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Many Hospitals Still Employ Non-Evidence Based Practices, Including Auscultation, Creating Serious Patient Safety Risk in Nasogastric Tube Placement and Verification

Beth Lyman MSN, RN, CNSC, FASPEN, Christine Peyton MS, Brian Lane, MD

Case Study:
A 10-day old male infant s/p Coarctation of the Aorta (CoA) repair was fed breastmilk with minimal intake. The patient required nasogastric tube (NGT) placement for supplemental intake to meet caloric and protein needs. The infant's RN inserted a new NGT with assistance from charge nurse at 8:30 pm with moderate resistance noted during insertion. The patient demonstrated increased work of breathing and oxygen saturation decreased from 98% to 90%. Gastric aspirate was obtained, and the pH was 6.0. The RN obtained abdominal X-Ray order to confirm placement. The attending physician notified the RN at 9:30 pm that the NGT was not in the stomach. The physician requested nasogastric tube (NGT) be removed. The RN removed NGT at 2145 with minimal resistance at which time the patient's oxygen saturation decreased from 90% to 86%. Auscultated breath sounds and assessment showed diminished breath sounds in the right lower lobe. The RN notified MD who ordered oxygen 1 LPM via nasal cannula and another chest X-Ray. Chest X-ray was read at 2200 and showed a tension pneumothorax. The MD arrived at the bedside at 2205 and performed emergent needle decompression for tension pneumothorax.

1. What's the problem?

The use of nasogastric tubes (NGT) in patients provide a means to administer much-needed nutrition, fluids, and medications to children and adults unable to orally consume adequate nutrition. A recent study with 63 participating institutions showcased just how common the use of nasogastric feeding tubes are. It found approximately 24% of all pediatric patients require a nasogastric feeding tube and of this 24%, more than 60% were neonates.

There are risks associated with the placement of temporary NGTs because it is a blind placement procedure. The same risks that exist with blind placement of a transpyloric tube exist with a blind placement of an NGT. Although feeding and decompression tubes are routinely used in hospitals, they carry the risk of serious, potentially lethal complications across all patient groups, though the elderly and babies are the most at-risk populations.[1] A 2005 article by Ellett et al[2] reported NGT misplacement occurred in 20.9%–43.5% of placements, with some of these tubes mistakenly placed in the lung, esophagus, or the small bowel. Depending on the definition of malposition, other studies estimate that error rates range from 21% to 56%.[3-6] It's estimated that nearly 500,000 nasogastric and percutaneous endoscopic gastrostomy (PEG) tubes and suction tubes are misplaced each year, resulting in severe complications or even death.[7] Even more alarming, a recent study showed that more than 88% of nurses are currently using non-evidence based practices to verify NGT placement, creating a serious patient safety issue.[8] A misplaced nasogastric tube can have a lasting impact on both the patient, the family as well as nurses as a second victim. This article will discuss current research and best practices for nasogastric tube placement and verification with attention to the NICU population. Neonatologists, in particular, must understand the most appropriate methods of NGT verification given the risks, of both harm and litigation, for such a routine procedure.

Complications from misplaced NGTs can range from pneumothorax, requiring chest tube placement, to profound chemical pneumonitis and respiratory distress syndrome.[9-10] In some patients, this can be a terminal event, as was reported in a Patient Safety Alert issued by the United Kingdom National Health Service in 2013,[11-12] Even an experienced clinician may have difficulty recognizing pulmonary intubation when placing a temporary NGT. Although considered the "gold standard," radiographs are not commonly obtained before initial or repeated use of the tube due to concerns of radiation exposure.[13-15] A 2009 study found that there is a need for both (1) better methods to measure the distance between nose (lips) and the body of the stomach and (2) improved methods to confirm correct tube position in neonates.[16]

In most developed countries, correct placement of orogastric (OG) or nasogastric (NG) feeding tubes is confirmed using pH measurement. While this has been slow to be accepted in the United States, there is much work being done to make this a global patient safety initiative. The United States needs to "catch-up" and "join-in" this initiative by using a consistent, evidence-based approach to NG and OG tube placement verification.

2. What actions can be taken to improve the process?

a. Eliminate the Use of Non-Evidence Based Practices

Despite the risks associated with this common procedure, no universal standard of practice exists for bedside verification because each method has limitations.

> ***"Radiographs are currently the gold standard for NGT placement confirmation because they can visualize the course of the NGT."***

Radiographs are currently the gold standard for NGT placement confirmation because they can visualize the course of the NGT.[17] Despite being the gold standard, this method is not foolproof. Between 2005 and 2010, 45% of all cases of harm caused by a misplaced NGT reported by the United Kingdom's National Patient Safety Agency were due to misinterpreted X-rays, typically when staff without formal training relied solely on assessing the apparent placement of the tube tip, rather than tracking the path of the tube past key anatomical points, or reviewed the wrong x-ray.[18] A study specifically comparing resident physicians to a neonatologist and

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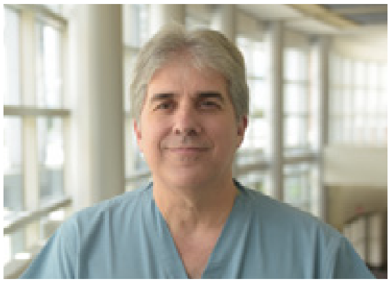

STEVE SPEDALE, MD, FAAP - PRESIDENT

Steve Spedale, MD, FAAP, is the director of neonatology for one of the country's largest women's hospitals. As an early adopter of electronic medical records in the NICU, Spedale recognized the need for improved technology not provided by the available EMRs. With that in mind, he began developing software add-ons independently to give him the tools he needed.

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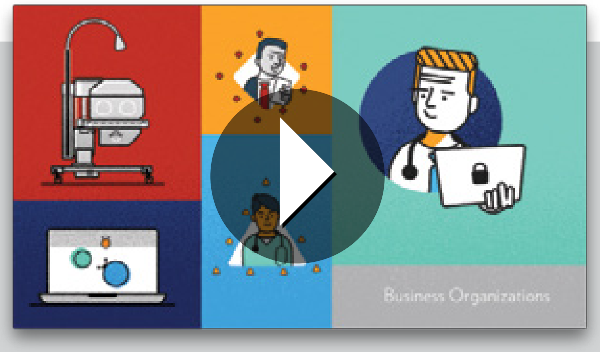

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radiologist read of an x-ray to confirm placement of an OG or oroduodenal tubes showed correct reading in 85.7 and 86.2% of the time respectively.[19]

However, most alarming is that hospitals and nurses are still using non-evidence based practices, including aspiration or auscultation to verify NGT placement as in the patient story which opened this article. Failure to detect misplaced NGTs are attributed to:

- use of non-evidence based methods to confirm initial placement (auscultation or aspiration),
- failure to recognize when an NGT has changed position,
- failure to properly read a chest and abdominal radiograph for 'four criteria,'
- failure to accurately interpret an electromagnetic device screen.[20]

In fact, in the American Society for Parenteral and Enteral Nutrition (ASPEN) prevalence study, 39 of the 63 hospitals surveyed were using appearance of aspirate or auscultation to verify tube placement, both procedures are noted to be non-evidence based.[21] In a survey of 60 neonatal nurses, one study found 32% of the nurses using the nose→ ear→ xiphoid process (NEX) method to measure how far to place the tube. This method is considered to be unreliable.[22] In that same study, 98% of the nurses use auscultation to verify placement with 83% also using aspiration of gastric contents.[23] A study of 435 pediatric patients, some of whom were intubated, found nurses were unable to discern gastric from pulmonary secretions by visual inspection.[24]

> ***"Although commonly used, auscultation carries with it the human cost of error, which is deemed so high that a Patient Safety Alert was issued in 2012 by the Child Health Patient Safety Organization recommending hospitals stop using this method as a means of verifying NG or OG placement. "***

Although commonly used, auscultation carries with it the human cost of error, which is deemed so high that a Patient Safety Alert was issued in 2012 by the Child Health Patient Safety Organization recommending hospitals stop using this method as a means of verifying NG or OG placement.[25] The basis of this alert is that the lungs and stomach are both resonant organs that can transmit sounds, and the ability to discern the difference from one organ to the other is negligible, yielding misleading results with potentially unrecognized NGT misplacement. Additionally, it has been well documented for almost 20 years that auscultation is often inaccurate; however, it is still widely practiced.[26] There has been a series of alerts published from the American Association of Critical Care Nurses (AACN 2005), the National Patient Safety Agency (NPSA 2011) and Children's Hospital Association (CHA 2012) surrounding the harm associated with relying on auscultation for NGT placement verification.

Frances Healey, Ph.D., RN, the Deputy Director of Patient Safety for the National Health Service Improvement also spoke out about the use of Auscultation in the United States while leading a panel at the Patient Safety Movement Foundation's 6th Annual World Patient Safety, Science & Technology Summit. She explains, "Research from the 1990s shows that auscultation is less reliable than tossing a coin. In test conditions, over 80% of clinicians failed to detect tubes in the lungs. In England, air auscultation is something we banned over 13 years ago, but when preparing for the Summit, I was shocked to realize just how commonplace this method has remained in some other countries. I found materials teaching parents, nurses, and physicians, apparently completely unaware of the research and the risks."

The American Society for Parenteral and Enteral Nutrition initiated an inter-organizational, interdisciplinary effort called the New Opportunities for Verification of Enteral tube Location (NOVEL) project in 2012 to promote an evidence-based best approach to NG/OG tube verification practice. While pH measurement has been recommended for decades, it has not been used consistently in the United States. There is a recognition that institutions have been unwilling to acknowledge this and change practice, thereby putting patients at risk. While the focus of this group was practice in the United States, it has members from other countries that do use pH measurement as the first line bedside placement verification technique.

The Patient Safety Movement Foundation, a non-profit that works with global leaders in healthcare to create free resources, worked with leaders from the UK's National Health Service, the NOVEL project, and Colorado Children's Hospital to create free Actionable Patient Safety Solutions (APSS) that encourages hospitals to closely scrutinize their own NGT placement and verifications. The APSS includes recommendations for safe equipment, staff training and competency, institutional policies, tube placement, confirmation of placement before first use, and reconfirmation of NGT placement after initial use.[27] The APSS also includes practices that should never be used.

The following non-evidence based practices are misleading and should never be used as methods to verify NGT placement:

- Auscultation
- Visual inspection of fluid from the tube
- Observation of bubbles – this method is NOT reliable and should no longer be used
- Litmus paper – should NOT be used to determine NGT placement.

The APSS, based on research and best practices from the NHS and the NOVEL project, also note current evidence-based best practices. These best practices include the use of X-ray and pH to verify tube placement. Current literature supports this. In fact, the

American Association of Critical Care Nurses procedure manuals for critical care and the pediatric acute care both recommend pH measurement as part of the procedure to verify temporary NGT placement.28-29 Both the NOVEL and APSS support the use of pH.

b. Implementation of Best Practices to avoid misplacement and properly verify placement

To confirm NGT placement, both NOVEL and the APSS recommend a multimodal verification system which includes:

- **Use of pH**[30] – to check the acidity of the stomach to verify placement. The existing British National Patient Safety Agency (NPSA) safety guideline recommends testing the pH of nasogastric (NG) tube aspirates. Feeding is considered safe if a pH of 5.5 or lower has been observed. Best evidence supports gastric placement when the pH level is 5.5 or lower. If unable to obtain gastric aspirate or confirm placement after testing gastric aspirate, request an order for chest and abdominal X-Ray.[32-33]

- **NEMU** - Nurses should measure NEMU (nose-ear-mid-umbilicus) every time they place an NGT.

- **Use Critical Thinking Skills** – If patients deteriorate during or soon after placement, then remove the tube.

- **X-ray Verification** – X-ray verification remains the gold standard but raises concern with repeated exposure, particularly in neonates. When X-rays are done, it must be read by someone validated competency in NGT placement verification, confirming the path of the tube at key anatomical points, rather than solely assessing the tip, and systematically confirming the most recent x-ray for the correct patient.

The APSS are free and are written in a checklist format so that hospitals can easily implement. For more information, or to review the APSS in their entirety, along with supporting documentation, please visit https://patientsafetymovement.org/actionable-solutions/challenge-solutions/nasogastric-feeding-drainage-tube-placement-verification/.

3. What are the barriers/myths against using pH?

With overwhelming evidence for the use of pH for nasogastric feeding tube verification, why hasn't it been widely adopted? The answer can be attributed to the myths and perceived barriers of using pH, which include:

- Point of care testing

- Validity with feeding substrate

- Acid-reducing medications

- Inability to get a gastric aspirate

- Preterm infants cannot produce gastric acid; the acidity changes with gestational age

Point of care testing: Point of care testing is often seen as a barrier to adoption of pH verification of NGT placement because it is labor intensive from an administrator's point of view. Although pH is easy to do, setting up the process takes work. It requires CLIA accreditation, and periodic quality control testing and annual competency. For example, staff can't be color blind, and products must be stored correctly and not exposed to sunlight. A great analogy for this myth is that of point of care testing for blood sugar. While many hospitals are hesitant to institute point of care testing for pH, point of care testing for blood sugar is the standard of care and is almost universally performed. This is a matter of getting the system set up and training. Additionally, there are products on the market that have CLIA waivers such as RightBio Metrics device.

Validity with feeding substrate: The solution for this perceived barrier is to wait between 10-20 minutes before testing again. For example: if the patient just had a tube placed but when tested for confirmation, a pH between 6-7 is read that means you got formula back or the NGT may be misplaced in the lung with this pH. The solution is to wait a few minutes, between 10-20 minutes. Wait 10-20 minutes check again and if pH is below 5.5 then feed. It is a balance of waiting a few minutes, such 10-20 minutes, versus exposure to radiation.

> ***" On occasion, an NG or OG tube may be difficult to obtain a fluid aspirate specimen for pH measurement. This could be due to the stomach being empty, the tube being kinked, the tube being in the distal esophagus or lung."***

Acid-reducing medications (H2 blockers; PPIs): The pH of gastric aspirates from critically ill infants is often 5.5 or less, regardless of the use of acid inhibitors, feedings, or both. Most likely a cut point of 5.5 or less would rule out respiratory placement because tracheal pH is typically 6.0 or higher.[34]

Inability to obtain a gastric aspirate: On occasion, an NG or OG tube may be difficult to obtain a fluid aspirate specimen for pH measurement. This could be due to the stomach being empty, the tube being kinked, the tube being in the distal esophagus or lung. If unable to obtain an aspirate, the nurse should: attempt to flush with air to discern if the tube is kinked, place the infant on the left side to allow for pooling of gastric contents and wait 10-15 minutes to re-check for an aspirate. If no fluid is obtained then, it is suggested the tube be removed and replaced, or an x-ray is

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Preterm infants cannot produce gastric acid; the acidity changes with gestational age: While it is true that the gastric aspirates of premature infants are less acidic than those of term infants, it in not true that this invalidates pH testing as a means of confirming NG/OG tube position in preterm neonates. Kelly et al demonstrated that, while gastric pH decreased with both increasing gestational age and postnatal age, even 24-week premature infants on DOL 1 will produce a pH <4.[35]

4. When should we check re-check pH?

It is recommended that verification of placement is performed once a shift and before irrigating or administering medication or feedings. Reconfirmation of NGT placement can be performed by assessing the exit point marker of the tube at the beginning of the shift, before administration of feeds or medications and every 4 hours during continuous feedings.

Reconfirm placement by pH testing if there is a change in patient status indicating concern or the patient vomits, the exit point marker is not visible, there is no record of initial confirmation by pH or X-ray, or the patient has been transferred from an outside facility. (Reference: from Chris' CHCO course).

5. What are indicators of misplaced tubes?

As previously noted, healthcare staff must use critical thinking skills and recognize indicators of misplaced NGTs. The patient should be assessed frequently with hospital staff observing for signs of respiratory distress or gagging and vomiting. The NG should be removed if these signs are present, as the NGT may have been dislodged into the airway or lungs. In some cases, NGT misplacement may be inadvertently overlooked if the patient has an underlying respiratory condition where their disease may be thought to be causing the distress as opposed to a misplaced NGT. It is important to rule out NGT misplacement with any signs of distress, gagging or vomiting.

Other indicators of misplaced tubes include:

- Respiratory instability/change in oxygen saturation, tachypnea, bradycardia
- Emesis/vomiting/reflux
- Cough/sneeze (emergence of; persistence)
- Difference in the pitch of the cry
- Feeding intolerance – variably defined
- There may be no signs the tube is misplaced until the patient condition critically deteriorates as fluid in the lung may not always elicit such signs as described above

6. An example of a change in practice

a. Children's Hospital Colorado's Approach

Children's Hospital Colorado updated their NGT verification procedures following a sentinel event related to a misplaced NGT ten years ago. After extensive research, their updates included eliminating auscultation as verification for NGTs and implemented house wide education to promote the change in policy. The policy is revised on an annual basis to review the literature and promote patient safety by implementing best practices. Policy revisions and education continue to be an ongoing process, and CHCO is now collecting data related to verification by pH and X-Ray confirmation. In 2018, CHCO will be utilizing high fidelity simulation to aid in the training of the revised procedures, and also incorporate interactive case studies to support multimodal verification.

Clinical Nurse Specialist Christine Peyton, RN who spearheaded the changes at Children's Hospital Colorado discussed the resistance to change and how the hospital found success.
"When we took auscultation out of the procedures, there was a lot of resistance. We had to go to our nurse managers and our home health agencies to educate and implement the new process. Since there was resistance, we had to take a step back. We told Grant Visscher's story, which involved a misplaced NGT in a neonate that had been "verified" by auscultation. In Grant's case, the NGT was misplaced into his lung, and enteral feedings were started. He passed away due to the error, and that was powerful. It was really hard for people to hear but they realized that [the change to the policy] was the right thing to do and that the literature supports it," explains Peyton.

Following the change in policy, Children's Hospital Colorado published a case study illustrating how new processes, including the use of pH for NGT verification, before tube use resulted in allowing a physician to save the life of an infant.

b. The United Kingdom's Approach

As noted, the APSS heavily mirror the United Kingdom's approach. In the UK, just 21 tubes were used to administer medication or feed after misplaced in lungs or pleura (whether full recovery or severe consequences) in England in 2017/18[36] out of around a million naso- and oro-gastric tube insertions each year (based on purchase data). That statistic ranks undetected misplacements to occur 1 in 50,000 instances. However, Dr. Healey notes that "most of these misplacements we think could still be prevented by the steps outlined in the APSS."

7. Why should every hospital/every nurse get on board?

- It usually takes a tragic event, like Grant's, for a hospital to take action
- Review the new evidence, download the recommendations and determine a plan for your hospital if you are in a leadership role
- If you are not in a leadership role, pass this to the decision makers. Use Grant's story to propel this program forward so that you don't have to experience this event within your organization and the loss of Grant's life can be used to ensure this doesn't happen anywhere else.

Example of on how to implement quickly and recommendations for implementation

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At Children's Mercy Kansas City, top hospital administrators decided to change to pH measurement, and within a few months, the point of care testing competency was rolled out to nursing staff. That was in 2012. Initially, the nursing staff was not aware sterile water used to flush the tube to allow for stylet removal changed the pH, but this was quickly made aware to staff, and now a specimen is withdrawn, discarded, and the pH aspirate is obtained for testing. In the years since this practice changes the policy about when to obtain an x-ray has added a comment about nursing staff using critical thinking skills to discern when a specific patient condition warrants it. This has served the patient population well. This hospital is an example of how practice change mandated from the top with scrutiny of adherence resulted in an improvement in patient care.

