, growing minds? Children are killed, abandoned, and forced to flee their homes daily. Because of the Russian-Ukraine war, children as young as infants are experiencing not only physical trauma but mental trauma as well.

According to Paul Wise, a pediatrics professor at Stanford University, "Children are extremely vulnerable to insecurity, not only the physical trauma but the psychological trauma, and it can reverberate and have repercussions for a long time" (ABC News.). How children are treated by their parents determines how they view things as they grow up. Because their parents are struggling with trauma themselves, children will not be able to receive the support they look for in a guardian. Kids are easily impressionable and will mirror what they see around them. In this case, they live in a war zone, meaning the children will reflect depression, anxiety, and self-isolation. A happy childhood is essential in the development of a person. These children have seen things that most adults will never know. This can damage a whole generation of young Ukrainians, who will grow up with unresolved trauma and a lack of childhood. Every child reflects trauma differently. Some may seem agitated, while others may be quiet and closed off. It is important not to assume a child is okay based on their physical behavior. According to Dr. Jack Shonkoff, director of the Center on the Developing Child at Harvard University, "Some children in these circumstances tend to be more withdrawn. They are not crying as much, they are not demanding much attention" (ABC News). Due to the war, a generation of Ukrainian children will display signs of PTSD, depression, anxiety, and other mental disorders. PTSD in children at war-inflicted zones is around 47%, depression around 43%, and anxiety disorders around 27%. According to Relief Web, "Previous studies have shown that more than 22% of conflict-affected people may end up with some form of mental health disorder. In the context of Ukraine, that would mean 4,595,591 people, 1,531,864 of them children, and the number is growing daily". However, children are surprisingly resilient and will be able to cope, given enough support.

Conclusion:

With the ongoing Russian invasion of Ukraine, thousands of children risk long-lasting mental health disorders. The impact of this is under-appreciated by society at large but may have significant consequences for the people of Ukraine for many years to come. Immediate intervention is essential to prevent significant harm.

"Psychosocial interventions for war-affected children should be multileveled and specifically targeted toward their needs. Interventions need to be trauma-informed and strength- and resilience-oriented."

Psychosocial interventions for war-affected children should be multileveled and specifically targeted toward their needs. Interventions need to be trauma-informed and strength- and resilience-oriented. The first step is to screen and assess the mental health needs of each child and decide what resources are needed. Immediate supportive interventions should focus on providing basic physical and emotional resources for these children to regain a sense of security. Intervention modalities could be creative-expressive, psycho-educational, and cognitive behavioral strategies. Examples of creative-expressive approaches are interactive activities such as drama, music, role-playing, and drawing. Psychotherapies could be trauma-focused, interpersonal psychotherapy, and traumatic grief psychotherapy. Treatment strategies could use specialized services, non-specialized group services,

community group services, and social activities. Specialized services use psychologists, psychiatrists, and mental health nurses. Focused nonspecialized group activities could use school as a platform for classroom-based intervention, group psychotherapy, and other interventions. Community and family support strategies include social networks, supportive child-friendly spaces, recreational activities etc. Creating awareness among the international community through various social media platforms is important. Efforts should be made to educate and train medical professionals to recognize, screen, and treat mental health issues in war-affected children.

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4. *https://abcnews.go.com/International/mental-health-effects-ukraine-war-zone -children/story?id=83203801*
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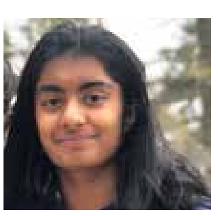

