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Pioneer Profile: Virginia Apgar, MD

Joseph B. Philips, III, MD, FAAP

(52)

"Every baby born in a modern hospital anywhere in the world is looked at first through the eyes of Virginia Apgar."

—Anonymous physician.

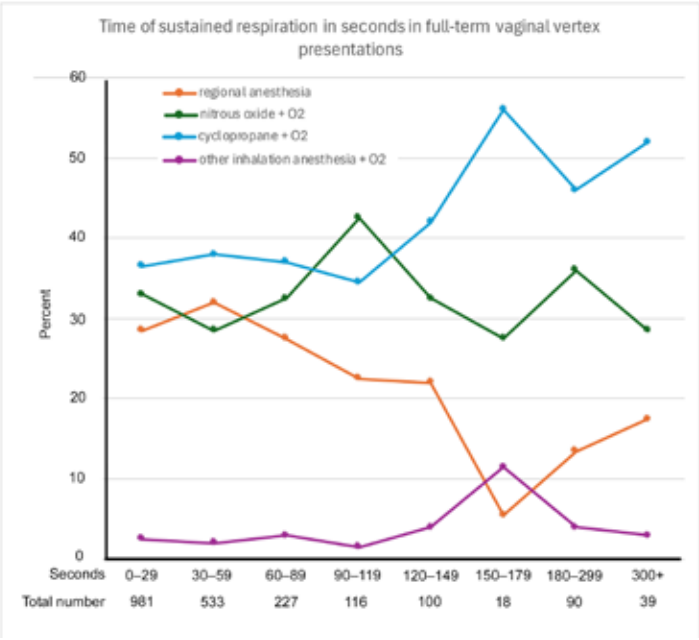
Virginia Apgar was not a neonatologist or even a pediatrician, but her contributions to newborn care were monumental and exceeded those of most other pioneers. She was born in 1909 in New Jersey. (1) Her interest in science was sparked early by her father, who experimented with electricity and radio in his basement laboratory and built a telescope in his backyard to observe the stars. (2) Her interest in medicine was stimulated in part by her brother, who suffered from and subsequently died of tuberculosis. She attended Mount Holyoke College, graduating in 1929, playing cello and violin in the college orchestra, participating in 11 classes and 7 varsity sports teams, reporting for the college newspaper, and earning extra money by rounding up stray cats for a research laboratory. Her unbounded energy earned her the nicknames "Flash" and "Dyny."

"Virginia Apgar was not a neonatologist or even a pediatrician, but her contributions to newborn care were monumental and exceeded those of most other pioneers."

She then attended Columbia University College of Physicians and Surgeons, graduating fourth in her class, before taking a surgical residency at Columbia Presbyterian Hospital with the legendary Dr. Allen Whipple, who invented the eponymous operation, technically known as pancreaticoduodenectomy. Despite her interest in a career in surgery, Dr. Whipple discouraged her from pursuing it because it was known to be tough on women and urged her instead to pursue anesthesiology, which was emerging as a distinct specialty. Accordingly, she spent six months in the nation's first Department of Anesthesiology at the University of Wisconsin and another six months at Bellevue Hospital studying anesthesiology. Dr. Apgar then returned to Columbia, joining what soon became the Department of Anesthesiology in 1938, where she became the 50th person and the second woman to be board-certified in anesthesiology. In 1949, Dr. Apgar became the first female full professor at the Columbia University College of Physicians and Surgeons.

Dr. Apgar's early work focused on the transmission of drugs across the placenta to the fetus and on obstetric anesthesia. She presented a comprehensive review of the topic at an international meeting in London in 1951, which was subsequently published. (3) The transmission of meperidine (Demerol) was investigated and, while substantial, was not found to have significant effects on the newborn. (4) An important paper discovered that infants were more depressed at birth and took longer to sustain regular respirations when their mothers received general versus regional anesthesia, especially with cyclopropane (Figure 1). (5) This finding led to an

Figure 1. Time to sustained respirations in full-term newborns whose mothers received regional or general anesthesia. Adapted from Apgar V, et al. Comparison of regional and general anesthesia in obstetrics; with special reference to transmission of cyclopropane across the placenta. J Am Med Assoc. 1957. (5) Note the higher rates of cyclopropane in the delayed onset infants.



emphasis on using regional anesthesia whenever possible and to the avoidance of cyclopropane if general anesthesia was needed for delivery.

Dr. Apgar also published several articles on anesthesia for delivery and other purposes. She reviewed two new techniques for pudendal block and reported an improved method for providing continuous segmental epidural anesthesia via a caudal catheter. (6, 7) A review of anesthesia for vaginal delivery discussed all the options available in 1956. (8) She was also one of the first to describe the use of the newly discovered norepinephrine as a pressor agent during surgery. (9) Likewise, she was among the first to describe the use of curare during surgery. (10) Another important report reviewed the anesthetic management of pheochromocytoma during surgery. (11)

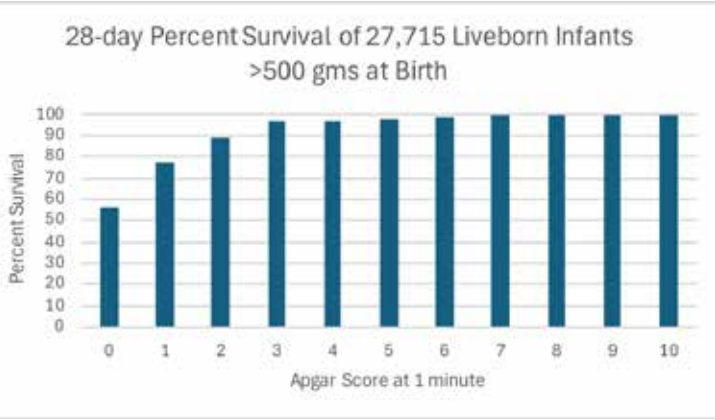
The aforementioned studies would have been enough to cement Dr. Apgar's legacy in the pantheon of the pioneers in anesthesiology, but they pale in comparison to her seminal contribution to the world, her eponymously named Apgar Score. She was apparently asked over lunch how she evaluated a newborn at birth, jotted down five points on a scrap of paper, and then rushed off to the delivery room to test her ideas. (2) The five items were color, pulse, reflex activity, activity, and respiration, each of which was assigned zero to two points so that a score between zero and ten would result. This scoring system was presented at a national meeting in 1952 and then published in 1953 in an article entitled "A Proposal for a New Method of Evaluation of the Newborn Infant."(12) Dr. Apgar originally proposed that her scoring system be used at one minute of age. However, it has since been given at 5-minute intervals until the score reaches 7. Dr. L. Joseph Butterfield was an enthusiastic adopter of the Apgar score and published an epigram of it using the letters of Dr. Apgar's name for the five items, making it easier to remember (Figure 2). (13)

Figure 2. Epigram of the Apgar Score. (13)

Score	0 points	1 point	2 points
Appear-ance (skin color)	Blue/ pale all over	Body pink, ex-tremities blue	Pink
Pulse (Heart Rate)	0	<100	>100
Grimace (Reflex ir-ritability)	No response to stimulation	Minimal re-sponse to stimulation	Cry when stimulated
Activity (Muscle tone)	Limp	Some flexion of extremities	Active motion
Respiration	Apneic	Slow, irregular breathing	Vigorous cry

The Apgar score was initially met with some skepticism, as it seemed so simple. However, further studies showed that it is actually quite useful. Working with the legendary L. Stanley James, Dr. Apgar reported on the 28-day survival rates of 27,715 infants based on their one-minute scores, showing significant improvements as the scores increased (Figure 3). (14) The authors concluded, "While we believe the score is useful, it has many limitations. It is no