> ***" In the years since this practice changes the policy about when to obtain an x-ray has added a comment about nursing staff using critical thinking skills to discern when a specific patient condition warrants it. "***

8. Conclusion

In conclusion, there are standard approaches to NGT placement and verification that are being routinely used in many countries but not in the US. This is unacceptable on many levels and is mostly attributable to the belief that "We don't have a problem here so why change practice?" This mind-set is disappointing at the least and will not allay the mental anguish felt by any healthcare provider involved in a patient event involving NGT misplacement. Because of the small margin for error in a neonate or small baby between accessing the trachea versus the esophagus, this population should be a priority for assuring evidence based methods are used every time an NGT in placed.

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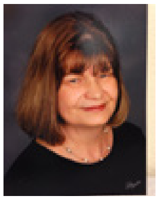

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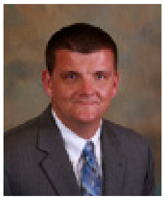

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Peer Reviewed

The Story of a Nasogastric Tube Gone Wrong

Deahna Visscher, Patient Advocate

When I was 18 weeks pregnant, I went in for an ultrasound. I remember the room getting quiet when they were looking at my baby's anatomy. We learned two things that day. One, we were having a boy. Two, he was going to be born with a heart defect. From that day forward my routine obstetrics exams included follow-up with a cardiologist to monitor my sons' heart development. It was amazing to see on the monitor his little heart through my body and his. At every cardiology appointment we watched his heart grow. Each time I would leave with a new fear of what might have caused his heart defect. I would go home and immediately search the new terms and potential syndromes my cardiologist would tell me might to explain the abnormality with my sons' heart. With the ones I especially disliked I would call my cardiologist and tell her "I don't like this one, it says he will die shortly after birth". She would in turn tell me how much she hated Google since it always seemed to give the worst case scenario.

During one of my obstetrics appointments we learned that my amniotic fluid was lower than it should be. I was sent to a specialist for that problem. They took lots of pictures and measurements. I was then sent home with instructions to drink as much water as I could, to sit submerged in a bath full of water for as long as I could stand, and to come back the next day. That follow up appointment would determine when my son would be born. His original due date was April 26. Since I would have a C-section we had planned to schedule it for April 24 to share my mother-in-law's birthday. That date was moved up to April 10 due to low amniotic fluid. I was ok with that since it was my grandmother's birthday. If my amniotic fluid didn't improve then my delivery would be earlier. When I went in for my next appointment, the fluid was lower and I learned that my son would be born the next day.

Grant Lars Visscher was born on April 8, 2008 at 5:58pm. He was beautiful and perfect despite the known heart defect. He was 6lbs 5oz and 18 inches long. He also shared my step-grandfathers birthday. Less than 24 hours after he was delivered he was taken by ambulance to the hospital where he would later have surgery. Although I had just had major abdominal surgery, I medically discharged myself so that I could be with him every step of the way. Together we rode with the ambulance team to the referral hospital. We almost didn't make it. A car was traveling the wrong way on a one way snowy street and almost collided with us!

Upon arrival at the new hospital the staff began evaluating Grant and scheduling CT scans and blood work. After review of his scans it was determined that Grant had coarctation of the aorta. The surgery would correct the coarctation by replacing his malformed valve with a gortex valve. Surgery was scheduled for 10:00am on Saturday, April 12, 2008. The surgery would be about 5 hours long.

On Saturday, April 12 Grant went into surgery around 9:00am and came out a little after 3:00pm. The surgery went well. The doctors were able to sever the coarctaction and tie the valve off on both sides. The gortex valve was inserted to replace the coarctation and put the replacement valve correctly in front of his esophagus and trachea. [They also tied off the left superior vena cava valve that led to his small mitral valve to see if it would help the mitral valve grow to normal size.] While inside his tiny little chest the doctors did find a small hole inside the top section of his heart so they corrected it with a couple of sutures. That was the only surprise they had and they said it was a minor surprise. He was doing so well post-op that he only needed one chest tube for drainage, 6 medications, a catheter and he was intubated. By Tuesday, April 15 Grant was weaned from his medications, with only oral Tylenol remaining. He also had his catheter, breathing tubes, pacer lines, and chest tube removed. He was doing so well that he was moved from the PICU to the Cardiac Progressive Care Unit.

By Wednesday Grant was having trouble with his feedings so the staff wanted place a feeding tube. They first tried a nasal feeding tube, but he struggled, so they moved to an oral feeding tube which he later coughed out. They ended up postponing milk feedings and put him back on intravenous fluids. He also started having trouble with low oxygen saturations in the low 80s. A chest x-ray was ordered to find out why he was suddenly having trouble getting oxygen. They discovered that his lower left lung had collapsed, a common side effect of open heart surgery in infants. They put him on a CPAP machine to re-open his lower left lung. He looked so cute snorkeling in bed. The next day he had improved and they took him off of the CPAP machine and put him back on a nasal cannula for oxygen. The staff also ordered an upper GI test to find out why the nurses were struggling to insert the feeding tube. He did not have any blockage in his esophagus, but he did have severe reflux. They then inserted the feeding tube under x-ray and he started feeds on milk again.

> ***"They first tried a nasal feeding tube, but he struggled, so they moved to an oral feeding tube which he later coughed out. They ended up postponing milk feedings and put him back on intravenous fluids."***

Grant did well with his feedings through the NG tube both Thursday and Friday that we were told that by Monday or Tuesday he would be going home. On Saturday, the morning nurse told me that she wasn't comfortable with his feeding tube as they had placed it trans-pyloric to help with his reflux. She requested and was approved to insert a new feeding tube that would not go past his stomach for feeds. I watched as she struggled to insert the new tube. I told her how the staff that inserted his current tube had struggled to get it in so they did it under x-ray. She struggled a bit and then got it in. She asked me if I wanted to learn how to do a feeding with an NG tube since Grant would probably be going home with it. She then proceeded to show me how to insert a burst of air into the NG tube and listen for the sounds in his body through the stethoscope. At this time I asked her how you would know if the burst of air was in his stomach or not. I stated, “Wouldn’t there be a burst sound regardless of where it is in the body?” The nurse said that she supposed that would be true. She then told me that is why they take a sample of fluid out of the tube to verify that it is taking fluid out of the stomach. She then did that and showed me the fluid in the tube. I asked her how she knew that was fluid from the stomach. She told me that she was confident it was there as she had been doing this for 20 years. The nurse then started Grant’s feeding of milk. We then discussed how to get Grant back onto the regular feeding schedule since the insertion of the NG tube delayed his feedings and we needed to coordinate the NG feeding with my breast feedings.

After his feeding I took Grant out of his bed and held him in the rocking chair. While holding him he was very fussy and his pulse ox started to fluctuate. The nurse checked things and said it could because of them weaning him down on his oxygen. She also took this time to switch out Grant’s bed to a crib. A couple of hours later I paged the nurse because Grant was sounding raspy and was blowing whitish bubbles out of his mouth. A different nurse came in because our regular day nurse was at lunch. I explained what was happening to Grant and the nurse had me put him in the crib. She then began to suction out his mouth with a long tube. Grant seemed to do a little better after that.

Later that day we had several visitors come see Grant, including his 15 month old brother Mason. We took a family picture with Grant since it was the first time we could all be together. My parents came by and gave my husband and me a little break. I hadn’t left the hospital in days. We ran a few errands and then came back to the hospital. When we returned to the hospital around 7:00pm my parents told us that Grant seemed to be distressed. They told us that when they called the evening nurse in she told him that the sounds from his monitors were going off probably because he was moving down in his crib and needed to be moved back up. They told us that the nurse then asked them if they would like to hold Grant and of course they did. They said that Grant seemed to do better when they held him upright. Shortly after that my parents left.

My husband hadn’t held Grant in a while so he picked him up and held him in the rocking chair. Around 8:00pm, while my husband was holding Grant, I noticed his color seemed off. He was ashen, and he was blowing whitish bubbles again. We paged the nurse and when she came in we told her that when Grant did this earlier in the day that the nurse suctioned him out. She then got a big suction tube to suction out his nose; we told her that the earlier nurse used the suction tube in his mouth, not his nose. She then got the other suction tube and started to suction him. This nurse seemed a bit distracted to us. We felt like we had to tell her what to do.

After she suctioned him she started a feeding for Grant. Just afterwards his color got worse. The nurse was doing something with the feeding tube or monitor when I told her that Grant was turning blue around his mouth. She then hit the call light and told the person that answered that we needed a nurse in there. The lady told her that she would send my nurse in. Our nurse told the lady that she was the nurse and needed a charge nurse in there right away. No one came in at that second so the nurse told me to go into the hall and call for a charge nurse. I ran into the hall and hollered that we needed a charge nurse now that Grant was turning blue. A few nurses ran into the room then and within in seconds an over head page was made requesting code blue to room 902. Immediately thereafter about 20 people charged into the room to help revive Grant.

We had Mason, Grant’s 15 month old brother, with us so Rich took Mason out into the hall while I stayed in the room watching them work on Grant. One of the doctors in the room started to ask me questions and I answered them. A nurse took Mason from Rich so that he could come back in the room to be with Grant while the team worked on him. While Rich and I watched them work on Grant we heard the doctor who was putting a breathing tube into Grant’s airway state that the NG tube had gone through Grant’s trachea. Sometime during this a nurse started describing what the team was doing to try to save Grant. Later another doctor turned to us to start to tell us that they had done all that they could for Grant. I cut her off and begged her to keep working on him and to not give up. She gave us sad eyes and said that they would try for 10 more minutes. The nurse that was describing things to us then asked us if we would like to hold Grant’s feet while they continued to work on him so we did, each of us taking one of Grant’s tiny feet into our hands. Shortly after that the doctor said that they had done all that they could for Grant. Rich and I both collapsed to the ground in sobs. Our beautiful baby boy was pronounced dead at 9:10pm on Saturday, April 19, 2008.

After we collected ourselves the staff let us be with Grant alone. Sometime after, while we were holding him together on the couch in the room, the doctor came in to tell us how sorry she was that they could not save him. I asked her how come this happened, that I didn’t understand since he was doing so well and was supposed to go home later that week. She told us that they think the NG tube had something to do with his death. I responded with, “So you’re telling us the nurse killed our baby?” The doctor just repeated how sorry she was.

> ***“She told us that they think the NG tube had something to do with his death.”***

The nursing staff came in later and told us they could take pictures of Grant for us. I asked if there was a professional that could do it and she said they would page the ‘Now I Lay Me Down To Sleep’ on call person to see if someone could come in for us. We then started making the calls to our family to let them know that Grant had passed away and asked them to come to the hospital to say goodbye to him. It was at this time that a nurse brought Mason back to us. He had no idea what was going on and why his parents were so sad and distraught.

Two doctors came back to see if we had any questions and to let us know again how sorry they were. I was so angry that I told them that they couldn't give me the things I wanted, which was to have my baby back and to have the two nurses that day fired. One of the doctors then told us that she was the doctor that gave the nurse the authorization to change the NG tube. She said that it is quite normal for the nurses to place them. They went on to say that they even teach parents how to do it. They apologized again for our loss and told us they didn't know what else to say. Then they left us when we told them we didn't have any questions.

Our family started arriving to say their "good-byes" to Grant. The coroner came and looked at Grant and then the photographer came and took pictures of Grant with us and our family. I have more pictures of Grant deceased then I do of him alive. The nurses then made a mold of Grant's hand and foot for us. Once the mold was ready we said our final goodbyes to Grant and handed him over to one of the nurses around 2:00am. That was the last time we saw Grant at the hospital.

We held his funeral on April 26, 2008. We were surrounded by family and friends as we said goodbye to our 11 day old son. My father did the eulogy. We asked people to come up and share with us their brief memories of Grant. My step-mom spoke and asked that from now on that every year, from April 8-April 19, she would like for us to do something kind in memory of Grant. We now call that anniversary Grant's Pay It Forward days.

In the days following Grant's death we were told by 3 separate medical professionals that Grant's death was a medical error and that we should think about suing the hospital to prevent this tragedy from happening to anyone else. During my post-op c-section care my OBGYN heard our story and referred me to a lawyer. My husband and I could not stand to be in our home that was prepared and waiting for our baby son to come home. It hurt every time that someone who had known we were expecting asked after the baby. So, we ran away with our son Mason to Puerto Rico. While at a pediatrician visit to see if Mason needed anything for travel to Puerto Rico, his doctor heard our story and referred us to the same lawyer as had my OBGYN. My sister is an operating room nurse and told her co-workers our sad story. One of the anesthesiologists recommended the same lawyer as the other two doctors had. We took that as a sign and made the call.

We worked with our lawyer and the risk manager at the hospital to come to terms on a settlement. We had done some research and learned that if the nurse had used a pH strip to test the fluid she had removed from Grant that he might still be alive. We made it part of our settlement that the hospital had to change their policy and procedure for feeding tube placement and verification so that no one else would have to suffer a death and loss like ours. We also invited the hospital to use our story to explain why they were making changes.

A few years after Grant died; we had another son, Liam. It was during his first few months of life that I started wondering if the hospital ever put in place the changes we requested on behalf of Grant. I decided to inquire and find out. I met with several staff members who reviewed Grant's case file with me. They told me that they had changed their policy and procedure at the hospital. In fact, they knew that at least 4 babies' lives had been saved because of this change. They told me that they were using a pH strip to verify placement and if any distress occurred they used x-ray to perform the procedure.

I left that meeting feeling empowered. Grant's death was not in vain. I asked myself how I could prevent more deaths and make feeding tube placement and verification safer. I reached out to the Chief Safety Medical Officer at the hospital where Grant died and he invited me to sit on one of the hospital committees. I chose the Patient Safety Committee. The hospital was implementing a new program called Target Zero. That stands for zero harm. The Patient Safety Committee split up into small groups to tour the hospital to talk to the staff about Target Zero. Of course, I looked at every single child while we were talking to the nurses. I saw one child who had a feeding tube. I started asking the nurse some very leading questions regarding placement and verification. She answered my questions and then explained to me: "Well, about five years ago we had an infant who had a feeding tube placed incorrectly and so that's why we do it here differently now." I looked at her, and I said thank you. You have just told my sons story back to me and validated that his death was not in vain. People have learned from it, they understand why it was important to change the procedures, and they remember him.

Through my work with the hospital I got involved with another committee called the NOVEL (seeking New Opportunities for Verification of Enteral tube Location) that is a sub-committee of the American Society of Parenteral and Enteral Nutrition (ASPEN). With the NOVEL project we have been seeking a gold standard for feeding tube placement and verification. Through our work we did a study in 2016 with 63 participating hospitals and found that there are probably at least 25% of children that are at risk of a misplaced feeding tube. We also learned there was wide variation in how placement of these tubes was verified. We found the prevalent method was to use aspiration and auscultation for verification. This is a direct contradiction to the 2012 safety alert that was distributed by the Child Heath Patient Safety Organization that recommended the immediate discontinuation of the auscultation method for the assessment and verification of nasogastric tube placement. This study only fueled my desire to find a solution in which all hospitals use a unified gold standard.

> ***"The Actionable Patient Safety Solution (APSS) #15 was formulated: pH testing should be used as the first-line method for checking bedside NG tube placement. If there are issues with placement or the pH is not at the correct value, then x-ray should be used to confirm placement. "***

A colleague told me about the work that the Patient Safety Movement Foundation does to get to zero harm by 2020. He, the nurse who reviewed Grant's case, and I went to their conference July 13-14, 2017. I proposed the idea that they help find a gold standard for feeding tube placement and verification. I shared my story and the NOVEL project research findings to illustrate why it is important to find the best practice for all hospitals nationwide and worldwide. The nurse also shared what her hospital had done to make changes there after Grant's death. Of all of the medical safety ideas proposed, ours was voted as the number one issue to be championed and solved by the next conference.

An international team was formed by the Patient Safety Movement Foundation to find the gold standard for feeding tube placement and verification. Team members were from England, Mexico, and the United States of America. We all came together with research, literature, and personal experiences that supported definition of the gold standard. The Actionable Patient Safety Solution (APSS) #15 was formulated: pH testing should be used as the first-line

About The Patient Safety Movement Foundation
More than 200,000 people die every year in U.S. hospitals and 4.8 million worldwide in ways that could have been prevented. The Patient Safety Movement Foundation is a global non-profit which creates free tools for patients and hospitals. The Patient Safety Movement Foundation was established through the support of the Masimo Foundation for Ethics, Innovation, and Competition in Healthcare to reduce that number of preventable deaths to ZERO by 2020 (0X2020™). Improving patient safety will require a collaborative effort from all stakeholders, including patients, healthcare providers, medical technology companies, government, employers, and private payers. The Patient Safety Movement Foundation works with all stakeholders to address the problems with actionable solutions for patient safety. The Foundation also convenes the World Patient Safety, Science & Technology Summit. The Summit brings together some of the world's best minds for thought-provoking discussions and new ideas to challenge the status quo. By presenting specific, high-impact solutions to meet patient safety challenges, called Actionable Patient Safety Solutions, encouraging medical technology companies to share the data their products are purchased for, and asking hospitals to make commitments to implement Actionable Patient Safety Solutions, the Patient Safety Movement Foundation is working toward ZERO preventable deaths by 2020.

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method for checking bedside NG tube placement. If there are issues with placement or the pH is not at the correct value, then x-ray should be used to confirm placement. On February 24, 2018 we shared our APSS at the conference held in London, England in front of an international audience.

I was naïve to think my work was done with the creation of the APSS that defines the gold standard for feeding tube placement and verification. I thought if we created the gold standard then it would be used. I was wrong. People and organizations need to be informed that the gold standard exists, that there are valid reasons for using it, and that it needs to be followed. It's been 10 years since Grant died and I am still blown away when I encounter a hospital that is still using auscultation as their method for verification. How many more people need to die before action is taken at those organizations? Does it have to be a death or a near miss that makes them embody change?

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National Black Nurses Association Announces Human Donor Milk Resolution

National Black Nurses Association, Inc.
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The National Black Nurses Association (NBNA) was organized in 1971 under the leadership of Dr. Lauranne Sams, former Dean and Professor of Nursing, School of Nursing, Tuskegee University, Tuskegee, Alabama. NBNA is a non-profit organization incorporated on September 2, 1972 in the state of Ohio. NBNA represents 150,000 African American registered nurses, licensed vocational/practical nurses, nursing students and retired nurses from the USA, Eastern Caribbean and Africa, with 92 chartered chapters, in 35 states.

The National Black Nurses Association's mission is "to represent and provide a forum for Black nurses to advocate and implement strategies to ensure access to the highest quality of healthcare for persons of color".

SILVER SPRING, MD, The National Black Nurses Association announces the passage of its resolution "Creating a Culture of Safety with Human Milk Banks" at the Opening Ceremony of its 45th Annual Institute and Conference in Las Vegas, Nevada. "In collaboration with Prolacta Bioscience, a corporate roundtable member, NBNA is pleased to partner to educate nurses and the community about the need for higher donor milk safety and screening standards", stated Dr. Eric J. Williams, NBNA President.