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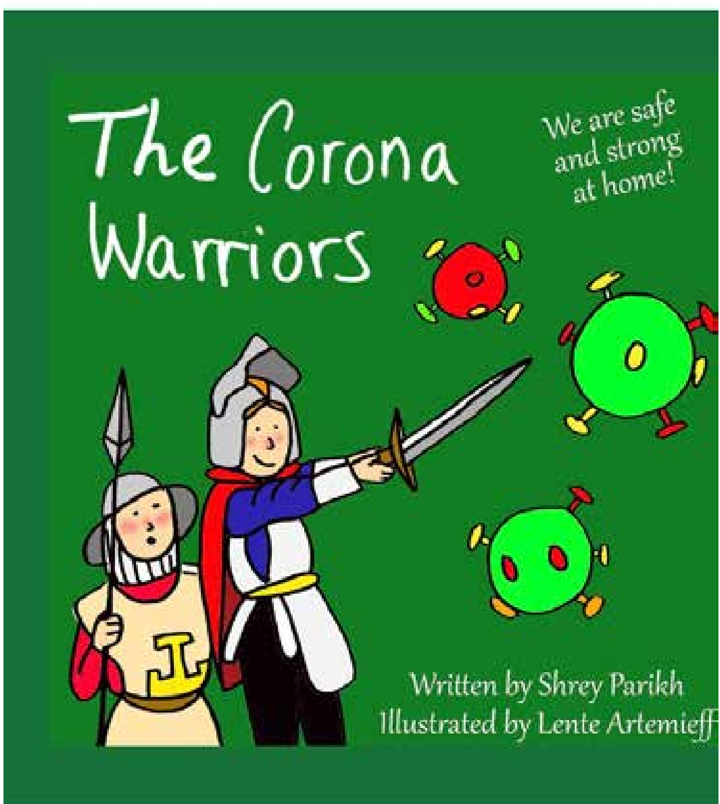

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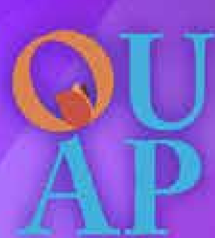

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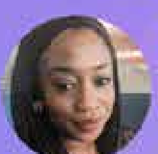

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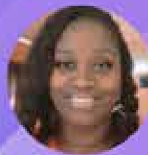

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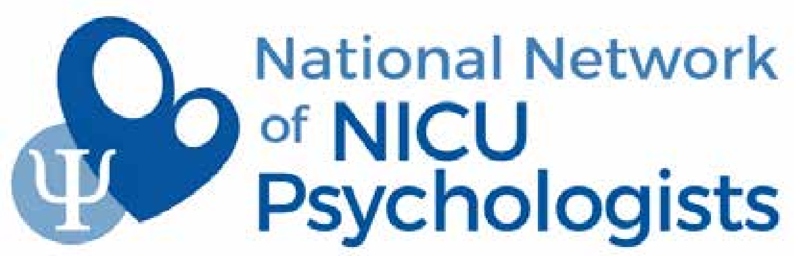

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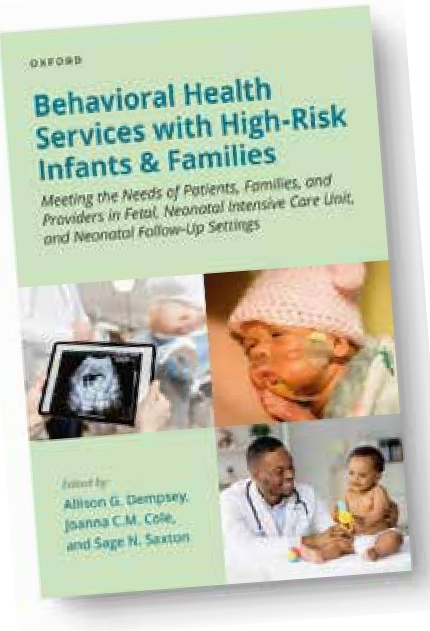

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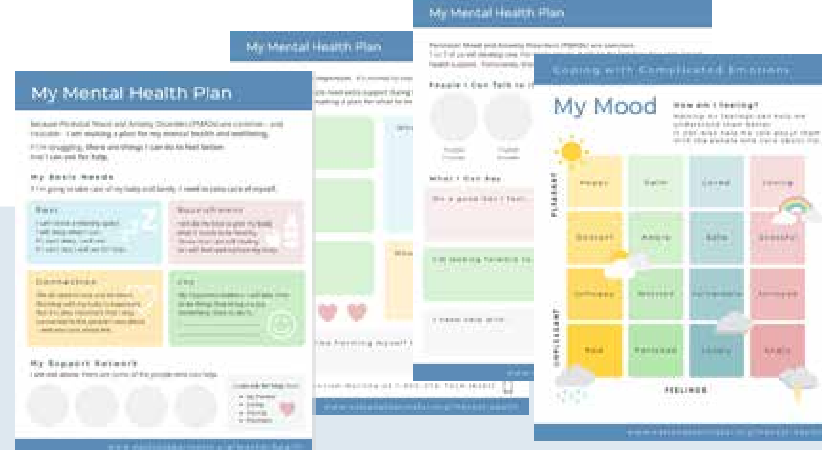

