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## An Innovative Educational Program for the Prevention of Sudden Unexpected Postnatal Collapse (SUPC) of Newborns

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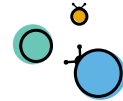
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# An Innovative Educational Program for the Prevention of Sudden Unexpected Postnatal Collapse (SUPC) of Newborns

Nancy A. Garofalo PhD, APN, NNP-BC, Elizabeth Ann Newkirk RN, MBA, Jaclyn L. Noto MSN RN, Lauren E. Filler BSN RN, Michelle M. Smith BSN RN, Joseph R. Hageman MD

## ABSTRACT

**Background:** Sudden Unexpected Postnatal Collapse (SUPC) is characterized by apnea, bradycardia, cyanosis, and cardiorespiratory collapse in healthy term newborns soon after birth, often during initial skin-to-skin contact, or with the first breastfeeding attempt. The etiology is not well understood, but accidental suffocation of the infant as a result of poor positioning, together with maternal fatigue and/or distraction, appear to play key roles. The aim of this quality improvement project was to educate clinicians and parents, in order to prevent SUPC cases. **Methods:** A task force spearheaded an educational program; using the words “pink and positioned” to teach staff how to educate parents about the proper distraction-free positioning of their infant. **Intervention:** Staff education consisted of poster presentations and lectures. A video depicting a simulated SUPC case and two other videos showing an obstetrician and post-partum nurse counseling a new mother about SUPC-prevention were created, circulated internally, and added to an online educational module. Practice changes included more frequent post-natal assessment of the newborn and documentation of ‘Pink and Positioned’ into our EMR. **Results:** After taking the module, nurses and PCTs (n=254) are more knowledgeable and report feeling more comfortable teaching parents about SUPC prevention. **Conclusions:** We anticipate that, as a result of this comprehensive educational program and practice changes, SUPC cases will be prevented.

**MESH Terms:** sudden unexpected postnatal collapse, SUPC, Sudden Unexpected Infant death, SUID.

## 1. Introduction:

A relatively new clinical phenomenon has been reported in Australian, European, and in the United States literature, and termed Sudden Unexpected Postnatal Collapse (SUPC) by several authors (1-15). While definitions vary slightly, SUPC is characterized by apnea, limpness, pallor, bradycardia, cyanosis, and cardiorespiratory failure (3, 7, 13). SUPC occurs in apparently healthy term newborns soon after birth, commonly during the initial skin-to-skin contact, in the prone position, or with the first attempt to breastfeed (1, 3, 13). While the etiology of this devastating phenomenon is not yet fully understood, maternal fatigue and/or distraction appear to play key roles (8, 14).

In the immediate postpartum period, as a result of prolonged labor, pain, and sleep-deprivation, mothers are often physically and mentally fatigued with an overwhelming sense of tiredness. Signs of fatigue include muscle weakness, decreased alertness, inability to concentrate, lethargy, and physical exhaustion (16). Fatigue leads to impaired judgment, a slowed reaction time, attention

lapses and impaired psychomotor skills (17-19). With increasing sleep deprivation, cognitive processes are significantly slower, reaction time and concentration are notably diminished, vigilance is lower, and emotional lability becomes evident (20). Research in both the healthcare and aviation industry has clearly demonstrated the detrimental effects of healthcare workers’ (physician or nurse) and pilots’ fatigue on the safety of patients and travelers; with errors resulting in many deaths and a significant financial burden to society (17-20). Studies have shown that sleep deprivation can actually mimic alcohol intoxication, with similar adverse effects. After 19 hours of wakefulness, an individual’s ability to perform tasks is equivalent to the ability of an individual with a blood alcohol level of 0.05% which is considered “under the influence” in most states (21). After 24 hours of wakefulness, reaction time is significantly slower and equivalent to the ability of an individual with a blood alcohol level of 0.1 %; which exceeds the legal limit for operating a motor vehicle in the majority of states in the U.S. (21, 22). In the early post-partum period, extreme fatigue, sleep deprivation and the use of narcotic analgesics for pain control can cause a mother to easily fall asleep while holding her infant; with devastating consequences. It is important to teach mothers to ask for help when they are feeling extremely fatigued.

*“It is important to teach mothers to ask for help when they are feeling extremely fatigued.”*

In the first hours post-delivery, mothers are also easily distracted by their smart phones and social media. Excited to share news about their baby, they tend to check their phone frequently, sending photos and text messaging. In the first two hours after giving birth, up to 30 text messages are sent (12). This does not include social networking on various media sites (i.e., Facebook, Twitter, Instagram, and Snapchat), posting photos, or talking on the phone. Significant distraction from the use of smartphones, in the immediate post-partum period, can affect bonding and is a significant safety concern if the mother is holding her infant. Comparable to the harmful effects of texting while driving- which has led to a 23-fold increase in risk for traffic accidents and is reported to be comparable to having a blood alcohol level of 1.5 mg/mL- (23), the visual-manual interaction required for smartphone-use is a major distraction (12, 24), to mothers in the immediate post-partum period and the consequences can be devastating. In a recent published report of 26 cases of SUPC in healthy newborn infants, three cases occurred during smartphone use by the mother (12).

When a mother is extremely fatigued, sleep-deprived and/or distracted because she is focused on her phone, she may not be paying attention to the positioning of her infant in their arms. She may not become aware that the infant’s airway has been



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obstructed due to poor positioning. The infant may easily suffocate and later be found completely unresponsive; with devastating consequences for the newborn, the entire family, and the hospital as well.

Recent news of a tragic case of SUPC in Oregon, which led to a major lawsuit for the hospital, has raised awareness in the U.S. of this phenomenon (25). While SUPC is recognized and discussed in other countries, there is reluctance among clinicians and hospital administrators in the United States and in Australia (11) to discuss SUPC cases. Yet, it is only through open discussion of the increasing incidence of SUPC in the United States, and throughout the world, that future cases can be prevented. As an example, when Sudden Infant Death Syndrome (SIDS) first became recognized, clear efforts were made to investigate and define the phenomenon. Open discussions and collaborative efforts raised awareness and led to educational campaigns. These campaigns were successful, and as a result, the lives of many infants have been saved. This new entity; SUPC, and its devastating consequences, must be addressed in the same manner. As smartphones become more integrated into our daily lives, it is possible that SUPC may become more prevalent (26). Importantly, while many authors suggest that infants born to primiparous mothers may be at higher risk for SUPC, others have reported cases of SUPC where the mother was a grand multipara and also experienced in lactation (26). Therefore maternal education about SUPC- prevention should not be limited to first-time mothers.

---

***“Excessive fatigue/sleepiness among healthcare workers and pilots, as well as a distraction from the use of smartphones while driving, have both been shown to have effects similar to those of alcohol intoxication, leading to fatal motor vehicle accidents and clinical errors that jeopardize patient safety.”***

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Excessive fatigue/sleepiness among healthcare workers and pilots, as well as a distraction from the use of smartphones while driving, have both been shown to have effects similar to those of alcohol intoxication, leading to fatal motor vehicle accidents and clinical errors that jeopardize patient safety. Campaigns to educate and raise awareness have been successful, and many lives have been saved. It is plausible that excessive maternal fatigue and/or smartphone distraction while holding the newborn infant, may be linked to the rising number of SUPC cases (8, 14). We theorize that this link exists and while future research is needed in this area, educational initiatives to teach nursing/medical staff and also parents about SUPC-prevention, must become a clinical priority. A recent study (3) showed that 53% (24/45) of SUPC cases were attributed to accidental suffocation, due to airway obstruction during breastfeeding, or in the prone position. In this same study, when mothers were left alone with

their infant, they recognized signs of collapse in only one-third of the cases (3). Therefore it is critical that clinicians raise awareness about SUPC and begin teaching staff and parents about SUPC prevention. This paper provides a brief overview of SUPC and also describes our quality improvement initiative, which includes a comprehensive staff education program and can serve as a model for other institutions.

## **2. Incidence:**

Recent reports suggest occurrence rates for SUPC range from 2.6 to 133 per 100,000 live births (6, 7, 12, 13). Based on these rates of SUPC occurrence, and using the number of full-term births in the United States (27), between 91 and 4,634 newborns could be affected yearly (7). However, the true incidence of SUPC is unknown due to the fact that SUPC is likely under-reported (13). This is most likely attributable to the lack of awareness and wide variation in definition and inclusion criteria. In published reports, inclusion and exclusion criteria range from: (1) gestational age (GA) > 35 weeks or > 38 weeks (9), (2) onset of the SUPC event < 2, <12, <24 or <72 hours of postnatal life or within the first week of life (9) and (3) the presence or absence of an underlying pathological condition (3). Also, infants who experience SUPC and are successfully resuscitated (near misses) are often not included in the statistics (13, 14).

## **3. Risk Factors:**

The Triple Risk Hypothesis (28) is currently used to understand SIDS (29, 30). Three factors (intrinsic vulnerability, developmental vulnerability and an extrinsic risk factor) combined can result in neonatal death. The hypothesis may apply to SUPC as well (7). It includes; (1) intrinsic vulnerability, such as transient hypoxemia before birth; (2) a developmental vulnerability, such as mild hypotonia, and (3) an extrinsic risk factor, such as maternal opioid medication during labor and/or improper positioning of the infant during skin to skin contact or breastfeeding (7). While intrinsic vulnerability and developmental vulnerability cannot be modified, it is important to identify potential extrinsic risk factors; which can be modified to reduce the risk for SUPC (7, 10).

In recent publications (8, 14), potential risk factors for SUPC, have been categorized as Maternal, Perinatal, Neonatal, and Environmental/Situational. While Maternal/Perinatal/Neonatal risk factors are not modifiable, Environmental/Situational risk factors can be modified through targeted education for both parents and staff, and nursing interventions to reduce the risk for SUPC. While many potential risk factors have been identified (see Table 1), prone positioning, first-time mother, an unsupervised first attempt at breastfeeding, and parental distraction (including the use of smartphones) appear to be primary risk factors (5, 9, 12). In a recent report involving 26 cases of SUPC, 15 of the infants were positioned prone during skin-to-skin contact, 18 were born to primiparous mothers, 13 events occurred during unsupervised breastfeeding within the first 2 hours of postnatal life, and 3 cases occurred during maternal use of a smart cellular phone (12).

## **4. The Timing of SUPC Events:**

Approximately one-third of cases occur in the first 2 hours after birth (often during the first breastfeeding session), one-third occur

Table 1. Risk Factors for Sudden Unexpected Postnatal Collapse (SUPC)

Maternal	Perinatal	Neonatal	Environmental/ Situational
<ul style="list-style-type: none"> <li>• Primiparous status</li> <li>• Maternal opiate analgesia</li> <li>• Regional or general anesthesia within 8 hours of the event</li> <li>• Magnesium sulfate administration during labor</li> <li>• Maternal body mass index &gt; 25 kg/m<sup>2</sup></li> <li>• Large breasts</li> <li>• Maternal fatigue/falling asleep during breast feeding</li> </ul>	<ul style="list-style-type: none"> <li>• Prenatal compromise</li> <li>• Passage of meconium in-utero</li> <li>• Need for extensive neonatal resuscitation post-delivery</li> <li>• Delivery via C- section</li> <li>• Need for extensive repair post-vaginal delivery</li> </ul>	<ul style="list-style-type: none"> <li>• Prone position of the infant while mother supine</li> <li>• Infant fatigue</li> <li>• Late preterm or preterm infant deemed safe to be left in the DR</li> <li>• Accidental suffocation due to occluded airway</li> <li>• Underlying conditions, including: <ul style="list-style-type: none"> <li>➤ <u>Cardiac Disease</u> (HLHS, Interrupted aortic arch)</li> <li>➤ Pulmonary disease (PPHN)</li> <li>➤ <u>Infection</u> (Pneumonia, Sepsis)</li> <li>➤ <u>Inborn Error of Metabolism</u> (Congenital lactic acidemia, Urea cycle defect)</li> <li>➤ <u>Otolaryngology</u> (prolapsed epiglottitis with laryngomalacia)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Breastfeeding (especially first attempt)</li> <li>• Unobserved skin to skin care with infant prone or side-lying on mother's chest</li> <li>• Mother in a supine position during skin to skin</li> <li>• Parental distraction (including the use of smartphones)</li> <li>• Fatigued parents</li> <li>• Mother left alone with the baby</li> </ul>

Rodriguez, N., Pellerite, M., Hughes, P., Wild, B., Joseph, M., & Hageman, J. (2017). Video Corner: An Acute Event in a Newborn. *NeoReviews*, 18 (12), e717-e720. Used with permission.

between 2 and 24 hours of age, and one-third between 1 and seven days of postnatal life (9). The median age at SUPC occurrence is 70 minutes after birth, for infants without an underlying pathology (3). For infants with an underlying condition (as detailed in Table 1), the median age of SUPC is 195 minutes after birth (3). It is important to note that SUPC cases are not limited to the postpartum setting. Friedman (26) reported two cases of healthy term newborns suffering respiratory arrest while breastfeeding; both within the first 90 minutes of life and while still in the labor/delivery unit.

#### 5. Outcomes:

The clinical outcomes for these infants are devastating with many infants dying either at the time of the event or after a prolonged

hospital course (3, 11-13). Survivors are at risk for hypoxic-ischemic encephalopathy, which is often severe, with seizures occurring as early as 6 hours after the period of asphyxia (12). Despite prompt hypothermia treatment, SUPC survivors may suffer severe neurodevelopmental disabilities (3, 12, 31, 32).

#### 6. Prevention of SUPC:

Obstetric and neonatal nurses play a key role in SUPC prevention by educating parents during the immediate post-partum period. Ideally, teaching should be initiated before delivery of the infant, and later reinforced after birth. It is important that education is provided in a manner that does not frighten parents and discourage breastfeeding or skin to skin sessions. Parental education should focus on proper positioning of the infant to





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maintain upper airway patency during breastfeeding sessions and skin-to-skin contact. The nurse should also emphasize the importance of 'distraction-free' breastfeeding and skin-to-skin contact. Parents must be cognizant that maternal distraction and fatigue are both very common. They must be taught that if the mother is overly fatigued, and without additional help, the infant should be placed 'back to sleep' in the bassinet. It is important that the mother feel comfortable asking the nurse for help so that she does not risk falling asleep while holding the infant. Parents should also be taught not to use their smartphone while holding their infant. Proper positioning of, and attention to, the newborn baby is crucial, and its importance needs to be emphasized to both parents and consistently reinforced by all healthcare providers.

---

***“Proper positioning of, and attention to, the newborn baby is crucial, and its importance needs to be emphasized to both parents and consistently reinforced by all healthcare providers. ”***

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Preventative strategies also include frequent monitoring of newborn infants during the first two hours after delivery; a high-risk period for SUPC (5, 10). If staffing allows, the 'baby nurse' should monitor the infant until delivery tasks are finished. It is critical that the nurse observes the first breastfeeding attempt and also the first skin-to-skin session, in order to reinforce teaching in regards to proper positioning of the infant. Parent education and assessment of the infant's status should be documented in the infant's electronic medical record (EMR). All of these preventative measures and interventions have been incorporated into our clinical practice. The remainder of this manuscript describes our quality improvement project and the comprehensive educational program that was undertaken, in order to prevent SUPC in our healthcare system.

## **7. Methods: Planning the Educational Program**

The topic of Sudden Unexpected Postnatal Collapse (SUPC) was first brought to the attention of our OB/NICU Corporate Education Council. This council serves to streamline and disseminate consistent nursing education, in the areas of obstetrics and neonatal care, throughout our hospital system. The Clinical Director for the Women's Hospital (A. Newkirk RN, MBA, NEA-

BC) introduced the topic of SUPC to the council, for the purpose of planning and spearheading a quality improvement and patient safety initiative. She presented council members with a recent article entitled "Sudden Unexpected Postnatal Collapse of the Newborn" written by Ferrarello & Carmichael (7). The topic of SUPC was unfamiliar to all council members.

As a next step, council members conducted a literature search of SUPC and found few articles published in the United States, while there were several publications throughout Europe. There appears to be reluctance in the U.S. among healthcare providers to discuss SUPC events, yet the topic is more openly addressed throughout Europe. This finding only emphasized the importance of quickly raising awareness about SUPC and spear-heading a prevention program. A task force (comprised of staff nurses, a neonatal nurse practitioner, clinical educators, and several managers) was assembled and discussed the need to get started quickly on this project; with a focus of (1) staff education, (2) parent education, (3) frequent monitoring of newborns during the immediate post-birth period and (4) appropriate documentation of infant assessments into our EMR system.

## **8. Immediate steps: Raising awareness and Staff education**

The OB/ISCU Corporate Education Council taskforce brainstormed and discussed opportunities and methods for staff education. The unfortunate outcomes of SUPC (death or severe neurological damage) made this an educational priority and prompted the immediate implementation of staff education for nurses and patient care technicians (PCTs) on all post-partum and labor / delivery units within our hospital system. Therefore, our initial steps were to begin immediate, informal staff education. Posters were developed and displayed in each unit, and the (SUPC) topic was introduced to shift huddles on each unit, in order to raise SUPC awareness and discuss preventative measures. Staff nurses were taught how to educate parents about proper positioning of their infant during skin to skin contact and during breastfeeding sessions. The term "Pink and Positioned" was coined by a committee member (Jaclyn Noto RN, MSN); a nurse who played a key role in staff education. Pink and positioned was described as: "The infant is positioned on a mother's chest in the sniffing position with the nares and mouth visible and not covered. The head is turned to one side during skin to skin, or directly facing the breast during breastfeeding, with nares visible, and the neck is straight and not bent. The infant's shoulders and chest face the mother. The infant's core color is pink with possible acrocyanosis as appropriate depending on age in hours of postnatal life." Our goal was to teach the nursing staff to use the term "pink and positioned" in order to create consistency in the message before bringing the education to parents. We also chose to use these words in order to keep the message positive, when teaching parents, and not cause unnecessary anxiety that would dissuade mothers from breastfeeding or holding their infant's skin to skin.

While the informal staff education was taking place on all post-partum and labor /delivery units within our hospital system, we also worked with clinicians and staff in our Grainger Center for Simulation and Innovation (GCSI) to film a video simulating a case of SUPC. Physicians, nurses, and students were recruited to participate in a simulated scenario of a SUPC event. In the

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**Omar Ishrak**

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**David B. Mayer, MD**

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- SKIN TO SKIN
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- INFANT TEACHING
- POSTPARTUM RECOVERY ...
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- SKIN TO SKIN
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- HEMORRHOIDS
- INCISION CARE INCLUDI...
- BREAST CARE
- NIPPLE CARE
- POSTPARTUM BLUES/DE...
- SIGNS OF ILLNESS

### OB LD/FBC Obstetric Patient Education Template

#### RECOVERY TEACHING IN LABOR AND DELIVERY

**SKIN TO SKIN** ^

Provide skin to skin contact for at least 30 minutes to all patients without complications regardless of feeding method within 2 hours of delivery. Define skin to skin as the baby is naked (or wears a diaper) and is prone, with the head turned on the side, on the mother's chest. The mother should be actively observing the baby while the baby is skin to skin. The infant should be in a position that maintains a clear and visible airway at all times. The infant should be covered to stay warm, but blankets should not be placed over the infants head or face, and it should not restrict interaction with mother or the baby's innate feeding behaviors.