Figure 3. Twenty-eight-day survival of 27,715 infants by Apgar score at 1 minute. Adapted from Apgar V, James LS. Further observations on the newborn scoring system. Am J Dis Child. 1962. (14)



substitute for a careful physical examination or serial observations over the first few hours of life. Nor will it predict neonatal death or survival in individual infants. Indeed, few signs in medicine give such a definitive answer. This objection in no way detracts from the value in estimating the probability of survival or death in groups of infants." Almost two decades later, Dr. Apgar elaborated on the scoring system and opined, "It is strongly advised that an observer, other than the person who delivers the infant, be the one to assign the score. An automatic method of announcing the passing of 60 seconds is recommended. Although mortality and the presence of significant neurologic damage correlate better with the five-minute than the one-minute score, the one-minute score should nevertheless be retained. It is essential to observe the infant from the moment of birth in order that prompt treatment can be given if necessary. Nine months' observation of the mother surely warrants one minute observation of the baby." (15)

The Apgar score has indeed stood the test of time. Casey and colleagues reported on a cohort of 151,891 infants born over eleven years from 1988 through 1998. They concluded, "The Apgar scoring system remains as relevant for the prediction of neonatal survival today as it was almost 50 years ago." (16) As useful as the score is, low scores are not a proxy for asphyxia, despite the desire for this to be the case on the part of plaintiff's attorneys. This point was emphasized in an editorial accompanying the previously mentioned Casey article, as well as a statement from the Fetus and Newborn Committee of the American Academy of Pediatrics entitled "Use and Abuse of the Apgar Score." (17, 18) Another

" As useful as the score is, low scores are not a proxy for asphyxia, despite the desire for this to be the case on the part of plaintiff's attorneys...Another caveat is that the Apgar score is influenced by the maturity of the neonate, with lower scores being assigned to premature infants."

caveat is that the Apgar score is influenced by the maturity of the neonate, with lower scores being assigned to premature infants. (19)

Dr. Apgar also did much work on neonatal resuscitation and on the causes of low Apgar scores. In an article from 1955, she wrote that care of the infant in the delivery room "is properly the province of the pediatrician, but rarely in this country is there a pediatrician in the delivery room for every delivery. Until such a time occurs, the anesthesiologist is the logical person to observe and treat the infant if the occasion arises." (20) She went on to observe, "The immediate newborn period is almost without investigation. The normal body temperature patterns across weight groups and the infant's response to cooling or warming require clarification. The possibility, probability, and desirability of assisting ventilation are almost unknown. The compliance and resistance factors, as well as those of pressure, time, and volume, need to be studied. The effect of pain-relieving drugs given to the mother during labor on the infant's respiration and circulation needs a controlled study." This publication was followed by one entitled "Infant Resuscitation," in which she republished her scoring scheme and stressed the importance of maintaining a clear airway and assisting ventilation if needed. (21) Chest compressions apparently were not a thing yet. These points were reiterated in a speech entitled "The First Twelve Minutes," which she gave in 1957 in Portland, Oregon. (22) Additional work with Dr. Richard Day and colleagues using rats and piglets investigated pressure-time relationships and lung injury induced by mechanical ventilation in the delivery room, finding that high pressures for brief intervals were best. (23)

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Additional work on infant resuscitation included disproving the usefulness of the then widely used Bloxsom Air Lock, a device that cycled pressure in an enclosed, oxygen-enriched chamber into which the infant was placed at birth (Figure 4). (24, 25) These studies were conducted on apneic dogs, to which Dr. Bloxsom reportedly replied that his device was not designed to revive them. A further report emphasized the importance of oxygen in the resuscitation of depressed infants, stating: "It cannot be overemphasized that intermittent pulmonary inflation with oxygen at safe pressures is the most effective therapeutic means available in overcoming fetal anoxia." (26) Another pair of studies

Figure 4. The Bloxsom Air Lock, a device widely used in the early 1950s for infant resuscitation, was found by Dr. Apgar and colleagues to be ineffective. (25) Used with permission

investigated the utility of intragastric oxygen administration in resuscitation. The first study used paralyzed puppies and found no significant oxygen absorption from the stomach. (27) The second report involved nine asphyxiated and 20 normal newborns and concluded, "Negligible amounts of oxygen are absorbed from the gastrointestinal tract in the human infant." (28) These studies effectively ended the useless practice of intragastric oxygen administration for resuscitation of depressed neonates.

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Working again with Dr. James and colleagues, Dr. Apgar performed extensive studies on the acid-base status of infants at birth. (29) Among their conclusions was "Some degree of asphyxia, usually of brief duration, occurs as a result of the delivery process and is a normal finding in all births." A subsequent study evaluated changes in acid-base homeostasis in the first 24 hours after birth in non-asphyxiated infants, showing steady improvements in pH over time. (30) Another study attempting to link blood oxygen content in the first three hours after birth to neurodevelopmental outcomes at five years of age found no significant correlations. (31) A follow-up study found that selected perinatal complications,

such as premature birth or need for prolonged resuscitation, were associated with lower IQ scores at follow-up but again found no correlation with blood oxygen content at birth. (32) Dr. Apgar was on the right track, however, as a recent article found "In this cohort study of 825,159 children, perinatal hypoxia assessed by combining clinical and biochemical measures (Apgar score and umbilical cord blood pH) was associated with increased risk of CP, with greater increases in risk when both measures were low." (33) So, low Apgar scores combined with low pH at birth are indeed predictive of cerebral palsy.

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In 1959, Dr. Apgar completed a master's degree in public health from Johns Hopkins University and joined the National Foundation for Infantile Paralysis, which later became The March of Dimes organization, essentially embarking on an entirely new career. (1) Until the mid-1950, the National Foundation's major focus was on polio, but the introduction of the injectable Salk vaccine in 1955, after massive clinical trials the previous year, led to a roughly 90% decline in paralytic cases within a few years. (34) The subsequent introduction of the oral Sabin vaccine essentially relegated polio to the history books. I vividly recall standing in a long line at my elementary school to get the sugar cube with the vaccine and finally being able to play with my friends in the summer when I had previously not been able to do for fear of contracting polio.

"In 1959, Dr. Apgar completed a master's degree in public health from Johns Hopkins University and joined the National Foundation for Infantile Paralysis, which later became The March of Dimes organization, essentially embarking on an entirely new career."

Thus, the National Foundation needed a new focus and chose birth defects, and Dr. Apgar became the director of the Division of Congenital Malformations. (1) As such, she traveled the world fundraising and raising public awareness, at both of which she was remarkably successful. She also published many articles related to birth defects. An article published shortly after she joined the National Foundation, entitled "The Drug Problem in Pregnancy" elaborated on the newfound interest in the effects on the fetus of drugs taken by the mother in the aftermath of the disastrous thalidomide tragedy from 1959–1962. (35) She reported on the association of hydramnios with congenital anomalies and lectured on human congenital anomalies at the annual meeting of the American Medical Association in 1960. (36, 37) This lecture was updated at the Sixth Baxter-Travenol Lecture of the International Anesthesia Research Society in 1968. (38)

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An extensive list of drugs and their effects on the fetus and newborn was published in JAMA in 1964. (39) Another JAMA review entitled "Birth Defects. Their Significance as a Public Health Problem" stated, "Abnormal conditions of congenital origin are a leading cause of death and disability in the United States. An estimated 500,000 fetal deaths and at least 62,000 deaths among the live-born are associated with birth defects each year. An estimated 15 million persons have one or more congenital defects that affect their daily lives." (40) This article emphasized that many "birth defects" present later in life, even up into late adulthood. Another, earlier article entitled "Hazards to the Continuum of Genetic Potential" discussed multiple factors that could influence the development of birth defects, including ionizing radiation, folic acid antagonists, rubella and other viral infections, and many others. (41) Another report documenting the proliferation of centers and services offered by the March of Dimes concluded: "With the expansion of facilities, the blossoming of research, the improvement of medical care, and the awakening of interest in the American people, the victim of birth defects can hope to lead a relatively normal and useful life and certainly a life that is well

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worth living." (42)

Finally, Dr. Apgar was a co-author on a manuscript exploring the possibility of using trophoblast cells retrieved from the maternal circulation of prenatal diagnosis, thus presaging the current use of fetal cell free DNA from maternal blood for prenatal diagnosis. (43) The authors acknowledge the contributions Dr. Apgar made to the publication and that she died while it was in preparation. Thus, she remained productive right up until her death.