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Accelerating the Health and Racial Equity in Maternal and Neonatal Care
University City Science Center
3675 Market Street, 2nd Floor
Philadelphia, PA 19104
November 17th, 2022
https://www.eventbrite.com/e/accelerating-health-and-racial-equity-in-black-maternal-and-neonatal-care-tickets-380986168887

39th Annual Advances In Care Conference – Advances In Therapeutics And Technology: Critical Care Of Neonates, Children, And Adults
Ontario, CA
https://paclac.org/advances-in-care-conference/

AAP Workshop on Perinatal Strategies
February 3-5, 2023
Scottsdale, AZ
https://shop.aap.org/2023-workshop-on-neonatal-perinatal-practice-strategies-scottsdale-az/

NEO: The Conference for Neonatology
February 22-24, 2023
Las Vegas, NV
https://www.mednax.com/neo-conference/

California Association of Neonatologists (CAN) Annual Conference
San Diego, CA
March 3-5, 2023
https://canneo.org

36th Annual Gravens Conference on the Environment of Care for High Risk Infants
The Future is Now for Babies, Families, and Systems
Sand Key, FL
March 8-11, 2023
https://paclac.org/https-paclac-org-gravens-conference/

Southeastern Association of Neonatologists (SAN)
Marco Island, FL
May 25-28, 2023
www.southeastneo.com

Perinatal District 8 Conference
June 1-4, 2023
San Diego, CA
https://district8sonpm.org/

Perinatal District 6 Conference
Date: TBA
Chicago, IL
https://www.d6an.org

For up to date Meeting Information, visit NeonatologyToday.net and click on the events tab.

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Outstanding BC/BE Neonatologist Opportunities in Florida's Collier County

Nicklaus Children's Health System and Nicklaus Children's Pediatric Specialists (NCPS), the health system's physician-led multispecialty group practice, have three exceptional opportunities for board-certified or board-eligible (BC/BE) fellowship-trained neonatologists with a minimum of three years of experience (preferred) for a 19-bed Level II NICU located on Florida's Gulf Coast in Collier County.

Each position will be part of a comprehensive perinatal and neonatal program for babies in a Level II NICU. These roles present a unique and exciting opportunity for motivated candidates to flourish in a burgeoning market. Applicants should possess a passion for advocacy and improving care for all children. The BC/BE neonatologists will be responsible for attending deliveries, providing prenatal consultations to high-risk babies, resuscitating and stabilizing newborns in the delivery room, rounding on well babies, as well as provide leadership, oversight and supervision in the Level II nursery. Candidates should be proficient in newborn resuscitation, including neonatal intubation, umbilical line placement and peripheral cannulation, lumbar punctures, etc. These roles offer salaries that are competitive and commensurate with experience.

Nicklaus Children's neonatology program is consecutively ranked among the best in the nation by *U.S. News & World Report*. It was the first of its kind in South Florida and receives referrals of the most critically ill neonates from hospitals throughout Florida, Latin America and the Caribbean. The Level II NICU will be a part of the NCPS Section of Neonatology and the neonatologists will have access to the educational and professional development resources of Nicklaus Children's Health System.

Founded in 1950, the rebranded Nicklaus Children's Hospital, a 309-bed freestanding children's hospital and Level I trauma center, is renowned for excellence in all aspects of pediatric medicine and has numerous subspecialty programs that are routinely ranked among the best in the nation. It is also home to the largest pediatric teaching program in the southeastern U.S. Many of our physicians have trained or worked at other leading medical institutions. Join a phenomenal team that brings lifelong health and hope to children and their families through innovative and compassionate care.

Collier County is located on the Southwest Coast of Florida with easy access to Southwest Florida International Airport. Outdoor activities include golf, boating, fishing and beautiful beaches.

Competitive compensation and benefits package.

Qualified candidates please contact:

Joyce Berger, Physician Recruiter

joyce.berger@nicklaushealth.org or 786-624-3510

nicklauschildrens.org/NCPS

DFW

Overview

St. Luke's Neonatology in Idaho is seeking an NNP to join 11 BC Neonatologists and 11 NNPs to assist with coverage of our four St. Luke's NICUs. This position is primarily based at the Level IV NICU in Boise, Idaho. An additional position is available in Twin Falls, Idaho, which is in the process of expanding its scope of coverage to Level III status.