Not started

**PINK AND POSITIONED** ^

"Pink and Positioned" is defined as: Infant is positioned on a mother's chest in the "sniffing" position with the nares and mouth visible and not covered, the head is turned to one side and the neck is straight and not bent. The infant's shoulders and chest face the mother. The infant's core color is pink with possible acrocyanosis as appropriate depending on age in hours of life.

Not started

#### POSTPARTUM RECOVERY TEACHING

**SKIN TO SKIN** ^

Figure 1 (above) OB Patient Education Record, Figure 2 (below) Newborn Flowsheet, and Figure 3 (upper image next page) Newborn Intake and Output Flowsheet

	11/10/16	0900	1200	01/17
Tone *				
Respiratory Assessment: WNL/Respiratory effort easy with no retractions, breath sounds clear and equal bilaterally, air exchange present in all lung fields				
Assessment WNL				
Respiratory Reassessment Done				
Respirations *				
Breath Sounds Right *				
Breath Sounds Left *				
Bottle Feeding				
Bottle Feeding Indication				
Bottle Feeding Time				
Feeding Type				
Feeding Route				
Amount Fed (mL)				
How was feeding tolerated?				
Breast Feeding				
Breast feeding Assessed?				
First breastfeeding attempt observed?				
Feeding Time				
How Nursed?				
Length of Feeding (minutes)				
How was feeding tolerated?				
Skin To Skin				
Skin To Skin Initiated				Yes
Pink and Positioned				During breast f.
Time				
Length (minutes)				
Skin To Skin Provider				
Urine				
Urine				
Stool				
Stool				
Infant Undocumented HIV Status				
Rapid HIV Test Result - Infant				
Date Infant Rapid HIV Result Given To Mother				
Time Infant Rapid HIV Result Given To Mother				
Infant HIV Care Referred To				

Figure 4 (lower image next page) SUPC Module: Prevention of SUPC.

Mother's Feeding Preference		6/9/17	1200
✓	Mother's Feeding Preference		
✓	Mothers Feeding Preference		
✓	Bottle Feeding		
✓	Bottle Feeding Indication		
✓	Bottle Feeding Time		
✓	Feeding Type		
✓	Expressed Breastmilk Given Immediately		
✓	Breast Milk ID checked with:		
✓	Feeding Route		
✓	Amount Fed (mL's)		
✓	How was feeding tolerated?		
✓	Breast Feeding		
✓	Breast feeding Assessed?		
✓	First breastfeeding attempt observed?		
✓	Feeding Time		
✓	How Nursed?		
✓	Length of Feeding (minutes)		
✓	How was feeding tolerated?		
✓	Latch Assessment		
✓	L Latch		
✓	A Audible Swallowing (Nutritive Suckle)		
✓	T Type of Nipple		
✓	C Comfort (Breast/Nipple)		
✓	H Hold (Positioning)		
✓	Latch Score		
✓	Lactation Consultation		
✓	Skin To Skin		
✓	Skin To Skin Initiated	Yes	
✓	Pink and Positioned	During breast f.	
✓	Time	1:10	
✓	Length (minutes)		
✓	Skin To Skin Provider		
✓	Urine		
✓	Urine		
✓	Urine Color		
✓	Stool		

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**SUPC** (00:48 / 02:13)

Sudden Unexpected Postnatal Collapse

## Prevention of SUPC

- Frequently monitor "at risk" infants during the first two hours of postnatal life<sup>6</sup>
- If staffing allows, have baby nurse monitor infant until delivery tasks are finished
- Parental education is key to prevention**
  - Use the term "Pink and Positioned"
  - Document teaching regarding Pink and Positioned
- Observe the first breastfeeding/skin-to-skin session

Education must be provided in a manner that *does not frighten parents* and discourage breastfeeding/skin-to-skin sessions

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SUPC (00:54 / 02:13)

## Sudden Unexpected Postnatal Collapse

### Parent Education

Instruct parents:

- Proper positioning of the infant to maintain upper airway patency ("pink and positioned")
- Distraction-free breastfeeding and skin-to-skin contact
  - Do not use **smartphone** during sessions of skin-to-skin contact and/or breastfeeding
- If mother is fatigued and without help, place the infant "back to sleep" in the bassinet to avoid risk of falling asleep while holding the infant



◀ PREV NEXT ▶

Figure 5. SUPC Module: Parent Education.

video, a healthy term infant is found unresponsive by the post-partum nurse. The Pediatric (NICU) team is called, and a simulated code situation ensues. Sadly, the infant does not respond to resuscitative efforts and is pronounced dead by the neonatologist after 20 minutes of resuscitative efforts. The neonatologist then proceeds to visit the mother in the post-partum unit. After introducing himself, he delivers the tragic and shocking news that her infant has died. This video was viewed by nurses and physicians in our Obstetrics and Pediatrics departments, and the vast majority had never heard of SUPC. Many asked for guidance in choosing the correct words to use when providing this (SUPC) education to parents so that the parents do not become overly anxious. For example, it was agreed upon, that the word "suffocation" should never be used when counseling parents about SUPC. Several pediatricians expressed concerns that the SUPC-prevention education needed to be given in a manner that would not frighten mothers, and deter them from breastfeeding or holding their infant skin to skin. In response to this feedback from physicians and nurses who attended the SUPC presentations, we filmed two more videos demonstrating how an obstetrician physician and a post-partum nurse would provide this teaching appropriately. The videos were circulated internally and would later be added to a web-based module and publications. What began as a nurse-led initiative evolved into a collaborative effort among nurses, physicians, and GCSI staff to raise awareness about SUPC.

While nursing education was taking place, physician education

was also being conducted simultaneously. Our collaborating neonatologist (J. Hageman MD) presented the topic of SUPC during Grand Rounds for obstetricians, and also at a Morbidity and Mortality Conference for pediatricians at the NorthShore University HealthSystem. He also presented the topic during conferences for the pediatric residents and neonatologists at Comer Children's Hospital. In order to further raise awareness amongst pediatricians, a video corner feature article (14) was submitted and accepted for publication in December 2017 for NeoReviews; an online CME journal published by the American Academy of Pediatrics. Also, a Question of the Week feature article was accepted for publication by the American Board of Pediatrics (8). Our physician colleagues also presented the topic at the American Academy of Pediatrics National Meeting (M. Pellerite MD, poster presentation) and at the annual meeting of the American Association of SIDS Prevention Professionals in September 2017 (J. Hageman MD; podium presentation).

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***"What began as a nurse-led initiative evolved into a collaborative effort among nurses, physicians, and GCSI staff to raise awareness about SUPC."***

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**Table 2. Responses to Pre- and Post- Test Questionnaire for SUPC Module**

Questions and Responses	Pre-test N%	Post-test N%
<b>Does SUPC happen to just a specific at-risk population?</b>		
I'm not sure	12 (4%)	0
No, it can happen to any infant	236 (93%)	248 (98%)
Yes, it only happens to infants with a need for extensive neonatal resuscitation	2 (1%)	0
Yes, it only occurs with first-time mothers who are unsupervised during the first breastfeeding session	4 (2%)	5 (2%)
Total Responses	254	253
<b>How often do we assess "pink and positioned" in the recovery phase?</b>		
Every 15 minutes	196 (77%)	250 (99%)
Every 30 minutes	34 (14%)	2 (1%)
Every 45 minutes	1	0
Every 60 minutes	1	0
I'm not sure	22 (9%)	0
Total Responses	254	252
<b>When should we be teaching parents about safe positioning for their newborns?</b>		
I'm not sure	2 (0.8%)	0
In both labor and delivery, as well as during the post-partum stay	242 (95%)	251 (99.6%)
It should be taught at the first follow-up visit, after discharge	3 (1.2%)	1 (0.4%)
Prior to discharge	7 (3%)	0
Total Responses	254	252
<b>If the mom is too exhausted to stay awake, should we encourage skin-to-skin contact if she is alone?</b>		
I'm not sure	4 (1%)	0
No, it is safer for baby to be on his back in the bassinet	235 (93%)	247 (98%)
Yes, skin-to-skin contact is encouraged as much as possible	15 (6%)	5 (2%)
Total Responses	254	252
<b>Is it ok for a mother to use her phone for talking/texting/photos/social media while holding her newborn infant during the first hours after delivery?</b>		
I'm not sure	3 (2%)	0
No, the mother should not use her phone or be distracted while holding her newborn during the first hours after delivery	242 (95%)	251 (99.6%)
Yes, it is okay as long as there are no risk factors for SUPC	9 (3%)	1 (0.4%)
Total Responses	254	252
<b>I am comfortable providing parent education about proper positioning to maintain the baby's airway open during breastfeeding and/or skin-to-skin contact.</b>		
Strongly disagree	28 (11%)	18 (7%)
Disagree	16 (6%)	0
Undecided	13 (5%)	9 (3%)
Agree	84 (33%)	80 (32%)
Strongly agree	108 (43%)	145 (58%)
I'm not sure	5 (2%)	0

## Secondary Steps: Developing an Online Educational Module

As staff education about SUPC was being carried out, it became evident that implementing a larger, more formal program would be needed. The committee began discussing long-term education initiatives. The development of a user-friendly online educational module became an important goal. We worked closely with an expert eLearning Instructional Designer (Sarah Snow Dlouhy) from our corporate Learning Management System (LMS) to develop this program. An on-line teaching module for clinical staff was created and included the three aforementioned videos; a simulation of SUPC as well as parent education conducted by both a nurse and physician. Also, incorporated into this module were pre- and post-test questionnaires. The completion on this online module became mandatory for all OB/Nursery nurses and patient care technicians (PCTs) within our hospital system.

## 9. Changes to our Practice: Frequent assessments and documentation

Throughout all aspects of our educational program for SUPC prevention, the phrase “Pink and Positioned” was used consistently when teaching both staff and parents. As a preventative strategy, we now assess and document that the newborn infant is “Pink and Positioned” every 15 minutes, for the first 2 hours of postnatal life. The first breastfeeding session is observed by a nurse, and “Pink and Positioned” teaching is reinforced at this time, and documented in our EMR. Once beyond the recovery phase, “Pink and Positioned” is documented with any observed breastfeeding attempt. We revised the definition of ‘Skin-to –Skin’ in our EMR to more clearly describe the positioning of the infant’s head; to prevent occlusion of the airway. The definition of “Pink and Positioned” was also added to our Education Record in our EMR. See Figures 1, 2 and 3.

## 10. Methods of Evaluation and Plans to Measure Outcomes:

Figures 4 and 5 are examples of slides from our online teaching module. Thus far, feedback has been positive, and nurses and PCTs have found this educational tool beneficial. A key aspect of evaluating results is comparing responses to the pre-and post-test questionnaires for the module, in order to determine whether clinicians have grasped the information. Table 2 shows the results of the pre- and post-test questionnaires. Thus far, 254 nurses and PCTs have completed the module. Prior to beginning the module, the nurses and PCTs were asked the following question: Have you ever heard of the clinical entity called Sudden Unexpected Postnatal Collapse? Their responses were as follows: 170 (67%) responded Yes, 58 (23%) responded No, and 26 (10%) responded: “I’m not sure.” The fact that 67% of respondents had heard of SUPC prior to taking this mandatory module, likely reflects the learning that took place (i.e., poster presentations) on all post-partum and labor /delivery units, as part of our immediate steps to raise awareness and begin educating staff about SUPC-prevention. As shown in

Table 2, responses to the questions suggest that, after completion of this module, nurses and PCTs are more knowledgeable and report feeling more comfortable teaching parents about SUPC prevention. To assess whether they have retained the education, they will be required to retake the post-test again 6 months later. Since this patient-safety initiative has recently been implemented, we do not yet have any patient outcomes to report. However, we will track cases of SUPC events and near misses corporate-wide, and we anticipate that after implementation of this mandatory training, cases of SUPC will be prevented.

## 11. Conclusions:

SUPC is a potentially fatal clinical phenomenon, characterized by pallor, limpness, apnea, bradycardia, cyanosis, and cardiorespiratory failure in apparently healthy term newborns soon after birth. Many infants die, likely from suffocation, as a result of airway occlusion from improper positioning. Survivors are at risk for severe neurological adverse sequelae. The incidence of SUPC appears to be rising, and we theorize that this may be partly linked to the increased use of smartphones and the distraction they cause, but also as a result of maternal fatigue. While the etiology for SUPC is yet unclear, and future research is needed, educational initiatives to target maternal fatigue and/or smartphone-distraction may significantly decrease SUPC risk. Preventative strategies should include staff training, parental (especially maternal) education, and increased surveillance of newborns in the early hours post-birth. Our quality improvement project was comprised of a multipronged approach to SUPC prevention; (1) staff education, (2) parent education, (3) frequent monitoring of newborns during the immediate post-birth period, particularly during the first breastfeeding session (4) documentation of “Pink and Positioned” infant assessments (and maternal teaching reinforcement) into the EMR, and (5) creation of an online teaching module for staff. As a model approach, our online educational curriculum and EMR- based charting tool will serve to identify and moderate the risk of SUPC. Ongoing research will enable us to determine whether this quality improvement and educational initiative reduces the incidence of SUPC, and positively impacts health outcomes for our newborn patients.

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The National Perinatal Association (NPA) is an interdisciplinary organization that gives voice to the needs of parents, babies and families and all those interested in their health and wellbeing. Within NPA, parents and professionals work together to create positive change in perinatal care through education, parent programs, professional guidelines and events.

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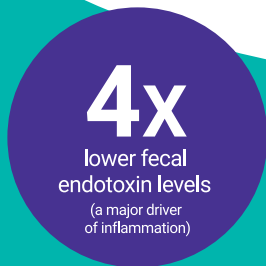
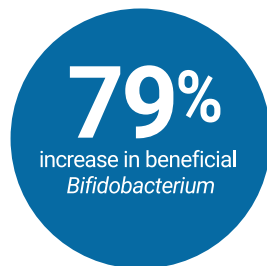
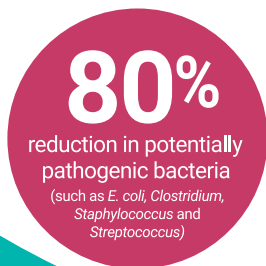


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# Manifestations of a Terminal 5p Trisomy and a Terminal 6q Deletion Caused by an Unbalanced Chromosome Translocation in a Neonate

Timothy D Ho, MS IV, Robin Clark, MD, Mitchell Goldstein, MD

## Abstract

*This case report will focus on the clinical features found in a patient who was diagnosed with the combination of rare chromosomal abnormalities of a 5p trisomy and a 6q deletion due to an unbalanced translocation. These genetic anomalies have not been well documented, with previous cases numbering below 50 for 5p trisomy and 6q deletion individually. Trisomy 5p has been shown to display phenotypes such as long head length (dolichocephaly), large head circumference (macrocephaly) (1), ear malformations (2), and cardiac defects (3). Reports of the 6q deletion demonstrated structural brain malformations (4, 5, 6, 7, 8, 9), seizures (10, 11), facial abnormalities (12, 13, 14), and necrotizing enterocolitis (15).*

## Case Report

A male baby was born via Cesarean section for preeclampsia at 25 weeks and six days gestation to a 30-year-old G2P1A0 mother who was given antenatal steroids for respiratory distress syndrome prophylaxis. At birth, he was noted to have atraumatic macrocephaly with a full anterior fontanelle. He had a birth weight of 955 g (67th percentile for EGA = 25.6 weeks), length of 36.2 cm (81st percentile for EGA = 25.6 weeks), and a head circumference of 26 cm (93rd percentile for EGA = 25.6 weeks)(16). Although the baby cried at birth, he had poor respiratory effort thereafter and required intubation. He was admitted to the NICU following delivery for respiratory difficulty.

In the NICU, the baby was placed on Nasal Intermittent Mandatory Ventilation at 40% with PEEP increased to as high as 7 cm H<sub>2</sub>O. The chest X-ray was consistent with respiratory distress syndrome. He was intubated and given beractant. Hydrocortisone was started at 11 days of life. Cranial ultrasound confirmed hydrocephalus with moderately enlarged bilateral lateral ventricles and third ventricle without obvious enlargement of the fourth ventricle and a possible absence of the corpus callosum. A patent ductus arteriosus was detected via echocardiogram at eight days of life and was ligated the following day.

Initial blood sugar was 40 mg % but follow up was 29 mg %. IV dextrose was started with TPN of 3 g/kg of protein. PICC lines were started, but the catheter could not be threaded centrally, and an umbilical line was unable to achieve vascular access. A Broviac line was placed in the neck at 15 days of life. During this time, the baby began to gain weight rapidly with low sodium levels.

At 18 days of life, free air was noted under the diaphragm on KUB cross-table lateral, and surgery was consulted. An exploratory laparoscopy was done and a spontaneous intestinal perforation was detected and resected, followed by an ostomy. By 35 days of life, the infant's head circumference had increased to 33 cm and a ventricular reservoir was placed at this time.

Chromosome analysis at 15 days of life showed an unbalanced translocation with the presence of additional chromosome material of unknown origin on the long arm of one chromosome 6. Thirteen days later, microarray results showed an unbalanced translocation with a terminal duplication of the short arm of chromosome 5 (31.91 Mb, > 50 OMIM genes) and a terminal deletion of the long arm of chromosome 6 (7.87 Mb, 27 OMIM genes). The mother's chromosomal test results were pending at this time.

Of note, the baby tested positive for neonatal screening of severe combined immunodeficiency (SCID), as well as a follow-up test for SCID at 33 days of life. However, further testing via flow cytometry demonstrated lymphocyte counts consistent with corticosteroid use.

At 49 days of life, the mother requested the cessation of reservoir tapping. The following day, life support was discontinued, and the infant was disconnected from the ventilator per the mother's request. The infant passed away from cardiorespiratory failure at 50 days of life.

## Discussion

There are multiple difficulties in counseling patients who are carriers for unbalanced translocations. Most translocation breakpoints are unique to each affected individual, and so it is difficult to obtain information from the medical literature about other individuals with the same combination of a particular deletion and/or duplication. Often the best we can do is identify pure examples of trisomy or deletion for the chromosome regions in question and offer information about each chromosome change separately. That was the strategy used in this case.

Dolichocephaly, macrocephaly, and ear malformations were a recurring theme in patients with a chromosome 5p trisomy. Our patient displayed both dolichocephaly and macrocephaly but did not demonstrate any noticeable ear malformations. Trisomy 5p has also been noted to include cardiac defects. While the patient had a patent ductus arteriosus, this is consistent with his prematurity and is unlikely to be related to the patient's chromosome 5 abnormality.