"NBNA firmly believes that mother's breast milk is best for babies, providing important nutrients for a healthy baby. It is well documented that women of color have a high rate of preterm babies. There is a need to make sure that premature babies have access to high quality and safe donor milk."

The National Black Nurses Association, Inc (NBNA) believes there are a few simple procedures the FDA could put in place to regulate human milk collection that would ensure the same protections for those receiving blood donations and transfusions for our most vulnerable population, babies.

These include:

- Validation of the donation immediately upon receipt, and before mixing with any other donated milk.
- Validation that consist of a check for drugs, including nicotine, and ensure that the milk is 100% human, no cow or other adulterants have been mixed with the donor's milk supply.
- Validation of pathogen reduction processes (e.g.) pasteurization.
- Require human milk banks to report adverse effects of their products, such as disease or infection
- Require standard testing and labeling
- Require annual FDA audit of milk banks
- Codify best practices for hygienic processing and pasteurization.

The theme of the Conference is "Nursing Innovations: Building a Culture of Health". The Opening Ceremony was open to the public on Tuesday, August 1, 2017 6 p.m., Mandalay Bay Conference Center, Las Vegas, NV.

The NBNA mission is "to serve as the voice for black nurses and diverse populations ensuring equal access to professional development, promoting educational opportunities and improving health".

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National Black Nurses Association Resolution: Creating a Culture of Safety with Human Milk Banks

National Black Nurses Association, Inc.

Whereas, human milk is the best source of nutrition for the vast majority of babies, especially those born premature supporting the developing immune system, protecting against infections, allergies and diseases such as diabetes and certain types of cancer;

Whereas, the American Academy of Pediatrics (AAP) recommends human milk as the main source of nourishment for all babies for at least the first six months of life;

Whereas, human milk has been linked to higher Intelligence Quotient (IQ) scores;

Whereas, for a wide variety of reasons, not all mothers are able to breastfeed their babies. As a result, there are human milk banks for mothers producing extra milk to donate their surplus to supplement or replace the milk of birth mother that cannot produce for her own baby;

Whereas, over the last decade, there has been a rapid growth in the number, size and use

of human milk banks, a trend we hope to see continue. However, there is a lack of standardization and guidelines to ensure patient safety and protect this vulnerable infant population;

Whereas, the resulting rapid growth in the number and size of human milk banks for mothers producing extra milk to donate their surplus to supplement or replace the mother's milk, the suggested guidelines for the collection, storage and donation of milk were created decades ago and remain optional, self-imposed and self-regulated;

Whereas, these collection guidelines generally include screening and testing the mother for diseases or infections prior to her first donation, having the milk bank's staff: (1) wash their hands, (2) transfer/pour donated milk into glass flasks, (3) pool the milk (usually a batch contains milk from three to five donors), (4) fill bottles with pooled milk, (5) pasteurize the bottles of milk, and (6) freeze the pasteurized milk.;

Whereas, safe collection and pasteurization are important to ensuring safe milk supply for babies, there remain significant safety concerns in having non-uniform self-imposed, self-regulated and optional guidelines for the collection of human tissue;

Whereas, in the US, three states (CA, MD and NY) regulate human milk as human tissue and require licensing of donor milk banks. The US Food and Drug Administration (FDA) has indicated that human milk is a food and preliminarily explored current practices in the field, but has not seriously considered specific regulations for human milk as of yet;

Whereas, the rapid recognition of human milk's value, human milk is widely sold without any processing, testing, or oversight. With the growth of internet commerce, anyone can go to Craigslist.com, Farebook.com, or even athletes' supplement websites to buy human milk that is completely untested and unprocessed; it is time for the federal government to recognize that human milk carries the same risks as other biologics such as Blood and Plasma;

Whereas, blood and plasma regulations are designed to deal with the safety risks associated with materials from a biological source, they are a very good starting point for human milk regulations necessary to protect the public health;

Whereas, human milk is a critical nutritional source for babies, and regulations should not be so burdensome that they prohibit the continued increase in supply. History shows that the regulations FDA placed on human blood collection did not stop the supply of blood to those in need, it made the supply safer. It protected the recipients, as well as the donors;

Whereas, human milk is a vital resource, and crucial for the healthy development of babies, it is critical that the federal government ensures it is safely accessible for those most in need;

Whereas, history shows us what happens when human biologics are processed under subpar regulations. The HIV epidemic that resulted from infected blood transfusions in the 1970s and 1980s is a tragic example;

Whereas, with human milk use now growing as rapidly, the FDA must address the need for regulations on the collection and processing of human milk, and treat it as stringently as other human biologics, and;

Whereas, FY 2017 Appropriations Request (the Subcommittee on Agriculture, Rural Development, Food and Drug Administration, and Related Agencies bill) provides viable protection and the Committee is aware of the growing commercial human milk industry, and it's important to, in particular our most vulnerable preterm infants; now

1. Therefore, Be It Resolved: The National Black Nurses Association, Inc (NBNA) believes there are a few simple procedures the FDA could put in place to regulate human milk collection that would ensure the same protections for those receiving blood donations and transfusions for our most vulnerable population, babies.
    a. These include:
        - Validation of the donation immediately upon receipt, and before mixing with any other donated milk.
        - Validation that consist of a check for drugs, including nicotine, and ensure that the milk is 100% human, no cow or other adulterants have been mixed with the donor's milk supply.
        - Validation of pathogen reduction processes (e.g.) pasteurization.
        - Require human milk banks to report adverse effects of their products, such as disease or infection
        - Require standard testing and labeling
        - Require annual FDA audit of milk banks
        - Codify best practices for hygienic processing and pasteurization
2. Therefore, Be It Resolved: The NBNA supports the need for adequate regulations and laws to ensure the safety and national quality of donor human milk supply.
3. Therefore, Be It Further Resolved, that the NBNA respectfully request the Food and Drug Administration make known its efforts to implement regulations to protect a safe and stable supply of human donated milk.

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The The Morgan Leary Vaughan Fund and NEC Unplugged: Meeting Overview

Jennifer Degl

Many organizations from the Preemie Parent Alliance had members to represent them at the event, including Speaking for Moms and Babies, Once Upon a Preemie, NICU Helping Hands, The Tiny Miracles Foundation, and Nurtured by Design.

Speaking of NEC: Unplugged was made possible because of the generosity of Prolacta Bioscience, The Petit Family Foundation, Speaking for Moms and Babies, Inc., Team Grayson, and ThriveRX. Events photos were taken by Le Petit Studio of Connecticut.

The Morgan Leary Vaughan Fund (Morgan's Fund) is a 501(c)(3) public charity dedicated to NEC. Morgan's Fund produced a podcast series on Necrotizing Enterocolitis, called "Speaking of NEC". You can listen to them on iTunes or download them from this link: http://www.morgansfund.org/category/podcast/. Morgan's Fund has also partnered with the National Organization of Rare Disorders to create a first of its kind natural history registry where those affected by NEC can enroll to help further the research into both the causes of NEC and what NEC patients may face as they grow. You can find more information on the NEC Registry by clinking here: https://www.necregistry.org/.

For more information on The Morgan Leary Vaughan Fund, please visit http://www.morgansfund.org/

You can read the press release on the event by clicking HERE.

The inaugural Speaking of NEC: Unplugged was held on June 11, 2018 at the Courtyard by Marriott in Cromwell, Connecticut and it was very well received. This one-day regional conference that focused on identifying practical solutions for reducing the devastating effects of Necrotizing Enterocolitis (NEC) on premature infants and their families, was presented by The Morgan Leary Vaughan Fund (Morgan's Fund). The event drew more than 100 participants from the Northeast and beyond.

Stephanie Vaughan, Mother of NEC Survivor and Co-Founder of The Morgan Leary Vaughan Fund

"The attendance was fantastic, and it was very responsive to the quality of the speaker agenda that The Morgan Leary Vaughan Fund assembled. The message was clear: NEC is not only a dreaded disease, but also one that continues to attract clinical and research energy and expertise to combat. What a testament to Morgan and all the other infants and families who have been caught up in the battle!" said Stephanie McGuire, an Advanced Practice Registered Nurse at Connecticut Children's Medical Center's Newborn Intensive Care Unit.

Dr. Robert Touloukin, Yale School of Medicine

NEC is a rare, inflammatory disease that leads to necrosis (death) of the intestine and it affects about 9,000 of the 480,000 infants born preterm each year in the United States. Although all newborn infants born preterm or born with a low birth weight (less than 5.5 pounds) are at increased risk for NEC, very low birthweight babies are at an even greater risk for developing this deadly disease.

Speaking of NEC: Unplugged was designed to bring together relevant NEC experts with preemie parent influencers and advocates so that all stakeholder groups could leave the conference with new information and renewed drive to continue looking for better treatments for NEC and ways to implement those we already know prevent NEC. This was most certainly accomplished.

The education objectives were designed so that the attendees

Dr. Madson from Connecticut Children's Medical Center would be able to discuss challenges that health care workers face when caring for an infant with NEC, discuss the epidemiology of NEC and initial findings of the Natural History Registry for Necrotizing Enterocolitis (NEC Registry), learn about the benefits of using an exclusive human milk diet, discuss current healthcare and policy issues related to the use of donor human milk and human milk-based fortifiers, discuss the traumatic impact regarding the diagnosis of NEC on families, and discuss the long-term impact of NEC on neurodevelopmental outcomes. Connecticut Children's Medical Center offered 4.5 CME credits to those who attended the full day of speakers.


Dr. William Petit, former physician and current Connecticut State Representative of the 22nd District

The event hosted more than 20 distinguished speakers including neonatologists, clinicians, and researchers from Connecticut Children's Medical Center, Maria Fareri Children's Hospital at Westchester Medical Center, The Children's Hospital of Philadelphia, University of Connecticut School of Medicine, University of Pennsylvania School of Nursing, and Yale School of Medicine; executives and patient advocates from Caring Essentials Collaborative, LLC, National Organization for Rare Disorders, NICU Helping Hands, Once Upon a Preemie, Short Bowel Syndrome Foundation for Children of New England, Team Grayson, The New York Milk Bank, The Tiny Miracles Foundation, and The Wonder Twins Fund; and parents from the Northeast and beyond.


NICU parents hugging after an emotional presentation

Attendees included physicians, parent advocates and nurses from thirteen hospitals and ten states.

The speakers had the audience engaged at all times, many of whom naturally couldn't help being overcome with emotion when parents shared some of their personal NEC stories. When preemie parents speak, it's impossible not to feel their pain and rejoice in their triumphs. These stories help drive research, build momentum between doctors and researchers -- encouraging them to be relentless in their ongoing quest to find better ways to treat NEC and ultimately prevent it from occurring.

Jennifer Degl, Micro Preemie Mom, Author, Advocate and Founder of Speaking for Moms and Babies. Inc.


Crystal Grogan from NICU Helping Hands and the Preemie Parent Alliance, sharing her story of delivering a micro preemie in another country and his struggle to survive NEC and other complications

Medical speakers included:

- Dr. Adam Madson, Attending Neonatologist at Connecticut Children's Medical Center-Newborn Intensive Care Unit (A Neonatologist's Perspective)
- Dr. Robert Touloukian, Professor Emeritus Surgery and Pediatrics at Yale School of Medicine (A Surgeon's Perspective)
- Dr. Naveed Hussain, Professor of Pediatrics at UConn School of Medicine and Director of Neonatal Research at Connecticut Children's Medical Center (Epidemiology and Risk Factors for NEC)
- Dr. Maushumi Assad, Neonatal-Perinatal Fellow at Connecticut Children's Medical Center (Exclusive Human Milk Diet as the Standard of Care)

- Dr. Diane L. Spatz, PhD, Nurse Researcher & Manager of Lactation Program at The Children's Hospital of Philadelphia (10 Steps to Promote and Protect Human Milk and Breastfeeding in Vulnerable Infants)
- Julie Bouchet-Horwitz, Executive Director of The New York Milk Bank (Donor Milk Banking and Policy in NY State)
- Kristen Agnell, Associate Director of Advocacy at the National Organization of Rare Disorders (Current Healthcare Policy Issues)
- Mary Coughlin, CEO of Caring Essentials Collaborative, LLC (Trauma-informed Care for Hospitalized Newborns, Infants & Families)
- Dr. Dorothy Vittner, Assistant Clinical Professor at UConn School of Nursing and Nurse Scientist at Connecticut Children's Medical Center (The Future is in our Hands: Using a NIDCAP Approach)
- Elizabeth Schneider, Director of Family Services at The Tiny Miracles Foundation (Psychosocial Support for Families with NEC)
- Jenné Johns, Preemie Mom and (Speaking of NEC and Health Disparities)
- Dr. Jordan Kase, Associate Professor of Pediatrics at New York Medical College and Neonatologist at Maria Fareri Children's Hospital at Westchester Medical Center (NEC and Neurodevelopmental Outcomes in Very Preterm Infants)
- Dr. Karan Emerick, Director of Hepatology at Connecticut Children's Medical Center (Short Bowel Syndrome)
- Kate Samela, Clinical Care Coordinator, Intestinal Rehabilitation Program at Connecticut Children's Medical Center (Short Bowel Syndrome)

Parent speakers included:

- Morgan's Fund Co-Founder and President Stephanie Vaughan, who shared the story of the birth of her premature twins and Morgan's battle with NEC
- Laurel Kapferer, Vice President of Team Grayson, who lost her son Grayson to NEC
- Matt Sullivan who shared the heartache of losing his premature daughter Rosalie, to NEC
- Tracey Falcone, Founder of The Wonder Twins Fund, mother of twin premature babies, one who lived for only a few days and the other who after 8 months in the NICU, succumbed to complications of NEC
- Cristal Grogan, Digital Marketing Manager at NICU Helping Hands and the Preemie Parent Alliance, who delivered a premature baby in another country and her son's fight to overcome many obstacles, including NEC
- Ann Alford, Vice President of Short Bowel Syndrome Foundation for Children of New England who, along with her son Charlie, shared Charlie's experience of growing up with complications of NEC

Dr. William Petit, former physician and current Connecticut Representative of the 22nd General Assembly District, honored us by dropping in to say a few words about why The Petit Family Foundation proudly supports the work that Morgan's Fund is doing and why they are happy to provide funding for their research and events such as this!

The Morgan Leary Vaughan Fund will publish an executive summary highlighting the practical solutions discussed for reducing the devastating effects of NEC on premature infants and their families. A post-event survey is currently underway and based on its analysis, Morgan's Fund plans to host an additional conference of this nature in early 2019 in Austin, Texas.

Leveraging the outcomes of the Speaking of NEC: Unplugged conference, Morgan's Fund will continue to empower and educate parents, providers, researchers, policy makers, and the public about NEC. Research continues in the face of an ever-widening conclusive body of evidence that NICUs throughout the nation should enhance lactation services to help mothers with breastfeeding, provide human donor milk as a bridge to help these mothers, and educate parents about the reasons why an exclusive human milk diet is critical and why cow-based formulas and fortifiers are detrimental.

The Morgan Leary Vaughan Fund urges all parents to understand their nutritional options and to advocate for low birth weight and premature babies (especially those born under 2.2 pounds) to receive only breastmilk, human donor milk and human milk-based fortifiers. While we continue to search for other ways to prevent NEC, in this way alone we can reduce NEC rates by as much as seventy-seven percent (1). Morgan's Fund, along with many other organizations and advocates, has signed the NEC Petition being sponsored by Preemie World to encourage this very outcome. Please see the link and consider signing on by visiting https://preemieworld.com/nec-petition.

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Speaking for Moms & Babies, Inc
www.speakingformomsandbabies.com
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Peer Reviewed

National Perinatal Association Statement June 2018: NPA Advocates for the Health and Wellbeing of Migrant Families

Jerasimos (Jerry) Ballas, MD, MPH, Cris Glick, MD, IBCLC, MaryAnne Laffin, RN, MS, CNM, FACNM, Erika Goyer, Cheryl A. Milford, Ed.S.

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.

National
Perinatal
Association
Educate. Advocate. Integrate.

Over the last two months, nearly 2,000 migrant children, ranging from infants to teens, have been removed from their parents' care and incarcerated in makeshift detentions centers as part of the current administration's "zero tolerance" interpretation of long-standing immigration statutes. Such internment, without plans for interim care or reunion, is a crisis for these children, their parents and our society as a whole.

Based on medical, ethical, and moral grounds the National Perinatal Association - a multidisciplinary organization of parents and professionals who serve and advocate for pregnant women, newborns, and their families - unequivocally denounces the practice of separating migrant children from their parents as part of the current administration's immigration policy. We call on all our elected officials to address the harm that this policy has inflicted and continues to inflict on migrant families.

Decades of research in child development clearly show that this kind of traumatic separation has long-lasting detrimental health effects, including a greater vulnerability to chronic health problems, increased risks for mental health disorders, eating and sleeping disturbances, poor academic progress, and unresolvable grief.[1-3]

For babies who need breast milk, this separation has interrupted normal immunologic and emotional development, while at the same time placing the lactating woman at risk for various medical complications.

For older children and teens that may have already witnessed violence, experienced poverty, and lived with insecurity this separation represents a secondary trauma that has served to reinforce these negative experiences and circumstances they were fleeing from.

> ***"Separating families subjects migrant children to the same level of toxic stress and trauma that we as professionals see in cases of child abuse and abandonment, and it represents a level of cruelty that is untenable in civil society "***

The scientific evidence is clear: Separating migrant children from their caregivers is tantamount to child abuse.

Since the inception of immigration laws in the 1980's aimed at prosecuting undocumented immigrants that have entered the United States, these matters had been handled as civil matters, allowing for families to remain intact while immigration proceedings were held. In April of this year, these proceedings were turned into criminal cases by the Department of Justice as part of a "zero tolerance" policy, thus justifying the separation of parents from their children. This change has resulted in an unprecedented number of children being remanded to custody of the state and detained in makeshift facilities, tent cities, and empty, re-purposed warehouses and stores, with little legal, medical, or educational oversight and a complete lack of transparency.

The members of NPA believe we have a moral and ethical obligation to protect children through preservation of the family unit. Separating families subjects migrant children to the same level of toxic stress and trauma that we as professionals see in cases of child abuse and abandonment, and it represents a level of cruelty that is untenable in civil society.[4]

Clear medical and developmental evidence demands immediate termination of this practice and requires that we provide positive, evidence-based interventions that will help to heal these families.[5]

The National Perinatal Association will continue to support and speak out for women, children and their families from all walks of life, regardless of documentation, and we hope that our colleagues in the medical, developmental, and advocacy fields will do the same until this administration reverses this cruel and traumatic policy and creates a plan for reunification and trauma-informed intervention that can help these families heal and be restored.

On behalf of the National Perinatal Association,

Jerasimos Ballas, MD, MPH, President Elect

Amy Akers, NPA President

JaNeen Cross, DSW, MSW, MBA, LCSW, BCD, Advocacy Committee Chair

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The authors have no conflicts of interests to disclose.