The Level IV facility is within St. Luke's Children's Hospital, a CHA-designated children's hospital-within-a-hospital located in downtown Boise, Idaho. The NICU was built in 2002 and is a modern 61-bed unit, with advanced technology support (HFV, iNO, therapeutic hypothermia, noninvasive ventilation), semi-private rooms, and a priority of family-centered care. It maintains an ADC of 37 and approximately 900 admissions peryear. NNPs provide daily rounding support and in-house night coverage with an in-house Neonatologist at this facility. Our Level II NICU is located 10 miles away in Meridian, Idaho, and this 12-bed facility was fullyrenovated in 2007. NNPs assist with weekend coverage and home call at the Meridian facility. Coming in fall of 2017 will be our new Nampa facility with 8 private NICU rooms and 7 NICU/LDRP Family Care Suites.

The Children's Hospital provides a full complement of Pediatric Subspecialty services with the exception of ECMO or complex congenital heart surgery. The program is supported by a skilled Obstetrical department including 4 full time MFM specialists.

ABOUT BOISE:
Known as the "City of Trees," Boise is Idaho's capital city—both a cultural center and a playground for those who love the outdoors. A vibrant downtown area affords fine dining, theatre, music, and college and semi-professional sports. Whole Foods, Trader Joe's, The Boise Co-op, and seasonal farmers markets are within a mile of the hospital. The Greenbelt follows the beautiful Boise River corridor for more than 30 miles, and the Boise foothills are home to miles of hiking and biking trails.

MINIMUM REQUIREMENTS:
1. Graduation from a School of Nursing, passing results on the certification examination administration by an organization recognized by the Idaho Board of Nursing, and a Nurse Practitioner Program with current RN, APRN and controlled substance licensure from Idaho.
2. Current, unrestricted DEA certificate.
3. Current national certification as NNP. Exception: Flex NNPs will not be required to maintain Idaho Controlled substance licensure or unrestricted DEA certificate.
4. Excellent communication skills to include oral and written comprehension/expression.

WHY ST. LUKE'S?
St. Luke's, Idaho's largest employer, has been recognized for distinguished patient care, named a best state to practice, and rated in the top 15 health systems in the country by Truven Health

https://provider-slhs.icims.com/jobs/59747/neonatal-nurse-practitioner/job

Clinical Trial Center (Full-Time, Day Shift) - Research Coordinator

The Loma Linda University Health's Clinical Trial Center is actively seeking and recruiting top clinical research coordinator talent.

Our mission is to participate in Jesus Christ's ministry, bringing health, healing, and wholeness to humanity by Creating a supportive faculty practice framework that allows Loma Linda University School of Medicine physicians and surgeons to educate, conduct research, and deliver quality health care with optimum efficiency, deploying a motivated and competent workforce trained in customer service and whole-person care principles and providing safe, seamless and satisfying health care encounters for patients while upholding the highest standards of fiscal integrity and clinical ethics. Our core values are compassion, integrity, humility, excellence, justice, teamwork, and wholeness.

Able to read, write and speak with professional quality; use computer and software programs necessary to the position, e.g., Word, Excel, PowerPoint, Access; operate/troubleshoot basic office equipment required for the position. Able to relate and communicate positively, effectively, and professionally with others; provide leadership; be assertive and consistent in enforcing policies; work calmly and respond courteously when under pressure; lead, supervise, teach, and collaborate; accept direction. Able to communicate effectively in English in person, in writing, and on the telephone; think critically; work independently; perform basic math and statistical functions; manage multiple assignments; compose written material; work well under pressure; problem solve; organize and prioritize workload; recall information with accuracy; pay close attention to detail. Must have documented successful research administration experience focused on managing clinical trials function. Able to distinguish colors as necessary; hear sufficiently for general conversation in person and on the telephone; identify and distinguish various sounds associated with the workplace; see adequately to read computer screens and written documents necessary to the position. Active California Registered Nurse (RN) licensure preferred. Valid Driver's License required at time of hire.

The Clinical Trial Center is actively involved in many multi-center global pediatric trials, which span different Phases of research to advance health care in children. Please reach out to Jaclyn Lopez at 909-558-5830 or JANLopez@llu.edu with further interest. We would love to discuss the exciting research coordinator opportunities at our Clinical Trials Center.