Patients with a deletion of chromosome 6q can have structural brain malformation, seizures, facial abnormalities, and necrotizing enterocolitis. The findings of our patient have been consistent with this literature, showing a possible corpus callosum agenesis and macrocephaly at birth. His head ultrasound showed bilateral dilation of his lateral ventricles, but his fourth ventricle was not enlarged. This is diagnostic of non-communicating hydrocephalus which may have been a result from structural brain malformation. The baby did not show signs of facial abnormalities and did not suffer from necrotizing enterocolitis. However, the baby had a spontaneous intestinal perforation, which is a risk factor for necrotizing enterocolitis.



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**“Spontaneous intestinal perforation has neither been documented in chromosome 5p duplications nor chromosome 6q deletions but is a major risk factor for necrotizing enterocolitis, which has been found in patients with a 6q deletion.”**

### Conclusion

Of the symptoms discussed in published articles detailing the phenotypes associated with trisomy 5p and 6q deletion, our patient demonstrated some qualities of both, but his phenotype was more consistent with that of a 6q deletion. The size of the chromosome segment may be less relevant to the final phenotype than the particular gene content of the deleted or duplicated segments, as the duplicated area on 5p was much larger than the deleted segment on 6q. While the baby had both dolichocephaly and macrocephaly which are found in trisomy 5p, the patient's non-communicating hydrocephalus was likely due to brain malformations which are found in chromosome 6q deletions. Spontaneous intestinal perforation has neither been documented in chromosome 5p duplications nor chromosome 6q deletions but is a major risk factor for necrotizing enterocolitis, which has been found in patients with a 6q deletion. Of course, this complication also occurs in extremely premature infants without chromosome anomalies.

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# My Digital Clone and Me: Time to Establish My Lakshman Rekha

Anamika Banerji, MD, MS

A man, his wife, and his younger brother were banished over a fight for the throne of a kingdom. If after 14 years, they returned alive and intact, they could claim the throne. One morning the brothers set out to hunt and gather food. Before they left, the younger brother used a blessed/magical arrow to draw a line around the dwelling. He warned his sister-in-law – no stranger could tread past the line of protection to enter the dwelling – but should she choose to venture beyond it, it would no longer keep her safe. An evil man arrived at the dwelling after the brothers had left, seeking alms. She ventured beyond the protection to give him food – and was kidnapped. This famous parable from the Ramayana used the Lakshman Rekha as an allegory for creating and remaining true to personal, professional, and spiritual boundaries (1).

The concept of boundaries remains challenging for the majority of physicians (2). A pattern of self-sacrifice and delayed gratification to achieve and be part of a greater good often goes hand-in-hand with a generous spirit. But the same quality which contributes to achieving success simultaneously can create great anguish. It turns out that establishing clear separations between different realms, people, and concepts in our lives – in a way that keeps our souls centered and elevated – is necessary but extremely difficult to do. The concept of boundaries has become especially interesting and relevant to the evolution of technology's role in our lives.

I watched the Grand Rounds presentation at our hospital with excitement and trepidation. The Digital Twin/Clone was a fascinating concept. Two bright residents in new suits, exuding an impenetrable wall of hope, stood fearlessly to present to a roomful of experienced clinicians, masters in their own fields. They described a theoretical implantable technology in a patient that allowed the interface between individuals and their physicians through a smartphone. The potential for benefit was immense: in the example of a teenager with diabetes, the digital twin would prevent manipulation of blood glucose values, ensuring complete accuracy and transmission of data to the treating physician. And in the event of a few missed appointments, the digital twin could receive and deliver medication adjustments, replacing the need for a visit with the physician completely.

Or would it? More importantly – should it? Call it my restrained idealism, my greater experience with the human condition, or respect for the face-to-face, physician-patient interaction – but I remain skeptical. In our world that daily becomes more reductionist, constantly looking for short-cuts and quick fixes, I am concerned about the impact on patient care. Is it possible that an office visit with one's physician could be reduced to a two-way transfer of information on a smartphone? Should the primary goal be the elimination of the annoying co-payment, the inconvenience of scheduling, or changing the business model of patient flow? Or is there a deeper value to the visit that no technology could replicate? Building a relationship over time, with trust that improves delivery of care, cannot be mimicked by technology. And no technology has yet been able to adequately convey the most important element of the physician-patient visit – the physical exam.

Technology's over-reliance on objective data – lab values, blood reports, and imaging – necessarily devalues interpretation within a context. A digital clone concept would also make it more difficult for physicians to use their instinct (3), arguably the most valuable element of a master clinician's repertoire. Medical instinct represents the accumulation of medical knowledge, training, apprenticeship, and years of experience. Ultimately instinct is the most significant aspect of decision-making, and cannot be taught. It develops individually and would be overlooked in a digital clone concept. That instinct drives our passion, helps us to best advocate for our patients, and prevents missing the forest for the trees. For example, with our diabetic teenager, the reality of poor compliance with medication and diet is more likely related to social stresses. The face-to-face visit allows for recognition of anxiety or depression. As such, the appropriate treatment regimen requires far more than an adjustment of an insulin dose.

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***“This generation sees their true identities and their digital identities as a distinction without a difference. They lack the construct to mistrust or understand that the digital world – like most things in life – has limitations and great potential for harm.”***

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The evolution of the digital age has been a fascinating one to live through (4). My grandparents' generation, born in the 1920's, had minimal access to technology. Their construct of the world was, by definition, based on human interaction, whether face-to-face, by phone, or letter. I call them the “pre-tech” era. If any of my grandparents were alive today, my guess is that they would have had minimal trust in the Internet, computers, or smartphones. My parent's generation is one of the most intriguing in the co-evolution of people and the digital age. Digital interfaces and forums became easily accessible during their mid-late adulthood. Depending on professions, personalities, and sub-cultures, those within my parents' generation had differential willingness to incorporate technology into their lives. They live with it, use it, perhaps are not completely facile with it – but they understand its potential harms and failings. They may create hard copy duplicates for example, because they understand the fallibility of a computer or website, and they are not reliant on it. They lived their formative years without it. I call them the “tech-wary” era. My generation began to have easy access to computers and the Internet during our formative years. I would hazard that most in my generation are reliant on the technology. We are more comfortable with electronic communication, banking, scheduling than with paper and pen, hard copy checkbooks, calendars. We have been guilty of the loss of certain arts – the art of letter-writing, with a coincident dependence and



a rising obsession with social media platforms such as Facebook, Twitter, and Instagram. My generation, in our 30's and early 40's, carries a sense of caution as we have lived just enough to witness some of the tragedies derived from overreliance on social media. I call us the "tech-savvy" era; we use the technology well but are not defined by it. The generation just after mine is brilliant in so many ways but has only existed in the digital world. I fear for them the most; they approach all things digital as a favorite doll or stuffed animal, an ever-present companion since infancy. I call them the "tech-xistential" era. This generation sees their true identities and their digital identities as a distinction without a difference. They lack the construct to mistrust or understand that the digital world – like most things in life – has limitations and great potential for harm.

Cyber-bullying, long-term sequelae from inappropriate email or text communication are a few examples of serious realities from our digital age. Paired with easy accessibility, a culture that makes you "the odd one" if you don't use or have a digital device, and incompletely developed frontal lobe function in young adults, the rising incidence of "permanent mistakes" has already resulted in suicide attempts and successes of so many of our impressionable youth (5). I am not sure we realize as a society how much we depend on what I call the "second chance" phenomenon. The "second-chance" phenomenon is what I define as the opportunity life affords to make mistakes in our youth, and then to morph our image in adulthood, sometimes continuously, to live the life we want to live. Whether changing one's hairstyle or changing one's persona - change requires buy-in and the belief that what you are now is a "truer version" than what you were in your past. A great deal of that second chance comes from fallible, imperfect, generally forgiving nature of memory and the blurriness of emotions that expands with time. My theory is that God, Fate, biology, and Darwin created second chances for a reason. If we were always defined by decisions of our past, there would be no place for evolution or maturation, change or improvement. The digital age, for its strengths, has made the "second chance" phenomenon an almost impossible feat. With the advent of a permanent record, a non-expungable imprint in the fabric of digital space, the potential for an unpredictable reminder by competing interests with less savory motives becomes a reality. A picture intended for private use taken by Polaroid could be saved by an individual, fade with time, or be thrown away. The same picture captured, or worse, digitally communicated, exists forever. And once distributed in that world, without context or rules, its intent might be warped and stripped of its innocence. The rules of what remains proprietary (13) or what can be filtered become murky. It has affected hundreds of lives of our youth, and it has brought many of our political and religious leaders to their knees – but we will never know the number of people who were never allowed to reach their full potential because choices in their past were made permanent in the digital age.

The consequences are arguably more significant for physicians.

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Although we see ourselves as imperfect human beings with innumerable flaws - society around us does not see us that way (6). We are blessed and often unaware of our power as role models. Most of us have been educated about the dangers of company bias during our training – and we partake of pharmaceutical sponsored events and paraphernalia with caution. But whether being witnessed purchasing a brand of yogurt at a grocery store or commenting on a social media platform, the same risks apply. The metaphorical extension is that our social media presence is our digital clone – with potential that patients/friends/family see it as an unspoken endorsement. And unlike a doctor's office, in which doctor and patient roles are clearly delineated with desks, patient tables, visit times, and white coats, the roles become blurred on social media platforms (7). On those interfaces – are you friends/acquaintances? Or doctor and patient? Do the interaction and content change accordingly? How does one maintain boundaries in that forum? On a different note – how well can we communicate reservations or exceptions for social media use to those who see us using it?

Are we, then, simply the sum total of our emails, texts, Facebook posts, and Twitter tweets? Can our digital selves equal or accurately convey our true selves? Both literally and metaphorically, making them the same causes loss of dimensionality – like trying to interpret the intent of a text without the benefit of associated body language or facial expression. Email/text/social media are a mixed blessing; they allow for instant communication AND the burden of instantaneous and constant response. It has created a vicious cycle and a serious quandary – the more we use it, the more we need to use it and the less we are able to extricate ourselves from it. Where does that leave us?

It isn't all bad. The digital world should be used and appreciated for what it can do. As I have understood it, Pinterest (11) has become a version of PubMed for non-medical pursuits. It is a wonderful interface that allows individuals to share and celebrate their talents and expertise in limitless arenas. The focus is not only publishing one's own talents in a popular forum but also sharing them with the world. So for example, both expert and novice cooks can find inspiration, recipes, and tips to allow them to try new things. Another terrific use of social media is the growth of support groups (12) on that interface. It is an empowering and accessible resource simplifying the concept that we are not alone. It has also created forums for mentorship, collegiality, and support for physicians and other professions.

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***“Our society has started to define us by our “digital selves” – our digital stamps. But that medium lacks the ability to understand, interpret, and weigh change over time, perhaps the most complex and important aspect of the human condition.”***

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The digital clone concept does not currently exist in a literal sense as introduced by those bright residents. Our society has started to define us by our “digital selves” – our digital stamps. But that medium lacks the ability to understand, interpret, and weigh change over time, perhaps the most complex and important aspect of the human condition. It is my humble opinion that no technology or digital accomplishment should attempt to replace the human interface, iden-



tity, or relationships - or reduce our beings or skills to an electronic interface. But make no mistake: The digital world has tightly woven itself into the tapestry of our existence – and grows by orders of magnitude threatening to consume. We are daily forced to make harder decisions about the Lakshman Rekha separating our digital selves from our authentic selves. We carry the onus of protecting ourselves, our patients, and the next generation.

What can we do? Pediatricians need to expand counseling (8) of parents, currently focused on TV and media use in toddler age and include smart devices and digital forum use. Emphasis should be placed on in-depth communication about the dangers with our children, and on “hard-stop” smartphone apps and time-limited use restrictions. A recent study discussed the fact that “educational toys” in and of themselves did not produce “smarter” children – the critical element was parents interacting with their children and the media. It seems that human interaction then is the key component to most successful interventions. Studies have linked obesity and decreased outdoor or physical activity (9) with increased hours of television watching in our pre-school and early school-age children. There is a different potential for harm in our teens and young adults. The hours spent shopping online instead of shopping in person, Facebook posting instead of conversing in-person, and engaging in online or home-school education instead of in-person curricula are lost opportunities to learn what cannot be taught from any book – empathy, social etiquette, and finesse (10). Many of us know that who we are – our passions, our strengths, and weaknesses, our personalities – came from formative positive and negative human interactions throughout our lives. As our youth progressively spend less time in the non-digital world, they are robbed of those same interactions and formative aspects of their personalities. Will they develop the skillset to stand up to a bully, or receive compliment or criticism? As each individual approaches the issue, the answer lies in drawing a unique and self-determined Lakshman Rekha defining what parts of our lives may be shared by our digital clones – and what portions they may not breach. At the crossroads of possibility in the digital age, I imagine we are at a yellow light. It is time to slow down, evaluate our surroundings, and proceed with caution.

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# From National Perinatal Information Center: The new Joint Commission Perinatal Care (PC) Measure: PC-06 Unexpected Complications in Term Newborns

Janet H. Muri, MBA and Sandra Boyle, BS

**The National Perinatal Information Center (NPIC) is driven by data, collaboration and research to strengthen, connect and empower our shared purpose of improving patient care.**

**For over 30 years, NPIC has worked with hospitals, patient safety organizations, insurers, and researchers to collect and interpret the data that drives better outcomes for mothers and newborns.**



On July 31, 2018, The Joint Commission announced it would require accredited hospitals with at least 300 live births per year to report on a new Perinatal Care (PC) performance measure, PC-06 Unexpected Complications in Term Newborns, beginning with January 1, 2019 discharges.

## MEASURE BACKGROUND/DESCRIPTION

The new PC measure was originally endorsed by the National Quality Forum in January 2011 as Measure 0716: Healthy Term Newborn. It was re-endorsed in October 2016 as Unexpected Complications in Term Newborns and is also referred to as Unexpected Newborn Complications (UNC).

The measure is a hospital level outcome measure that reflects the percent of infants (inborn only) with Unexpected Newborn Complications (UNC) among full-term newborns with no (known) preexisting conditions. The overall UNC is further subdivided into infants with moderate or severe complications according to the algorithm developed by the measure steward, California Maternal Quality Care Collaborative .

A combination of diagnosis and procedure codes and neonatal Length of Stay (LOS) is used to categorize complications. Severe complications include neonatal death, transfer to another hospital for a higher level of care, severe birth injuries/neurologic damage and severe respiratory and infectious complications. Moderate complications include less severe birth trauma and respiratory complications (such as TTN), infections with a longer LOS (excluding sepsis) and infants with a prolonged length of stay greater than five days.

## RATIONALE

Term babies represent 90% of all births and the expectation for their families is the delivery of a healthy infant. While this result is true in most cases, there are times when “unexpected” complication occur intrapartum requiring attention and intervention by the care team. These complications, depending on the level of severity, can unsettle the family and require varying degrees of intervention, such as possible admission/transfer to a special care nursery which can interrupt family bonding and breastfeeding. This measure was designed to identify adverse outcomes resulting in severe or moderate morbidity in term infants without preexisting conditions. These outcomes, in addition to requiring immediate, expert management and decision making by the entire team can alert the hospital to needed improvements in care delivery so as to mitigate complications in the future.

## ADDITION TO THE PERINATAL CARE MEASURES

There are currently five PC Measures required for Joint Commission reporting; three maternal measures (PC-01 Elective Delivery, PC-02 Cesarean Birth and PC-03 Antenatal Steroids) and two newborn measures (PC-04 Health Care-Associated Bloodstream Infections in Newborns and PC-05 Exclusive Breast Milk Feeding).

PC-06 Unexpected Complications in Term Newborns adds another newborn measure and is seen as a balancing measure to PC-01 and PC-02, a measure designed to guard against unintended or unanticipated consequences of quality improvement initiatives aimed at reducing elective deliveries and NTSV cesarean sections.

## NPIC EXPERIENCES WITH UNC

NPIC is a member of The Joint Commission Perinatal Care Technical Advisory Panel and has reported on UNC rates for member and contract hospitals since shortly after the measure was approved by the NQF. We have found the measure to be a widely accepted method for tracking newborn complications in the lowest risk newborn population. Since complications can occur in the best of circumstances, this measure provides a way for hospitals to systematically quantify the shortfall for their perinatal team and when coupled with comparative rates

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<b>NQF #716 - Unexpected Complications in Term Newborns</b>	
<b>Timeframe of Data: 04/01/2017-03/31/2018</b>	<b>NPIC Database Average</b>
<b>A. Inborns</b>	
Total Inborns	3,857
UNC Final Denominator: Inborns in measure population without preexisting conditions <sup>1</sup>	2,977
<b>B. Unexpected Newborn Complication Rates</b>	
Total UNC Rate:	3.1%
Inborns with severe or moderate complications	3.1%
Severe UNC Rate: Inborns with severe complications	1.3%
Moderate UNC Rate: Inborns with moderate complications	1.8%
<b>C. Neonatal Complication Sub-Categories <sup>2</sup></b>	
Respiratory	60.0%
<i>Severe</i>	10.0%
Infection	12.2%
<i>Severe</i>	12.2%
Transfer to Higher Level of Care ( <i>Severe only</i> )	3.3%
Neurologic/Birth Injury	17.8%
<i>Severe</i>	14.4%
Shock/Resuscitation ( <i>Severe only</i> )	1.1%
Long Length of Stay without clear diagnosis ( <i>Moderate only</i> )	6.7%
<sup>1</sup> Includes singletons; birthweight ≥ 2500 grams; gestational age ≥ 37 weeks. Excludes fetal malformations; maternal/fetal complications; exposure to maternal drug use.	
<sup>2</sup> Does not include neonatal deaths.	

across peer subgroups, a way to determine outlier status and opportunities for quality improvement initiatives.

NPIC reporting includes overall UNC rates along with the rates of severe and moderate complications and complications by sub-category (e.g., respiratory, infection, birth injury). The distribution by sub-category assists hospitals with the identification of problem areas and can provide direction for their quality improvement efforts. The Table displays NPIC Perinatal Center Data Base information for the period 4/1/2017-3/31/2018. It is important to remember that the NPIC Data Base is not a representative sample. While many of our members are large, subspecialty facilities, several non-specialty, non-academic facilities are also included in the Data Base. All members are focused on perinatal QI initiatives where comparisons to peer subgroups can help guide their efforts.

#### PLANNING FOR PC-06

The Joint Commission released updated specifications (V2018B1) for PC-06.0 (Overall Rate), PC-06.1 (Severe Rate)

and PC-06 .2 (Moderate Rate) on November 1, 2018. Administrative and medical record data are the sources for the required data elements, and unlike some of the other PC measures, there is no sampling. The Joint Commission requires submission of PC-06 data each quarter for all live-born single term newborns over 2500 grams in birth weight.

NPIC encourages hospitals to review the PC-06 algorithm carefully and, if possible, model their UNC metrics to determine where they have rates higher than expected. Since the metric is driven by ICD-10 coded data, reviewing clinical documentation and coding for accuracy is a critical step in determining opportunities to improve data and/or quality. Only after hospitals have confidence that their underlying data is correct, will they be able to move to quality improvement initiatives around these “unexpected complications.”

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# BLACK + PREGNANT = DEATH?