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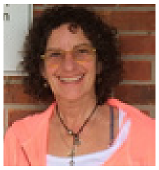

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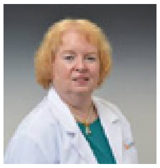

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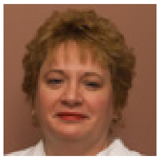

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Peer Reviewed

How Congress Can Help with Coverage Parity for Medically Necessary Foods and Treatment for Infants and Children

Alliance for Patient Access (AfPA) Government Affairs Team

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

As a parent, it is often hard to convince a toddler or child to try and eat a variety of fruits, vegetables, and proteins. Families are often faced with the additional challenge of monitoring and managing inherited metabolic disorders or digestive disorders diagnosed during infancy and childhood. Federal legislation to aid families in their access to "medically necessary foods" was introduced in Congress last year and continues to gather cosponsors as a means to help families combat their child's access to treatment for these conditions.

According to congressional findings listed in federal legislation introduced last year, medically necessary foods are not "uniformly reimbursed by health insurance," and therefore the financial burden falls to families for coverage of treatment to accommodate basic, life-sustaining needs, i.e. to keep their medically-challenged child nourished.

In May 2017, the Medical Nutrition Equity Act (S. 1194/H.R. 2587) was introduced with the intent to improve coverage, under Federal health programs (including Medicare, Medicaid, other specified federal health-care programs) and private health insurance, for foods and vitamins that are medically necessary for the management of certain digestive and metabolic disorders and conditions.

The legislation is bipartisan and the House and Senate bills are identical.

According to the American Partnership for Eosinophilic Disorders (Apfed) there are twenty states that have passed laws to increase insurance coverage for medical foods. Apfed also notes that families in the Eosinophilic gastrointestinal diseases (EGIDs) patient community can pay as much as "$1,200 or more out-of-pocket for a one-month supply of prescribed formula," as part of the patient's treatment regimen. The conditions and covered diseases contemplated in the federal legislation for coverage parity include: inflammatory bowel disease (e.g. Crohn's disease and ulcerative colitis), eosinophilic digestive disorders, food protein induced enterocolitis syndrome (FPIES), Immunoglobulin E and non-Immunoglobulin E-mediated food allergies, and malabsorption due to liver or pancreatic dysfunction, or short bowel syndrome.

> ***" Cognitive development and physical growth failure are well-known consequences for those that have nutrient deficiencies or inadequate nutrition. "***

U.S. Senator Chuck Grassley (R-Iowa), one of the original cosponsors of the Senate version of the bill, captured some of the conditions he hopes to impact and improve access to treatment for with the introduction of the legislation. His office noted in his support for the bill the example of Phenylketonuria (PKU), a rare inherited metabolic disorder, and mentioned further that "untreated, PKU can result in severe intellectual disability or even death." Because of the success of a federally-sponsored, newborn screening program, however, "PKU can be identified early, and treatment with special foods and medication can lead to a healthy life."

The solutions in the bill are also intended to make "clear that medical nutrition is as important to certain patients as prescription drugs or other medical treatment."

Healthcare Nutrition Council (HNC), an organization dedicated to raising awareness of malnutrition and the profound impact nutritional status has on overall health and treatment outcomes, notes that without access to medical nutrition, the results for infants, children, and adolescents can be dire. Cognitive development and physical growth failure are well-known consequences for those that have nutrient deficiencies or inadequate nutrition. Hospitalization and even death are likely outcomes though if treatment cannot be acquired.

In addition to patient protections through insurance coverage requirements, the Medical Nutrition Equity Act also accounts for preservation of the patient-physician relationship. The bill's provisions acknowledge that those medical foods and medically necessary treatments that are prescribed, ordered, and recommended by a qualified physician or health care provider, should justify coverage by health insurance plans. Parents and patients faced with these conditions trust their medical provider or pediatrician to design a treatment plan based on the patient's interaction with the provider, the provider's medical expertise, and the provider's unique knowledge of the patient's medical history. Insurance companies that make coverage determinations do not experience this direct interaction with the patient requiring significant nutritional interventions.

Finally, the bill does not limit coverage to only foods and vitamins, but provides requirements for coverage of medical supplies and medical equipment (such as feeding tubes) that are a conduit to absorption of food and nutrients.

The American Academy of Pediatrics (AAP) has endorsed the legislation.[1]

[1] https://downloads.aap.org/DOFA/5-23-17%20Medical%20Nutrition%20Equity%20Act%20Support%20Letter%20Senate.pdf

NT

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 to request a free copy of the 2017 whitepaper, "Reaching Preemie Parents Today" (*Heather McKinnis, Director, Preemie 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.

Graham's FOUNDATION
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Visit **www.GrahamsFoundation.org** to learn more.

Compiled and Reviewed by Mitchell Goldstein, MD Editor in Chief

Springer Nature Announces Search for New Editor-in-Chief of the Journal of Perinatology (Originally posted in NT May, 2018)

An international search for a new Editor-In-Chief is under way.

Editor-in-Chief

Journal of Perinatology

The official journal of the Section on Neonatal-Perinatal Medicine, American Academy of Pediatrics,and of the National Perinatal Association of the United States

Springer Nature, together with the Section on Neonatal-Perinatal Medicine, American Academy of Pediatrics and the National Perinatal Association of the United States, announce an exciting opportunity for an exceptional candidate to serve as Editor-in-Chief of the Journal of Perinatology (JPER).

The Journal of Perinatology provides all members of the perinatal/neonatal healthcare team with original information pertinent to improving maternal/fetal and neonatal care, embracing the full scope of the specialty, including clinical, professional, political, administrative and educational aspects. The Journal also explores legal and ethical issues, neonatal technology and product development.

Candidates should have a Ph.D., M.D., or equivalent degree, and a comprehensive knowledge and understanding of the field of perinatal and neonatal healthcare. In addition, candidates should have a distinguished research and publication record, high standing among peers, and prior experience in peer-review activities related to the publication of research in the field of perinatology.

Responsibilities include timely review of manuscripts under consideration by the journal, closely collaborating with the Publisher to appoint Section Editors and the Editorial Board, and commissioning submissions in areas of interest and scope. The Editor-in-Chief will work routinely with the Publisher, the Section on Neonatal-Perinatal Medicine, American Academy of Pediatrics and the National Perinatal Association of the United States, on journal development with the goal of raising the journal's impact and advancing the field of perinatology.

A full description of the responsibilities involved is appended to this announcement. The appointment will be a five-year term, and a small editorial stipend is included.

Interested candidates should submit their curriculum vitae, statement of interest, and a vision statement for the journal to Nickie Roake, Publishing Manager of JPER, at nickie.roake@nature.com.

Deadline for applications: 31st July 2018

Duties and responsibilities of the Editor-in-Chief

The Editor-in-Chief is responsible for driving the strategic direction of the journal in collaboration with the Editorial Board and Springer Nature, and with input from the Section on Neonatal-Perinatal Medicine, American Academy of Pediatrics and the National Perinatal Association of the United States. He/she is the figurehead of the journal and is responsible for raising the journal's profile within the community, and ensuring that content published meets the editorial strategy and policies of the journal, as stated in the journal's aim and scope.

The Editor-in-Chief is responsible for the content of the journal, normally making all final decisions (i.e., accept, revise, or reject) regarding the disposition of manuscripts. In addition, the Editor-in-Chief has the following responsibilities:

- To work with the Publisher and editorial team to develop improved ways to optimized the content, quality and speed of publishing of high quality articles. This includes:
    i. Soliciting content and encouraging potential authors,
    ii. Commissioning Review papers and Editorials, and
    iii. Coordinating/commissioning themed special issues.
- To continually seek to improve the journal's standing among perinatal/neonatal journals via maintaining and increasing the impact factor.
- To recruit an international and diverse expert panel of Section Editors and Editorial Board members.
- To ensure that all Section Editors are properly trained to perform their duties, and to monitor their performance (including acceptance rate and manuscript handling times).
- To perform initial evaluation of submitted manuscripts to ensure that they are properly within the scope of the journal

and meet minimum requirements for a research paper, and to reject outright swiftly those which do not merit external review.

- To monitor the progress of manuscripts to ensure timely processing with help from the Editorial Assistant.
- To ensure that the review process is carried out with fairness and integrity. In particular, to ensure that procedures for exposing and managing conflicts-of-interest or misconduct are in place and adhered to.
- Chair an annual Editorial Board meeting, in collaboration with the Springer Nature JPER Publishing Manager.
- To manage the annual publication target/ page budget as set by Springer Nature.
- To promote the journal among the community of authors in order to maintain a pipeline of quality submissions.

NT

CDH (Congenital Diaphragmatic Hernia) International is looking for: Grant Writer / Fundraisers

An international search is under way..

Wake Forest, NC – 21 Jun

JOB OPPORTUNITY: Grant Writer / Fundraiser

23 year old international medical non-profit based locally in Wake Forest, NC is looking for a part-time grant writer / fundraiser. Job duties would include; finding and applying for operating and research grants, follow up on all grant applications, networking with potential donors and grantors, planning and executing large annual gala, assisting with annual on-line telethon, overseeing fundraising committees, assisting volunteers planning smaller fundraisers through information and guidance and social media posts of fundraisers.

Office located in beautiful downtown Wake Forest. Required 3 days a week on a flexible schedule. Preferably in house but telecommunication considered for the right applicant. Base salary. Bonus compensation for goals met. No benefits at start. Quarterly goals set and expected to be met.

We have a great working environment and our goal is to make this position full-time by the end of the year (dependent upon success of employee to achieve funding goals).

CDH International works with children born with Congenital Diaphragmatic Hernia (CDH). CDH occurs when a baby's diaphragm fails to fully form, allowing organs to enter into the chest cavity and prevent lung growth. 50% of babies diagnosed with CDH do not survive. The cause is unknown. CDHi works with over 6400 families in 70 countries, provides research, support services and raises global awareness. Learn more at http://www.cdhi.org

This is an incredible opportunity to work with the largest CDH charity in the world and to directly help save the lives of 1000's of children.

No recruiters please.

Please send cover letter, CV and 2 references to dawn.ireland@cdhi.org

NT

American Academy of Pediatrics, Section on Advances in Therapeutics and Technology Membership Drive (Originally posted in NT June, 2018)

American Academy of Pediatrics (AAP), Section on Advances in Therapeutics and Technology (SOATT) announces a membership drive

The American Academy of Pediatrics' Section on Advances in Therapeutics and Technology (SOATT) invites you to join our ranks! SOATT creates a unique community of pediatric professionals who share a passion for optimizing the discovery, development and approval of high quality, evidence-based medical and surgical breakthroughs that will improve the health of children. You will receive many important benefits:

- Connect with other AAP members who share your interests in improving effective drug therapies and devices in children.
- Receive the SOATT newsletter containing AAP and Section news.
- Access the Section's Website and Collaboration page – with current happenings and opportunities to get involved.
- Network with other pediatricians, pharmacists, and other health care providers to be stronger advocates for children.

- Invitation for special programming by the Section at the AAP's National Conference.
- Access to and ability to submit research abstracts related to advancing child health through innovations in pediatric drugs, devices, research, clinical trials and information technology; abstracts are published in Pediatrics.

AAP members can join SOATT for free. To activate your SOATT membership as an AAP member, please complete a short application at http://membership.aap.org/Application/AddSectionChapterCouncil.

The Section also accepts affiliate members (those holding masters or doctoral degrees or the equivalent in pharmacy or other health science concentrations that contribute toward the discovery and advancement of pediatrics and who do not otherwise qualify for membership in the AAP). Membership application for affiliates: http://shop.aap.org/aap-membership/ then click on "Other Allied Health Providers" at the bottom of the page.

Thank you for all that you do on behalf of children. If you have any questions, please feel free to contact:

Mitchell Goldstein, MD, FAAP, Section Chairperson, MGoldstein@llu.edu and

Christopher Rizzo, MD, FAAP, Membership Chairperson, crizzo624@gmail.com

NT

Researchers Design Delivery Sysem to Treat Premature Infants with Necrotizing Enterocolitis that may have applications beyond NICU

Columbus - 07/11/2018

Most of the time, we think biofilms are bad news. And when pathogenic microbes form biofilms, they are. The biofilms created by pathogenic microbes create fortresses that make them resistant to attack by the immune system and to current antimicrobial treatments. These fortresses make eradicating infections difficult.

But what if you could use biofilms for good? That's just what Gail Besner, MD, Steve Goodman, PhD, Michael Bailey, PhD, Lauren Bakaletz, PhD, and their teams at Nationwide Children's Hospital are investigating.

They have developed Lactobacillus reuteri biofilm formulations that protect against experimental necrotizing enterocolitis (NEC), first described in Journal of Pediatric Surgery in 2016. A new iteration of the technology may help further reduce the incidence of NEC.

"NEC is a devastating problem for premature infants. Despite decades of research, 10 percent of infants born under 1500 g will develop NEC, and we haven't made significant progress in the prevention or treatment over the years — mortality remains as high as 30 percent for these babies," says Dr. Besner, chief of Pediatric Surgery at Nationwide Children's.

Bacterial colonization of the infant's gut is critical to healthy development. Although variability exists among individuals, premature infants tend to have reduced microbiome diversity and stability, and increased numbers of pathogenic Gammaproteobacteria, according to the publication.

"Using probiotics to treat NEC is not a new idea, but administering free-living probiotics has had variable results in clinical trials," explains Dr. Besner, also a professor of Surgery and Pediatrics at The Ohio State University. "Our idea was to develop a safe, effective delivery mechanism to support a one-dose treatment to prevent NEC. In our animal models of the disease, this is what we appear to have accomplished."

To create the biofilm, cultures of L. reuteri are introduced to porous, biocompatible, biodegradable 50 μm diameter dextranomer microspheres. During a brief incubation, the bacteria adhere to the microspheres and form a biofilm. In the biofilm state, the probiotics have increased resistance to gastric acidity and increased adherence to the gastrointestinal mucosa compared to free-floating bacteria.

Now, the team has published the results of their latest iteration of the technology — testing the effects of enhancing the microspheres with sucrose or maltose as diffusible cargo. The study, published in American Journal of Physiology, reports enhanced performance of the single dose L. reuteri biofilm in experimental NEC.

According to the authors, in addition to reducing the incidence of NEC in animals, the enhanced formulation improved animal survival, reduced intestinal mucosal barrier breakdown and limited intestinal inflammation. The L. reuteri microspheres loaded with maltose also augmented the persistence of numerous Lactobacillus species in the intestinal tract and shifted the gut microbiome to be more similar to that of breast-fed babies.

"Given the microbiome disruption observed in preterm infants who go on to develop NEC, a treatment that preserves the microbiome holds great promise as an intervention to prevent NEC," says Dr. Besner, who is senior author of the recent publication. "Furthermore, our novel probiotic delivery system limits the expansion of pathogenic bacteria such as Enterobacter species, providing further evidence that it attenuates detrimental NEC-induced dysbiosis."

All of the components — the probiotic, the microsphere, the sucrose/maltose — used in the proposed intervention are "Generally Recognized as Safe" (GRAS) by the U.S. Food and Drug Administration (FDA). The scientists hope that this will be an advantage as they begin to work to *develop clinical trials using the L. reuteribiofilm preparation.*

"The use of these microspheres represents an exciting development in improved probiotic administration. As we continue to learn more about the human microbiome and its relationship to health and disease, probiotic administration may play an increasingly important role in disease prevention and management — not just for the application to NEC," says Dr. Besner.

Previous clinical trials of probiotics to prevent NEC have had variable results. Dr. Besner and her colleagues believe that the novel delivery system that they have developed will offer significant advantages over L. reuteridelivered in its free-living form. To that end, they are in talks with the FDA to design a clinical trial to test the delivery system in humans.

Drs. Besner, Goodman, Bailey and Bakaletz are the scientific founders of a preclinical stage company — Scioto Biosciences — created to bring microbiome therapeutics to the marketplace.

NT

KY Moms: U.S. Should Not Discourage Breastfeeding

Just 13 percent of moms are able to breastfeed their child six months after birth. (Pixabay)

July 16, 2018

FRANKFORT, Ky. — Some parents are still reeling from word of the United States' opposition to a global resolution supporting breastfeeding. According to a New York Times article, the U.S. wanted to water down a World Health Assembly resolution promoting and protecting breastfeeding around the world.

Alex Turpin with the Le Leche League of Louisville said she is worried about threats to the scarce breastfeeding resources that are available. She said a lot of parents are not able to get the support they need.

"So then they rely on other government-funded resources such as WIC, where if you're on Medicaid, you could go to the hospital you delivered at and see the lactation consultant there," Turpin said. "And even with those resources, still a lot of parents don't meet their own breastfeeding goals."

Turpin said while it's understandable that not everyone chooses or is able to breastfeed, she contends the U.S. should not be speaking out against a biologically important source of nutrition for babies. A spokesperson for the U.S. Department of Health and Human Services denied the U.S. is anti-breastfeeding, and argued the issue was about protecting "women's abilities to make the best choices for the nutrition of their babies."

Co-founder of Moms Rising Kristin Rowe-Finkbeiner said only 13 percent of moms are able to breastfeed at six months out, sometimes because of barriers in the workplace. She said the United States is behind other industrialized nations when it comes to supports for working mothers

"One hundred seventy-seven other countries do have a paid family medical leave program," Rowe-Finkbeiner said. "And studies show that when you have paid family medical leave programs, there is more time to establish breastfeeding to bond and to establish a healthy start in life."

Rowe-Finkbeiner noted that infant formula is a $70 billion industry, and said she believes the Trump Administration is putting corporate interests above public health.

"That's not to say that infant formula isn't needed," she said. "Women need to be able to choose whether they can breastfeed or need formula or need both. We want people to have an option; we don't want people to be railroaded."

She added that breastfeeding also has economic benefits. A Cambridge Health Alliance and Harvard School of Medicine study found the U.S. could save nearly $13 billion a year in pediatric health costs and premature deaths if mothers could meet current medical recommendations for breastfeeding.

Mary Kuhlman, Public News Service - KY

NT

"Stuck in Bed: The pregnancy bed rest picture book for kids … and moms" is now available on Amazon!

Maternal care and high-risk pregnancy experts Jennifer Degl & Angela Davids release Stuck in Bed, a picture book for children whose mothers are on bed rest

NEW YORK, UNITED STATES, April 19, 2018 /EINPresswire.com/ -- Experts in Maternal Care and High-Risk Pregnancy Release Stuck in Bed: The pregnancy bed rest picture book for kids ... and moms

In recognition of World Maternal Mental Health Awareness Week (April 30 - May 6) and just in time for Mother's Day, maternal care and high-risk pregnancy experts Jennifer Degl and Angela Davids have released Stuck in Bed, a picture book for children whose mothers are coping with bed rest or restricted activity, due to a high-risk pregnancy.

Purchase Stuck in Bed on Amazon here: http://amzn.to/2H5JJYS

Stuck in Bed is a story about a boy whose mother is on bed rest, and it weaves positive and practical tips for moms throughout, making it an uplifting and emotionally supportive resource for women on bed rest or who have been advised to restrict their activity during pregnancy. Maternal care experts Jennifer Degl, Founder of Speaking for Moms and Babies, Inc., and Angela Davids, Founder of the high-risk pregnancy website KeepEm-

Cookin.com, are the co-authors.