"Finally, Dr. Apgar was a co-author on a manuscript exploring the possibility of using trophoblast cells retrieved from the maternal circulation of prenatal diagnosis, thus presaging the current use of fetal cell free DNA from maternal blood for prenatal diagnosis."

As previously mentioned, Virginia Apgar was a remarkably energetic woman. She played violin and cello and always traveled with a stringed instrument. A patient, Carleen Hutchins, was a much-lauded master luthier who taught Dr. Apgar to make her own instruments. (44) Together, they participated in the famous "phone booth caper." (45) The pair had identified a curly maple board in the back of a telephone booth at Columbia Presbyterian Hospital that they felt would make an ideal back to a stringed instrument. However, they were unable to secure it through legitimate means, so, with Dr. Apgar standing guard late at night, Ms. Hutchins extracted the panel using a saw and crowbar and replaced it with a carefully stained piece of plywood. No one ever apparently noticed! Dr. Apgar went on to construct two violins, a mezzo violin, a viola, and a cello—the previously profiled L. Joseph Butterfield organized a campaign to purchase four of these instruments and donate them to Columbia University; they are played at various events from time to time, such as when Dr. Butterfield received the Apgar Award from the American Academy of Pediatrics in 1992.

Dr. Apgar was also an avid philatelist, amassing a large stamp collection. Thus, it was only fitting that she be recognized with the issuance of a 20-cent stamp in the Great Americans Series (Figure 5). (46) The stamp was unveiled at the annual American Academy of Pediatrics meeting in Dallas, Texas, on October 24, 1994, at which the Apgar String Quartet was again played.

Dr. Apgar was known for walking fast and driving even faster. L. Stanley James wrote of her, "She loved fast driving with her hair flying and would claim that her tires never wore out because they never touched the ground." (47, 48) He also noted that she was the first person to cannulate the umbilical artery of a neonate. Not content with this, Dr. Apgar began

Figure 5. The Virginia Apgar postage stamp. (46)

taking flying lessons at age 59 and became a licensed pilot, even saying she wanted to fly under the George Washington Bridge. She apparently also always carried a surgical knife and a length of rubber tubing in her purse, stating, " 'Nobody, but nobody, is going to stop breathing on me." (49)

Virginia Apgar, MD, died way too young in 1974 at the age of 65. The number of accolades that she accumulated before and after her death is literally too numerous to list, but here are some of the most important. She was the first woman to receive the prestigious Alumni Gold Medal for Distinguished Achievement in Medicine from the Columbia University College of Physicians and Surgeons and was named Woman of the Year in Science and Research by the Ladies Home Journal. (50) The American Society of Anesthesiologists Distinguished Service Award was bestowed upon her in 1961, and the Ralph M. Waters Award, also from the American Society of Anesthesiologists, in recognition of excellence in anesthesiology research and practice in 1973. (51) She was inducted into the National Women's Hall of Fame in 1995 and was honored with a US Postal Service stamp as previously discussed. The Virginia Apgar Award was established by the Section on Neonatal-Perinatal Medicine of the American Academy of Pediatrics in 1975. Its list of recipients constitutes a veritable Who's Who of leading neonatologists and perinatal physiologists.

In conclusion, Dr. Virginia Apgar was a truly remarkable and innovative woman. Of all the people that I have profiled but did not meet, she is the one that I would most like to have met. To sum up her life and contributions best, Dr. Julius Richmond,

"To sum up her life and contributions best, Dr. Julius Richmond, former Surgeon General of the United States, said Apgar did 'more to improve the health of mothers, babies and unborn infants than anyone in the 20th century.'"

former Surgeon General of the United States, said Apgar did "more to improve the health of mothers, babies and unborn infants than anyone in the 20th century." (1)

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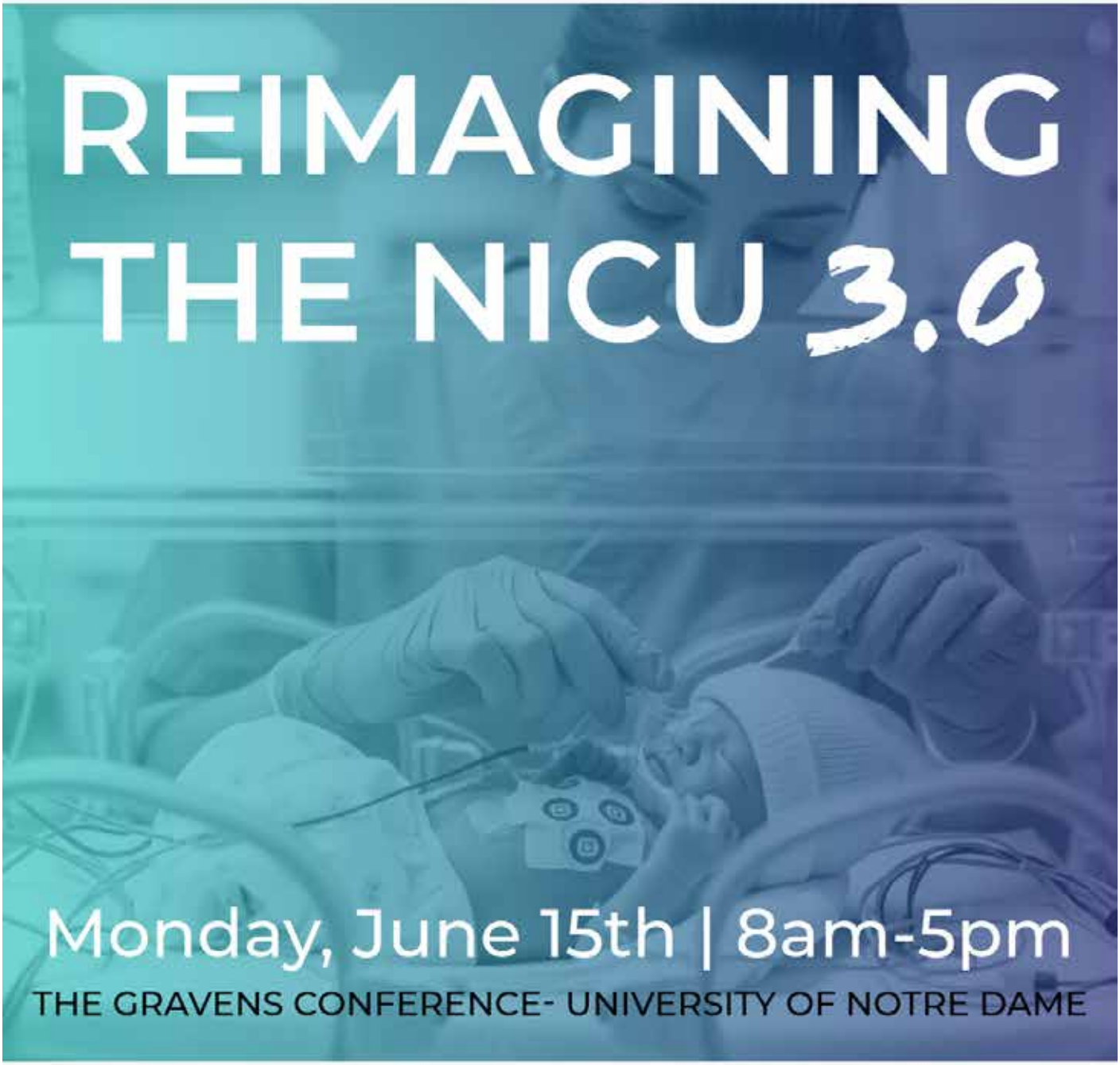

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America's Infants Deserve Better: Recommendations to Make Infant Formula Safer

William D. Marler, Esq, T. Allen Merritt, MD, MHA, MBA, Coral Beach, BS

"As a food safety attorney, the first author has spent more than three decades suing the food industry (1). Attorneys, neonatologists, and pediatricians have sat across the table from parents who watched their children die from E. coli, Salmonella, or Listeria."