## Racial disparities in perinatal morbidity and mortality in the United States

C Cody Miller, MS-4 and Ealing Tuan, MS-3

*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.*



In 2016, a study published in *Obstetrics & Gynecology* on maternal morbidity and mortality in the United States shook the foundations of our trust in the safety and effectiveness of the American healthcare system. The study found a nationally (excluding California and Texas) averaged maternal mortality rate (MMR; defined as number of deaths per 100,000 live births) of 23.8, a 26.6% increase from 2000-2014; while all other developed nations globally experienced reductions in their MMR. (1) Now, increasing evidence has brought to light a new aspect of our perinatal healthcare woes – or rather, a new awareness of our long-standing history of racial inequity.

The problem of racial inequity in perinatal mortality and morbidity is not new. By the time *JAMA* published an article on the matter in 1999 (nearly 20 years ago), previous

studies had already attempted to explain racial discrepancies in maternal mortality. (2) Now, almost two decades later, the matter irrefutably persists with disturbingly little improvement. Even in 2010, black women were still over three times more likely than white women to die in the peripartum period. (3) Studies have shown that black women in the United States are 60% more likely than white women to suffer from preeclampsia or eclampsia, (4) 88% more likely to have a postpartum hemorrhage, (5) and 48% more likely to undergo a cesarean section. (6) Even when accounting for known differences in educational attainment, black women still fare worse; a black woman with a college degree or higher is still more than twice as likely to suffer severe maternal morbidity than a white woman who never graduated high school. (7) All of the aforementioned findings are from studies published within the past decade, highlighting the ongoing and current nature of this concern.

***“Even when accounting for known differences in educational attainment, black women still fare worse; a black woman with a college degree or higher is still more than twice as likely to suffer severe maternal morbidity than a white woman who never graduated high school.”***

Infants are by no means insulated from these disparities. Although medical advances have precipitated an overall decrease in US infant mortality, from 1950 to

2005, the African American infant mortality rate rose from 1.6 to 2.4 times the white infant mortality rate. (10, 11) In March 2018, *JAMA Pediatrics* published a study that examined nearly 596,000 very preterm births across 40 New York City hospitals. Among the many contributing factors assessed (including mother's race, socioeconomic status, and the highest level of education), the impact of the hospital of birth on infant mortality was second only to a given infant's inherent health risk. Unsurprisingly, black and non-white Hispanic very-preterm birth infants were more likely than their white peers to be born at hospitals associated with higher risk-adjusted rates of neonatal morbidity and mortality. (12)

These egregious disparities in outcomes between racial groups in US perinatal healthcare are simply unacceptable. In 2015, the American Congress of Obstetricians and Gynecologists (ACOG) published a committee opinion acknowledging that more than a third of all women in the US are members of a racial or ethnic minority demographic; the opinion called for immediate efforts to reduce racial inequities in MMR. (8) However, academic literature and professional society recommendations have not proven to be effective in the last two decades at addressing racial inequity in perinatal healthcare.

Addressing the complex and multifactorial nature of these disparities will require interdisciplinary interventions at the levels of healthcare systems and institutions, individual providers, and research initiatives. (13,14,15) First, broad system-level remedies include ensuring that women of color have universal and easy access to preventative, prenatal, and post-partum care, including contraception. Moreover, a standardized system for accurately documenting patients' self-identified race, ethnicity, and preferred language should be adopted by all healthcare institutions. Second, all healthcare providers and support staff should be trained and educated about implicit bias, shared-decision making models, and specific heightened health



risks for minority patients. Lastly, research on socioeconomic determinants of perinatal health should be widely encouraged and pursued in order to improve interventional strategies.

**“The time to address egregious racial and ethnic disparities in perinatal health has long since passed.”**

The time to address egregious racial and ethnic disparities in perinatal health has long since passed. To assure high-quality care for all mothers and their babies (before and after birth), actionable measures must be taken to educate patients, train providers, and reform healthcare systems and policy.

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# Reducing Staphylococcus aureus Infections in a Neonatal Intensive Care Unit through Parent Skin Cleansing Prior to Skin to Skin Care

Gwen Westerling, BSN, RN, CIC, Beth Huizinga, MSN, RN, RNC-NIC, Daliya Khuon, MD

## Abstract:

**Background:** In 2016 an increase in hospital-acquired infections in the Neonatal Intensive Care Unit (NICU) caused by Staphylococcus aureus (SA) was observed. Process changes occurring around this time included increased skin to skin care, meaningful touch between neonates and parents, and two-person staff care. It was hypothesized the process changes were exposing neonates to increased amounts of SA and potentially contributing to infections.

**Methods:** The study occurred in a Level IV, 108 bed NICU. NICU continued current care practices but implemented increased awareness of hand hygiene, educated staff about SA, and implemented parent skin cleansing prior to skin to skin care for all low birth weight neonates, and all neonates with central lines. For one year prior to and one year after the interventions, infections caused by SA were measured. Infections measured included clinical cultures positive for SA, Central Line-Associated Blood Stream Infections (CLABSI) and Ventilator infections (VENT).

**Results:** Overall Infections decreased from 1.63 to 0.62. Of these, Non-HAI Infection rates decreased from 0.83 to 0.46, CLABSI decreased from 0.19 to 0.06 and VENT infections decreased from 0.61 to 0.09.

**Implications for Practice:** Study results show a significant decline in measured infections and support the study hypothesis that meaningful touch, skin to skin care, and increased exposure to caregivers in NICUs may carry a risk for acquisition of SA infections. Interventions were effective in reducing SA infections in NICU.

**Implications for Research:** Further research on this topic is necessary to validate the results of this study.

## Abbreviations:

HAI: Hospital Acquired Infection  
NICU: Neonatal Intensive Care Unit  
SA: Staphylococcus aureus  
SBU: Small Baby Unit  
CLABSI: Central Line Associated Blood Stream Infection  
NHSN: National Healthcare Safety Network  
VENT: Ventilator related infection

## Key Words:

Neonatal Intensive Care, Staphylococcus aureus, Skin to Skin Care, Hospital Acquired Infections, Central Line Associated Blood Stream Infections,

## Background:

Healthcare-associated infections (HAI) are an important cause of morbidity and mortality in neonatal patients. The immune system of the neonate is immature, and the skin is an inadequate barrier because it is fragile, permeable, and easily traumatized. The immaturity of the immune system and immature skin predisposes the neonatal patient to infection(1, 2). Although prevention of infection for premature infants is an ongoing challenge, it is essential to the health and safety of neonatal patients.

In 2016, an increase in HAI was noted in the Neonatal Intensive Care Unit (NICU) caused by Staphylococcus aureus (SA) through diligent Infection Prevention Surveillance. Most of the infections occurred in low birth weight neonates housed in our Small Baby Unit (SBU). Literature was examined for risk factors of SA acquisition for neonates.

In the first few days of postnatal life, as many as 50% of newborns can become colonized with SA and these rates can increase with prolonged hospital stay(1). Acquisition can occur from the parents, other colonized or infected patients in the nursery, transient carriage on the hands of health care workers, or a contaminated environment(1). SA is a common colonizing bacterium on the skin of healthy persons and can be transmitted by direct contact with skin(3-5). Of particular interest was an article published in the American Journal of Infection Control showing a correlation between the practice of kangaroo mother care and the development of Methicillin-Resistant Staphylococcus aureus infections in a NICU(6).

***“The most successful management comes with the timely recognition of initial symptoms, appropriate diagnosis, and selection of the necessary intervention.”***

Process changes that occurred in the NICU prior to the increase in infections were increased promotion of skin to skin care, meaningful touch between neonates and parents, and two-person patient care. It is hypothesized that the process changes were exposing neonates to increased amounts of SA and contributing to the increase in infections.

## Methods:

The study occurred in a Level IV, 108 bed NICU. The NICU has 40 private rooms and 68 beds in shared nurseries that can house between 5 and eight patients. The NICU also houses an SBU in

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Table 1: Evaluating Infections Pre and Post Interventions

Infections	Pre Intervention	Post Intervention	P-value
Non HAI Infections	0.83	0.46	0.06
CLABSI	0.19	0.06	0.13
Vent	0.61	0.09	< 0.001
Total Infections	1.63	0.62	<0.001

Rate = Infections/Patient Days \*1000

the shared nursery area in which infants less than 27 weeks gestational age are admitted. Patients stay in the SBU until they reach at least 32 weeks of age and meet developmental criteria. In the year 2017, our NICU had 1,334 admissions and 28,338 patient days.

The study involved implementing three interventions. First, the team increased awareness of the existing hand hygiene program. This program required a beginning of the shift scrubbing of bare arms from fingertips to elbows using soap and water washing and a nail pick. The program also included washing in and washing out with soap and water, or alcohol-based hand sanitizer every time a room was entered or exited. This was accomplished through leadership rounding, huddles, and newsletters. Second, staff were educated about SA and increased risk of acquisition for NICU patients. Third, the NICU implemented parent skin cleansing prior to skin to skin care for all SBU patients and all neonates with central lines. Parent skin cleansing was accomplished at the bedside using pre-packaged bath wipes. All exposed skin that would come in contact with the patient was cleansed. Parents were educated about this process by the bedside nurse.

---

***“Malrotation, particularly with a volvulus, presents with abdominal pain, distension, and emesis. As bowel can actively necrose, this condition is often emergent and requires surgical intervention.”***

---

Infections caused by SA the year after the interventions were compared with SA infections the year prior. The infections measured included: clinical cultures that did not meet any HAI defini-

tions (Non-HAI), Central Line Associated Blood Stream Infections (CLABSI) as defined by the National Healthcare Safety Network (NHSN), and Ventilator Related Infections (VENT). Rates were calculated as infections divided by patient days multiplied by 1,000. Once a patient became positive for SA, they were considered colonized and were not counted if subsequent cultures became positive. Since the rate of parent skin cleansing could not be audited due to limitations within the electronic medical record, staff was surveyed to determine if changes became part of NICU culture as a proxy measurement.





Figure 1: Staff Survey Question 1



**Results:**

In the year prior to the interventions, the rate of total patients that developed SA infections was 1.63 (n= 59). The rate for Non HAI infections was 0.83 (n= 30), 0.19 (n= 7) met NHSN definition for CLABSI and 0.61 (n= 22) developed VENT infections.

In the year post-intervention, the rate of total patients that developed SA infections decreased to 0.62 (n= 20). Of these, 0.46 (n= 15) developed Non HAI infections, 0.06 (n= 2) developed CLABSIs and 0.09 (n= 3) developed VENT. Results show an overall decline in measured infections with statistical significance for VENT and Total Infections. P-value was calculated using chi-squared test via Open Epi <http://www.openepi.com/PersonTime2/PersonTime2.htm>. (Table 1).

Compliance for parent skin cleansing prior to skin to skin care could not be audited due to limitations in our electronic health record. Instead, an electronic survey was emailed to approximately 300 NICU registered nurses. Of the 93 staff that responded to the post-intervention survey, 98% of registered nurses knew of the requirements for parent/family cleansing (Figure 1). Of surveyed respondents, 75% performed the cleansing 76-100% of the time (Figure 2). Additionally, interventions were completed in the NICU unrelated to skin to skin care, including education on standardization of central line care, which may have had an impact on CLABSIs but not other infections.

**Conclusion:**

While results are likely not the only factor affecting reductions in infections, they do support the hypothesis that meaningful touch, skin to skin care, and increased exposure to caregivers in NICU may carry a risk for acquisition of SA infections. Interventions of hand hygiene awareness, education of staff about SA and parent skin cleansing prior to skin to skin care were effective in a multifaceted strategy to reducing SA infections in our NICU. Limitations of the study include the inability to measure adherence to the parental skin cleansing directly.

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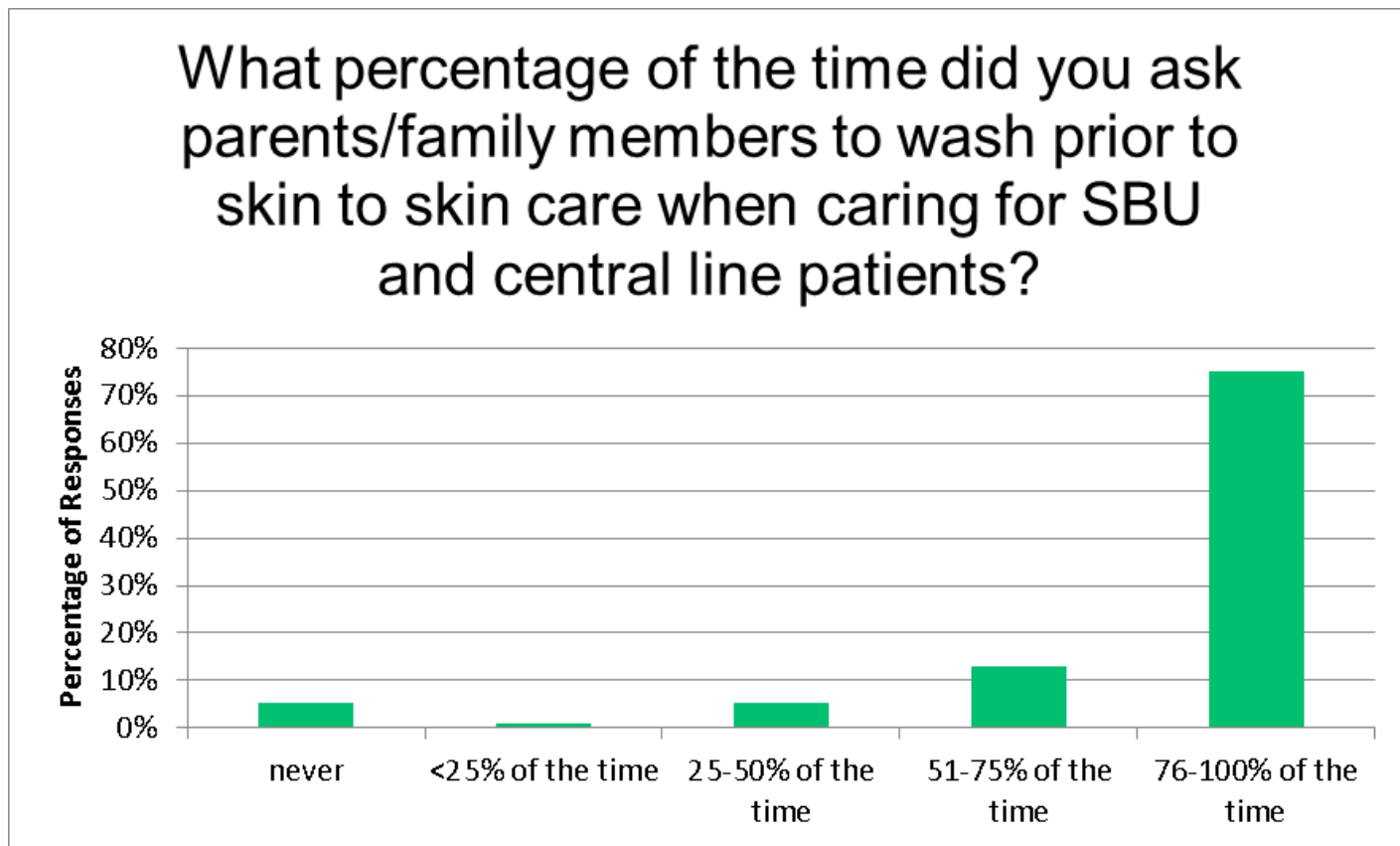
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Figure 2: Staff Survey Question 2



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# Respiratory Syncytial Virus:

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including those  
with CLD, BPD, CF,  
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their babies from  
respiratory infections

Advocate for insurance  
coverage for palivizumab  
prophylaxis so more babies  
can be protected \*



Use your best  
clinical judgement



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RSV prophylaxis

Tell insurers  
what families need



and provide the  
supporting evidence



\*See the NPA's evidence-based guidelines at  
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## NT Welcomes Andrea Goodman: Senior Editorial Project Director

Andrea Goodman is a leader in public health programs and stakeholder engagement. In addition to her new editorial role with *Neonatology Today*, Ms. Goodman currently directs Genetic Alliance's PCORnet Coordinating Center and oversees engagement projects and partnerships aimed at elevating stakeholder participation in health and research. She has a decade of experience in nonprofit leadership and multi-program thought leadership.

Ms. Goodman also contributes to the strategic direction of the *Expecting Health* division, with a passion for re-imagining the maternity and pediatric experience in a way that meets families where they are. In this role she has been leading the Perinatal Nutrition Collaborative for more than five years- a coalition of leading maternal and infant health organizations with an invested interest in optimal nutrition pregnancy, lactation, and early childhood.

Prior to this role, Ms. Goodman served as Maternal and Child Health (MCH) Director for the National Healthy Mothers, Healthy Babies Coalition (HMHB), where she managed content, national partnerships, and provider and consumer engagement strategy for all programs including the award-winning Text4baby service. As MCH Director she also led activities for the National Premature Infant Health Coalition (now the National Coalition for Infant Health), where she convened key multidisciplinary stakeholders with a shared goal of improved resources for premature infants, their families, and neonatal providers. She is extremely passionate about identifying potential duplication, efficiencies, synergy, and shared vision between programs and public-private partnerships, and streamlining care to make health decisions easy and actionable for families.

Previous content areas include immunization and infant development, nutrition and breastfeeding, maternity care, tobacco cessation, reproductive health, and domestic violence. Ms. Goodman holds a Master of Public Health from The George Washington University and a Master of Science in Social Work from Columbia University. Most importantly, she is inspired and humbled every day in her role as mom to two young boys.



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# Senators Champion PREEMIE Act to Support Research into Preterm Births

Darby O'Donnell, JD

*The Alliance for Patient Access ([allianceforpatientaccess.org](http://allianceforpatientaccess.org)), founded in 2006, is a national network of physicians dedicated to ensuring patient access to approved therapies and appropriate clinical care. AfPA accomplishes this mission by recruiting, training and mobilizing policy-minded physicians to be effective advocates for patient access.*



Congress is working on renewing legislation that brings support and attention to infant health challenges. The full name for the bill is Prematurity Research Expansion and Education for Mothers who deliver Infants Early Reauthorization Act (S. 3029 – the PREEMIE Reauthorization Act).

This past month, when the National Coalition for Infant Health (NCfIH) hosted their fourth annual Infant Health Policy Summit in Washington, D.C., Summit attendees heard from key congressional staff about the legislation and how they can help push it across the finish line.

***“This past month, when the National Coalition for Infant Health (NCfIH) hosted their fourth annual Infant Health Policy Summit in Washington, D.C., Summit attendees heard from key congressional staff about the legislation and how they can help push it across the finish line.”***

Congressional staff representing the bill's Senate champions,

Senator Lamar Alexander (R-Tenn.) and Senator Michael Bennet (D-Colo.), participated in a panel discussion to explain how the bill would reauthorize pivotal Centers for Disease Control and Prevention (CDC) research and activities on preterm births.

They discussed how the bill, introduced this past summer, passed the full Senate in early September. In the House of Representatives, companion legislation is being championed by Rep. Anna Eshoo (D-Calif.) and Rep. Leonard Lance (R-NJ). The House bill (H.R. 6085) now has nearly 20 cosponsors.