"While high-risk expectant mothers are monitored by health care providers, there is still a lack of emotional support for moms who are prescribed bed rest," explains Degl. "Much of the time they are by themselves at home or in a hospital bed, feeling very isolated. Stuck in Bed let's them know they aren't alone and gives them a tool to help explain their bed rest to a younger child."

Given that the U.S. preterm birth rate is 9.8 percent of all deliveries, Stuck in Bed is a valuable and in-demand resource as about 1 million U.S. women are prescribed bed rest each year in order to reduce the likelihood of a premature delivery. Bed rest is prescribed for many serious conditions, including preterm labor, short cervix, premature rupture of membranes, preeclampsia, and several placental disorders, making Stuck in Bed an invaluable tool for obstetricians, maternal-fetal medicine specialists, social workers and psychologists who work in maternal care. Mental health professionals who work with young children experiencing stress related to their mother being on bed rest can also benefit by using Stuck in Bed as a tool for discussion.

"Stuck in Bed helps kids and moms adjust to their new reality," adds Davids. "We want to show high-risk mothers how they can still be the best moms ever in the eyes of their children. We teach them how to make the most of their time together and guide them in talking to their children about bed rest in a positive way."

The Stuck in Bed co-authors are available for press interviews and bookstore engagements. Wholesale opportunities are available to health care providers and organizations in the maternal care field. Email info@stuckinbedbook.com for more information. Stuck in Bed is a collaborative partner of Better Postpartum and is a partner in The Blue Dot Project's Maternal Mental Health Awareness Week. Speaking for Moms and Babies, Inc. and KeepEmCookin.com are members of the Preemie Parent Alliance. Learn more at StuckInBedBook.com.

About Stuck in Bed

Stuck in Bed is a picture book about pregnancy bed-rest from a young boy's perspective. Kids ask a lot of questions, and Stuck in Bed's mom answers her son's questions with optimism and excitement. She reassures her son that although things will be different for a little while, the two of them can have a lot of fun in the meantime! Moms having a high-risk pregnancy can also use some reassurance, so Stuck in Bed includes tips for being a fantastic mom, even when stuck in bed. Moms are also shown how to make the most of time together with their children and guides them in talking to children about bed rest in a positive way. Learn more and participate in free giveaways and live-chats on Facebook and Twitter and email info@stuckinbedbook.com for more information or visit: http://www.stuckinbedbook.com/ and purchase the book at http://amzn.to/2H5JJYS.

About the Authors

Jennifer Degl is the founder of Speaking for Moms & Babies, Inc., that advocates for maternal and neonatal health by sharing the parent voice, and is the author of another book called From Hope to Joy: A Memoir of a Mother's Determination and Her Micro Preemie's Struggle to Beat the Odds. She endured 6 weeks of both home and hospital bed rest, due to a life-threatening case of placenta accreta, while her youngest child was just 3 years old and he had a difficult time understanding what was happening. Jennifer has since become an advocate in maternal and neonatal health care and spends her free time speaking about maternal and neonatal health at events both locally, nationally and on Capitol Hill. Jennifer is a high school science teacher and lives in New York with her husband and four children. To learn more, please visit Speakings for Moms and Babies.com

Angela Davids is the creator of KeepEmCookin.com, an educational website and online support group for women who are experiencing a high-risk pregnancy or who are at risk of delivering prematurely. She spent a total of 21 weeks on bedrest during her two pregnancies. She faced multiple complications, but ultimately delivered her daughter at 39 weeks and her son at 39 weeks and 3 days. Her favorite part of running KeepEmCookin.com is reading the many success stories she hears from members. She can say with confidence, "Anything is possible." Visit KeepEmCookin.com to connect with other women on bed rest.

NT

Mom's Voice May Help Babies Sleep Better in the NICU

" Does a stay in the NICU result in long term sleeping issues?"

Newswise — ANN ARBOR, Mich. – Babies who spend their first days or weeks of life in the Neonatal Intensive Care Unit may not sleep as soundly as those who go home.

Now, researchers are examining whether one simple difference could help soothe these infants to sleep: the sound of their mother's voice.

When they were played recordings of their mothers reading children's books, babies in the NICU slept better and woke up less often, according to a new abstract presented at this week's annual meeting for Sleep Medicine hosted by the Associated Professional Sleep Societies.

"In the hospital, we take care of babies who are not in their usual environment, which can hinder their ability to have normal sleep," says lead author Renée Shellhaas, M.D., M.S., a pediatric neurologist at University of Michigan C.S. Mott Children's Hospital.

"Even though we do our best to make the ICU as quiet an environment as possible, there are hospital disruptions that are unavoidable. Alarms, monitors, ventilators, bedside care and even just the building's heating and cooling noises may be disruptive. We designed this study to see how the sound environment in the NICU potentially influences sleep and to see if there are relatively simple interventions that may make a difference."

"What we found was that babies in the NICU were more likely to stay asleep when the recordings of their mothers' voices played than they were without them."

More about the study

The study enrolled 50 babies born after at least 33 weeks gestation, who were medically stable and lacked any congenital conditions increasing risks of sleep troubles. For six hours, a recording of their mother reading books played continuously. The babies' sleep was monitored during the recordings and for another six hours without the recordings.

NT

Trump Signs Order to End Separations Condemned by Pediatricians

June 21, 2018
AUSTIN, Texas – Following widespread outrage over the forced separation of children from their parents arrested on suspicion of entering the country illegally along the southern U.S. border, President Donald Trump on Wednesday signed an executive order to end the practice.

Trump previously had said he could not end the separations, repeatedly blamed Democrats for them and said it was up to Congress to act.

Both Republicans and Democrats strongly opposed the separations, as did many ordinary Americans, and medical and mental health experts.

Dr. Dennis Conrad, president of the Texas Pediatric Society, says separating and institutionalizing children can put their health at substantial risk.

He notes the initial impact is fairly clear to parents or anyone who has cared for children.

"Pictures of them crying and screaming, and wishing to remain with their parents as they're forcibly removed, is evidence of the anxiety that they feel with that immediate separation and that fear," he states. "That creates what's called increased stress."

If that stress continues over a period of time, Conrad says it creates what's known as a toxic stress environment.

"Children who actually are in a persisting toxic stress environment do not develop appropriately," he explains. "They're subject to anxiety, night terrors, fear of separation and other adverse consequences."

Conrad adds children separated for prolonged periods of time frequently don't recognize a parent for direction and guidance, which can create additional problems if they're reunited.

Forced separations are not unprecedented in the U.S. Children of slaves were often sold away from their parents, and after the Wounded Knee massacre, officials moved Native American children into government or church-run boarding schools.

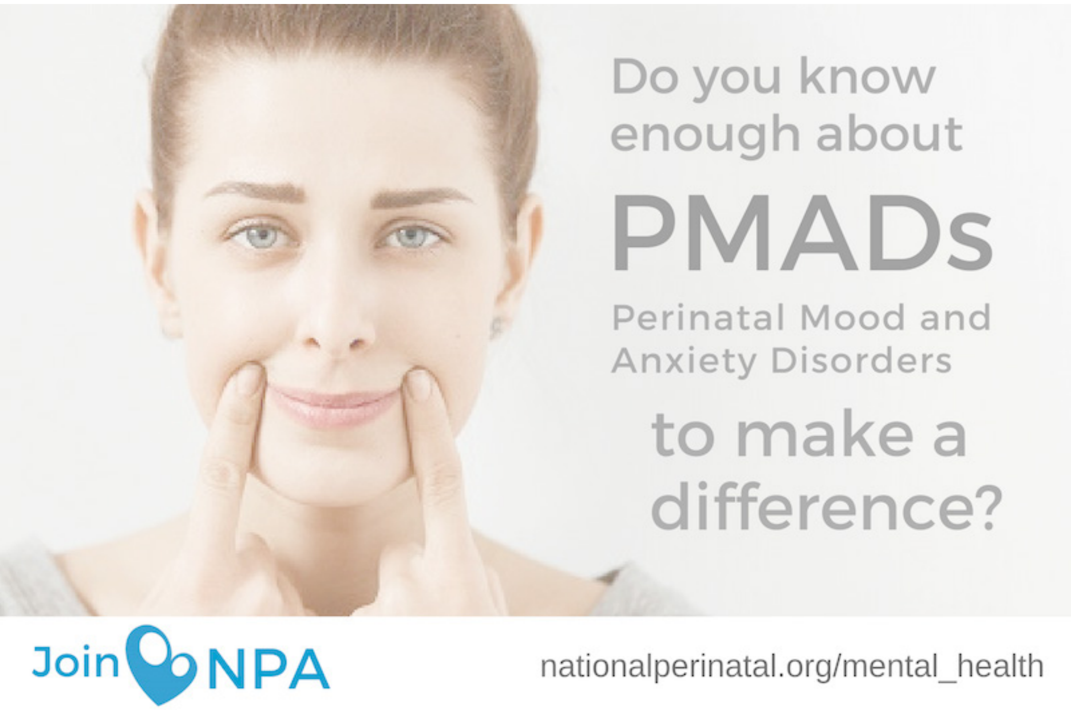
Conrad says a body of research shows how disrupting a family unit can lead to long-term consequences.

"They have an increased risk for certain mental health problems, including depression," he explains. "They have a potential for having higher suicide rates when they're specifically looked at under those conditions. And they have a higher probability of substance abuse."

The Texas Pediatric Society and the American Academy of Pediatrics have publicly condemned the separation of children from parents at the U.S. border, calling the practice "inhumane and unnecessary."

Eric Galatas, Public News Service - TX

NT



Peer Reviewed

FROM THE NATIONAL PERINATAL INFORMATION CENTER

Special Report: Maternal Substance Use Disorder and Neonatal Substance Use Exposure

Sandra A. Boyle, BS and Janet H. Muri, MBA

Sandra A. Boyle has over 18 years experience in health care data management and analysis. She joined NPIC in 1996 as a Data Coordinator and Hospital Liaison. As Director of Membership Services, Ms. Boyle is responsible for managing the recruitment, enrollment and reporting for all member and non-member hospitals. She has played an integral part in the design and development of NPIC performance measurement reporting and is the principal contact with The Joint Commission regarding the Core Measure services NPIC offers. Ms. Boyle has a Bachelor of Science in Health Services Administration from Providence College.

Janet H.. Muri has been with the National Perinatal Information Center since 1986 and it's President since 2007. Ms. Muri oversees all collection, processing and analysis of clinical and financial data submitted by NPIC member hospitals and other state, federal and private data sources related to contract work. She is the principal on many of the NPIC contracts including the Defense Health Agency Perinatal Performance Information Project, the Georgia Regional Perinatal Care Network project and the Alliance for Innovation in Maternal Health (AIM).

NPIC

National Perinatal Information Center

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, public and private entities, patient safety organizations, insurers and researchers to collect and interpret the data that drives better outcomes for mothers and newborns.

Background

Substance Use Disorder (SUD) is a growing concern nationwide. SUD is particularly challenging during pregnancy. It is estimated that 5% of women use illicit drugs during pregnancy and 49%-94% of infants exposed to opioids in utero experience neonatal abstinence syndrome (NAS).[1,2] Women face several pregnancy risks while using substances including pregnancy loss and premature births.[3]

Pregnant women are often unwilling to disclose their habits of substance abuse out of fear for legal repercussions, shame, and biased, negative responses from health care providers. The importance of providing staff with education and sensitivity training helps to provide patients with a balance of control and support and create a non-judgmental attitude by staff to help build a trusting relationship with women who have substance abuse problems.[4] The problem of under reporting needs serious attention and may be improved when women feel SUD will be addressed in an unbiased and caring manner.

The Maternal and Child Health Bureau of the Health Resources Services Administration (MCHB/HRSA) Alliance for Innovation on Maternal Health (AIM) program recently introduced the "Obstetric Care for Women with Opioid Use Disorder" patient safety bundle designed to identify hospital specific opportunities to improve the readiness, recognition/ prevention, response, and reporting/ systems learning when reaching out to and managing pregnant women with opioid/substance use disorder. The 4th R: "reporting/ systems learning" encourages providers to "develop mechanisms to collect data and monitor process and outcome metrics to ensure high quality healthcare delivery for women with SUDs" .[5]

The AIM Opioid Use Disorder Task Force and Data Workgroup are actively engaged in operationalizing all aspects of the bundle but recognize that data collection is a particularly challenging undertaking when attempting to define critical prenatal, delivery and postpartum information needed to identify, track and care for OUD/SUD women. Until all the data elements identified are fully integrated into an electronic medical record, some manual data collection is highly likely.

NPIC Maternal Substance Use Disorder and Inborn Substance Use Exposure Analysis

The National Perinatal Information Center recently completed an analysis of maternal substance use disorder and inborn substance use exposure on its CY 2017 Perinatal Center Data Base (PCDB) of administrative/inpatient discharge data. The data set includes 329,856 delivery discharges and 333,879 inborn discharges. The administrative data set provides readily available secondary data from which providers can glean their overall coding/recognition of delivering women with SUD and their impacted infants.

This analysis is the third report NPIC has issued on the complications and outcomes of substance use during pregnancy that are documented in the administrative data set at the time of delivery. Previous reports were created using ICD-9 codes, a much more limited diagnosis and procedure code set. The introduction of ICD-10 coding in October, 2015 allowed for greater specificity of substance use on the maternal side and substance exposure on the neonatal side.

Some key maternal findings from the CY 2017 analysis include:

- For hospitals participating in the PCDB, the average rate of deliveries with Substance Use Disorder (SUD) coding was 2.4% of total deliveries (range: .1-11.1%); these cases stayed an average of 3.3 days compared to 2.8 days for deliveries without SUD coding.
- On delivery discharge records with SUD coding, opioid use was coded on 31.7% and cocaine use on 10.3%. The specific type of substance was not identified on 5.2% of the records and 60.7% were coded with substances included in the category “other”.

Key inborn findings:

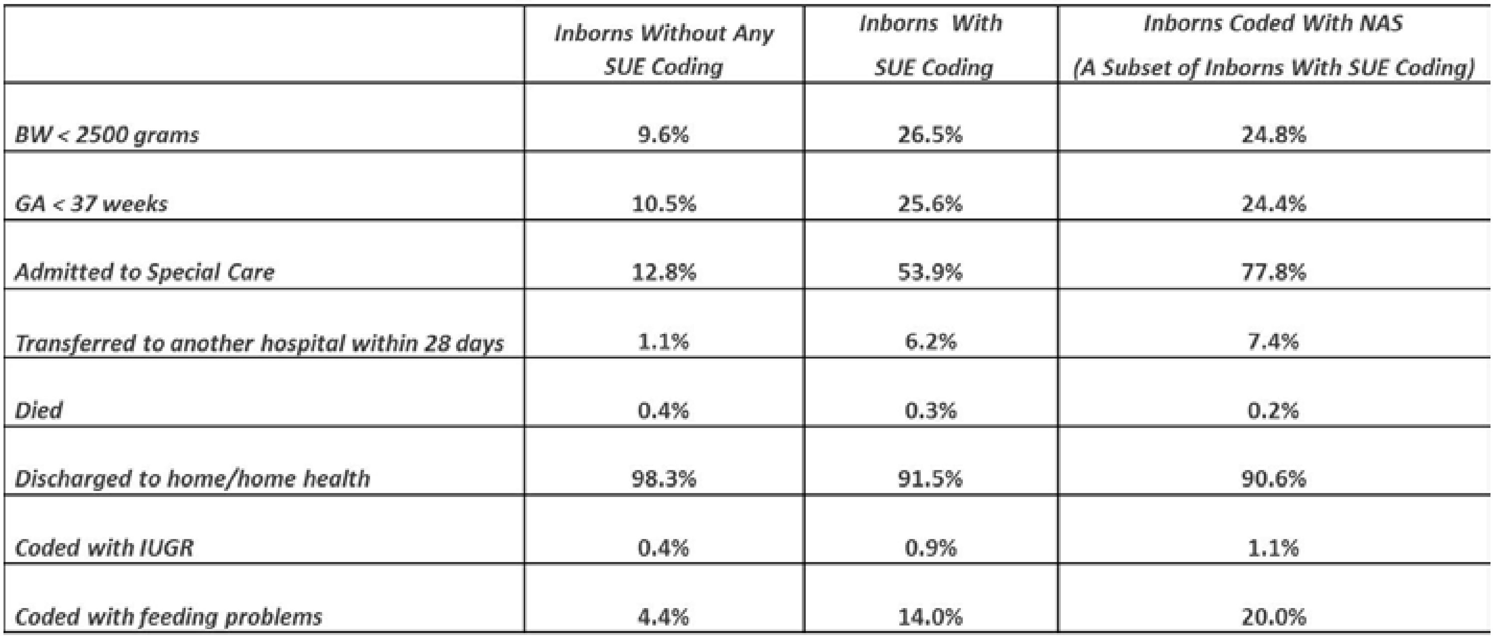
- On average, 2.1% of total inborns (range .4%-10.0%) had Substance Use Exposure (SUE) coding on their records. ALOS for these inborns was 13.3 days compared to 3.8 days for those without any SUE coding.
- Of the inborns with SUE coding, on average, 45.4% were coded with Neonatal Abstinence Syndrome (NAS). The table below shows the comparison between inborns without any SUE coding and those with SUE coding overall and specifically NAS.

Linked Mother/Baby Analysis

NPIC has one of the largest linked mother/baby data sets in the country. Looking at maternal complications and co-morbidities and their impact on the baby is a very helpful way to look at the dyad in the birth experience. When NPIC has examined SUE/NAS cases in the past we have found that often an infant will be identified at birth with SUE/NAS but when linked back to the mother, the mother’s record is not coded with any substance use. This CY 2017 analysis was no different. On average, 49.2% of inborns with SUE coding were linked to a mother with SUD coding. Unfortunately, this implies there was no documentation of substance use in the mother’s record for over 50% of the linked inborns with SUE coding.

Trends

The analysis also included trend information from a subset of hospitals that have participated in the PCDB for the previous five years. The rate of deliveries with SUD coding and rate of inborns with SUE coding and/or NAS were all shown to be statistically stable over the nine quarter period since ICD 10 coding was introduced, Q4 2015-Q4 2017. NPIC’s 2015 analysis on NAS covered the period 2010-Q1 2015 and showed a statistically significant upward trend with NAS rates increasing from .45% (4.5/per 1,000 live births) in 2010 to .76% (7.6 per 1,000 live births) in Q1 2015. The current rate of .8% (8/1,000 live births) mirrors the Q1 2015 rate and seems to suggest that the identification of inborns with NAS has leveled off over the last 2.25 years. NPIC looks to the clinical leadership at our PCDB hospitals to comment on the profile of the coded data relative to the incidence of SUD/SUE at their own institutions.