Additional Information

- Organization: Loma Linda University Health Care
- Employee Status: Regular
- Schedule: Full-time
- Shift: Day Job
- Days of Week: Sunday, Monday, Tuesday, Wednesday, Thursday, Friday, Saturday

Loma Linda University Children's Hospital is hiring Neonatal Nurse Practitioners

Children's Hospital, centrally located in Southern California, has earned Magnet Recognition as part of the American Nurses Credentialing Center's (ANCC) Program.

We are looking for experienced or new graduate Neonatal Nurse Practitioners (NNPs) who are excited to join a cohesive team that practices in a collaborative, fast-paced, high-acuity setting.

- Full-time and part-time positions available
- Level IV, 84-bed Neonatal Intensive Care Unit (NICU)
- Regional referral center encompassing Tiny Baby unit, ECMO, Cardiac ICU, Neuro NICU and Surgical services
- Maternity services and delivery center
- 24/7 coverage by NNP team and Fellows
- Competitive employee benefit packages

*Offering a **sign-on bonus** with relocation reimbursement for full-time, direct applicants who meet requirements.

For more information, please contact:
Karin Colunga, MSN, RN, PNP-BC
Director of Advanced Practice Nursing
kecolunga@llu.edu | 909-558-4486

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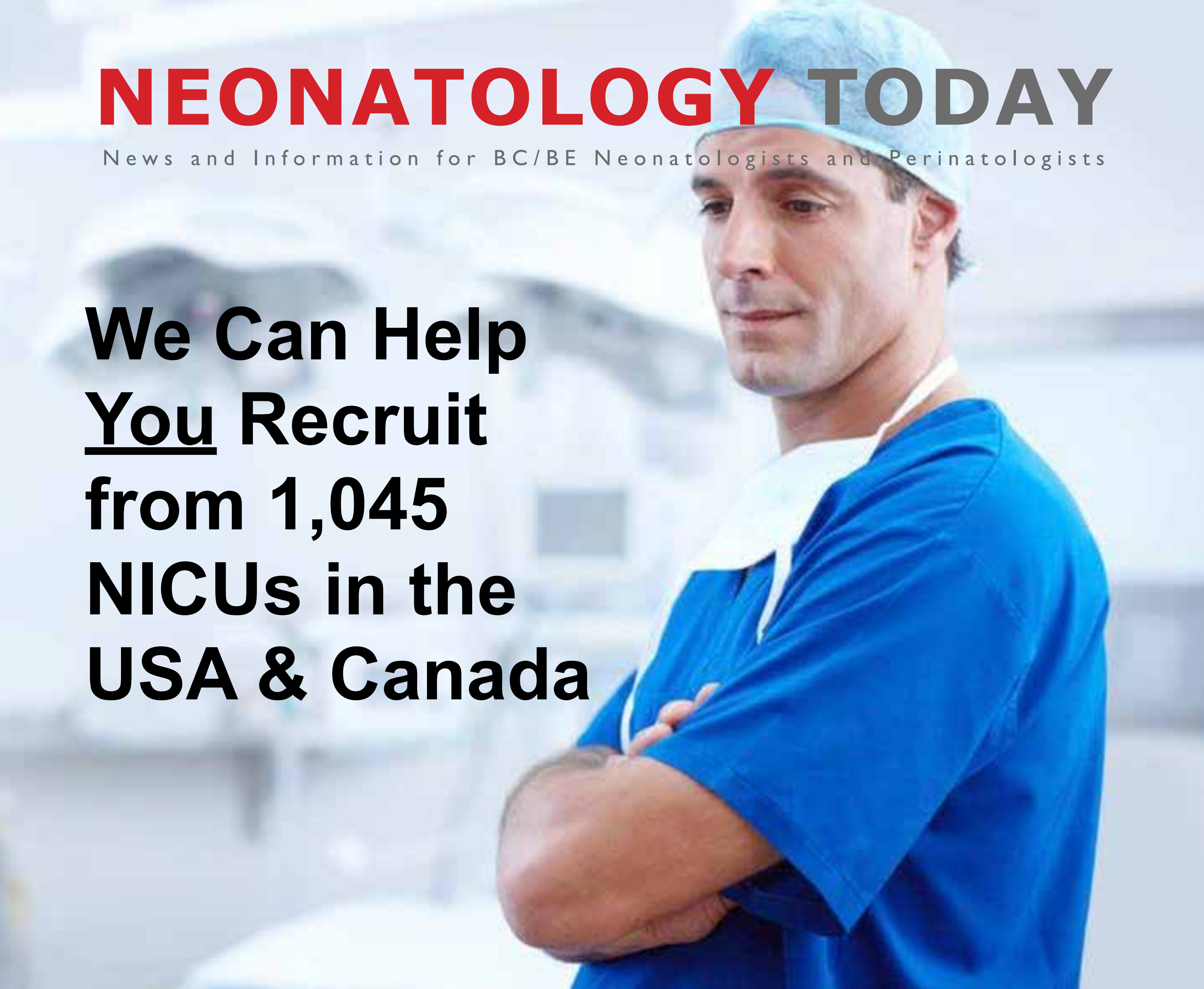