What does the bill do exactly?

In short, the bill renews and reauthorizes programs focused on combatting preterm labor and delivery. This is achieved through federal support for research of contributing factors to preterm birth, and programs including national data tracking of preterm births, which would collect maternal-infant clinical and biomedical information. The bill also provides support for federal programs and activities that focus on healthy pregnancies, as well as inter-agency cooperation to examine infant mortality, maternal morbidity, and other adverse birth outcomes.

***“The bill also provides support for federal programs and activities that focus on healthy pregnancies, as well as interagency cooperation to examine infant mortality, maternal morbidity, and other adverse birth outcomes.”***

According to a fact sheet provided by the March of Dimes, “Every year, more than 380,000 infants are born preterm in the United States, or 1 in 10 births.” The fact sheet also acknowledges that those born preterm are more likely than their full-term counterparts to suffer from “intellectual and physical disabilities” from infancy through childhood and even adulthood.

The PREEMIE Reauthorization Act (S 3029/HR 6085) will be an update and improvement on legislation that was originally passed in 2006 and renewed in 2013.

Advocates are asked to contact their House members to express support for the legislation and ask that it be voted on before Congress adjourns for the year. Should the legislation not get passed this year, Congress will have to start anew next year.

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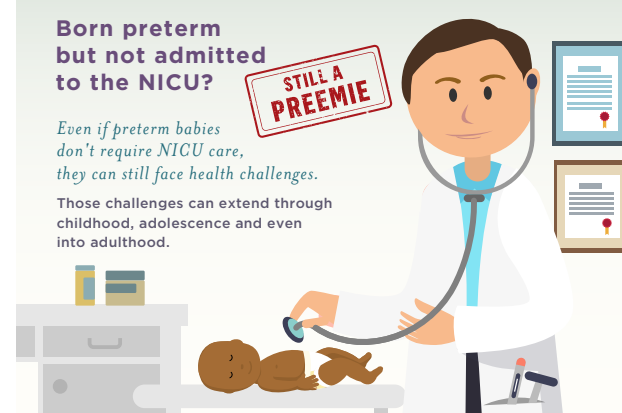


### Born preterm but not admitted to the NICU?



Even if preterm babies don't require NICU care, they can still face health challenges.

Those challenges can extend through childhood, adolescence and even into adulthood.



#### Some Premies

- Will spend weeks in the hospital
- Will have lifelong health problems
- Are disadvantaged from birth

#### All Premies

- Face health risks
- Deserve appropriate health coverage
- Need access to proper health care

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# Medical News, Products & Information

Compiled and Reviewed by Mitchell Goldstein, MD Editor in Chief

## Grandparents: Raising their Children's Children, They Get the Job Done

Research presented at American Academy of Pediatrics 2018 National Conference & Exhibition in Orlando finds the growing number of grandparents serving as sole caregivers for their grandchildren are coping well.

Released: 12:01 a.m. EST Friday, November 2, 2018

Source Newsroom: AAP contacts:  
Laura Alessio, 630-626-6276 or lalessio@aap.org  
Lisa Black, 630-626-6084 or lblack@aap.org

AAP — ORLANDO, Fla. – Millions of children are being raised solely by their grandparents, with numbers continuing to climb as the opioid crisis and other factors disrupt families. New research being presented at the American Academy of Pediatrics (AAP) 2018 National Conference & Exhibition shows that caregivers who step up to raise their grandchildren are overcoming unique challenges to manage just as well as biological and adoptive parent caregivers.

The study abstract, "Grandparents Raising Grandchildren: Are They Up to the Job?" will be presented on Monday, Nov. 5, at the Orange County Convention Center in Orlando, Fla. The study is the first to examine a nationally representative sample of children and directly compare households where children are being raised by their grandparents with those being raised by their parents.

"A large and increasing number of mothers and fathers aren't able to meet the responsibilities of parenthood, prompting their own parents to take on the primary caregiver role for their grandchildren," said senior author Andrew Adesman, MD, FAAP, Chief of Developmental and Behavioral Pediatrics for Cohen Children's Medical Center of New York. "Although these children are more likely to have endured one or more adverse childhood experiences and the grandparents themselves often face extra health and socioeconomic hurdles, our findings suggest they appear to be coping well."

The researchers analyzed and compared 2016 National Survey

of Children's Health data from 44,807 parent-led households and 1,250 grandparent households. They determined that caregivers raising their grandchildren were more likely to have a greater number of physical and mental health problems, have household incomes at or below the federal poverty line, have lower levels of education, and be single.

In addition, the grandchildren they were raising were more likely to become angry/anxious with transitions, lose their temper and have other behavioral issues.

"This was not surprising, since we know that children in non-parental care are likely to have experienced more adverse childhood experiences and have an increased risk of behavioral problems as a result," said abstract co-author Sarah Keim, PhD, Principal Investigator at Nationwide Children's Hospital.

However, Keim said, grandparents and parents showed no difference when asked if the child "does things that really bother" them, is "harder to care for" than peers, or if they "felt angry with this child." In fact, grandparents and parents did not differ on most measures of parent coping, parenting stress, or caregiver-child interactions when stratified by child health and child age.

The study also found that a substantial proportion of both grandparent caregivers (31 percent) and parent caregivers (24 percent), reported that they did not have anyone "to turn to for day-to-day emotional support with parenting."

"Given that children being raised by their grandparents may pose greater behavioral challenges, and that nearly a third of the parenting grandparents reported they had no one to turn to for day-to-day emotional support with parenting, pediatricians and other health professionals caring for 'grandfamilies' must be mindful of these issues and be ready to refer families to counseling when needed, as well as refer them to supports groups locally and online," Dr. Adesman said.

Abstract co-author Nallammai Muthiah will present the study abstract, available below, from 2:50 p.m. to 3:10 p.m. ET in the Barrel Spring room at the Orange County Convention Center. To request

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an interview with Dr. Adesman, journalists may contact him at [AAdesman@northwell.edu](mailto:AAdesman@northwell.edu) or 516-232-5229 (cell).

In addition, Dr. Adesman will be among highlighted abstract authors available during an informal Media Meet-and-Greet session Saturday, November 3, after a brief presentation at 12:55 p.m. EST in room W208AB of the Orange County Convention Center (Press Office).

During the meeting, you may reach AAP media relations staff in the National Conference Press Room at 407-685-5404.

Please note: only the abstract is being presented at the meeting. In some cases, the researcher may have more data available to share with media, or may be preparing a longer article for submission to a journal.

###

The American Academy of Pediatrics is an organization of 67,000 primary care pediatricians, pediatric medical subspecialists and pediatric surgical specialists dedicated to the health, safety and well-being of infants, children, adolescents and young adults. For more information, visit [www.aap.org](http://www.aap.org). Reporters can access the meeting program and other relevant meeting information through the AAP meeting website at <http://www.aapexperience.org/>

NT

## Soft Furniture Doesn't Cushion Risk of Falls by Young Children

Research presented at American Academy of Pediatrics 2018 National Conference & Exhibition in Orlando shows more than 230,000 children land in the emergency department each year after tum-

bling off beds and sofas – now the leading cause of injury to patients under 5.

Released: 12:01 a.m. EST Friday, November 2, 2018

Source Newsroom: AAP contacts:  
Laura Alessio, 630-626-6276 or [lalessio@aap.org](mailto:lalessio@aap.org)

Lisa Black, 630-626-6084 or [lblack@aap.org](mailto:lblack@aap.org)

AAP -ORLANDO, Fla. – Most parents know how easily young children can fall down stairs or tumble off tables at home. Soft, padded furniture like beds and sofas may seem like less of an injury threat. But a new research abstract being presented at the American Academy of Pediatrics (AAP) 2018 National Conference & Exhibition shows more than 2 million children under age 5 were treated in hospital emergency departments for soft furniture-related injuries between 2007 and 2016.

The study abstract, “Bed and Sofa-Related Injuries to Young Children Treated in US Emergency Departments, 2007-2016,” will be presented on Monday, Nov. 5, at the Orange County Convention Center in Orlando, Fla.

“Parents often leave young children on a bed or sofa, stepping away for a bit and thinking it’s not dangerous,” said lead researcher and author Viachaslau Bradko, MD. “But our research shows that these types of falls are now the most common source of injury in this age group,” he said. In fact, he said, children were 2.5 times more likely to be hurt by falls from beds and sofas than they were from stair-related injuries.

For the study, the first to use a nationally representative sample to study bed and sofa-related injuries, researchers analyzed the U.S. Consumer Product Safety Commission National Electronic Injury Surveillance System data from 2007 through 2016. They found that an estimated 2.3 million children age 5 and younger were treated for soft furniture-related injuries during that time period, averaging

230,026 injuries per year.

Among other findings:

- Approximately 62 percent of children had injuries to the head and facial region. Fortunately, severe, life-threatening trauma was rare, but 2.7 percent of patients were hospitalized.
- Children younger than a year old when they were injured accounted for 28 percent of injuries among the patients, and they were more than twice as likely to be hospitalized than children over age 1.
- Boys (56 percent of cases) were more likely to be injured than girls.

In addition, bed and sofa-related injuries among children under age 5 increased by more than 16 percent during the study period, said Dr. Bradko, a Post-Doctoral Clinical Research Fellow in the Department of Orthopaedic Surgery at Texas Children's Hospital.

“With falls from beds and sofas hurting such a large and growing number of infants, toddlers and young children, there’s a serious need to step up prevention efforts,” he said. This includes reminding parents to constantly keep their eyes on young children when they’re on elevated surfaces, including soft furniture, for example. In addition, he said, the findings should prompt manufacturers to improve safety design and consider warning labels. For example, furniture manufacturers might advise consumers against allowing young children to be left unattended on beds without properly installed guard rails or allowing children to jump on or off furniture above a certain height.

David Liu, Baylor College of Medicine fourth-year medical student and an author on the paper, will present an abstract of the study, available below, between 5:10 and 6 p.m. in the convention center’s Plaza International Ballroom. To request

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an interview with Dr. Bradko or Dr. William Phillips, senior author and pediatric orthopaedic surgeon, journalists may contact Lindsey Fox at [lffox@texaschildrens.org](mailto:lffox@texaschildrens.org), 832-824-2040, or 713-269-2539 (cell).

In addition, Mr. Liu will be among highlighted abstract authors available during an informal Media Meet-and-Greet session Saturday, November 3, from 1 p.m. to 1:45 p.m. EST in room W208AB of the Orange County Convention Center (Press Office).

During the meeting, you may reach AAP media relations staff in the National Conference Press Room at 407-685-5404.

Please note: only the abstract is being presented at the meeting. In some cases, the researcher may have more data available to share with media, or may be preparing a longer article for submission to a journal.

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## Former NBA Star and Arizona Librarian Celebrate Breastfeeding and Animal Babies through Bilingual Children's Literature

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*Watercolor illustrations of animal families promote science education, bilingual learning, and healthy attitudes toward breastfeeding in new children's book*

Released: June 1, 2018

Platypus Media Washington, D.C., June 1, 2018: Platypus Media announces the release of a stunning bilingual children's book, *Babies Nurse / Así se alimentan los bebés*, by Phoenix author and elementary school librarian, Phoebe Fox. The author's father-in-law, former NBA star Jim Fox, created the vibrant watercolor illustrations to capture a child's attention and introduce the most natural and loving of activities—mothers nursing their young. In a May 2018 review, Kirkus praised the “the inherent gentleness and warmth” of the watercolor medium as “an ideal complement to the text.”

The rhythmic text and engaging facts provide parents, librarians, educators, and healthcare providers with new ways of sharing the importance of breastfeeding. The back matter extends the learning with pages of exciting animal facts and keywords. This book serves as a springboard to introduce natural science concepts such as habitats, biology, survival instincts, and classification.

The bilingual poetry can help readers develop literacy in English and Spanish. Nationally, nearly a quarter of U.S. students are Latinx, and this percentage is growing. The number of emerging bilingual children in the U.S. rose to roughly 12 million in 2016, an increase of 1.2 million over the past decade [Kids Count data].

The accompanying Teacher's Guide extends the book's effectiveness. Written by Paola Segnini, ESL teacher and La Leche League leader, the Guide includes additional content, vocabulary, hands-on activities, and games to develop cognitive skills, teach science concepts, and improve literacy. It is available for free download, in both English and Spanish, at [PlatypusMedia.com](http://PlatypusMedia.com).

José Avilés, Head of School at the dual-language Academia Antonia Alonso Charter School, says, “The bilingual narrative educates our children about love, care, and the bonds created between parents and their young across the mammal world.

I read this book to my five and six year old kids, and they were captivated by the tender message and beautiful images. I strongly recommend this book for parents and educators!”

Books like this build positive images around breastfeeding. Kristin Struble, M.D., FAAP, pediatrician and mother, explains, “This beautiful children's book magnificently demonstrates the natural and instinctual connection between a mother and her young. Breastfeeding is the first step in cultivating a healthy mind, gut, and spirit for both mommy and her little ones.”

*Babies Nurse / Así se alimentan los bebés* will be released simultaneously in hardback, paperback, and eBook. It will also be released in an English-only edition in October 2018.

*Babies Nurse / Así se alimentan los bebés* can be purchased in atwo-book set with another new release, *Cuddled and Carried / Consentido y cargado*. Together, these books about care and bonding create a foundation for healthy growth, introduce science topics, and encourage bilingualism. Both titles are part of Platypus Media's new Beginnings book collection.

Phoebe Fox wrote this book to show children the warmth and beauty of nursing. To ensure this book directly supports breastfeeding promotion, she arranged for a percentage of the profits to be donated to La Leche League, International. This is her third book. Fox lives in Phoenix, Arizona with her husband and their three sons. She can be reached at [PFox@PlatypusMedia.com](mailto:PFox@PlatypusMedia.com).

Jim Fox makes his artistic debut with *Babies Nurse / Así se alimentan los be-*

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bés. He is retired from the NBA, where he played for the Phoenix Suns, and now enjoys creating watercolor art. Father-in-law to Phoebe, and grandfather of five, Jim lives in Phoenix, Arizona. Contact Jim at [JFox@PlatypusMedia.com](mailto:JFox@PlatypusMedia.com).

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Contact: Anna Cohen  
Publicity Manager  
[Anna@PlatypusMedia.com](mailto:Anna@PlatypusMedia.com)  
Work: 202-546-1674 | Cell: 202-841-9946

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## Sucking Your Baby's Pacifier to Clean It May Prevent Allergies

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*Hispanic infants born with heart disease have worse outcomes in the first year than those born to white mothers.*

Released: 8-Nov-2018 8:00 AM EST

Source Newsroom: American College of Allergy, Asthma and Immunology (ACAAI)

Newswise — SEATTLE (November 16, 2018) – If the thought of sucking your baby's pacifier to clean it and then popping it in your baby's mouth grosses you out, think again. New research being presented at the American College of Allergy, Asthma and Immunology (ACAAI) Annual Scientific Meeting suggests a link between parental sucking on a pacifier and a lower allergic response

among young children.

"We interviewed 128 mothers of infants multiple times over a period of 18 months and asked how they cleaned their child's pacifier," says allergist Eliane Abou-Jaoude, MD, ACAAI member and lead author on the study conducted by Henry Ford Health System in Detroit. "We found the children of mothers who sucked on the pacifier had lower IgE levels." IgE is a type of antibody related to allergic responses in the body. Although there are exceptions, higher IgE levels indicate a higher risk of having allergies and allergic asthma."

Of the 128 mothers completing multiple interviews, 58 percent reported current pacifier use by their child. Of those who had a child using a pacifier, 41 percent reported cleaning by sterilization, 72 percent reported hand washing the pacifier, and 12 percent reported parental pacifier sucking.

"We found that parental pacifier sucking was linked to suppressed IgE levels beginning around 10 months, and continued through 18 months," says allergist Edward Zoratti, MD, ACAAI member and co-author of the study. "Further research is needed, but we believe the effect may be due to the transfer of health-promoting microbes from the parent's mouth. It is unclear whether the lower IgE production seen among these children continues into later years."

"We know that exposure to certain microorganisms early in life stimulates development of the immune system and may protect against allergic diseases later," says Dr. Abou-Jaoude. "Parental pacifier sucking may be an example of a way parents may transfer healthy microorganisms to their young children."

Abstract Titles: Association Between Pacifier Cleaning Methods and Child Total IgE

Author: Eliane Abou-Jaoude, MD

For more information about allergies and to locate an allergist in your area, visit [AllergyandAsthmaRelief.org](http://AllergyandAsthmaRelief.org). The ACAAI Annual Meeting is November 15-19, 2018 at the Washington State Convention Center in Seattle, WA. For more news and research from the ACAAI Scientific Meeting, go to our

newsroom - and follow the conversation on Twitter #ACAAI18.

About ACAAI

*The ACAAI is a professional medical organization of more than 6,000 allergists-immunologists and allied health professionals, headquartered in Arlington Heights, Ill. The College fosters a culture of collaboration and congeniality in which its members work together and with others toward the common goals of patient care, education, advocacy and research. ACAAI allergists are board-certified physicians trained to diagnose allergies and asthma, administer immunotherapy, and provide patients with the best treatment outcomes. For more information and to find relief, visit [AllergyandAsthmaRelief.org](http://AllergyandAsthmaRelief.org). Join us on Facebook, Pinterest and Twitter.*

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## Bohr scientists figure out how to measure electrical activity in a fetal heart

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Public Release: 2-Nov-2018

Source: FACULTY OF SCIENCE - UNIVERSITY OF COPENHAGEN

EurekAlert! -- Electrodes are placed on the patient's chest area to record cardiac electrical activity - e.g. to determine whether the heart rhythm is so irregular that treatment is required; a type of medical examination for which ECG serves well as a diagnostic tool.

Not quite so when it comes to examining fetal cardiac electrical activity - for the obvious reason that it is impossible to place electrodes on a fetus's chest area, which makes ECG a no-go in this context. Instead doctors will typically try to get an impression of the cardiac electrical activity by conducting an ultrasound scan;





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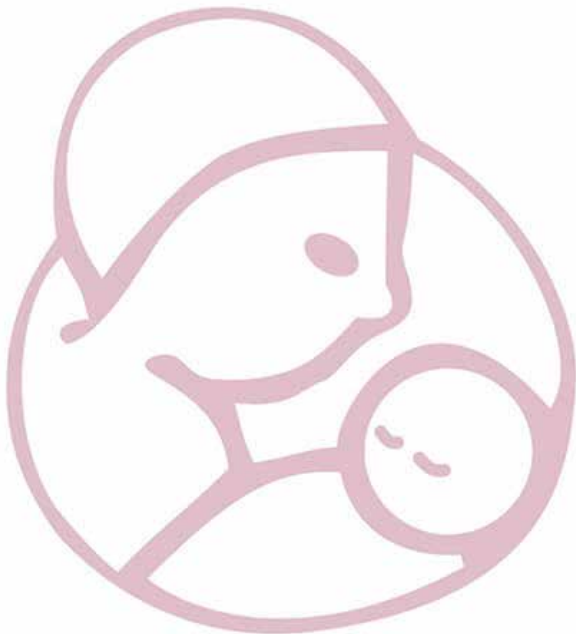
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which, however, will not provide precise answers as to what is wrong should the heart e.g. be beating too fast or too slow.