	Inborns Without Any SUE Coding	*Inborns With SUE Coding*	*Inborns Coded With NAS (A Subset of Inborns With SUE Coding)*
BW < 2500 grams	9.6%	26.5%	24.8%
GA < 37 weeks	10.5%	25.6%	24.4%
Admitted to Special Care	12.8%	53.9%	77.8%
Transferred to another hospital within 28 days	1.1%	6.2%	7.4%
Died	0.4%	0.3%	0.2%
Discharged to home/home health	98.3%	91.5%	90.6%
Coded with IUGR	0.4%	0.9%	1.1%
Coded with feeding problems	4.4%	14.0%	20.0%

Questions regarding this analysis should be directed to web_admin@npic.org

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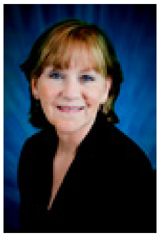

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Peer Reviewed

Awards and Abstracts from the Perinatal Advisory Council, Leadership, Advocacy, and Consultation (PAC-LAC) Annual Meeting

Aida Simonian, MSN, RNC-NIC, SCM, SRN

Awards:

*The **Ellen R. Silver Award for Nursing Leadership** is being awarded to two nurses this year. These two nurses consistently go above and beyond their duties as nurse leaders. They have shown exceptional determination, commitment and passion for the improvement of perinatal healthcare. This year, the Ellen R. Silver Award for nursing leadership goes to Aida Rodriguez and Carolyn Arnold.*

***Aida Rodriguez,** Neonatal Nurse Practitioner, is the CNS at Arrowhead Regional Medical Center, formally known as “San Bernardino County Medical Center.” She grew up in El Salvador in Central America. At the age of seventeen she was accepted into the Bachelors nursing program at Southern Adventist University in Tennessee. At 22 years of age Aida was called to assist as a nursing instructor in Puerto Rico. In 1981, she moved to Loma Linda and embarked on the love of her life, Neonatal Intensive Care Nursing! While working at Loma Linda University Medical Center’s NICU, she completed a Master’s of Science in nursing with an emphasis in Maternal-Child Health and Education. A few years later she became certified as a Neonatal Nurse Practitioner, while married and raising a family of 4 children (all breastfed)! Aida worked at Ventura County Medical Center as an NNP and was then offered a position as an NNP/CNS at San Bernardino County Medical Center (now Arrowhead Regional Medical Center) where she continues to serve in the role of CNS. Aida has been a board-certified lactation consultant since 2000 and is one of the authors of the Model Hospital Breastfeeding Policy.*

***Carolyn Arnold** earned her bachelor’s degree at Oregon Health Sciences University and obtained her Master’s degree in Nursing Leadership at Grand Canyon University. She has 38 years of experience in Maternal Child Health in L&D, Post-Partum, NICU and Pediatrics. Carolyn has worked as a bedside nurse, as well as an educator, charge nurse, manager, and director. She loves educating and is an instructor for NRP, AWHONN Fetal Monitoring and STABLE. She has led teams in the IHI Perinatal Improvement Initiative and in the Premier Perinatal Safety Initiative as well as helped to develop the Arizona Perinatal Education Coalition and the Inland Empire InsteP program. Carolyn is the Principled Investigator on a Pilot Study on Breast Milk Storage Methods and a co-author on a Model Hospital Breastfeeding policy. In 2004, while working as a Perinatal Educator, Carolyn earned the Nightingale Nurse of the Year Award for Maricopa Integrated Health System, in Phoenix, AZ. Carolyn is also the proud grandmother of a 6-year-old boy who keeps her very busy at T-Ball games, Ju Jitsu and Parkour Classe*

*The recipient of this year’s **William Ginsberg Integrity Award** is a respected physician with a passion for neonatal care. He often challenges himself and others in seeking best practices. His dedication to lead others is truly epitomized by his actions as well as his commitment to lead by example. His exemplary service to our Perinatal and Neonatal services are often cherished by the mothers and families of this unique patient population. His style of collaboration is to seek a plan of care to keep mother-baby dyads together whenever possible.*

*This year the **William Ginsberg Integrity Award** goes to **Dr. Steven Chin**. Dr. Steven Chin is the Regional Director of Neonatology for Children’s Hospital LA and Providence Hospital Health System, as well as the Head of Quality and Performance Improvement of Neonatology.Dr. Chin is also an Associate Clinical Professor of Pediatrics at the Keck School of Medicine at USC. He graduated from Harvard and completed residencies at both RUSH and Harvard.He is passionate in the sciences related to informatics, antibiotic stewardship as well as maternal and infant mental health. Dr. Chin was responsible for rolling out the “Newborn Sepsis Calculator” at three Providence NICU’s in Southern California. Dr. Chin educated the staff and Medical Committees on the tool and its implications. Due to this practice change, a reduction in newborn admissions to the NICU has resulted in a decrease in the numbers of mothers and their newborns being separated. At the Providence Hospital in Tarzana alone admissions to NICU were reduced by 27%. The quality of NICU care has been improved through this project and Dr. Chin’s leadership.*

*In 2015 PAC/LAC began awarding the **“Mitchell Goldstein Dedication to Community Award.”** Individuals were recognized as leaders in health who exhibited exceptional dedication and commitment to improving pregnancy outcomes across the PAC/LAC region. This year’s awardee is a highly respected nurse in our community. She has a passion for increasing the quality of care for pregnant women especially those facing challenges of economic barriers. To achieve this impressive goal, she works closely with physicians and community stakeholders. The 2018 annual Mitchell Goldstein dedication to community award goes to **Asun Williams**.*

Asuncion Williams is the Maternal, Child and Adolescent Health Coordinator for San Bernardino County. Asun started working with San Bernardino County in 1992 as a maternal health clinic nurse. She worked directly with pregnant women and providers as a CPSP practitioner. This opportunity prepared her to understand the barriers of low income pregnant women in her community as well as the difficulties providers face in overcoming the social, economic, and cultural barriers affecting the health of their patients. It is through Asun’s multiple roles as Perinatal Services Coordinator, CHDP Supervisor and MCAH Coordinator that she has learned to navigate and link the resources of different programs to advance the goals and objectives involving this unique patient population. She has fostered a culture of collaboration among public and private providers, managed care plans and community clinics as well as community stakeholders. Asun works to help identify opportunities where the programs she oversees can be more present in community settings with the goal of meeting and connecting with people in their own spaces.

NT

Abstracts:

PACLAC18001:
Keeping Moms and Babies Together: Oral Glucose Gel and Management of Neonatal Hypoglycemia. Sharon McMahon, MSN, CNS, RNC-NIC, RNC-LRN, Henry Mayo, 13845 McBean Parkwa, Valencia, CA 91387, mcmahonsk@henrymayo.com, 661-713-3314
Focus area: Best Practices

In a continuous endeavor to maintain best practice for neonatal care, increasing and maintaining exclusive breastfeeding rates stays at the forefront of our perinatal department's agenda. With the intention to lower the rate of separation of mom's and babies, and positively impact breastfeeding we joined together. In collaboration with all perinatal areas, lactation, pediatrics, neonatology, information systems and the families we serve, in July 2017 we launched the use of oral glucose gel for treatment of neonatal hypoglycemia. Evidence was presented to all staff (Harris,et al, 2013)(AAP, 2011). Following AAP guidelines an algorithm was established, policy and practice were updated and the staff trained one on one. Through two quarters we fine-tuned our data collection, adjusted to the unexpected new glucometers, and managed to drop our rate of admission to NICU with a primary diagnosis of hypoglycemia from 12% to 3% of all hypoglycemic neonates born at our community NICU.

PACLAC18002:
Title: Implementation of Glucose Gel Use for Neonatal Hypoglycemia and Its Impact on Reducing Mother/Baby Separation and Improving Exclusive Breastfeeding Rates. Carolyn Arnold MSN, RN, Mary Haft MSN, MSN, RNC, Dipti Vallabh, RNC, Sarah Wilson, BSN, RNC, Kathleen Clark, RNC. Trina Tu, RN, Alisa Summers BSN, RNC. Memorial Care Orange Coast Medical Center, Email: carnold@memorialcare.org, Phone: 714 378-7645

Focus area: Neonatal Hypoglycemia is a common problem in the first 24 hours of life at times requiring supplementation with breastmilk substitutes, admission to the NICU and the need for IV glucose administration.

Background: AAP recommends routine screening of blood glucose levels for neonates born with risk factors for hypoglycemia. A 2012 clinical trial done in Australia and New Zealand, "The Sugar Babies Study", identified a 51% incidence of hypoglycemia in those at- risk neonates. At Orange Coast Medical Center babies identified with hypoglycemia were treated with breastmilk substitutes and/or IV glucose if unable to normalize the blood glucose levels with breastfeeding and expressed breastmilk. This led to interference with breastfeeding, possible separation of mother and baby, and subjected the neonate to painful procedures.

Methods: Data has been gathered through a retrospective study comparing outcomes for neonates experiencing hypoglycemia prior to implementation of the use of glucose gel to those after implementation of the glucose gel policy. The outcome measures evaluated were amount of mother/baby separation and exclusive breastfeeding at discharge. An order for use of glucose gel for hypoglycemia was added to the newborn order set and a policy and algorithm developed in October 2017.

Results: The use of glucose gel has resulted in a reduction in separation of Mom and Baby due to admissions to our NICU for hypoglycemia and the need for IV glucose and an increase in exclusive breastmilk feeding at discharge in these at-risk neonates. Prior to implementation of the policy 23% of babies with hypoglycemia were discharged exclusively breastfeeding compared to 52% post implementation. Quantitative results will be presented identifying NICU admissions for hypoglycemia, blood glucose levels pre and post treatment, and exclusive breastmilk feeding at discharge for the six months post implementation compared to the six months prior to implementation.

Discussion: The use of glucose gel is a simple, cost -effective treatment for hypoglycemia that can reduce mother/baby separation and can have a positive impact on exclusive breastfeeding rates.

PACLAC18003:
"Modeling Safe Sleep Practices for the Newborn in the Hospital, is it Happening?" Kimberly Kohlieber, RN; 805-558-8233; kimkohlieber@gmail.com and Marietta Sperry, RN BSN, RNC-MNN, CLC; 805-750-6094; MariettaVS@gmail.com
Focus area: Best Practices

Background: Nurses have been noted to model unsafe sleep practices for the newborn in the hospital, despite having been extensively trained. Parents report they repeat this behavior at home. There is a reluctance of nurses to comply, notwithstanding implementation of Back to Sleep programs and documentation of parents being taught safe sleep practices, causing a plateau in the reduction sudden infant death syndrome (SIDS).
Methods: Systematic review of literature from CINHAL, Indiana State University Library, Google Scholar, and PubMed from last five years.
Results: Nurses were found to agree with many guidelines. Personal bias, or habit influenced poor implementation. Although provided with the knowledge, infants were continually placed in unsafe sleep positions, resulting in an inconsistency from knowledge to practice by nurses.
Discussion: Every nurse must model a consistent safe sleep message at every bedside interaction throughout the hospital stay. Interventions could include nurse re-education with mandatory declaration of education, and a Nurse Champion to follow up on unsafe sleep observations. Education should resolve the perceived risk of aspiration for supine positioning by nurses, the primary reason for

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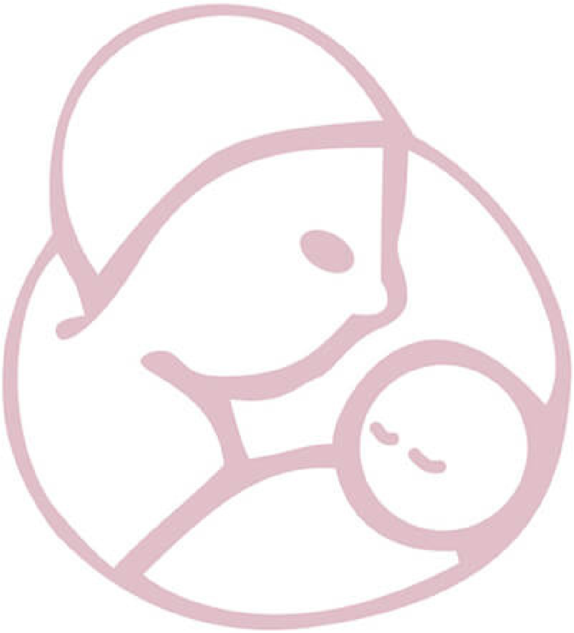

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Providing guidance to healthcare professionals, hospitals and healthcare systems, stimulating higher levels of excellence and improving outcomes for mothers and babies.

Advocacy

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

Consultation

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

non-compliance. Under educated parents use sleep positions modeled by nurses. Nurses must be educated that modeling unsafe sleep behaviors, such as using rolled blankets, bulb syringes to support side lying, or propping the bassinet up in the crib cannot be used in the hospital. Non-supine positioning should be utilized only when medically indicated, and with clear education for parents.

PACLAC18004:

CCS Guidelines for Newborn Hearing Screening Program. Shu-No Chen, Au.D- CCS Audiologist, shunochen@ph.lacounty.gov , 626-569-6197, Cheryl Vidal, RN, MSN- Senior Nursing Instructor, cvidal@ph.lacounty.gov, 626-569-3921, Elizabeth Russel, PhD- Outcomes and Research Coordinator, erussel@ph.lacounty.gov, 626-569-6114

Focus Area- Access to Care, Health Prevention, Best Practices

Background: Hearing loss occurs in newborns more frequently than any other health condition for which newborns are screened. Historically, moderate-to-severe hearing loss was not detected until after the newborn period while mild and unilateral hearing loss until after school age. In 1999, Department of Health Care Services (DHCS) directed CCS-approved NICUs and hospitals with perinatal services to screen for hearing loss prior to discharge. The 2007 Position Statement of the Joint Committee on Infant Hearing, followed by California AB 2651, further defined and expanded early hearing loss detection and interventions for infants. Additional guidance for authorization of diagnostic services was provided by DCHS in 2016 with N.L.:04-0816.

Methods: Hospitals are mandated to perform automated brainstem response (ABR) hearing screening on all infants. If not screened prior to discharge, or failed inpatient screening, the hospital will schedule an initial screening at an outpatient setting. All infants who are considered high risk by their physician or who have failed outpatient results are to be referred to CCS for authorization of further diagnostic services at a CCS approved Type C Communication Disorder Center (CDC).

Results: LA County has developed an algorithm for authorization of diagnostic services. Data on infants referred to LA County CCS for these diagnostic and early intervention services will be presented.

Discussion: The goal of screening is to maximize linguistic competence and literacy development for children with hearing loss. Providing access to care with diagnosis and intervention by three to six months of age makes this goal possible.

Reference: Joint Committee on Infant Hearing. Year 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. Pediatrics. 2007; 120 (4).

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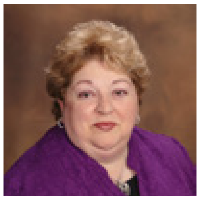

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Perinatal/Neonatal Medicolegal Forum

Gilbert Martin, MD and Jonathan Fanaroff, MD, JD

Healthcare professionals continue to have concerns about medical legal issues dealing with the newborn. Fewer pediatricians are being sued today than during periods of liability 'crisis'. Are we still at risk for litigation?

The answers is certainly "yes". In the United States medical malpractice expenditures are in the billions. The number of neonatal intensive care units in the United States continues to increase. The number of premature babies that are delivered continues to increase. As obstetricians and maternal fetal specialists benefit from expanded and more precise technology, neonatologists and other healthcare professionals are caring for increased numbers of babies at lower gestational ages. The limits of viability continue to decrease and are "blurry". The costs of neonatal intensive care continues to increase.

It is often difficult to determine the cause of a neonate's injuries. Additionally, juries have great sympathy for newborn babies. Finally, a number of factors related to the care of neonates such as individualized medication dosing increase the risk of an adverse event.

When evaluating a neonatal medical malpractice allegation, the maternal and family history, the labor and delivery information and the neonatal course all need to be considered. It is often difficult to separate these time periods.

Neonatologists must be aware of medicolegal issues when dealing with neonatal patients. Although mortality in general is improving, morbidity secondary to gestational age and the rigors of neonatal intensive care is increased, leading to the risk of a malpractice claim.

Questions remain:

1. Can we predict outcomes?

   While treatment ideally incorporates evidence-based practice, evidence is not always available and thus anecdotal therapies continue to be utilized. The media tends to emphasize the "miracle baby". In today's digital world, parents search the internet for cases similar to their own and may demand therapies without truly understanding the risks involved.

2. Will the new approach, augmenting the "quality assurance" process decrease mortality and morbidity? We can now collect and analyze data more efficiently. Once a specific problem has been identified, recommendations can be presented, that over time will lead to discussion and ideally eliminating the error or problem. Root cause analysis with comprehensive data collection including checks and balances have reduced medical errors.

The healthcare professional can minimize his/her malpractice risk by following well-accepted guidelines. These include consultations with other colleagues, careful and complete documentation, awareness of applicable laws which are present at the time in question, and most important is honest communication with parents and families. Physician mistakes have not been part of the culture of medicine. Today, patients understandably expect to know that an error has occurred, why it occurred and what will be done to prevent a reoccurrence. A simple apology is often necessary. Blame and shame should be replaced by trust and leadership.

There is a typical road map which occurs in malpractice cases. The "complaint" when served is often a surprise to the healthcare professional. After the initial shock, there is discovery of the factual information, depositions followed by trial if necessary. If a trial does occur there is jury selection, opening statements, the presentation of the plaintiff's case, the presentation of the defendant's case, closing arguments and finally jury instructions. In today's world, arbitration of cases is increasing as the costs as well as the time it takes to get to a trial can be staggering.

This forum will attempt to educate on medical legal issues such as the road map of a lawsuit, the benefits an experienced attorney, and the method for choosing appropriate experts.

Malpractice cases will be presented from both the plaintiff and defense perspective. Was there a breach of the standard of care? Is the neonatal injury acute, sub acute or chronic?

The ultimate goal is to for the healthcare professional caring for mothers and babies to become more aware and knowledgeable of medical malpractice issues.

The authors have no conflicts of interests to disclose.

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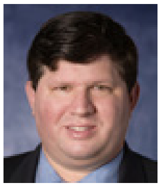

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Feeding Options Exist: So Why Aren't We Discussing Them at Bedside?

Deb Discenza, PreemieWorld (www.PreemieWorld.com)

PreemieWorld was honored to have the following organizations sign on in support of this petition:

NEC Society www.NECSociety.org

The Morgan Leary Vaughan Fund http://www.morgansfund.org/

National Black Nurses Association www.nbna.org

National Association of Perinatal Social Workers www.napsw.org

National Coalition for Infant Health www.infanthealth.org

Hand to Hold www.HandtoHold.org

Connected Forever www.connected4ever.org

Courageous Steps http://couragessteps.org

PeekaBoo ICU www.peekabooicu.org

Team Grayson www.teamgrayson.org

The Tiny Miracles Foundation www.ttmf.org

Kelley French, author of Juniper: The Girl Who Was Born Too Soon, mom to 23-weeker who perforated twice www.juniperbook.com

Nurtured by Design www.nurturedbydesign.com

Zoe Rose Memorial Foundation www.zoerose.org

The Tangerine Owl Project www.tangerineowl.org

Dandy-Walker Alliance dandy-walker.org

Patient Advocacy Strategies www.patientadvocacystrategies.com

Jen Degl, author of From Hope to Joy: A Memoir of a Mother's Determination and Her Micro Preemie's Struggle to Beat the Odds www.fromhopetojoy.com

I am writing about a very personal, very sensitive topic that many feel squeamish about discussing after having a baby. Every mother struggles with how to be the best parent to her child in order to give that infant the best start possible. But imagine having a premature baby and thrust into the Neonatal Intensive Care Unit (NICU) where medicine prevails, and doctors and nurses are Gods. You have to ask for permission even to simply hold your baby, the simplest of nurturing actions. Guilt for the early birth hits you at every turn. You try to be the best mom, but you don't even feel like a mother as you watch others tend to your infant's every single need. Even feeding. All you seem useful for, is for providing breast milk which is assumed and expected. But if providing breast milk is an issue and then there is extra guilt thrown into the mix. The lack of control, ongoing fear and the guilt all collide to make a parent want to crawl into a corner and hide.