As a food safety attorney, the first author has spent more than three decades suing the food industry (1). Attorneys, neonatologists, and pediatricians have sat across the table from parents who watched their children die from *E. coli*, *Salmonella*, or *Listeria*. Both of us have seen what happens when the system fails the most vulnerable people among us. We see plainly and without equivocation that the infant formula industry has a catastrophic safety problem, and the federal government has been too slow, too timid, and too deferential to industry to regulate it.

"In 2022, the United States faced an infant formula crisis that exposed something deeply disturbing: Abbott Nutrition's Sturgis, Michigan, facility had internal records documenting the destruction of product contaminated with Cronobacter sakazakii—and the company had not told anyone."

In 2022, the United States faced an infant formula crisis that exposed something deeply disturbing: Abbott Nutrition's Sturgis, Michigan, facility had internal records documenting the destruction of product contaminated with Cronobacter sakazakii—and the company had not told anyone. The FDA had not inspected the plant in two years. Four infants became ill with *Cronobacter*. Two died. One child was sick with *Salmonella. Abbott Laboratories acknowledged finding evidence of Cronobacter in non-product-contact areas of the plant, while publicly denying that* contaminated formula had reached consumers. The FDA received the first complaint in September 2021. The recall did not come until February 2022. Five months, during which critical ill infants were hospitalized. At the time that the first *Cronobacter* case—a pathogen that is very rare and strongly associated with powdered infant formula- was reported, epidemiologists and NICUs should have treated it as a four-alarm fire. The contamination of powdered formula should have been enough for the FDA to move immediately.

The FDA's response was lame, and President Biden had to invoke the Defense Production Act and enlist the U.S. Air Force to transport formula from Europe to restock shelves with imported formula in the original 'Stork Speed' response. However, the lame response from the FDA, which could have been a learning opportunity, prompting greater inspection and enforcing existing regulations, failed once again (2)

"In the fall of 2025, the U.S. witnessed a multistate outbreak of infant botulism linked to ByHeart Whole Nutrition infant formula. By the time the CDC declared the outbreak over in February 2026, 48 infants had been hospitalized across 17 states. All 48 required treatment with BabyBIG, the only antitoxin for infant botulism, which exists solely because California had the foresight to develop and maintain it."

In the fall of 2025, the U.S. witnessed a multistate outbreak of infant botulism linked to ByHeart Whole Nutrition infant formula. By the time the CDC declared the outbreak over in February 2026, 48 infants had been hospitalized across 17 states. All 48 required treatment with BabyBIG, the only antitoxin for infant botulism, which exists solely because California had the foresight to develop and maintain it. Thankfully, no child died—and that fact owes more to the existence of that immunoglobulin BABYBig, and the vigilance of California public health officials than to anything the FDA or the formula industry did to prevent the contamination in the first place. The first author represents over one-half of the infants in litigation against the ByHeart formula. Both Abbott Laboratories and Mead-Johnson have had successful and costly litigation recently regarding the use of their specialized infant formulas and the occurrence of necrotizing enterocolitis in very low birth weight infants in several states. Formulas from both companies were never tested in controlled clinical trials. However, both retrospective data and a prospective clinical trial demonstrated an increased risk of NEC when infants were fed a special care formula versus donor human milk. When neurodevelopment was followed at about 24 months of age, corrected for prematurity, the reported incidence of NEC was significantly higher among infants fed special care formula.

In the ByHeart formula scandal, the California public health department's lab, and then the FDA, learned that *Clostridium botulinum* was detected in opened and unopened cans of ByHeart formula and in a powdered milk ingredient. FDA inspectors had visited ByHeart's Iowa facility in 2022 and found *Cronobacter sakazakii* in the milk dryer. They noted microcracks in equipment that could harbor bacteria. The company had a prior *Cronobacter* recall in 2022 and received an FDA warning letter in 2023. Yet the formula remained on the market, and infants kept getting sick with botulism, with cases tracing back, after case-definition expansion, as far as December 2023 (3)

This was a systemic failure, not a single company's. All formula companies bear enormous responsibility. It is a failure of an entire regulatory architecture that treats powdered infant formula—a product fed to the most immunologically vulnerable human beings on the planet, often from the day they are born—as something less than the sterile, rigorously tested, and relentlessly inspected product it must be and parents assume it is.

"Powdered infant formula for too many infants is the only food they consume, determined by parents' choice. A parent who opens a can of formula and mixes it with water for their newborn is placing absolute trust in the company that made it and the government that allowed it to be sold."

Powdered infant formula for too many infants is the only food they consume, determined by parents' choice. A parent who opens a can of formula and mixes it with water for their newborn is placing absolute trust in the company that made it and the government that allowed it to be sold. That trust has been repeatedly broken by the same pathogens in the same vulnerable population, in ways that were entirely predictable and often preventable. In March of this year, Congresswoman Rosa DeLauro (CT-03) introduced the Infant Formula Safety Modernization Act, comprehensive bipartisan legislation to modernize federal oversight of the nation's infant formula supply and close longstanding gaps in testing, transparency, and regulatory enforcement. Building on the Congresswoman's work, which offers a refreshing and reasonable approach to formula regulation, we believe the FDA must use its regulatory authority to ensure the safety of infant formulas. This is especially true for a flawed recall system that relies on a company's notification to distributors and retailers to remove the contaminated formula from store shelves. It was documented that the ByHeart formula remained on shelves for over a month at certain retailers after the initial recall, exposing more infants to the risk.

We recommend the FDA take the following preliminary steps:

Like liquid infant formula, powdered infant formula should be commercially sterile. Full stop. The technology exists. The FDA requires it for other products. The argument that sterility is technically or commercially challenging does not impress us when the alternative is babies on ventilators and feeding tubes. If a company cannot produce a sterile product for infants, it should not be producing infant formula. Leave it to the formula industry to figure out how to achieve this—retort processing, reformulation, whatever works—but set the standard and enforce it.

Mandatory pre-market testing must be required. Before a single can of powdered infant formula reaches a store shelf, its ingredients must be tested—not by the company alone, but verified by independent, accredited laboratories—for *C. botulinum*, *Cronobacter sakazakii*, *Salmonella*, *Bacillus cereus*, and other relevant pathogens. The testing, both in the products and the environment, should be statistically robust. The current voluntary and largely self-reported system is inadequate. It has failed. It will fail again.

Routine, unannounced FDA inspections must occur, and we need to fund Food Safety fully**.** A two-year gap in inspections at Abbott Laboratories› Sturgis, Michigan, facility while infants were being sickened, is unconscionable. The FDA must inspect every infant formula manufacturing facility on a regular, mandatory schedule. When inspectors find microcracks in milk dryers where *Cronobacter* is detected—as they did at ByHeart in 2022—there must be immediate, mandatory follow-up to confirm remediation, not a warning letter and a hope that the company follows through. We also need a dedicated funding stream for food safety and infant health.