In a foreseeable future these problems regarding the examination of fetal cardiac electrical activity are about to be solved - thanks to the joint effort of two groups of scientists from University of Copenhagen: from Quantum Optics (Quantop) at the Niels Bohr Institute (NBI) and from Department of Biomedical Sciences, respectively.

In a research paper - which the two groups have just published in the journal *Scientific Reports*- they describe an experiment which demonstrates that it is indeed possible to get a detailed read-out of fetal cardiac electrical activity. That is, if you ally yourself with a cloud of caesium atoms locked up in a hermetically closed glass cell.

"Our next challenge will be to incorporate this technique in a diagnostic sensor - and that is doable", says assistant professor Kasper Jensen, Quantop.

Kasper Jensen and Professor Eugene Polzik, head of Quantop, have been in charge of the experiment as far as tests conducted via the locked up caesium atoms go. While Bo Hjorth Bentzen, associate professor at Department of Biomedical Sciences, has coordinated the biological part of the experiment - which includes the use of isolated guinea-pig hearts.

#### CLOUD OF ATOMS

The locked up cloud of caesium atoms is the cornerstone of a technique tailored for observations and measurements which Eugene Polzik and his team at Quantop have refined over a number of years - and applied to a number of tasks.

Put simply, the technique allows extremely precise observations and measurements at quantum level -if laser light at certain wavelengths are transmitted through the locked up atom cloud. One project, which

Quantop is currently involved in, thus aims at boosting the capacity of gravitational wave detectors through the 'cloud of atoms-principle'.

"The locked up caesium atoms are capable of detecting very small magnetic fields. That is the reason why we also started to study this technique as a possible way of measuring fetal cardiac electrical activity - through the pregnant woman's belly. And our experiments demonstrate that this is indeed possible - which we also conclude in our article in *Scientific Reports*", says Kasper Jensen.

#### GUINEA-PIG HEARTS

In order to conduct the experiments, the Quantop-scientists needed hearts which they could measure - and these hearts were provided by associate professor Bo Hjorth Bentzen and his team at Department of Biomedical Sciences.

They chose guinea-pig hearts which are similar in size to that of a human fetus at gestational age of approximately 20 weeks - and in a number of other respects also are well suited for this kind of experiments, says Bo Hjorth Bentzen, who specializes in heart rhythm analysis:

"Guinea-pigs have a heart rhythm fairly close to that of a human fetus - and a number of the proteins which regulate heart functions in guinea-pigs resemble the corresponding proteins in humans".

During the experiment the scientists at Department of Biomedical Sciences euthanized a total of six guinea-pigs - in accordance with protocols approved by the Danish Veterinary and Food Administration. The hearts were surgically removed from the animals, cooled down - and then transported to the Quantop-lab at NBI just a few hundred meters away.

At Quantop the hearts were gradually warmed up to body temperature - and subsequently placed in a Plexiglas chamber with a constant supply of oxygen and water in the form of a salty solution. This

environment made the guinea-pig hearts start beating - which they would typically do for the next three to four hours.

The equipment was placed behind a magnetic shield in order to keep all outside electromagnetic activity away - and while the heart was beating, the scientists measured the electrical activity from the organ through the Plexiglas wall.

By measuring in this fashion - at a distance of approximately one centimeter and without attaching electrodes to the heart - the Quantop-scientists mimicked a situation where fetal cardiac electrical activity is recorded via an instrument placed directly on top of the pregnant woman's belly.

In order to show that the equipment is capable of detecting electrical signals stemming from heart problems, the team of scientist from Department of Biomedical Sciences added a chemical to the salty solution that was continuously pumped into the Plexiglas chamber. This chemical changes the electrical signal in the heart - (triggering a reaction similar to what is seen in association with long QT syndrome, a hereditary heart condition) - which the system was also fully able to detect.

#### FUTURE TREATMENT

New equipment which can conduct ECG-examinations of fetuses based on the NBI-method could have a significant impact on future treatment, says Niels Vejlstrop, MD, Ph.d, and a specialist in treatment of fetal heart problems at Department of Cardiology at Rigshospitalet in Copenhagen:

"Such equipment could make a difference in relation to e.g. AV-block - a rare condition which blocks certain electrical pulses in the heart. AV-block can develop in a fetus if the mother suffers from lupus or Sjogren's disease - and if doctors suspect that a fetus is developing AV-block, they will start treating the mother medically in an attempt to protect the fetus. However,



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at present we only have one option when it comes to evaluate how severely damaged a fetus's heart conduction system actually is - namely doing an ultrasound scan. This method is encumbered with uncertainty - which is not the case when you conduct a direct measurement of fetal cardiac electrical activity", says Dr. Vejlstrop.

Rigshospitalet is keen on participating in clinical trials in order to develop the new method, says Niels Vejlstrop - adding that the method will be equally beneficial when it comes to diagnosing all other types of fetal heart rhythm disturbances.

#### AT ROOM TEMPERATURE

Around the world groups of scientists are developing advanced measuring-systems - in some cases based on superconductors or on the use of rubidium, a chemical element. These methods, however, require extreme temperatures - close to absolute zero at -273.15 C, or in the vicinity of +200 C.

"In both cases the temperature bars the technique from 'just' being incorporated in equipment designed to detect e.g. fetal heart rhythm. Our equipment, on the other hand, operates at room temperature - which is an advantage in this con-

text. We estimate that within three years doctors can start using our equipment to measure fetal cardiac electrical activity", says Kasper Jensen.

The principle behind the method will also be applicable to other forms of biological registrations and examinations, he says: "E.g. measuring brain activity when looking for signs of epilepsy".

###

Scientific publication: <https://www.nature.com/articles/s41598-018-34535-z>

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## Masimo Announces FDA Clearance for Masimo RD Sensors with Improved Accuracy Specifications for SET® Pulse Oximetry

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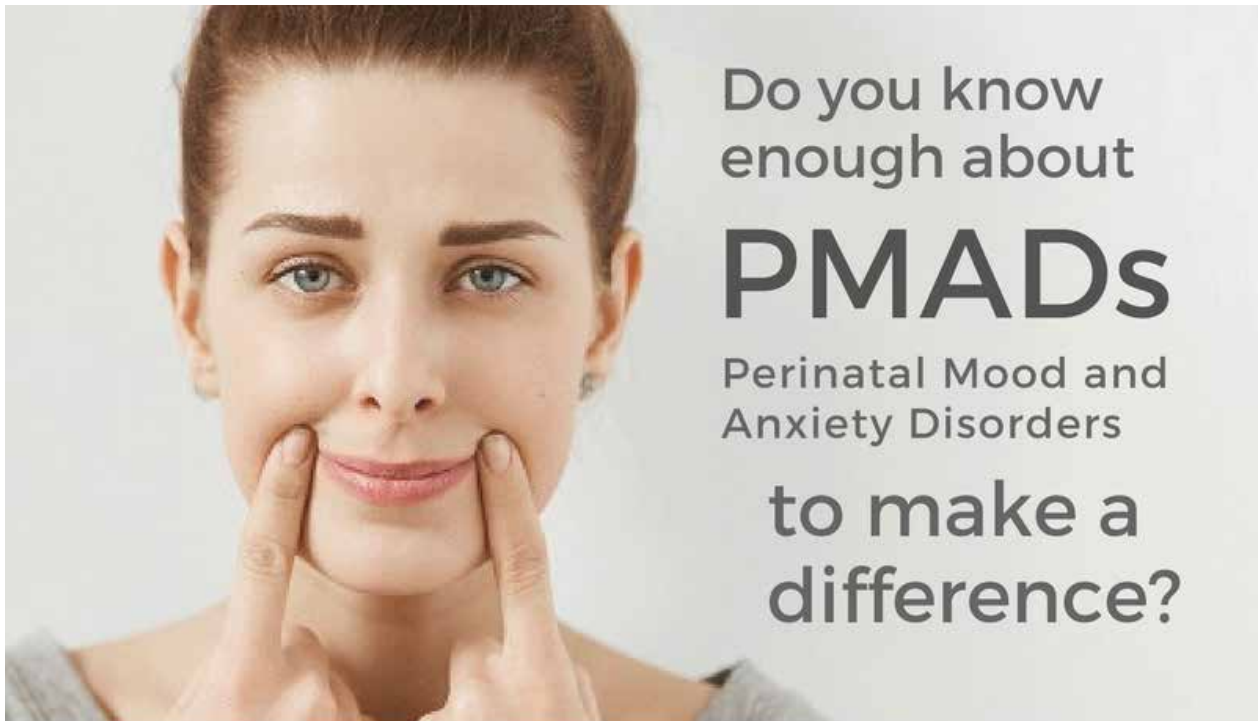
*Results from the UNC Early Brain Development Study, led at UNC by John Gilmore, MD, suggest that early detection and intervention could help children at risk for*

*emotional problems..*

Released: 9-Oct-2018 2:05 PM EDT  
Source Newsroom: University of North Carolina School of Medicine

Irvine, California – October 25, 2018 – Masimo (NASDAQ: MASI) announced today that RD SET™ sensors with Masimo Measure-through Motion and Low Perfusion™ SET® pulse oximetry have received FDA clearance with improved SpO2 accuracy specifications for all patients > 3 kg. RD SET single-patient-use sensors with the improved accuracy specifications are now available. The new RD SET sensors' SpO2 accuracy specifications during patient motion have improved for adult, pediatric, and infant patients to 1.5% (at 1 SD), compared to previous accuracy specifications of 3%.

In addition to offering improved accuracy, RD SET sensors are designed to enhance patient comfort, optimize clinician workflows, and help hospitals meet green initiatives. The sensors are lightweight and have a flat, soft cable with smooth edges, so that they lie comfortably on a patient's hand or foot. The sensors feature an intuitive sensor-to-cable connection. Their lightweight design results in up to 84% less waste, and their sleek, re-



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The clinical benefits of Masimo's revolutionary SET® pulse oximetry have been demonstrated in a variety of clinical conditions. Studies have shown:

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- Masimo SET® enabled pulse oximetry screening for critical congenital heart disease (CCHD), helping save many full-term newborns' lives whose disease would otherwise have gone undiagnosed. (2-4)
- With Masimo SET® on post-surgical wards, rescue calls and ICU transfers were reduced by 65% and 48%, respectively. (5) Post-operative continuous surveillance monitoring, combined with Masimo SET®, led to zero preventable deaths or brain damage due to opioids over five years. (6)

Joe Kiani, Founder and CEO of Ma-

simo, said, "We're delighted to be able to announce our continued innovation in our foundational SET® pulse oximetry. Thanks to the brilliance and dedication of our engineers and the continuing support of our customers, we've been able to once again raise the standard for pulse oximetry performance. Even though no one has been able to create pulse oximetry that outperforms SET®, we have not allowed that to stop us from continuing our pursuit of perfecting the technology. We have significantly improved our accuracy during motion and this is just the start of further improvements in what clinicians can expect from pulse oximetry." In addition to excellent accuracy and reliability, the SET® platform with rainbow® is also the only oximetry technology that also allows clinicians to measure physiological parameters such as total hemoglobin, carboxyhemoglobin, methemoglobin, and PVi®.

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**SYMPOSIUM ON GENE THERAPY IN MODERN MEDICINE:  
GLOBAL AND LOCAL ADVANCES**

**THURSDAY, NOVEMBER 29, 2018 NOON–2:00PM  
11175 CAMPUS STREET, LOMA LINDA, CA  
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**INTRODUCTION TO LOMA LINDA HEMATOLOGY**

**Loma Linda University**



Presented by:

**Akshat Jain, M.D. , M.P.H.**

Assistant Professor of Pediatrics  
& Clinical Medicine  
Pediatric Hematology-Oncology  
LLUCH

12:00 p.m. – 12:20 p.m.

**Emory University**



Presented by:

**Chris Doering, PhD.**

Associate Professor  
Division of Hematology/Oncology  
Department of Pediatrics  
Emory University School of Medicine  
Atlanta, GA

12:20 p.m. – 1:00 p.m.

**Christian Medical College**



Presented by:

**Alok Srivastava, M.D.**

Professor of Medicine  
Department of Haematology  
Head, Centre for Stem Cell Research  
Christian Medical College  
Vellore 632004, Tamil Nadu, India

1:00 p.m. – 1:40 p.m.

## PEDIATRIC *Grand Rounds*

# Adventures in Child Health 2018: an update from the American Academy of Pediatrics

Presented by:



**Colleen A. Kraft, MD, MBA, FAAP**  
President of the American Academy of Pediatrics

**Friday, November 30, 2018**  
**8:00 - 9:00a.m.**  
**MC Lobby-Level Amphitheater**

**Objectives:** To Recognize emerging political, economic, and environmental factors affecting child health in 2018; to identify the priorities of the American Academy of Pediatrics in the Agenda for Children, and how this agenda addresses child health, to commit to at least one advocacy activity in the next six months.

The Loma Linda University School of Medicine is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians. The Loma Linda University School of Medicine designates this Live Activity for a maximum of 1 AMA PRA Category 1 Credit(s)<sup>™</sup>. Physicians should claim only the credit commensurate with the extent of their participation in the activity. **Disclosure** This program has been planned and implemented in accordance with ACCME essentials and standards. The Loma Linda University School of Medicine Office of Continuing Medical Education relies on its CME faculty to provide program content that is free of commercial bias. Therefore, in accordance with ACCME standards, any faculty and/or provider industry relationships will be disclosed and resolved.

**Statement of Purpose or Overall Objective** - This program is designed to provide current, concise information on patient safety and risk management that is relevant to physicians and other health care providers in all specialties. The attendee will be informed of practices that will improve patient safety and enhance risk management skills. In addition, a short lecture on stress will provide an overview on the importance of the nature of psychological stress and will describe the mechanisms that link stress with disease and appropriate interventions.



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Department of Pediatrics

Please RSVP. Breakfast will be served at 7:30 am. The presentation will begin promptly at 8:00 am, please arrive early if you wish to have breakfast.

Nathy Delgado  
Administrative Assistant,  
Loma Linda University Health | Department of Pediatrics  
Coleman Pavilion, A1109| 11175 Campus Street - Loma Linda 92354  
Ext 44130 | Phone (909) 558-4130 | Fax (909) 558-0408 | [nadelgado@llu.edu](mailto:nadelgado@llu.edu)

# 36<sup>th</sup> Annual Advances in Therapeutics and Technology: Critical Care of Neonates, Children, and Adults

March 26 to March 30, 2019  
The Cliff Lodge - Snowbird, Utah

**Registration:** <http://paclac.org/advances-in-care-conference/>

## Topics and Speakers Include:

**Rashmin Savant, MD** BPD New Concepts in Pathogenesis and Prevention

**Cynthia Blanco, MD** Metabolic Disturbances of Prematurity When How and Who to Treat

**Sinjo Hirose, MD** Fetal Surgery

**Arun Pramanick, MD** Game Changers in Neonatal-Perinatal Medicine- A View Through a Retroscope

**Don Null** Persistent Pulmonary Hypertension in the Preterm Newborn Etiologies and Cardiopulmonary Management

**Marty Keszler, MD** New Modalities in High Frequency Ventilation

**Mitchell Goldstein, MD** Rediscovering the Denominator

**Steve Derdak, DO** Pediatric Origins of Adult Disease



## Conference Description

This conference will present high quality education to advance pediatric health and well-being through collaboration, communication and education on the discovery and development of therapeutics and technology and their successful translation into practice. The conference aims to improve communication and relationships within industry, academia and government agencies as well as educate on the discovery, development, and implementation processes. Networking opportunities for healthcare professionals who provide care for patients with a focus on advances in therapeutics and technology will be provided. Along with featured speakers, the conference includes abstract presentations on research.

## Special Panel Discussion

Avoiding the Conflict, Working to Develop Better Relations with Industry. Don Null, MD and Mitchell Goldstein, MD.

**Special Lecture: President of AAP, Colleen Kraft, MD**

## Continuing Education Credit

The Perinatal Advisory Council: Leadership, Advocacy, And Consultation is providing physician, nursing, and respiratory continuing education units.



*Thank you to our exhibitors!*





# Bringing a Web Community to an Offline Conference

Francesco Cardona, MD, MSc and Stefan Johansson, MD, PhD



WA warm welcome from me as well. I will be alternating with Stefan Johansson to write this column and share some of the activity going on in the 99nicu community of neonatal professionals. If you missed our first column last month, you can check it out in the October issue of Neonatology Today (<https://www.neonatologytoday.net/newsletters/nt-oct18.pdf>).

I would like to focus this month's column on our offline activity, i.e., our annual conferences. While the online discussion forum was attracting people from all over the world, we got curious how it would be to meet up offline. Despite the power of the Internet to bring people together, would it not be attractive to speak in person about differences in treating patients in various corners of the world and learn from each other face-to-face?

Before our first meeting in Stockholm 2017, we discussed in depth the best way to convert online presence to offline activity. The first strategy was to tap into the "wisdom of the crowds," i.e., to crowd-source our topics by simply asking our members what they wanted. And that strategy turned out to be successful. Around two-thirds of our topics in our final program came from the community. The second step was to find speakers that could lecture on the identified topics. We thought this would be challenging as we could not offer much. But in fact, most of the well-regarded experts we approached were eager to come. In hindsight, I believe that Faculty members were also attracted by the idea to limit lecture time (maximum of 30 minutes) and allow ample time for discussions (at least 15 minutes). To further enhance interactivity and discussion, we also wanted to make it easy for asking questions. So, we found a smartphone app (<https://sli.do>) that allowed everyone to ask questions.

***"To further enhance interactivity and discussion, we also wanted to make it easy for asking questions. So, we found a smartphone app (<https://sli.do>) that allowed everyone to ask questions."***

Our first conference in Stockholm 2017 was located in a simple hospital lecture hall, at Soderjukhuset in Stockholm. Our budget got terribly tight, and we were forced to cut down on most

administrative support, which meant that I and Stefan Johansson did a lot of work the week before the meeting. Even printing and cutting out lunch coupons for the hospital canteen... Not too many consultant neonatologists have that experience. 😊

But the conference was a success. The 23 speakers had excellent and short lectures on a range of neonatal topics for our 60 delegates. The thorough discussions kept going in a small-scale and familial atmosphere.

Given the feedback from speakers and delegates, we felt obliged and excited to plan for a 2nd conference, in my hometown of Vienna. Our strategy was the same, i.e., crowd-sourcing of topics first, and then identify potential speakers. In April 2018, we gathered in total 125 people, 25 Faculty members and 100 delegates from 33 countries. And once again, feedback was exceptionally good. Like "This was one of the best neonatology meetings I have ever visited!!!!"