That was me almost 15 years ago when my daughter Becky was born at 30 weeks at 2 lbs. 15.5 oz and spent 38 days in the NICU before going home on medical equipment and landing back in the hospital for a readmission for feeding issues. Feeding my preemie daughter was honestly the only thing I felt I had control over in the NICU, and that meant a lot. But even then, and at home, feeding her was a slippery slope, with the nasal cannula and heart monitor tethered to her ready to "grade" my motherly skill at any second with a chirp that seemed cruel and unending.

With no help except my maternal instinct, I started pumping breast milk within hours after my daughter was born. I was so proud of my ability to provide breast milk that when Becky had trouble feeding at the breast, I figured I needed to keep pumping. I pumped and pumped and pumped and still the team added bovine or cow-based fortifier (formula) to her diet. I didn't know until they had already done it. I was not asked in advance and I had no idea what that meant at the time. Add in a nurse guilting me for not getting Becky to feed from my breast and all of that pride turned to more guilt. Why wasn't my voice in involved in this discussion?

Today, a lot has changed in terms of the clinical data around the need for exclusive human milk in very low birthweight babies.[1-5] Though mother nature has not showed us all the reasons preemies develop necrotizing enterocolitis or NEC, we do know it is one of the most common and life-threatening conditions of the GI system. And we know that a 100% human milk diet inclusive of mom's milk or donor milk plus a human milk-based fortifier can reduce NEC by 77%.[6] Implementing this as the standard of care in our nation would go a very long way to helping preemies thrive.[7] And today, there have been changes in relation to the options available to patient families. So why is this a secret?

Simply put, parents have the right to be educated about all of their options for feeding and understand the ramifications of their choice.

In my mind every NICU should have a mandatory consent form on feeding options for the baby just as there is a signature required for all vaccines. Most especially for preemies born under 1,250 grams (roughly 2 and a half pounds), nutrition is not simply food, it is medicine. Anything fed to them beyond mom's milk, human donor milk and a human milk-based fortifier is going to be problematic. Nutrition can be life-saving, or it can be life-threatening.

PreemieWorld's petition is to call on NICUs to implement nutritional education and consent forms for ALL feeding options available to premature babies in the NICU. That would include mother's breast milk, donor breast milk, human milk fortifier, bovine-based fortifier and bovine-based formula.

It is crucial that parents and professionals come together to make a change in the NICU for the better. To have them actually discuss feeding options at bedside and truly partner with each other for the good of the baby is the best outcome of all.

I ask that you sign this petition and forward it to your families and colleagues as well. Together we can make a change for the better for the tiniest of babies.

Deb Discenza is the Founder and CEO of PreemieWorld (www.PreemieWorld.com) and co-author of The Preemie Parent's Survival Guide to the NICU, and moderator of the almost 45,000 global membership of the Inspire Preemie Community at http://preemie.inspire.com

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

Agenda:

1. Rashmin Savant MD BPD New Concepts in Pathogenesis and Prevention
2. Cynthia Blanco MD Metabolic Disturbances of Prematurity When How and Who to Treat
3. Sinjo Hirose MD Fetal Surgery
4. Arun Pramanick, MD. Game Changers in Neonatal-Perinatal Medicine- A View Through a Retroscope
5. Don Null Persistent Pulmonary Hypertension in the Preterm Newborn Etiologies and Cardiopulmonary Management
6. Marty Keszler, MD New Modalities in High Frequency Ventilation
7. Mitchell Goldstein, MD. Rediscovering the Denominator
9. Steve Derdak, DO. Pediatric Origins of Adult Disease

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The Genetics Corner: A Consultation for Orofacial Cleft: Van der Woude Syndrome

Subhadra (Subha) Ramanathan, MSc, MS, Ruben Marchosky and Robin Clark, MD

Case History:

A 32 day old male infant with bilateral cleft lip and palate was evaluated in the Craniofacial Team. He was brought to his appointment by his mother, who had a history of cleft palate repair. The prenatal history was noncontributory. Bilateral cleft lip was detected on fetal ultrasound in the second trimester. There were normal fetal movements. Teratogenic exposures were denied. The infant was delivered to a 22 year old G2 P1 SAb1 mother at term, by normal vaginal delivery. Birth weight was 8 lb 3 oz. The baby was discharged home with mother in 2 days as there were no postnatal complications associated with the oral cleft or otherwise. He passed the newborn hearing screen.

Examination of the infant's lower lip revealed bilateral paramedian lip pits. Examination of mother's lower lip revealed bilateral paramedian lip pits. No other health concerns were identified in the infant.

The family history was significant for orofacial clefts in mother's family: two maternal half-brothers with bilateral cleft lip and palate and one maternal half-sister with unilateral cleft lip and palate. These half siblings have different fathers. Our patient's maternal grandmother reportedly does not have any oral clefts or lip pits.

Assessment:

A diagnosis of Van der Woude syndrome (VWS) was made clinically based on the findings of orofacial clefting in mother and infant and the presence of bilateral paramedian lip pits in both.
Mixed clefting is the rare occurrence of cleft lip +/- cleft palate and cleft palate alone in the same pedigree, as was seen in this family. Mixed clefting is a feature of Van der Woude syndrome (VWS), with the associated finding of paramedian lower lip pit and mounds with a sinus tract leading from a mucous gland of the lip. It is caused by heterozygous pathogenic variants in the IRF6 gene and, in about %5 of families with VWS, in the GRHL3 gene. These pathogenic variants are inherited in an autosomal dominant manner.

The differential diagnosis for VWS includes syndromes associated with mixed clefting, such as TP63-related disorders (e.g., ankyloblepharon-ectodermal defects-cleft lip/palate), FGFR1-related disorders and 22q11 deletion syndrome. Mixed clefting can also be seen in families with pathogenic variants in the MSX1 gene. Lower lip pits can be a feature of Kabuki syndrome and branchiooculofacial syndrome (Schutte BC et al., 2014). Each of these syndromes has other associated anomalies or physical features that offer clues to their diagnosis.

Van der Woude syndrome is a classic example of the phenomena of clinical variability and penetrance. Expressivity refers to the range of phenotypes that can be seen among individuals with the same underlying disorder. In the case of VWS, affected individuals may have unilateral or bilateral cleft lip +/- cleft palate, cleft palate alone, or only paramedian lip pits. Penetrance is a binary function, with a trait or disease either manifesting or not (Jarvik GP, Evans JP, 2016). The penetrance for VWS due to pathogenic variants in the IRF6 gene is estimated to be 92%. This means that 8% of individuals who are heterozygous for a pathogenic variant in the IRF6 gene will have NO clinical features of the disorder. This may result in a pedigree where the disorder appears to "skip generations", as appears to be the case with our patient's maternal grandmother.
The incidence of orofacial clefts (OFCs), including cleft lip +/- cleft palate and cleft palate alone, is about 1 in 1000, making them among the most common congenital anomalies (Beaty TH et al., 2016). The incidence varies based on racial and ethnic backgrounds, socioeconomic status and family history. Syndromic clefts are associated with additional clinical findings, including other congenital anomalies, developmental problems dysmorphic features or documented maternal teratogenic exposures. Orofacial clefts can be isolated and nonsyndromic when there are no other associated birth defects, developmental problems or maternal environmental exposures (Schutte BC and Murray JC, 1999).
Isolated nonsyndromic orofacial clefts are usually inherited as multifactorial traits with both genetic and environmental factors contributing to susceptibility. Almost two dozen genes influence the risk for OFCs. Most of the genes confer only modest effects individually to modify the risk for the birth defect (Beaty TH et al., 2016). Environmental factors implicated in the risk for OFCs include maternal smoking, alcohol consumption, diabetes and some medications such as certain anti-epileptic drugs during pregnancy. Common variants in a few genes strongly influence the risk for OFCs. Rare pathogenic variants in the same genes may also be causative of Mendelian syndromes with OFCs and include IRF6, GRHL3, MSX1, TP63 and TFAP2A (Kousa YA, Schutte BC, 2016). In general, the genetic risk factors for nonsyndromic cleft lip +/-

Figure 1: Infant with oral cleft and bilateral paramedian lip pits.

Figure 2. Mother's lip with bilateral paramedian lip pits

cleft palate are distinct from those for cleft palate alone. In other words, these birth defects "run true" in families. Cleft lip +/- cleft palate is more common in males whereas cleft palate alone is more common in females. Counseling for recurrence risks for nonsyndromic OFCs is based on empirical data, and takes into account the gender, severity and the relatedness of the affected individual (i.e. the recurrence risk in a first degree relative will be higher than in a second or third degree relative).

The recurrence risk for OFC to a first degree relative (sibling, offspring, parent) can range from 2%, for an isolated unilateral birth defect in the gender more commonly affected, to up to 10% if there is more than one affected family member, especially first-degree relatives.

The diagnosis of a syndromic etiology for an OFC, besides guiding clinical management, allows for accurate prediction of recurrence risks. For VWS, the risk for each offspring of the affected mother (and our patient) to inherit VWS will be 50%. It will not be possible to predict the type or severity of the orofacial cleft.

Practical applications:

- Always examine babies with orofacial clefts for paramedian lower lip pits/ mounds/ cysts.
- Recurrence risk counseling for orofacial clefts will be significantly different (and will be typically lower) for an isolated nonsyndromic OFC due to multifactorial inheritance when compared to an OFC due to autosomal dominant syndrome.
- VWS demonstrates the phenomena of mixed clefting, incomplete penetrance and clinical variability within the same family.

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The authors have no conflicts of interests to disclose.

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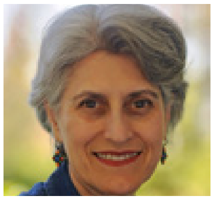

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NCfIH National Coalition for Infant Health

Protecting Access for Premature Infants through Age Two

A collaborative of professional, clinical, community health, and family support organizations improving the lives of premature infants and their families through education and advocacy.

The National Coalition for Infant Health advocates for:

- **Access to an exclusive human milk diet** for premature infants
- **Increased emotional support resources** for parents and caregivers suffering from PTSD/PPD
- **Access to RSV preventive treatment** for all premature infants as indicated on the FDA label
- **Clear, science-based nutrition guidelines** for pregnant and breastfeeding mothers
- **Safe, accurate medical devices** and products designed for the special needs of NICU patients

www.infanthealth.org

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 heath and breast feeding 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.

Learn more about
Neonatal Abstinence Syndrome
at www.nationalperinatal.org

National Perinatal Association

Peer Reviewed

Fish Consumption for Pregnant Women

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The National Coalition for Infant Health is a collaborative of more than 150 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.

Dear Colleagues,

Pregnant women today are mindful about the importance of prenatal care and prevention, particularly with respect to nutrition. However, with a steady barrage of new information, some of it seemingly contradictory, even the most conscientious mother-to-be may struggle to determine the best choices for her baby.

This Fast Facts outlines current scientific research and clarifies potentially confusing information.

Q. Should pregnant women eat cooked fish?

The experts unequivocally say: yes. The U.S. Food and Drug Administration and the 2015-2020 Dietary Guidelines for Americans recommend that pregnant women eat at least two to three servings[1] of adequately cooked fish each week. Pregnant women should avoid undercooked seafood, which may contain listeria or other harmful bacteria.

Greater maternal fish intake overall has been proven to be associated with higher child developmental scores.[2] In 2014, the FDA finished a nine-year study[3] weighing the risks and benefits of fish consumption during pregnancy. It examined 120 peer-reviewed studies and concluded that eating fish during pregnancy can benefit a child's developing nervous system.

The findings aligned closely with a joint study by the Food and Agriculture Organization of the United Nations and the World Health Organization. Other prominent organizations like the American Heart Association and American Academy of Nutrition and Dietetics also recommend two to three servings of seafood weekly for its health benefits.

The following table lists just some of the most important studies over the past 20 years that confirm the net beneficial effect of eating seafood during pregnancy.

Q. What benefits does fish consumption provide during pregnancy and childhood?

Omega-3s. The human body needs three types of polyunsaturated fats referred to as the omega-3 fatty acids. Unlike other types of fat, omega-3s are considered "essential" fats and can be absorbed only from food.

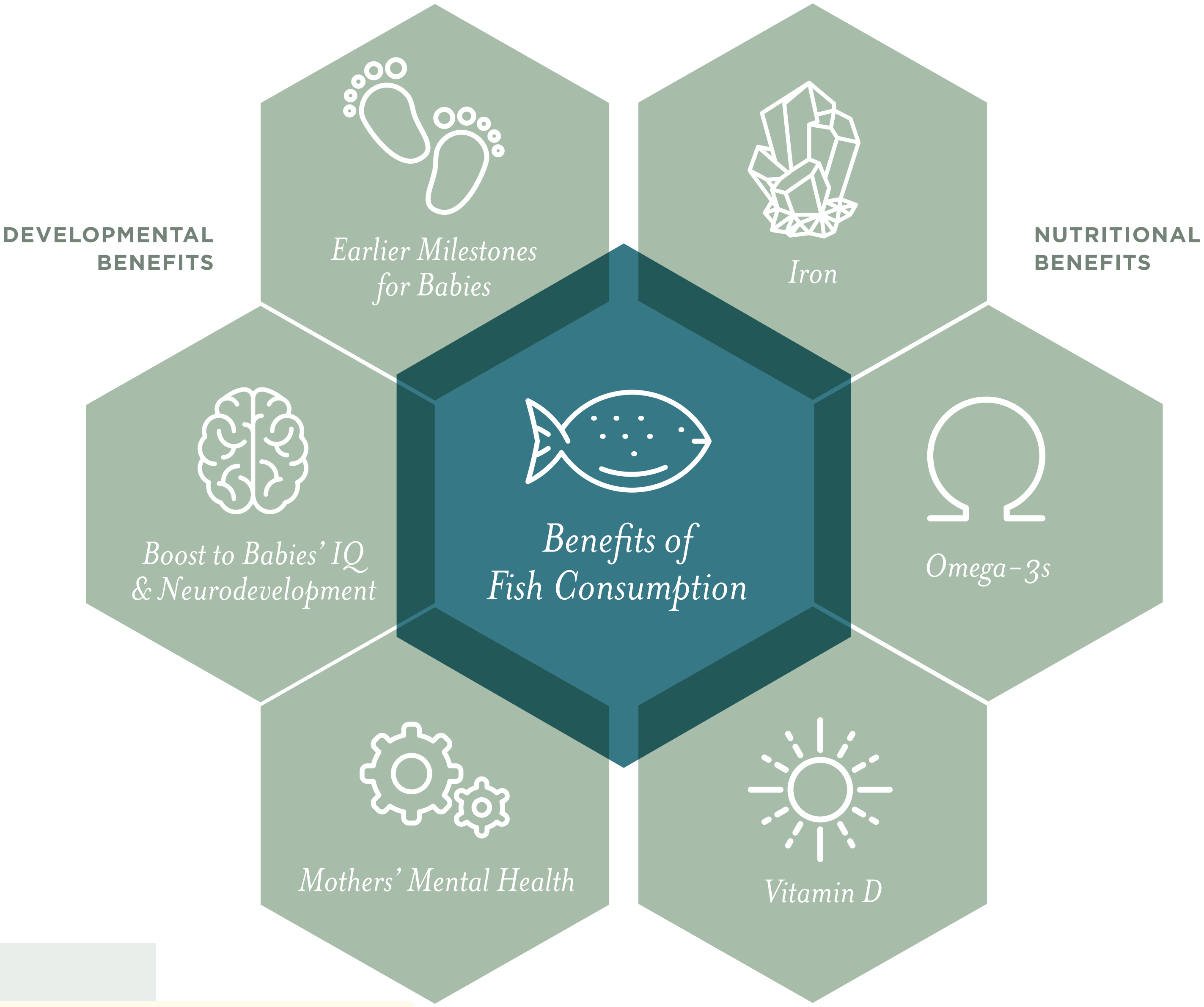
These fatty acids are critical for a mother's brain and heart health. They also promote a baby's normal brain development.[4] During the last trimester, a fetus's brain and nervous system rapidly develops, requiring about 65 milligrams a day of the omega-3 known as DHA. The heightened demand for DHA continues to two years of age.

Research shows that consuming two to three servings of seafood each week boosts brain development by 2.63 IQ points.5 It also suggests that babies of moms who eat seafood-rich diets reach milestones such as sitting up and putting words together sooner than babies of moms who don't eat fish.6 Mothers' mental health may also benefit from fish.[7]

Vitamin D and Iron. Fish provides high amounts of iron and vitamin D, which are otherwise difficult to obtain naturally. Both iron and vitamin D are important for healthy circulation and bones, for

Figure 1. Scientific Milestone Studies Confirm the Benefits of Eating Fish during Pregnancy

YEAR	AUTHOR(S)	SOURCE
2008	Innis, et al.	*American Journal of Clinical Nutrition*
2008	Jacobson, et al.	*Journal of Pediatrics*
2008	Oken, et al.	*American Journal of Epidemiology*
2008	Oken, et al.	*American Journal of Clinical Nutrition*
2007	Budtz-Jorgenson, et al.	*Environmental Health Perspectives*
2007	Hibbein, et al.	*The Lancet*
2006	Mozaffarian, et al.	*Journal of the American Medical Association*
2005	Oken, et al.	*Environmental Health Perspectives*
2005	Cohen, et al.	*American Journal of Preventative Medicine*
2003	Meyers, et al.	*The Lancet*
1998	Davidson, et al.	*Journal of the American Medical Association*



both mother and baby. Seafood is also a valuable alternative to meat because it is a plentiful source of energy and high-quality protein necessary to encourage growth in young children, yet typically much lower in saturated fat.

Q. What's the cause of mothers' confusion?

The average pregnant woman in the United States currently eats 1.89 ounces of seafood weekly, a quarter of the minimum recommendation.[8] This discrepancy may stem in part from a misguided and misleading media narrative.

In 2004 the FDA and the U.S. Environmental Protection Agency (EPA) published joint advice that encouraged fish consumption, stating that "women and young children in particular should include fish or shellfish in their diets due to the many nutritional benefits." The balanced advice also contained an innocuous acknowledgement that "nearly all fish and shellfish contain traces of mercury."

Some media outlets transferred that very limited mercury statement to their headlines, amplifying that message while minimizing—or overlooking entirely—the overwhelming value of fish consumption. Sensationalized interpretations led to widespread confusion about the matter.

Understandably, concerned mothers mostly heard the warning rather than the advice to eat fish. Some health care providers responded similarly. So by 2012, average fish intake among pregnant mothers was far below the official 2004 FDA/EPA recommendation of up to 12 ounces per week.

Q. Are all fish good for pregnant women?

The FDA and EPA advise avoiding four types of fish with high levels of mercury: tilefish, shark,swordfish, and king mackerel. The advice also recommends checking local fish advisories about the safety of fish caught non-commercially in lakes, rivers, and coastal areas.