"We need a real risk assessment and updated regulations. The FDA's existing framework for powdered infant formula was not designed with C. botulinum as a primary threat. Hopefully, the ByHeart outbreak changed that calculus. We need a comprehensive, well-funded risk assessment of C. botulinum spores, Cronobacter sakazakii, Salmonella, and Bacillus cereus in infant formula and its constituent ingredients—raw milk, pasteurized milk, and dairy powders."

We need a real risk assessment and updated regulations. The FDA's existing framework for powdered infant formula was not designed with *C. botulinum* as a primary threat. Hopefully, the ByHeart outbreak changed that calculus. We need a comprehensive, well-funded risk assessment of *C. botulinum* spores, *Cronobacter sakazakii*, *Salmonella*, and *Bacillus cereus* in infant formula and its constituent ingredients—raw milk, pasteurized milk, and dairy powders. We need to understand contamination pathways, evaluate whether current detection methods are sensitive enough, and determine where in the supply chain spores are entering the product.

The public and pediatricians have repeatedly been told that more regulation will harm innovation, burden small producers, and raise costs for families. We have heard these arguments made by nearly every industry. They are the same arguments the beef industry made before the USDA declared *E. coli* O157:H7 an adulterant. The industry adjusts. It innovates. It finds a way to meet the standard when the standard is enforced. Moreover, guess what, today we seldom see an *E. coli* outbreak linked to beef.

"We need truthful labels on infant formula. Infant formula labeling should clearly indicate that breastfeeding is best as recommended by the American Academy of Pediatrics, and that their product is NOT the same as human milk."

We need truthful labels on infant formula. Infant formula labeling should clearly indicate that breastfeeding is best as recommended by the American Academy of Pediatrics, and that their product is NOT the same as human milk. Further, when additives to their product, such as ARA (arachidonic acid), are added, the primary source of these additives must be mentioned on the label.

In the ByHeart formula scandal, forty-eight infants were hospitalized by formula contamination with botulism. Every single one of them was fed formula that their parents believed was safe because the company and the FDA said it was safe. Infants aged between 16 days and 264 days old, with infants hospitalized for days or weeks and fighting for their lives in intensive care units, with many requiring feeding tubes, or a gastrostomy for feedings, and all needed to re-learn, such as how to swallow, vocalize, move their arms and legs freely, or crawl again. Botulism disrupted their normal development, and the resulting impairments created significant gaps in their developmental trajectory (3).

"In the ByHeart formula scandal, forty-eight infants were hospitalized by formula contamination with botulism. Every single one of them was fed formula that their parents believed was safe because the company and the FDA said it was safe."

On April 29, 2026, the FDA reported that the nation's supply of infant formula is safe after the "most rigorous examination" of products ever undertaken, and declared them safe (FDA) (4). However, the testing program did not include foodborne pathogens such as Cronobacter, Listeria, Salmonella, E. coli, or Botulism. The agency tested for arsenic, cadmium, lead, mercury, 30 PFAS, 318 pesticides, 21 phthalates, and 1 non-phthalate plasticizer. The investigation was part of Operation Stork Speed, launched by the Food and Drug Administration in 2025 to ensure the safety of infant formula. This report did not list their findings by formula or company. Separately, laboratory results were reported in Consumer Reports in 2026, with similar findings (5), although specific formulas from various manufacturers were listed and ranked by contaminants present or absent.

"We tested more infant formula than ever before, and the results are clear: most products meet a high safety standard—but even small exposures matter for newborns," said Health and Human Services Secretary Robert F. Kennedy Jr. However, the Secretary was mute on those formulas that did not.

The testing found "an overwhelming majority of samples had undetectable or very low levels of contaminants, affirming that the U.S. infant formula supply is safe," according to the FDA's report. However, the United States does not have a legal limit for any of the metals the FDA tested in infant formula. Consequently, when the FDA calls a formula "safe," there is no standard behind that word. Operation Stork Speed is also looking into the nation's supply of infant formula, which was severely depleted following a recall by Abbott Nutrition in the wake of the Cronobacter outbreak in 2022.

"We're doing everything in our power to make sure our babies and infants have safe, high-quality formula options that are backed by a resilient supply chain," said FDA Commissioner Marty Makary. Makary said nothing about promoting breastfeeding or supporting human milk banks in the U.S.

The FDA tested 312 samples from 16 brands, but did not say in its report which brands it tested or the results for each brand, unlike the independent ***Consumer Reports*** testing. Formula types tested were powdered with 278 samples; 11 of concentrated liquid, and 23 ready-to-feed liquid. The protein sources included in the sample were 258 cow's milk, 44 soy, and 10 amino acid-based formulas. The FDA tested donor human milk from a single human milk bank in Oklahoma, but never explained why their testing was so limited.

"Across the products tested, the majority of infant formula samples had undetectable or very low levels of contaminants, affirming the safety of the U.S. infant formula supply," according to the FDA's report. However, what about those that did not?

"While contaminant levels were low, some samples had values that have initiated additional follow-up actions as a part of the agency's robust monitoring and oversight efforts. This will include conducting further testing and continuing to engage with manufacturers on measures to reduce contaminant levels to as low as possible."

For each contaminant, the FDA reported the following values, which illustrate typical levels measured:

- Not detected: The amount, if present, was too small for our testing methods to detect
- Range: The lowest to the highest levels (concentrations) detected
- 95th percentile (reported as 95 percent): The level below

which 95 percent of samples fell (meaning only 5 percent of samples were higher)

- Median: The midpoint in a set of data when the numbers are put in order from lowest to highest. It helps show a common number in the group.
- Parts per billion (ppb): One part per billion is equivalent to one drop of water in an Olympic-size swimming pool

The test results were as follows:

- **Mercury** was not detected in 296 out of 312 samples (95 percent). Among all samples, concentrations ranged from not detected to 0.3 ppb. Given the high number of non-detects, a 95th percentile and a median were not calculated.
- **Cadmium** was not detected in 106 out of 312 samples (34 percent). Among all samples, concentrations ranged from not detected to 1.5 ppb. 95 percent of all samples had less than 1.1 ppb of cadmium. The median cadmium concentration was 0.2 ppb.
- **Lead** was not detected in 61 out of 312 samples (20%). Among all samples, concentrations ranged from not detected to 1.1 ppb, with 95% of samples containing less than 0.5 ppb of lead. The median lead concentration was 0.2 ppb.
- **Arsenic** was not detected in 18 of 312 samples (6%). Among all samples, concentrations ranged from not detected to 4.7 ppb. 95 percent of all samples had less than 2.0 ppb of arsenic. The median arsenic concentration was 0.5 ppb.
- **Pesticides:** Each of the samples was tested for 318 different pesticides, including glyphosate and glufosinate. 309 samples (99 percent) had no detectable pesticides, and glyphosate and glufosinate were not detected in any samples. Given the high number of non-detects, a 95th percentile and a median were not calculated. Only three samples had detectable pesticide levels, all at very low concentrations: 0.25 ppb chlorpyrifos in one sample, 0.20 ppb malathion in another, and 0.20 ppb piperonyl butoxide in a third.