***"If you are interested to meet up with us in Copenhagen, visit the conference web site on <https://99nicu.org/meetup>"***

We are now finalizing plans for the 3<sup>rd</sup> 99nicu Conference, in Copenhagen 7-10 April 2019. Similar to our previous two conferences, the program is focused on topics with high clinical relevance. When it comes to content, our strategy is to promote evidence-based medicine. But we also want to tune topics into take-home-messages of practical knowledge. How to improve diagnostics and management of common neonatal diseases in the NICUs. The program will include lectures and workshops on a variety of topics, for example, blood transfusions, treating pain, feeding strategies, CPAP weaning, NEC prevention, use of inotropes and echocardiography.

If you are interested to meet up with us in Copenhagen, visit the conference web site on <https://99nicu.org/meetup>

Hope to see you there!

A handwritten signature in black ink, appearing to read "F Cardona".

Francesco, Cardona, MD, MSc

*The authors indicate that they have no disclosures*

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## Family Centered Care is trendy, but are providers really meeting parents needs in the NICU?

Consider the following:

Surveys show hospital support groups are being widely underutilized by parents.



And only 10% of NICUs surveyed connect parents with non-hospital support.

**Graham's Foundation**, the global support organization for parents going through the journey of prematurity, set out to find the missing piece that would ensure all parents have real access to the support they need.

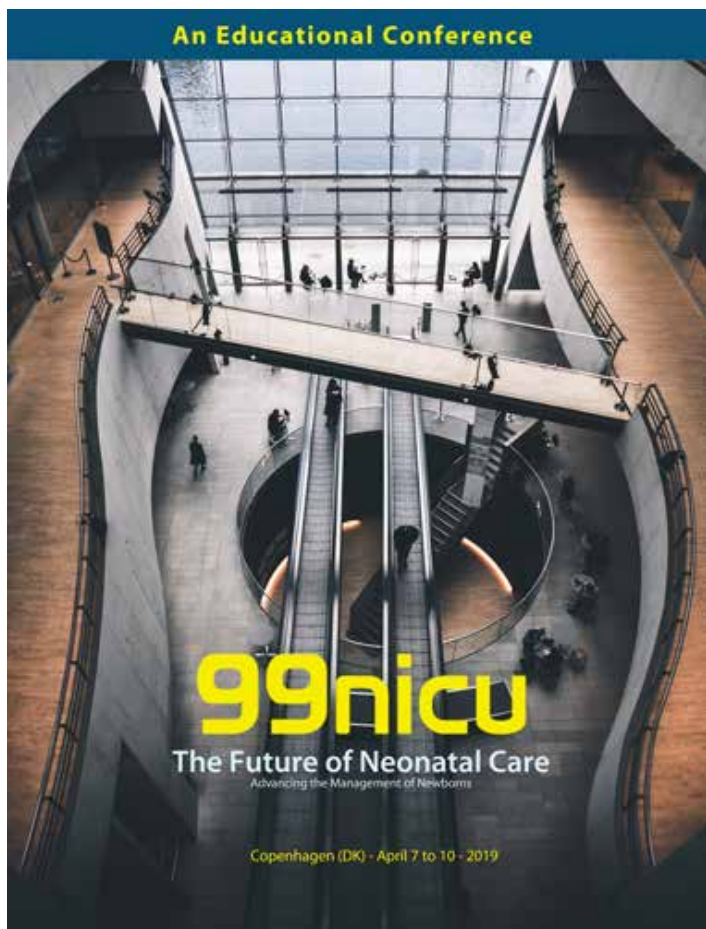
See what they found by emailing [info@grahamsfoundation.org](mailto:info@grahamsfoundation.org) to request a free copy of the 2017 whitepaper, "Reaching Premie Parents Today" (Heather McKinnis, Director, Premie Parent Mentor Program, Graham's Foundation).

You may be surprised to see what NICUs are doing right and where their efforts are clearly falling short.

Graham's Foundation empowers parents of premature babies through support, advocacy and research to improve outcomes for their preemies and themselves.



Visit [www.GrahamsFoundation.org](http://www.GrahamsFoundation.org) to learn more.





# National Perinatal Association NICU AWARENESS MONTH

[nationalperinatal.org/NICU\\_Awareness](http://nationalperinatal.org/NICU_Awareness)



NICUs exemplify interdisciplinary collaboration.

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- nurse practitioners
- nutritionists
- psychologists
- neonatal therapists
- perinatologists
- social workers
- respiratory therapists
- lactation consultants
- nurses
- psychologists
- pharmacists
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# A genetics consultation for multiple congenital dislocations

Robin Clark, MD and Subhadra Ramanathan, M.Sc., M.S.

## Case History:

This six-day-old term SGA female was born to a 22-year-old G2P0->1TA b1 mother by primary C-section because of breech presentation. During the pregnancy, the mother was treated with Keppra for seizures. She smoked cigarettes ½ ppd. Malpresentation (frank breech) was noted on fetal ultrasound, but the discussion of its significance with parents was limited to its impact on mode of delivery. Apgar scores were 4 at one, 7 at five, and 8 at ten minutes of age. BW was 2575 g (6th percentile), BL 45.5 cm (2nd percentile) and HC 34 cm (54th percentile). At birth, she was diagnosed with bilateral hip dysplasia and genu recurvatum. She was transferred to a tertiary care NICU on the second day of life for micrognathia, poor feeding, stridor, and difficulty swallowing. She passed the newborn hearing screen. An ultrasound of the hips showed hip dysplasia and bilateral hip dislocations. X-rays confirmed anterior subluxation of the tibia and fibula compared to the femur bilaterally.

The family history was significant for joint problems in the father and his relatives, although their phenotype was considered to be normal in their family. The patient's father was 26-years old and 6' 6" in height. He was diagnosed with spastic cerebral palsy at age 7. He had bilateral club feet and multiple joint dislocations in childhood including the shoulder, wrist, and fingers. A diagnosis of Marfan syndrome had also been considered. Two of his three maternal half-sisters had joint problems and dislocations, and one of them had a son with bilateral club feet. The paternal grandmother, her brother, his son and his granddaughter had strikingly similar facial features that were also shared by the father and the baby.

In the newborn period, the head was scaphocephalic with an occipital shelf ("breech head"). The forehead was broad with frontal bossing. The profile was flat with a short nose, a pinched nasal tip, and micrognathia. The palate was intact and normally vaulted. The knees were hyperextended and could not be flexed. Elbows could not be fully extended. Fingers and toes were long but otherwise normal. The hips were fixed in flexion and could not be adducted or abducted. When the infant returned to the outpatient Genetics clinic for a follow-up evaluation at seven months of age, her bilateral genu recurvatum was being treated with serial casting, and hip surgery was planned for bilateral dysplasia.

## Consultant's report:

This infant has facial features, congenital dislocations and a compatible family history typical for Larsen syndrome (MIM 150250). This syndrome is usually inherited as an autosomal dominant connective tissue disorder, caused by a heterozygous variant in FLNB located at chromosome 3p14.

***"This syndrome is usually inherited as an autosomal dominant connective tissue disorder, caused by a heterozygous variant in FLNB located at chromosome 3p14"***

Larsen syndrome can present in the newborn with congenital dislocations of large joints (hips, knees and elbows), scoliosis, cervical kyphosis (posing a risk for cervical myelopathy), club feet, spatulate distal fingers with short nails, and characteristic hyper-

telorism, depressed nasal bridge, flat midface, and a prominent forehead. Some affected patients have short stature, cleft palate, hearing loss.

Genetic testing in the infant revealed a pathogenic missense variant in FLNB (c.679G>A, p.Glu227Lys) that confirmed the diagnosis of Larsen syndrome. Her father was examined, and he shares similar facial features and joint problems consistent with Larsen syndrome. He is undergoing targeted genetic testing for this variant. Making this diagnosis in the newborn period, allowed a more aggressive approach to treatment because treatment for hip dysplasia is surgical in most children with Larsen syndrome. In the face of this information, the father's previous diagnosis of spastic cerebral palsy was revised.



*Photo 1: Note the frontal bossing, flat profile, hip flexion and genu recurvatum in this female infant with Larsen syndrome.*

FLNB encodes filamin B, an actin-binding cytoplasmic protein that crosslinks F-actin networks to cellular membranes. This network is a component of connective tissue that is expressed primarily in epiphyseal growth plate chondrocytes. Larsen syndrome, which is caused by gain-of-function missense variants or small in-frame deletions in FLNB, is on the mild end of a spectrum of disorders caused by pathogenic variants in this gene. Depending on the type of variant and the functional domain that is affected, heterozygous pathogenic variants in FLNB can cause isolated talipes equinovarus, scoliosis, joint dislocation and the relatively mild spondylarcarpotarsal syndrome (caused by loss-of-function mutations), a skeletal dysplasia associated with 46,XY gonadal dysgenesis (caused by biallelic mutations in FLNB), or the more severe and lethal skeletal dysplasias: atelosteogenesis, types I and

III, and boomerang dysplasia. The latter is a lethal short-limbed dwarfing condition in which the vertebrae and long bones have diminished or absent ossification, and tubular long bones have a “boomerang” shape.



Photo 2: These dysmorphic facial features were also seen in the father of this baby with Larsen syndrome: hypertelorism, depressed nasal bridge, pinched nasal tip, and a prominent forehead.

Although heterozygous *FLNB* mutations cause most cases of Larsen syndrome, other genes have been implicated in autosomal recessive forms of this disorder. Biallelic mutations in *CHST3*, *B4GALT7*, and *GZF1* have been recently described.

---

***“Although heterozygous *FLNB* mutations cause most cases of Larsen syndrome, other genes have been implicated in autosomal recessive forms of this disorder.”***

---

Practical applications:

1. Examine infants who deliver in the breech presentation for signs of joint dislocation and connective tissue disorders.
2. Take a detailed family history. The expected hereditary pattern of transmission of a genetic disorder may be masked

by misdiagnosis (“cerebral palsy” is a notoriously heterogeneous term) or mischaracterization of a feature as a normal trait (in this case, the flat facial profile) by family members. Ask to see photos of other family members.

3. Consider the diagnosis of Larsen syndrome in infants with genu recurvatum or other congenital dislocations.

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The author has no relevant disclosures.

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# How to Care for a Baby with NAS



## Use the Right Words

I was exposed to substances in utero. I am not an addict. And my mother may or may not have a Substance Use Disorder (SUD).



## Treat Us as a Dyad

Mothers and babies need each other. Help my mom and me bond. Whenever possible, provide my care alongside her and teach her how to meet my needs.



## Support Rooming-In

Babies like me do best in a calm, quiet, dimly-lit room where we can be close to our caregivers.



## Promote Kangaroo Care

Skin-to-skin care helps me stabilize and self-regulate. It helps relieve the autonomic symptoms associated with withdrawal and promotes bonding.



## Try Non-Pharmacological Care

Help me self-soothe. Swaddle me snugly in a flexed position that reminds me of the womb. Offer me a pacifier to suck on. Protect my sleep by "clustering" my care.



## Support Breastfeeding

Breast milk is important to my gastrointestinal health and breastfeeding is recommended when moms are HIV-negative and receiving medically-supervised care. Help my mother reach her pumping and breastfeeding goals.



## Treat My Symptoms

If I am experiencing withdrawal symptoms that make it hard for me to eat, sleep, and be soothed, create a care plan to help me wean comfortably.

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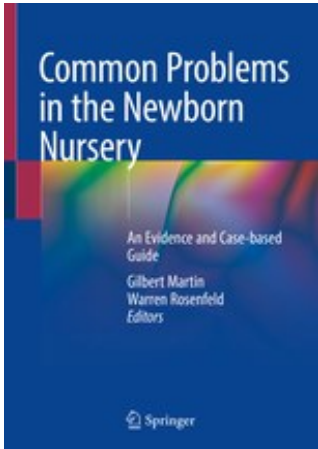
Learn more about Neonatal Abstinence Syndrome at [www.nationalperinatal.org](http://www.nationalperinatal.org)





Editors: **Martin, Gilbert, Rosenfeld, Warren** (Eds.)

## **Common Problems in the Newborn Nursery An Evidence and Case-based Guide**



- **Provides practical, state of the art management guidance for common clinical problems in the newborn nursery**
- **Written by experts in the field in a clear, easy-to-use format**
- **Utilizes a case-based approach**

This comprehensive book thoroughly addresses common clinical challenges in newborns, providing an evidence-based, step-by-step approach for their diagnosis and management. *Common Problems in the Newborn Nursery* is an easy-to-use, practical guide, covering a full range of clinical dilemmas: bacterial and viral infections, jaundice, hypoglycemia, hypotonia, nursery arrhythmia, developmental dysplasia of the hips, newborn feeding, cardiac problems, late preterm infants, dermatology, anemia, birth injuries, ocular issues, and hearing assessments in the newborn.

Written by experts in their fields, each chapter begins with a clinical case presentation, followed by a discussion of potential treatment and management decisions and various differential diagnosis. Correct responses will then be explained and supported by evidence-based literature, teaching readers how to make decisions concerning diagnosis encountered on a daily basis.

While this guide is directed towards health care providers such as pediatricians, primary care physicians, and nurse practitioners who treat newborns, this book will also serve as a useful resource for anyone interested in working with this vulnerable patient population, from nursing and medical students, to nurses and residents in pediatrics or family practice.

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# The Fourth Annual Infant Health Policy Summit in Washington, D.C.

Susan Hepworth



*The National Coalition for Infant Health is a collaborative of more than 180 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.*

Advocates cannot reach every infant or every family, acknowledged National Coalition for Infant Health Medical Director Mitchell Goldstein, MD, as he welcomed attendees to the fourth annual infant health policy summit on Thursday. But, he emphasized, “We can impact policy.”

***“The day long event brought together health care providers, parents, advocates and congressional staff in Washington, DC, to consider how policy can address the challenges facing infants and their families.”***



Photo 1: Dr. Mitchell Goldstein welcomes attendees to the conference

The day long event brought together health care providers, parents, advocates and congressional staff in Washington, DC, to consider how policy can address the challenges facing infants and their families. But as the day's discussion made evident, those challenges can be staggering.

## Congenital Heart Disease

Congenital heart disease, for instance, loomed large during the summit. Katie Mooshian of Mended Little Hearts described her son Charlie's experience with single-ventricle physiology, whereby only one of the heart's two ventricles pumps blood as it should.



Photo 2: Katie Mooshian of Mended Little Hearts describes her son Charlie's experience with critical congenital heart disease.

Of Charlie's birth, Mooshian recalled, “I handed over a vulnerable, tiny infant to have his heart stopped, to be put on bypass, and hopefully to be given back to me.” Katie's son Charlie ultimately survived multiple surgeries. Meeting the challenges of congenital heart disease, Mooshian emphasized, requires providing infants and their families with “continued support, advocacy, and intervention.”

Beyond those measures, another factor plays an important role in the lives of infants with congenital heart disease: nutrition. In a panel discussion, Jodi Lemacks of Mended Little Hearts described struggling to breastfeed her infant son Joshua, who was born with congenital heart disease. “Feeding your child is the one way you know your child's going to be nourished, that your child's going to



Photo 3: Amanda Conschaffer, David Rechtman, MD and Jodi Lemacks of Mended Little Hearts describes the challenges of breastfeeding a child with CHD



survive,” Lemacks explained. Ultimately, Lemacks noted, breast-milk helped Joshua gain weight and boost his immunity.

Clinical research is underway to more closely examine the benefits of human milk for infants like Joshua.

David Rechtman, MD, of Prolacta Bioscience explained that human milk – whether breastmilk, donor milk or human milk-based fortifier – has been shown to help protect premature infants from deadly intestinal conditions. Now researchers hope to confirm that human milk also provides benefits for infants born with congenital heart disease. “If you give them more calories and more protein, they’re going to grow better,” Dr. Rechtman noted.

### Respiratory Syncytial Virus

Another struggle also generated vigorous discussion: Respiratory syncytial virus, or RSV. Suzanne Staebler, DNP, of Emory University presented results from the National Coalition for Infant Health’s national survey on awareness of RSV. The virus is the leading cause of hospitalization in children under one year of age. The survey revealed that parents have high levels of concern about RSV but feel unprepared to protect their young children. Specialty health care providers such as neonatologists and NICU nurses, meanwhile, reported seeing RSV cases regularly and proactively monitoring patients for the disease.



Photo 4: Suzanne Staebler, DNP, of Emory University presents results from the National Coalition for Infant Health’s national survey on awareness of RSV.

Blogger and former television news anchor Shanisty Ireland brought that research to life by describing her own family’s battle with the disease in a panel discussion on RSV. Ireland recalled taking her son Adam to the hospital after he exhibited signs of distress, explaining, “I still didn’t know how close he was to dying.”

---

**“Palivizumab reduces RSV infections by at least 55 percent — Yet inadequate insurance coverage prohibits as many as three-quarters of infants who need it from receiving the indicated dosing.”**

---

“I asked people, ‘Pray for him. He has RSV,’” Ireland recalled, adding, “Not a single person had ever heard of it.”

Neonatologist Mitchell Goldstein, MD, acknowledged widespread misinformation about the potential severity of the disease. Ireland recalled thinking of it as something akin to the common cold. “For some babies,” Dr. Goldstein explained, “it’s a whole lot more.”



Photo 5: Mitchell Goldstein, MD, Shanisty Ireland and Brian Kennedy of AfPA participate in a frank discussion on the risks of RSV.

The experience turned Ireland into an advocate. “RSV had a hold on my baby,” Ireland explained, “but now I feel like I have a hold on RSV.”



Photo 6: Stephen Bowen, former NFL player, and his wife Tiffany Bowen, PhD discuss losing their premature infant son with Susan Hepworth.

### Support for Families

Ireland was not the only event speaker who turned adversity into advocacy.

---

**“The nonprofit aids unprepared families in paying for the funerals of premature infants who do not survive.”**

---

Keynote speakers Stephen Bowen, former NFL player, and his wife Tiffany Bowen, Ph.D., lost their premature infant son Skyler to intestinal infection just days after his birth at 24 weeks. In the face of overwhelming grief, the couple persevered – “staying strong”



for Skyler's surviving twin brother and the couple's older daughter.

Stephen's strength under stress led him to receive the Ed Block Courage Award. Tiffany earned her doctorate and came through post-traumatic stress disorder to create Skyler's Gift Foundation along with her husband. The nonprofit aids unprepared families in paying for the funerals of premature infants who do not survive. The organization also provides funding for those families' grief counseling.

In recalling the loss of young Stephen, the couple reflected upon the worry and grief they felt – but also the dedication of their sons' health care providers. "People who work in the NICU "are heroes," Tiffany emphasized.

### NICU Safety

Those heroes face challenges of their own. Just consider the issue of hospital tubing. Addressing the summit audience, Rebekah Thacker, MSN, of the University of Arkansas Medical Center described concerns about the use of tubing connectors known as ENFit in NICUs. As described in a 2017 video from the National Coalition for Infant Health, liquid can "hide" in the reservoir at the tip of the connector – potentially dosing tiny infants with more medication than intended.

Thacker described her efforts to push back against industry's drive for ENFit adoption. "Nobody knows the neonatal population like a neonatal nurse," Thacker insisted.