The FDA and EPA also offer several examples of fish to include in a prenatal diet for their nutritional value: shrimp, salmon, canned light tuna, pollock, catfish, tilapia, and cod.

Q. What's the most current advice on pregnant women, nutrition and fish consumption?

Various elected officials and other leaders have called on the agencies to "speak with one voice" on the matter. Fortunately, the U.S. Departments of Agriculture (USDA) and Health and Human Services (HHS) released 2015 Dietary Guidelines for Americans recommending that pregnant and breastfeeding women consume at least two to three seafood meals each week. When the EPA and FDA released updated guidance in 2017, however, they conveyed a message that may perpetuate rather than clear up confusion. The one-page guidance document prioritizes choices based on mercury content instead of emphasizing the nutritional benefits of fish consumption. It also assigns fish to "best," "good" and "avoid" categories based on distinctions that may be hard for consumers to follow.

> ***"The FDA and EP A offer several examples of fish to include in a prenatal diet: Shrimp, Salmon, Canned Light Tuna, Pollock, Catfish, Tilapia, and Cod."***

The agencies' approach could have the unintended consequence of increasing the number of pregnant women who err not by eating too much fish, but by eating too little.

Conclusion:

The FDA, EPA and Dietary Guidelines for Americans advice to eat two to three servings of low-mercury seafood is based in scientificconsensus. Yet some media continue to sensationalize the message, emphasizing limited risks over significant and proven health benefits. Consequently, mothers have incorrectly understood the message and, on average, do not eat seafood in the necessary weekly amounts. Seafood promotes brain and heart health in mothers and their babies. Mothers and health care providers need to hear accurate, concise information based on the latest research.

Mitchell Goldstein, MD
Medical Director
National Coalition for Infant Health

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The author has identified no conflicts of interest.

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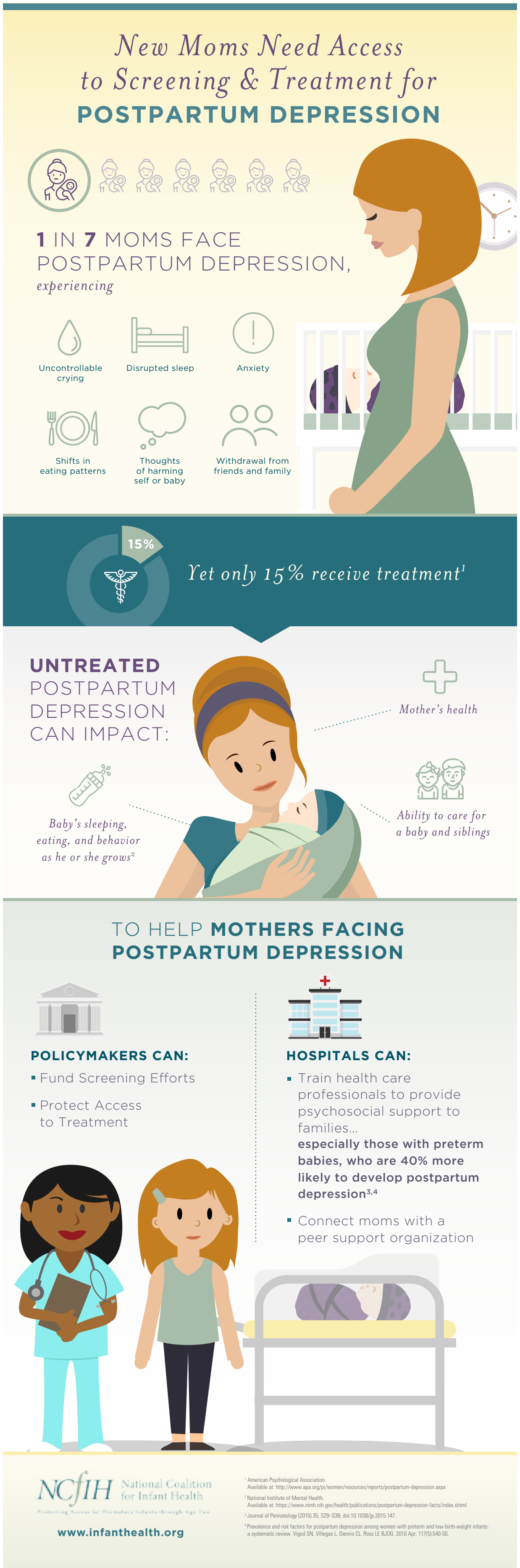
National Coalition for Infant Health Values (SANE)

Safety. Premature infants are born vulnerable. Products, treatments and related public policies should prioritize these fragile infants' safety.

Access. Budget-driven health care policies should not preclude premature infants' access to preventative or necessary therapies.

Nutrition. Proper nutrition and full access to health care keep premature infants healthy after discharge from the NICU.

Equality. Prematurity and related vulnerabilities disproportionately impact minority and economically disadvantaged families. Restrictions on care and treatment should not worsen inherent disparities.



New Moms Need Access to Screening & Treatment for POSTPARTUM DEPRESSION

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

- Uncontrollable crying
- Disrupted sleep
- Anxiety
- Shifts in eating patterns
- Thoughts of harming self or baby
- Withdrawal from friends and family

15%

Yet only 15% receive treatment[1]

UNTREATED POSTPARTUM DEPRESSION CAN IMPACT:

- *Mother's health*
- *Baby's sleeping, eating, and behavior as he or she grows*[2]
- *Ability to care for a baby and siblings*

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**[3,4]
- Connect moms with a peer support organization

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[1] American Psychological Association. Available at: http://www.apa.org/pi/women/resources/reports/postpartum-depression.aspx

[2] National Institute of Mental Health. Available at: https://www.nimh.nih.gov/health/publications/postpartum-depression-facts/index.shtml

[3] Journal of Perinatology (2015) 35, S29–S36; doi:10.1038/jp.2015.147.

[4] Prevalence and risk factors for postpartum depression among women with preterm and low-birth-weight infants: a systematic review. Vigod SN, Villegas 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 AFRONTA LA DEPRESIÓN POSPARTO, *experimentando*

- Llanto incontrolable
- Sueño interrumpido
- Ansiedad
- Desplazamientos en los patrones de alimentación
- Ideas de hacerse daño a sí mismas o al bebé
- Distanciamiento de amigos y familiares

15%

Sin embargo, sólo el 15% recibe tratamiento[1]

LA DEPRESIÓN POSPARTO **NO TRATADA** PUEDE AFECTAR:

- *La salud de la madre*
- *El sueño, la alimentación y el comportamiento del bebé a medida que crece*[2]
- *La capacidad para cuidar de un bebé y sus hermanos*

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

LOS ENCARGADOS DE FORMULAR POLÍTICAS PUEDEN:

- Financiar los esfuerzos de despistaje y diagnostico
- 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**[3,4]
- Conectar a las mamás con una organización de apoyo

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[1] American Psychological Association. Accesible en: http://www.apa.org/pi/women/resources/reports/postpartum-depression.aspx

[2] National Institute of Mental Health. Accesible en: https://www.nimh.nih.gov/health/publications/postpartum-depression-facts/index.shtml

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Peer Reviewed

Monthly Clinical Pearls: "Theophylline is Safe for Apnea of Prematurity: Drs. Carl Hunt and Jerold Lucey"

Joseph R. Hageman, MD

As I was working on one of the NICU quality improvement projects I am involved with coordinating for the unit at the University of Chicago, I was distracted by an announcement on my computer for a paper about the long term neurobehavioral outcomes of infants who had received caffeine therapy for apnea of prematurity (AOP) 11 years previously. This is a new outcome study from the randomized, double blind placebo-controlled Caffeine for Apnea of Prematurity (CAP) trial which involved 13 academic hospitals in Canada, Australia, Great Britain and Sweden just published in Pediatrics (1). The results are well worth reviewing as the caffeine treated infants had improved visuomotor, visuoperceptual, and visuospatial abilities at age 11 years. Also there were no adverse effects on general intelligence, attention and behavior (1).

What reviewing this paper did for me was to also result in a "clinical flashback" to 40 years ago when I was a pediatric resident at Children's Memorial Hospital (now Ann and Robert H Lurie Children's Hospital of Chicago) in the Northwestern University system and Drs. Carl Hunt, Bob Brouillette and Dick David were my neonatal attending physicians. We were treating our premature infants in the neonatal intensive care unit (NICU) with AOP with theophylline therapy. Like so many other things in neonatology, this just seemed like something we did because that is what our mentors taught us to do and we were taught that it worked. Once I became a fellow in the same program and I had time to review the literature, I found that our therapy was based originally on small clinical trials by Kuzemko and colleagues in 1973 and this was followed by a study by Usuay and colleagues, Bednarek and Roloff (and Jerrold Lucey, unpublished data) in 1975 and 76 (2). In his editorial entitled "xanthine therapy in apnea of prematurity, Dr. Lucey cautioned us as clinicians to further investigate and compare theophylline, aminophylline and caffeine (2). He suggested that we need to be aware of the diuretic effects and the potential long term effects as well (2). As he stated, "The possible risks of therapy must be carefully balanced against the gains (2)". His thoughts also included questions about the definition of apnea and the clinical effects of apnea…and what about the significance of bradycardia?(2).

So here we are 40 years later having the same discussions about apnea, bradycardia and desaturations and the "brady watch" prior to discharge in our units (3). We worry about the long term effects of intermittent hypoxia, which BTW… Carl Hunt, who is still my mentor, is studying in the Decaf trial the use of caffeine therapy beginning at 33 weeks post conceptual age in premature infants to prevent intermittent hypoxia (4). He is also looking at long term outcomes in these infants.

Thanks to the investigators of the CAP trial, we also have long term outcome data 11 years after caffeine therapy for AOP which suggests long term positive benefits of caffeine therapy (1). Specifically, they present improved visuomotor, visuoperceptual and visuospatial abilities and, almost as important, as cautioned by Dr. Lucey, no adverse effects (1).

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Optional Additional references

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The author has identified no conflicts of interest.

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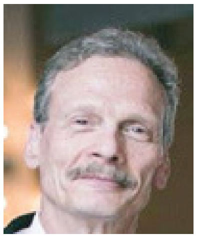

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Clinical Pearls are published monthly.

Submission guidelines for “Clinical Pearls”:

1250 word limit not including references or title page.

May begin with a brief case summary or example.

Summarize the pearl for emphasis.

No more than 4 references.

Please send your submissions to:

jhageman@peds.bsd.uchicago.edu

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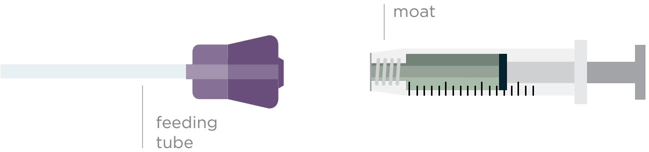
SAFETY IN THE NICU

New tubes, new problems?

A new tubing design meant to eliminate tubing misconnections has introduced new challenges for the NICU population. Pediatric providers must deliver medication in small volumes to tiny patients with high levels of accuracy. The new tubing design, known as ENFit®, could present dosing accuracy and workflow challenges.



DOSING ACCURACY

- The moat, or area around the syringe barrel, is difficult to clear. Medication can hide there, inadvertently increasing the delivered dose when the syringe and feeding tube are connected; patients may receive extra medication.

INFECTION RISK

- The moat design can increase risk for infection if residual breast milk or formula remains in the moat and transfers to the feeding tube.

WORKFLOW ISSUES

- Increased nursing workflow is seen with additional steps for clearing syringe moats, cleaning tube hubs, and using multiple connectors.

Improved standards are important to protect patients from the dangers of tubing misconnections. But we must avoid mitigating existing risks by creating new ones.

Individual hospitals should consider all factors impacting their NICU patients before adopting a new tubing design.

ENFit® is a registered trademark of GEDSA

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infanthealth.org

Letters to the Editor

To the Editor (via email),

From: Phillips, Raylene <RPhillips@llu.edu>

Subject: Letter to the Editor

Date: Sunday 7/15/2018 1349

Letter to the Editor,

Dear Dr. Goldstein,

I've enjoyed reading Neonatology Today for several years and have noticed that the byline now says "Peer Reviewed Research, News and Information in Neonatal and Perinatal Medicine." Can you please provide some information about the review process used by Neonatology Today?

Thank you,
Raylene

Raylene Phillips, MD, MA, FAAP, FABM, IBCLC
Medical Director, Neonatal Services,
Loma Linda University Medical Center-Murrieta
Associate Professor Pediatrics/Neonatology, Loma Linda School of Medicine
Director Newborn Neurodevelopment
Director Breastfeeding & Lactation
Loma Linda University Children's Hospital

(via email)

Dear Dr. Phillips,

Thank you for being a loyal reader and contributor to Neonatology Today. As you may have noticed, the format has changed significantly from our previous format. In the transition, Neonatology Today was acquired from Tony Carlson by Loma Linda Publishing Company (A Delaware not for profit 501 (c) 3 Corporation). Although very well read within the neonatal physician community, we wanted to bring additional readership to the publication. As such, we embarked on a 10 point plan which was originally introduced in our March edition. This plan is detailed below

1. All manuscripts submitted will be peer-reviewed. I will be contacting our editorial board and plan to add additional reviewers as needed to accommodate the demand. My commitment will be to provide feedback on any submission in fewer than 14 business days.
2. We will actively solicit and publish case reports that provide insights into management of complex conditions confronting practicing neonatologists. Although many journals have discouraged case report submission, it is our feeling that these provide a way of disseminating meaningful academic information that may not otherwise see the light of day.
3. We will be making Neonatology Today a multidisciplinary publication, open to all professionals who engage in academic pursuits in the fields of Neonatology, Perinatology, and Pediatrics.
4. We hope to increase our readership by striving to be first to report on innovative new concepts in all of the associated specialties.
5. We will expand our readership by adding an international component to our board.
6. We will continue to commit to not charge authors for publication of their manuscripts.
7. Highlighting the work of The patient and provider advocacy community including organizations like the National Coalition for Infant Health (NCfIH),(infanthealth.org).
8. We will start having monthly open conference calls for our readers to comment on and make suggestions on how to make NT a better publication.
9. We will have a dedicated message line for questions, concerns, and comments.
10. We will continue to provide the journal for free to our readers.

Of the 10 points, we have yet to begin our open conference calls. We aim to start these in August.

Our peer review process begins with review of the submission by one of the senior editors. It can be rejected, accepted or sent on to another reviewer for comment. Once the manuscript is placed in the journal in preparation for publication, it goes out again to a group of editors who review it for content, format, and appropri-

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

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

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ateness. This process allows for a rapid turn around but with the necessary oversight..

Thank you for your question. We look forward to receiving your next manuscript.

Sincerely,

Mitchell Goldstein, MD
Editor in Chief

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

Please submit your manuscript to: LomaLindaPublishingCompany@gmail.com

Upcoming Medical Meetings

National Black Nurses Association
46th Annual Institute and Conference
July 31 – August 5, 2018
St. Louis Union Station Hotel
St. Louis, MO
www.nbna.org

United States Breastfeeding Committee
Eighth National Breastfeeding
Coalitions Convening (NBCC)
August 4-5, 2018,
Atlanta, Georgia.
http://www.usbreastfeeding.org/p/cm/ld/fid=515

35th annual The Fetus & Newborn:
Improving Outcomes in Perinatal and Neonatal Care conference
September 5 - 8, 2018
Las Vegas, NV
http://fetusandnewborn.com

Innovative Care of the Newborn Brain
Lucile Packard Children's Hospital
September 26-27, 2018
Palo Alto, CA
https://tinyurl.com/neuronicu-sept

NANN's 34th Annual Conference
Anaheim Hilton and Convention Center
Anaheim, CA
October 17-20, 2018
http://nann.org/education/annual-meeting

The Eighth Annual Fetal Echocardiography Symposium at UCLA: "Real-Life Fetal Cardiac Screening—Pearls from the Masters,"
Los Angeles, CA
October 20, 2018
https://www.cme.ucla.edu/courses/cme-download?registration_id=241829

The AAP Experience
National Convention and Exhibition
Orlando, FL
November 2–6, 2018
http://aapexperience.org/

Hot Topics in Neonatology®
Marriott Marquis
Washington, DC
December 3-5, 2018
http://www.hottopicsinneonatology.org/

NEO
The Conference for Neonatology
Coming February 2019
Orlando, FL
http://www.neoconference.com/

The 36th Annual Advances in Therapeutics and Technology Conference
Snowbird, Utah
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
Apr 27-30, 2019;
Baltimore, MD
https://www.pas-meeting.org/

Perinatal Advisory Council, Consulting, Advocacy, and Consultation (PAC-LAC)
June 13, 2019
Los Angeles, CA
https://paclac.org/paclacconference/

For Additional Meeting Information, visit NeonatologyToday.net and click on the events tab.

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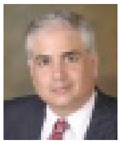

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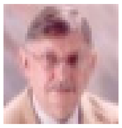

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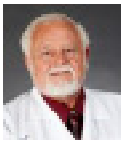

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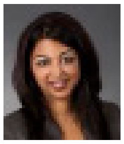

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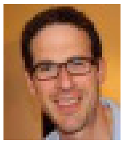

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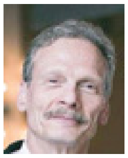

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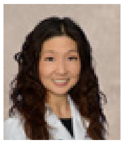

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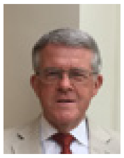

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Neonatology and the Arts

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 (see the next page) features a drawing (2 of 3 in a series) that Dr. Vasquez produced for the cover of the 2008 National Perinatal Association Annual Meeting brochure. The meeting focused on the topic of "The Spectrum of Violence in Perinatal & Neonatal Care: Reducing the Risks." In this graphic, the pregnant woman is approached by her violent partner. Her passive tears question the future for her and her baby.

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1. Manuscripts are solicited by members of the Editorial Board or may be submitted by readers or other interested parties. Neonatology Today welcomes the submission of all academic manuscripts including randomized control trials, case reports, guidelines, best practice analysis, QI/QA, conference abstracts, and other important works. All content is subject to peer review.

2. All material should be emailed to LomaLindaPublishingCompany@gmail.com in a Microsoft Word, Open Office, or XML format for the textual material and separate files (tif, eps, jpg, gif, ai, psd, or pdf) for each figure. Preferred formats are ai, psd, or pdf. tif and jpg images should have sufficient resolution so as not to have visible pixilation for the intended dimension. In general, if acceptable for publication, submissions will be published within 3 months.

3. There is no charge for submission, publication (regardless of number of graphics and charts), use of color, or length. Published content will be freely available after publication (i.e., open access). There is no charge for your manuscript to be published under open access

4. The title page should contain a brief title and full names of all authors, their professional degrees, their institutional affiliations, and any conflict of interest relevant to the manuscript. The principal author should be identified as the first author. Contact information for the principal author including phone number, fax number, email address, and mailing address should be included.

5. A brief biographical sketch (very short paragraph) of the principal author including current position and academic titles as well as fellowship status in professional societies should be included. A picture of the principal (corresponding) author and supporting authors should be submitted if available.

6. An abstract may be submitted.

7. The main text of the article should be written in formal style using correct English. The length may be up to 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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