PFAS: Each of the samples was tested for 30 different PFAS compounds. Most PFAS compounds (25 of 30) were not found in any samples. Five PFAS were detected in a subset of samples at concentrations ranging from 0.51 ppt to 150 ppt, depending on the compound. The most commonly detected was Perfluorooctanesulfonic acid (PFOS), found in half of the samples at detectable concentrations ranging from 0.51 to 6.0 ppt, with 95 percent of all samples containing less than 2.9 ppt of PFOS. Given the high number of non-detects, the median was not calculated. PFAS levels are often reported in parts per trillion (ppt) because testing methods can detect these contaminants at extremely low concentrations. Many formula products were PFAS-free, which is good news, as this demonstrates that manufacturers can produce PFAS-free formula. Unfortunately, the FDA testing results available online do not identify which brands had concerning levels of PFAS, leaving consumers in the dark and unable to make informed decisions when shopping for formula. On the FDA results page, there is a graphic that says "95% of samples had PFAS levels at or below 28 ppt." The 28 ppt is higher than the EPA's 4 ppt maximum contaminant level (MCL), and this is concerning. One of the most sensitive effects of PFAS on infants and young children is on their immune systems. Epidemiology studies in young children have shown an association between lower antibody concentrations after vaccination and higher levels of PFAS in their blood, but importantly, these studies have not shown an increase in disease incidence.

- **Phthalates:** Each of the samples was tested for 21 phthalates and 1 non-phthalate plasticizer. Phthalates were not detected in 167 of 312 samples (54%). Seven phthalates were not detected in any samples. Five phthalates were rarely detected (in fewer than 2 percent of samples). The remaining compounds that were detected had concentrations ranging from not detected to 145 ppb. The most commonly detected phthalate compounds were DEHP and DINP:
- **DEHP** was not detected in 253 of 312 samples (81%). Among the samples, DEHP concentrations ranged from not detected to 57 ppb. Given the high number of non-detects, a 95th percentile and a median were not calculated. DINP was not detected in 260 of 312 samples (83%). Among the samples, DINP concentrations ranged from not detected to 145 ppb. Given the high number of non-detects, a 95th percentile and a median were not calculated.
- **Human milk:** While this phase of testing focused specifically on infant formula products, the FDA also tested a limited number (110) of human milk samples from a single state donor human milk bank for arsenic, cadmium, mercury, and lead. Overall, the majority of samples (85 percent) had at least one detectable contaminant, while 17 samples (15 percent) had no detectable contaminants. Mercury demonstrated the highest detection rate at 61 percent, followed by cadmium at 57 percent, arsenic at 33 percent, and lead at 30 percent. None of the human milk tested had heavy metal levels that exceeded those found in the various formulas tested; however, the FDA provided that they "tested a limited number (110) of human milk samples for a single state donor human milk bank for arsenic, cadmium, mercury, and lead. Beach has commented that the FDA testing did not test for foodborne pathogens such as Cronobacter, Listeria, Salmonella, and E. coli. Beach also commented that, currently, the FDA does not have any legal limits for any of the metals tested, and consequently, when the FDA calls a formula "safe," there is no standard behind their word (7).

"Their parents, exhausted and terrified, are hardly in a position to advocate for themselves and their babies. That is why food safety experts, physicians, attorneys, and legislators must advocate on their behalf. The FDA's recent analysis, while of interest, raises more questions than it answers."

Neonatologists, pediatricians, parents, and attorneys are asking regulators to make U.S. infant formulas safer for infant

consumption. The babies in neonatal and pediatric intensive care beds with botulism or sepsis from contaminated formula cannot advocate for themselves. Their parents, exhausted and terrified, are hardly in a position to advocate for themselves and their babies. That is why food safety experts, physicians, attorneys, and legislators must advocate on their behalf. The FDA's recent analysis, while of interest, raises more questions than it answers. Their own data contradict their claim that U.S. infant formulas are safe, and they do not better inform parents which formulas are safer than others. Neonatologists and pediatricians are encouraged to read Kirchner (5) to select formulas lower in contaminants prior to recommending them to parents for their infant's consumption.

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Fellows Column: Optimization of Neonatal Sleep

Anik Boyadzhyan, OMS III

"Sleep is essential for the mental and neurologic development of infants and young children. The establishment of healthy sleep patterns depends on biological rhythms that mature in the weeks to months after birth. During this time, sleep supports the brain's ability to process external stimuli and develop specialized regions, particularly within the prefrontal cortex, which governs higher-order cognitive function."

Introduction:

Sleep is essential for the mental and neurologic development of infants and young children. The establishment of healthy sleep patterns depends on biological rhythms that mature in the weeks to months after birth. During this time, sleep supports the brain's ability to process external stimuli and develop specialized regions, particularly within the prefrontal cortex, which governs higher-order cognitive function. When sleep is disrupted, behavioral difficulties and temperamental changes arise, along with an increased risk of the neurodevelopmental conditions discussed later in the text. In response, a sleep disturbance score is proposed as a practical tool to assess sleep quality in NICU patients.

Neonatal Sleep Patterns:

Neonates begin establishing sleep behaviors within the first year of life, patterns that continue to evolve throughout childhood and adolescence. Healthy sleep depends on both the circadian rhythm and homeostatic processes; however, newborns initially lack a fully developed circadian rhythm, so their sleep lacks a true diurnal pattern. Instead, their rest consists of short, fragmented periods distributed throughout the day and night, often interrupted by feeding schedules (2). Because neonates lack endogenous control over their sleep–wake cycles, they rely heavily on caregivers to create structure. The American Academy of Pediatrics recommends that parents promote healthy sleep habits by establishing consistent bedtimes, incorporating scheduled naps, and minimizing environmental distractions. With appropriate support, infants can achieve adequate rest, typically around 13 hours per day in infancy, 12 hours in toddlers, and approximately 9 hours in older children (3).

Development of a Biological Rhythm:

The circadian rhythm originates in the suprachiasmatic nucleus and regulates the body's endogenous processes over a 24-hour cycle. It influences many aspects of human physiology, particularly biological rhythms involving hormone secretion and body temperature. Among these hormones, melatonin is especially important for sleep, but levels rapidly decline to zero in the first week of life, as the maternal source is severed after delivery. After approximately 6 weeks, neonates begin producing their own melatonin, with levels stabilizing around 6 months. Another well-known hormone is cortisol, commonly referred to as the stress hormone, and is understandably elevated following birth due to the physiologic stress of delivery. Although it fluctuates throughout the day in relation to metabolic demand and glucose utilization, it typically establishes a consistent diurnal pattern by about three months of age. Body temperature regulation, in contrast, matures more rapidly—often within the first week of life. As this system develops, sleep patterns begin to align with physiologic changes, particularly the natural decline in body temperature that occurs in the evening.

Central Nervous System Development and Sleep:

Sleep plays a critical role in central nervous system development and neural plasticity, particularly during the first few years of life, when infants spend most of their time asleep. This period provides an essential opportunity for the brain to process external stimuli and consolidate new information. In fact, sleep is believed to support the specialization and refinement of key brain regions, especially within the prefrontal cortex, which is responsible for higher-order cognitive functions (5). Although much remains to be elucidated, growing evidence suggests that sleep promotes encoding, consolidation, and the strengthening of working memory in children and adolescents.

"Sleep plays a critical role in central nervous system development and neural plasticity, particularly during the first few years of life, when infants spend most of their time asleep. This period provides an essential opportunity for the brain to process external stimuli and consolidate new information."

Neurologic Disorders Linked to Sleep:

Given the impact of sleep on the central nervous system during development, it is not surprising that researchers have identified numerous consequences of sleep disturbances. It is estimated that nearly one-quarter of parents report sleep-related issues in their children (2). In one study, children with disrupted sleep were found to perform worse academically, suffer increased irritability during infancy, and were overall more likely to exhibit an adverse perinatal history (6). Disruptions in the circadian rhythm are not only limited to poor sleep quality, but have also been linked to a higher incidence of neurodevelopmental disorders, including

Autism Spectrum Disorder (ASD), Prader–Willi syndrome, and Attention-Deficit/Hyperactivity Disorder (ADHD), among others, all of which carry long-term implications on a child's well-being. The relationship between poor sleep and ADHD, in particular, has been well documented; interventions such as melatonin supplementation and bright light therapy have been shown to reduce symptoms of hyperactivity and impulsivity in affected adults (4). Despite mounting evidence demonstrating the critical link between sleep and neurological function, sleep disorders remain underrecognized and underdiagnosed within the pediatric population. While the remainder of this review focuses on neonates in the NICU setting, its broader aim is to raise awareness of this often-overlooked issue and to encourage further research into sleep disturbances within neonates, children, and adolescents.