### "Still a Premie"

And that population is broader than one might expect. The National Coalition for Infant Health released at the summit a new video emphasizing the full spectrum of prematurity. "Still a Premie," explains that preemies do not always conform to stereotype. Late-preterm infants born from 34 through 36 weeks' gestation, or those who are born premature but at a "normal" birthweight, can still struggle with feeding issues, jaundice, respiratory conditions, and developmental delays. And their parents can feel the effects too.



Photo 7: Kelli Kelly of Hand to Hold discusses the need for support for parents of premature babies.

Just ask Kelli Kelly of the parent's support organization Hand to Hold. When Kelly's daughter Lauren was born at 34 weeks, she "looked good, looked healthy" Kelly recalled in an address to summit attendees. But the appearance was deceiving. Lauren required NICU care, so Kelly left the hospital "with empty arms." She recalled waking during the nights to pump breastmilk for her daughter, whose developmental challenges made it impossible to

breastfeed. Kelly suffered emotionally. "It's hard to bond with a baby that's in a glass box," she recalled.

Meanwhile, medical bills rolled in. Because of baby Lauren's size, she did not qualify for Medicaid coverage.

Several organizations are working to improve conditions for families like Kelly's. The Association of Women's Health, Obstetric and Neonatal Nurses has developed evidence-based clinical practice guidelines for late preterm infants. Meanwhile, the National Perinatal Association has published a similar document that also reaches parents, social workers, therapists, and lactation consultants, among others.



Photo 8: Susan Hepworth, Raylene Philips, MD and Sue Ludwig discuss the challenges of being born late-preterm.

In a discussion moderated by Sue Ludwig of the National Association of Neonatal Therapists, the group explored the challenges of infants born late-preterm. "Every organ in the body is premature," emphasized Raylene Philips, MD, of the National Perinatal Association.

Jean Salera-Vieira, MS, of the Association of Women's Health, Obstetric and Neonatal Nurses, noted the importance of support for these infants' parents. Nurseries for infants born after 32 weeks' gestation "don't have same level of parent support that a NICU might," she explained.



Photo 9: Staff representing the bill's authors, Senator Lamar Alexander (R-Tenn.) and Senator Michael Bennet (D-Colo.) discuss congressional action with Susan Hepworth.

## Congressional Action

Another opportunity for policy change lies with Congress' PREEMIE Reauthorization Act of 2018. Staff representing the bill's authors, Senator Lamar Alexander (R-Tenn.) and Senator Michael Bennet (D-Colo.), explained that the bill would reauthorize pivotal Centers for Disease Control and Prevention research on preterm births. The bill also includes screening measures and services for pregnancy depression and substance abuse treatment.

Introduced earlier this year, the PREEMIE Reauthorization Act passed the full Senate over the summer. Rep. Anna Eshoo (D-Calif.) and Rep. Leonard Lance (R-NJ) are working to advance the bill in the House of Representatives.

See more photos and social media highlights from the day at the National Coalition for Infant Health's [Facebook page](#).

*The author has no relevant disclosures.*

**NT**



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## 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
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# Medicolegal Forum: Pennsylvania Supreme Court Ruling on Who is Required to Obtain Informed Consent

Jonathan Fanaroff, MD, JD and Gilbert Martin, MD

## Abstract:

*A 28-week preemie in respiratory failure on an oscillator is tachycardic and has an increasing oxygen requirement. The CBC results with a hematocrit of 23 and the neonatologist and neonatal nurse practitioner agree a blood transfusion is indicated. The neonatal nurse practitioner, who has twenty-five years' experience, goes to obtain informed consent for the transfusion from the parents....a practice that may not be legal in Pennsylvania after a Pennsylvania Supreme Court ruling.*

Neonatologists are used to evaluating the medical literature and incorporating the principles of evidence-based medicine into their practice. As physiology doesn't change, the relevance of clinical trials is sustained across state lines and even across borders. Laws, on the other hand, vary considerably from state to state, which is important to clinicians as medicine is primarily regulated at the state level. Court cases are often decided based on specific facts and indeed may vary based on the particular judge or jury involved in the matter. Additionally, decisions by state courts will only apply to their particular state. However, since courts in other states may be persuaded by rulings from other states it is advisable to be aware of significant legal rulings even when they occur in a different state.

One such ruling was delivered by the Pennsylvania Supreme Court on June 20, 2017, in the case of *Shinal v. Toms*. Megan Shinal was diagnosed with a recurrent non-malignant tumor near the pituitary region of her brain. She had an initial meeting with the neurosurgeon Dr. Toms about removing the tumor, but written consent was obtained at a subsequent visit by a physician assistant. Unfortunately, during the operation, Dr. Toms perforated Mrs. Shinal's carotid artery, resulting in a number of complications. Mrs. Shinal and her husband filed a malpractice lawsuit against Dr. Toms for failure to obtain informed consent for the surgery.

The case went to trial, and the jury found in favor of Dr. Toms after being told that information conveyed by physicians assistants could satisfy informed consent requirements. The verdict, however, was reversed by the Pennsylvania Supreme Court, which ruled that "a physician may not delegate to others his or her obligation to provide sufficient information in order to obtain a patient's informed consent."

***"The verdict, however, was reversed by the Pennsylvania Supreme Court, which ruled that 'a physician may not delegate to others his or her obligation to provide sufficient information in order to obtain a patient's informed consent.'"***

Complex medical environments such as the Neonatal Intensive Care Unit (NICU) rely on teamwork to provide the best care for babies and their families. Nurses, Neonatal Nurse Practitioners, Residents and Fellows generally have the training and skill to participate in the consent process. The *Shinal* decision, however, does not allow the neonatologist to delegate the informed consent process. As a decision of the Pennsylvania Supreme Court, the

highest court in the state, this is the law today in Pennsylvania and is unlikely to change for the foreseeable future. Courts in other states may or may not elect to adopt similar rules, but it may be prudent for neonatologists in all states to review all aspects of the informed consent process.

## References:

1. *Shinal v. Toms*, 162 A.3d 429 (Pa. 2017)

The authors have no conflicts of interests to disclose.

**NT**

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## New Moms Need Access to Screening & Treatment for POSTPARTUM DEPRESSION



**1 IN 7 MOMS FACE POSTPARTUM DEPRESSION, experiencing**



Yet only 15% receive treatment<sup>1</sup>

### UNTREATED POSTPARTUM DEPRESSION CAN IMPACT:



### TO HELP MOTHERS FACING POSTPARTUM DEPRESSION



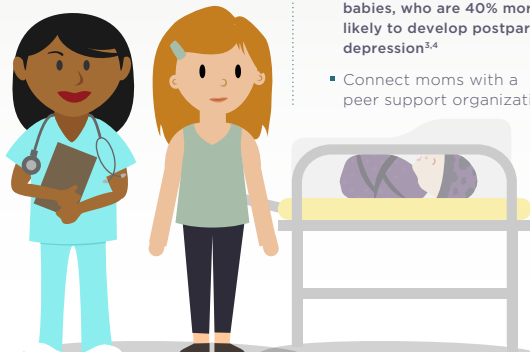
#### POLICYMAKERS CAN:

- Fund Screening Efforts
- Protect Access to Treatment



#### HOSPITALS CAN:

- Train health care professionals to provide psychosocial support to families... especially those with preterm babies, who are 40% more likely to develop postpartum depression<sup>3,4</sup>
- Connect moms with a peer support organization



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<sup>1</sup>American Psychological Association. Available at: <http://www.apa.org/women/resources/reports/postpartum-depression.aspx>  
<sup>2</sup>National Institute of Mental Health. Available at: <http://www.nimh.nih.gov/health/publications/postpartum-depression-facts/index.shtml>  
<sup>3</sup>Journal of Perinatology (2015) 35, 229–236. doi:10.1097/01.jp.0000000000.00000.00  
<sup>4</sup>Prevalence and risk factors for postpartum depression among women with preterm and low-birth-weight infants: a systematic review. Vigod SN, Vilgees L, Dennis CL. Ross LE BJOG. 2010 Apr; 117(5):540-50.

## Las nuevas mamás necesitan acceso a la detección y tratamiento para LA DEPRESIÓN POSPARTO



**1 DE CADA 7 MADRES AFRENDA LA DEPRESIÓN POSPARTO, experimentando**



Sin embargo, sólo el 15% recibe tratamiento<sup>1</sup>

### LA DEPRESIÓN POSPARTO NO TRATADA PUEDE AFECTAR:



### PARA AYUDAR A LAS MADRES A ENFRENTAR LA DEPRESIÓN POSPARTO



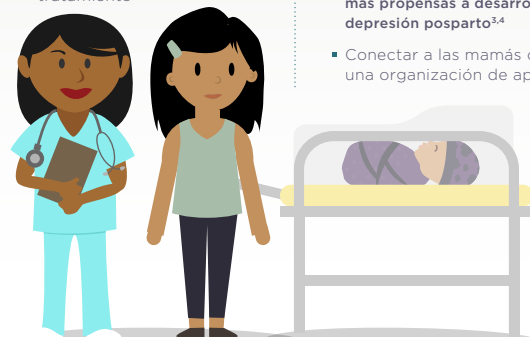
#### LOS ENCARGADOS DE FORMULAR POLÍTICAS PUEDEN:

- Financiar los esfuerzos de despistaje y diagnóstico
- Proteger el acceso al tratamiento



#### LOS HOSPITALES PUEDEN:

- Capacitar a los profesionales de la salud para proporcionar apoyo psicosocial a las familias... Especialmente aquellas con bebés prematuros, que son 40% más propensas a desarrollar depresión posparto<sup>3,4</sup>
- Conectar a las mamás con una organización de apoyo



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<sup>1</sup>American Psychological Association. Available at: <http://www.apa.org/women/resources/reports/postpartum-depression.aspx>  
<sup>2</sup>National Institute of Mental Health. Available at: <http://www.nimh.nih.gov/health/publications/postpartum-depression-facts/index.shtml>  
<sup>3</sup>Journal of Perinatology (2015) 35, 229–236. doi:10.1097/01.jp.0000000000.00000.00  
<sup>4</sup>Prevalence and risk factors for postpartum depression among women with preterm and low-birth-weight infants: a systematic review. Vigod SN, Vilgees L, Dennis CL, Ross LE BJOG. 2010 Apr; 117(5):540-50.



# Monthly Clinical Pearl: "Surfactant Therapy for Preterm Infants with Respiratory Distress Syndrome: What An Amazing Change!"

Joseph R. Hageman, MD

"Now remember, hold the chest to prevent that first breath and bring the baby to the Ohio Bed. Then you have to intubate the baby and instill the surfactant before the first breath to make sure the distribution of the surfactant is uniform." As I recall, that was 1983, and I was lucky enough to be the first attending neonatologist to be able to instill calf lung surfactant at my institution following this protocol. What I found amazing, as I bagged the infant after instilling the surfactant, was how I could feel the surface tension decreasing and the lower pressure I needed to make the chest rise with almost every breath. It was a transformational experience.

***"What I found amazing, as I bagged the infant after instilling the surfactant, was how I could feel the surface tension decreasing and the lower pressure I needed to make the chest rise with almost every breath. It was a transformational experience."***

Things have changed since that time. The FDA approved surfactant in 1990 (1). The approach to the preterm infant who is a potential candidate for surfactant therapy has evolved thanks to the pioneering research efforts of Bengt Robertson after van Neergaard first demonstrated the importance of pulmonary surfactant for normal lung function (1).

Today, the clinician first needs to decide if the preterm infant about to be delivered is a potential candidate for surfactant therapy as he/she is at risk for developing respiratory distress syndrome (RDS) (2). A major part of the pathophysiology of RDS involves surfactant deficiency. What I was involved with was instillation of calf lung surfactant through an endotracheal tube after delivery for all preterm infants at risk as soon as possible. All preterm infants are at risk for developing RDS, however, what has been shown is that only 30 to 60 percent of very preterm infants develop RDS (2,3) and therefore all may not require surfactant therapy. Secondly, antenatal corticosteroids have become the standard of care for attenuation/prevention of RDS (2,3). Thirdly, there are a variety of other clinical factors that may influence the risk of RDS

in this group of babies including chorioamnionitis, intrauterine growth restriction, the volume of amniotic fluid, and structural abnormalities (2,3). Therefore, the baby should demonstrate at least clinical evidence of respiratory distress/respiratory distress syndrome before a decision is made to provide surfactant therapy (2,3).

Moreover, the baby should have an opportunity to transition to spontaneous breathing in the delivery room, utilizing continuous positive airway pressure and just enough supplemental oxygen before thinking about the diagnosis of RDS and potential surfactant administration (2-4). Finally, once the clinician has determined that the baby would benefit from surfactant therapy related to his/her RDS, the surfactant should be administered in a reasonably atraumatic manner, exposing the infant to as little airway obstruction and lung injury as possible. Depending on the resources available, this could be done via gentle endotracheal intubation or by a thin catheter insertion followed by a chance to make the adjustment after the surfactant instillation prior to extubation or catheter removal. The infant can then be provided with CPAP or assisted ventilation in a noninvasive manner (2-4).

A strong case was made by Roberts and colleagues for the "best way" to administer surfactant using a laryngeal mask airway in an interesting article in the April 2018 issue of Neonatology Today (5).

According to Alan Jobe, "the clinical management of RDS is the greatest success story in neonatology" and my colleagues, and I have had the opportunity to be a part of it (3).

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5. Roberts K, Merritt A, Goldstein M. What is the "Best" Way to Administer Surfactant in 2018? The Case for the Laryngeal Mask Airway (LMA). *Neonatology Today* 2018; 13(4):3-11.

The author has identified no conflicts of interest.

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Summarize the pearl for emphasis.

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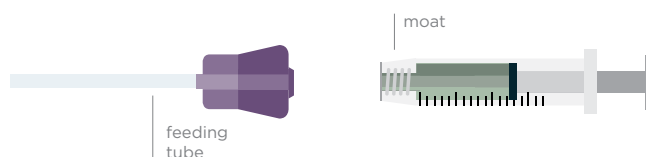
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# Letters to the Editor

From: Peesay, Morarji R <Morarji.R.Peesay@medstar.net>  
Sent: Tue 10/23/2018 6:54 AM  
To: Goldstein, Mitchell <MGoldstein@llu.edu>  
Subject: Dr. Peesay// RE: We noticed that you haven't seen Neonatology Today's October, 2018 Issue

The quality of this journal skyrocketed since you took over!! Dr. Goldstein,  
Thanks

Dr. Morarji Peesay, MD FAAP  
Associate Professor  
Division of Neonatal Perinatal Medicine, Suite M3400, Georgetown University Hospital,  
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Email : Morarji.R.Peesay@gunet.georgetown.edu

Dear Dr. Peesay:

Thank you very much for your vote of confidence, but it has not just been me.

We have had superb editorial support from Drs. Hageman and Merritt who have been immediately available for peer review. Both have also contributed a number of manuscripts. Dr. Hageman writes a monthly column entitled "Clinical Pearls" that sends many of us down memory lane, and for some, provides context to why the art of neonatology evolved the way that it did.

Dr. Clark has provided a "Genetics Corner" on a monthly basis. She has also stimulated and provided support for other case reports, largely in the field of genetics.

Drs. Martin and Fanaroff now provide a monthly column on medico-legal issues.

The National Perinatal Information Center has authored a monthly column which focuses on various analyses of trends in Neonatal/Perinatal Medicine.

The National Perinatal Association writes a monthly column and has contributed significantly with guidelines, position papers, and of course the multiple infographics that you will find scattered through the journal.

The National Coalition for Infant Health also authors a monthly column and has provided significant support for some of the networking that Neonatology Today does with the many organizations in the Neonatal/Perinatal space.

The Alliance for Patient Access contributes a column regarding advocacy and government matters. Neonatology Today is non-partisan, but we continue to search for new and innovative ways to involve our readership in issues that pertain to the health of our most fragile patients.

We have developed a very productive relationship with 99NICU, which has a significant international following. Our hope is to extend Neonatology Today to all of those interested in Neonatology the world over.

We have extended Neonatology Today beyond the original focus of physicians practicing Neonatology. We are hopeful that we will be able to reach all of those with an interest in Neonatal-Perinatal Medicine including nurse practitioners, nurses, therapists, respiratory therapists, and of course parents.

Our advertisers have continued to support us and have made it possible for us to continue to offer Neonatology Today to everyone free of charge. Neonatology Today is also able to offer free publication as well. Our hope is that this will remove barriers to dissemination of knowledge and provide access to the broadest number of readers.

I remains eternally grateful to Tony Carlson who gave us the opportunity to develop this journal, which for many years has been the most innovative format in Neonatal publications.

Sincerely,



Mitchell Goldstein, MD  
Editor in Chief

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Neonatology Today welcomes your editorial commentary on previously published manuscripts, news items, and other material relevant to the fields of Neonatology and Perinatology.

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**Erratum (Neonatology Today October, 2018)**

Neonatology Today has not identified any erratum affecting the October, 2018 edition. Corrections can be sent directly to [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com). The most recent edition of Neonatology Today including any previously identified erratum may be downloaded from [www.neonatologytoday.net](http://www.neonatologytoday.net).

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March 26-30, 2019

<http://paclac.org/advances-in-care-conference/>

Improving Access to Perinatal Care:  
Confronting Disparities and  
Inequities in Maternal-Infant Health  
National Perinatal Association  
April 3 - 5, 2019

Providence, Rhode Island  
<http://nationalperinatal.org/2019Conference>

### Pediatrics Academic Societies Meeting

April 27-30, 2019;  
Baltimore, MD

<https://www.pas-meeting.org/>

2019 Workshop on Neonatal  
Perinatal  
Practice Strategies  
Sponsored by the Section on  
Neonatal - Perinatal Medicine  
Paradise Valley DoubleTree Hotel  
Scottsdale, Arizona  
March 29-31, 2019  
[www.pedialink.org/cmefinder](http://www.pedialink.org/cmefinder)

Perinatal Advisory Council,  
Consulting, Advocacy, and  
Consultation (PAC-LAC)  
June 13, 2019

Los Angeles, CA

<https://paclac.org/paclacconference/>

The fifth annual 2019 iCAN Research  
& Advocacy Summit  
June 23-28, 2019  
Kansas City, Missouri  
<https://www.icanresearch.org/2019-summit>

The AAP Experience  
National Convention and Exhibition  
New Orleans, LA  
October 25-29, 2019.  
<http://aapexperience.org/>

*For Additional Meeting  
Information, visit  
[NeonatologyToday.net](http://NeonatologyToday.net) and click  
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## NEONATOLOGY TODAY

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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's selection is another one of the conference flyers from 99NICU's upcoming conference in 2019. This is a nice example of how photography can be used to create interest and drive attendance. Francesco Cardona, MD, MSc of 99NICU submitted this piece. This bicycle leaning against a red building photo is sourced from [Unsplash](#)

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### Manuscript Submission: Instructions to Authors

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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 5,000 words. Abbreviations which are commonplace in neonatology or in the lay literature may be used.
8. References should be included in standard JAMA format. 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.
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