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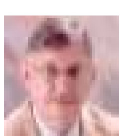
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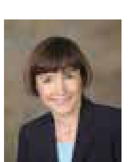
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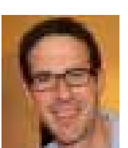
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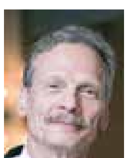
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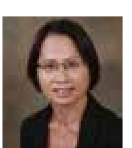
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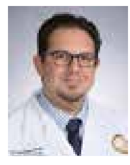
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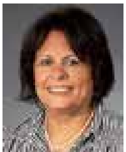

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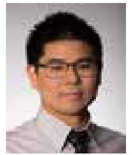

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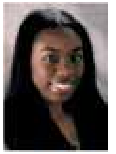

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often with soap and warm water.

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.

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https://olaw.nih.gov/policies-laws/phs-policy.htm

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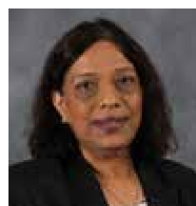
Neonatology and the Arts

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 one page as well as photographs of birds on another. This month's original artwork again features Paula Whiteman, MD who submitted an Orangutan. Our bird of the month is submitted by me this month. I have decided to call him Darth Vader because of the obvious similarities.



Mita Shah, MD,
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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, or pdf) for each figure. Preferred formats are ai, psd, or pdf. tif and jpg images should have 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 may also be used). Bibliography Software should be used to facilitate formatting and to ensure that the correct formatting and abbreviations are used for references.

9. Figures should be submitted separately as individual separate electronic files. Numbered figure captions should be included in the main file after the references. Captions should be brief.

10. Only manuscripts that have not been published previously will be considered for publication except under special circumstances. Prior publication must be disclosed on submission. Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.

11. NT recommends reading Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals from ICMJE prior to submission if there is any question regarding the appropriateness of a manuscript. NT follows Principles of Transparency and Best Practice in Scholarly Publishing(a joint statement by COPE, DOAJ, WAME, and OASPA). Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.

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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.

NICU PARENT NETWORK

Presented by:

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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NANT 13 - Call for Abstracts
Presented by the National Association of Neonatal Therapists (NANT)
Conference Dates:
Main Conference: April 14-15, 2023
Pre-Conference: April 13
Location: Tucson, AZ USA*

*Barring any restrictions to the contrary, NANT 13 is scheduled to be held in- person. However, in the event such restrictions occur, the event will be hosted online including all accepted sessions/posters.

The theme for NANT 13 is ***Inspiring Competence & Confidence***.

NANT and our Members aim to deliver best practices for NICU babies and parents all over the world. This advanced practice area requires a high level of competence, fueled by interprofessional collaboration and research.

Competence is not finite—it is an ongoing commitment to the pursuit of scientific knowledge and skill proficiency. We never arrive or are experts in all areas of practice. We rely on each other and use our unique professional lenses and experiences to advance the field of neonatal therapy.

We are calling upon you to share your research and clinical expertise. What can you contribute to the standard of care? How can you fill the gaps in neonatal therapy competency?

NANT intends to develop attendees' confidence to serve, lead, and implement collaboratively. We seek the right individuals, research, and tools to make that happen.

Sharing your valuable work in this internationally attended conference is a powerful way to inspire new levels of competence and confidence in this specialty.

We invite you to submit an abstract to present an oral or poster presentation at NANT 13.

Click here to submit an abstract.

Abstract Submission Deadline: Monday, August 15, 2022

Save the Date for the Second Fragile Infant Forum for the Implementation of Standards (FIFI-S)

January 18-20, 2023

"Implementing Evidence Based Strategies to Alleviate Stress in the Baby and Family in Intensive Care"

For more information contact

PACLAC.org

"Storyteller" painting by Sharron Montague Loree, 1982

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