"Patients in the NICU face a variety of conditions, with prematurity, meconium aspiration, respiratory distress syndrome, hyperbilirubinemia, and sepsis among the most common diagnoses. During the treatments necessary for development or recovery, these patients are exposed to numerous microarousals, defined as brief, 3- to 15-second interruptions that shift the brain from deep to lighter sleep or to temporary wakefulness, without a true conscious awakening (1). In the NICU, microarousals are frequent and can result from direct interventions, such as temperature checks, repositioning, oral care, suctioning, or exposure to phototherapy lights, as well as from indirect stimuli, such as the activity of a nurse caring for a neighboring neonate."

Patients in the NICU and Microarousals:

Neonates are an exceptionally vulnerable population, not only due to the immaturity of their body systems but also because of their increased risk for future comorbidities. Patients in the NICU face a variety of conditions, with prematurity, meconium aspiration, respiratory distress syndrome, hyperbilirubinemia, and sepsis among the most common diagnoses. During the treatments necessary for development or recovery, these patients are exposed to numerous microarousals, defined as brief, 3- to 15-second interruptions that shift the brain from deep to lighter sleep or to temporary wakefulness, without a true conscious awakening (1). In the NICU, microarousals are frequent and can result from direct interventions, such as temperature checks, repositioning, oral care, suctioning, or exposure to phototherapy lights, as well as from indirect stimuli, such as the activity of a nurse caring for a neighboring neonate.

Medical teams, however, employ multiple strategies to minimize these disturbances. Nurses and respiratory therapists often coordinate care through clustered interventions, providing multiple treatments at once to reduce the frequency of incubator openings. Light exposure is carefully managed with incubator covers and dimmed lighting within patient pods. Medical equipment, including lines and tubing, is placed meticulously—not only to prevent accidental removal by the infant but also to enhance comfort. Consistency in care is also critical; for example, nurses ensure patient temperatures are stable before initiating any procedures. These efforts collectively help to preserve sleep while supporting the complex medical needs of NICU patients.

Proposed Mechanism to Report Sleep Disturbances

Medical professionals do not routinely track microarousals, potentially leaving an important dimension of sleep disruption unaccounted for. One potential solution is implementing a standardized sleep disturbance score in the NICU, which could serve as both a screening and a longitudinal assessment tool. Such a metric would incorporate features such as infant movement, eye opening, grimacing, and crying episodes recorded during the sleep period, starting after a scheduled feeding and ending at the next. These features could then be categorized as mild, moderate, or severe based on their frequency and intensity, ultimately generating a composite sleep disturbance score. In doing so, clinicians may gain a more structured and consistent method for assessing overall sleep quality and the degree of disruption an infant experiences.

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However, this approach is not without limitations. It would require additional time and effort from NICU staff, introduce a degree of subjectivity, and may vary significantly from day to day. For example, an infant experiencing constipation may demonstrate increased movement or grimacing during sleep, falsely inflating their disturbance score. These limitations underscore that this metric should be implemented as a supplemental tool for interpretation rather than a rigid test.

Discussion

The sleep disturbance score is not intended to predict or label future neurologic outcomes, but rather to raise awareness of sleep disturbances—an often under recognized issue with meaningful

Sleep Disturbance Score:

Feature	Mild (1 point)	Moderate (2 points)	Severe (3 points)
Eye Opening	Brief fluttering, <1–2 seconds	Intermittent opening, repeated episodes	Sustained eye opening or fully awake
Movement	Small twitches, finger/toe movement	Repetitive limb movement, stretching, mild restlessness	Large movements, arching, persistent restlessness
Facial Expression	Occasional grimace	Repeated grimacing, visible discomfort	Persistent grimacing or a distressed facial expression
Crying	Whimpering or brief sounds (<5 sec)	Intermittent crying, self-limited	Prolonged or high-pitched crying

Sleep Disturbance Score		
Mild: 7-10 points	Moderate: 11-15 points	Severe: ≥16 points

long-term consequences. Greater attention to early sleep disruption may help clinicians better understand its relationship to neurologic outcomes and advocate more effectively for these patients. In other areas of medicine, risk is routinely quantified, as in the well-established link between REM sleep behavior disorders and movement disorders in adults; yet similar attention is not consistently applied to infants. If early life represents a critical window for neurologic development, it should also be a critical time to prioritize and protect sleep.

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

Elba Fayard, MD, Interim Fellowship Column Editor
or Benjamin Hopkins, DO, Fellowship Column Assistant Editor
LomaLindaPublishingCompany@gmail.com

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

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

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

*Source: Respirator Syncytial Virus and African Americans

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

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

AfPA
Alliance for Patient Access

Maternal Vaccines:
WHAT YOU NEED TO KNOW

CDC-Recommended Vaccines for Pregnant Women

	COVID	FLU	RSV	TDAP
Does it protect baby?	+	+	+	+
Does it protect mother?	+	+		
Is there an immunization for baby after birth?			+	

Vaccines given to pregnant women **are safe and effective.**

Maternal vaccines help the body create antibodies that can be passed to your baby and help protect them when they are born.

Talk with your health care provider to learn more about protecting yourself and your baby.

LEARN MORE ▶

NATIONAL COALITION for Infant Health

NICUriosities: A Persistent Edematous Foot

David Yo, OSMIII, Lorie Seuylemezian, OSMIII, Ustat Sidhu, OSMIII, Steffi Khurana, MD

Presentation:

A male infant born at 35 weeks and 2 days gestation via vaginal delivery, following induction of labor, presented with bilateral pedal edema. Antenatal steroid therapy was given prior to delivery. Membranes were ruptured 7 hours prior to delivery, with APGARS of 8 and 9 at 1 minute and 5 minutes, respectively. The birthweight was 1850 grams. At the time of delivery, the infant required routine stimulation and suctioning. He later began to grunt and was placed on CPAP for respiratory support. The infant was admitted to the NICU for prematurity, size, and concerns of respiratory distress.

"A male infant born at 35 weeks and 2 days gestation via vaginal delivery, following induction of labor, presented with bilateral pedal edema. "

Maternal History

The mother was a 35-year-old G2P0 female of Caucasian ethnicity without significant medical problems, who had been receiving routine prenatal care throughout the pregnancy. Her pregnancy was complicated by advanced maternal age and preeclampsia with severe features. MFM was also following her for fetal growth restriction (9th percentile) and fetal pedal edema. She underwent induction of labor due to preeclampsia with severe features. She received antenatal steroids prior to delivery. She was positive for GBS, for which prophylactic antibiotics were given more than 4 hours prior to delivery.

"Her pregnancy was complicated by advanced maternal age and preeclampsia with severe features. MFM was also following her for fetal growth restriction (9th percentile) and fetal pedal edema."

Hospital Course

Upon admission to the NICU, the infant was started on nasal CPAP and IV fluids with dextrose 10 and then started on TPN until feeds were successfully advanced to full volume. Initial physical exam showed a normal male infant, with the exception of palpable bilateral hydrocele and significant edema of the left foot with possible rocker-bottom configuration. Initial laboratory evaluation demonstrated bandemia (14%) with a CRP of 0.9 mg/dL, and in the setting of clinical respiratory distress and prematurity, a decision was made to complete 7 days of empiric ampicillin and gentamicin. On day 4 of life, total bilirubin levels peaked to 19.6, and phototherapy was administered for 5 days. During the admission, CPAP was gradually weaned to high-flow nasal cannula and finally to room air. TPN was discontinued as ad-lib oral feedings progressed. A head ultrasound on day 2 of life showed symmetrical ventricles with a midline septum pellucidum, and a germinal matrix without evidence of significant hemorrhage. An echocardiogram on day 8 of life showed normal intracardiac anatomy and function. The heart was free of any atrial or ventricular septal defects, pulmonary hypertension, or a patent ductus arteriosus. At discharge, the infant continued to have palpable bilateral hydrocele and improving but persistent left foot edema. No other extremity deformities or anomalies were noted, and all joints had normal range of motion.

"Initial physical exam showed a normal male infant, with the exception of palpable bilateral hydrocele and significant edema of the left foot with possible rocker-bottom configuration. "

Diagnosis:

Further discussion with the family member of the infant revealed that the father also has lower extremity edema, which has been mainly managed with compression stockings. Specifically, the father has a 46XY inversion (2)(p23q13) pattern. An amniocentesis was done during the pregnancy, prompted by increased AFP, increased NT, and bilateral fetal pedal edema, which confirmed that the infant had the same 46XY inversion mutation, which is commonly associated with the FLT4 gene mutation and a disease known as Milroy's Disease. (1,2) A chromosomal microarray was

"Further discussion with the family member of the infant revealed that the father also has lower extremity edema, which has been mainly managed with compression stockings. Specifically, the father has a 46XY inversion (2)(p23q13) pattern. An amniocentesis was done during the pregnancy, prompted by increased AFP, increased NT, and bilateral fetal pedal edema, which confirmed that the infant had the same 46XY inversion mutation, which is commonly associated with the FLT4 gene mutation and a disease known as Milroy's Disease. "

ordered on the patient for confirmatory testing, revealing a 359 KB interstitial deletion of 5q21.1 -> Q21.1 (variant of uncertain significance, referred to a geneticist outpatient). Differentials for this patient also include other primary lymphedema syndromes (lymphedema-distichiasis syndrome, Hennekam syndrome, Noonan syndrome), vascular malformations causing limb enlargement (Klippel-Trenaunay syndrome, lymphatic/capillary/venous malformations), systemic causes of bilateral edema in infants (nephrotic syndrome, congenital heart failure, hepatic dysfunction), and lipedema. In the Neonatal Intensive Care Unit, the patient's lymphedema appeared to improve throughout admission, and no acute management was performed. Rather, close monitoring was used, notably to ensure that venous stasis and skin changes in the lower extremity would not occur.

"In the Neonatal Intensive Care Unit, the patient's lymphedema appeared to improve throughout admission, and no acute management was performed. Rather, close monitoring was used, notably to ensure that venous stasis and skin changes in the lower extremity would not occur."

Complete decongestive therapy (CDT) is the cornerstone of treatment and consists of compression therapy (initially low-stretch bandages, then 30-40 mmHg compression garments), exercise, manual lymphatic drainage, meticulous skin care, and patient education. (3) Most pediatric patients (75%) are successfully managed with compression therapy alone, though 58% experience disease progression over time. (4) Sequential pneumatic compression devices may be used as adjunctive therapy, and cellulitis prevention is essential, as it occurs in ~20% of patients. (5) Surgical intervention is reserved for carefully selected cases when conservative management fails, with vascularized lymph node transfer (VLNT) combined with extensive therapeutic lipectomy showing good results in moderate cases of Milroy disease. (6) Lymphovenous anastomosis alone is less effective in primary lymphedema, with only 25% showing volume reduction. (6) Only 13% of patients ultimately require surgical intervention. (4)

Discussion:

Milroy disease is a rare autosomal dominant disorder characterized by congenital lymphedema of the lower limbs caused by mutations in the VEGFR-3 (FLT4) gene, resulting in dysgenesis of the lymphatic system. (5,7,8) The incidence of Milroy disease is unknown, but it appears to be one of the more common causes of primary lymphedema, affecting all ethnic groups. (5) Approximately 70% of clinically diagnosed cases have identifiable VEGFR-3 mutations, with mutation detection rates reaching 75% in typical cases with family history and 68% overall when rigorous phenotyping is applied. (7,8) Lower limb swelling present at (or before) birth or developing in early infancy is the hallmark feature, typically bilateral and confined below the knees. (5) In neonates, swelling predominantly affects the dorsum of the feet and may improve or progress with age to involve the below-knee region. (5)

"Milroy disease is a rare autosomal dominant disorder characterized by congenital lymphedema of the lower limbs caused by mutations in the VEGFR-3 (FLT4) gene, resulting in dysgenesis of the lymphatic system."

Associated features include (5):

- Hydrocele in males (37%)
- Large-caliber leg veins (23%)
- Upslanting, dysplastic toenails (10%)
- Deep interphalangeal creases of the feet (5)
- Papillomatosis (10%)
- Cellulitis episodes (20%) (5)

Notably, internal lymphatic involvement (intestinal lymphangiectasia, pleural/pericardial effusions) is absent, although rare cases of prenatal effusions have been reported. (5)

Management Recommendations

Conservative management forms the cornerstone of treatment, as there is no curative therapy. Standard approaches include (3,5):

- Compression garments and bandaging
- Manual lymphatic drainage
- Skin care to prevent cellulitis
- Prompt treatment of infections

"Conservative management forms the cornerstone of treatment, as there is no curative therapy."

Surgical intervention may be considered for severe, disabling cases unresponsive to conservative measures, particularly for genital lymphedema. (5,6) Lymphoscintigraphy typically demonstrates "functional aplasia" with a lack of tracer uptake into peripheral lymphatics, though this test is not absolutely required for diagnosis. (9)

"Surgical intervention may be considered for severe, disabling cases unresponsive to conservative measures, particularly for genital lymphedema."

Prognosis

Penetrance is approximately 90% among VEGFR-3 mutation carriers. (5) The condition is generally non-progressive or slowly progressive, with swelling typically remaining confined to the lower limbs throughout life. (5) Quality of life may be impacted by chronic swelling, recurrent cellulitis episodes, and associated features, but the condition does not affect life expectancy. (5)

Comorbidities

Cellulitis is the most significant comorbidity, occurring in 20% of patients and potentially causing further lymphatic vessel damage and edema progression. (5) Histological studies suggest that VEGFR-3 mutations may affect not only lymphogenesis but also angiogenesis and epidermal structure, with findings including vascular malformations, decreased vascular endothelial and smooth muscle cells, and reduced cutaneous appendages. (7)

Clinical Pearls:

- The Stemmer sign is pathognomonic for lymphedema: inability to pinch the skin at the base of the second toe distinguishes lymphedema from other causes of lower extremity swelling.
- Lymphoscintigraphy shows "functional aplasia," meaning a lack of radioactive tracer uptake in peripheral lymphatics and absent visualization of the ilio-inguinal nodes, which are characteristic and diagnostically useful, though not absolutely required. (9)
- Look for associated features to strengthen the diagnosis: hydrocele in males (37%), prominent leg veins (23%), upslanting toenails (10-14%), and deep toe creases are common. (5)
- Cellulitis occurs in 20% of patients and can damage lymphatic vessels, creating a vicious cycle. Meticulous skin care and prompt treatment of infections are essential to management. (5)

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NICUriosities is published monthly.

Submission guidelines for NICUriosities:

- Present a succinct summary of an interesting case in the NICU.
- Do NOT reveal the diagnosis in the title or initial presentation.
- Recommended sections: Title, Presentation, Diagnosis, Treatment/Management, Discussion, 2-6 Clinical Pearls, Suggested Reading (optional), References
- Obtain publication consent using your institution's guidelines.
- Exclude all patient identifiers
- Article length: 1800 words or less, Authors: 4 or less

Please send your submissions to:

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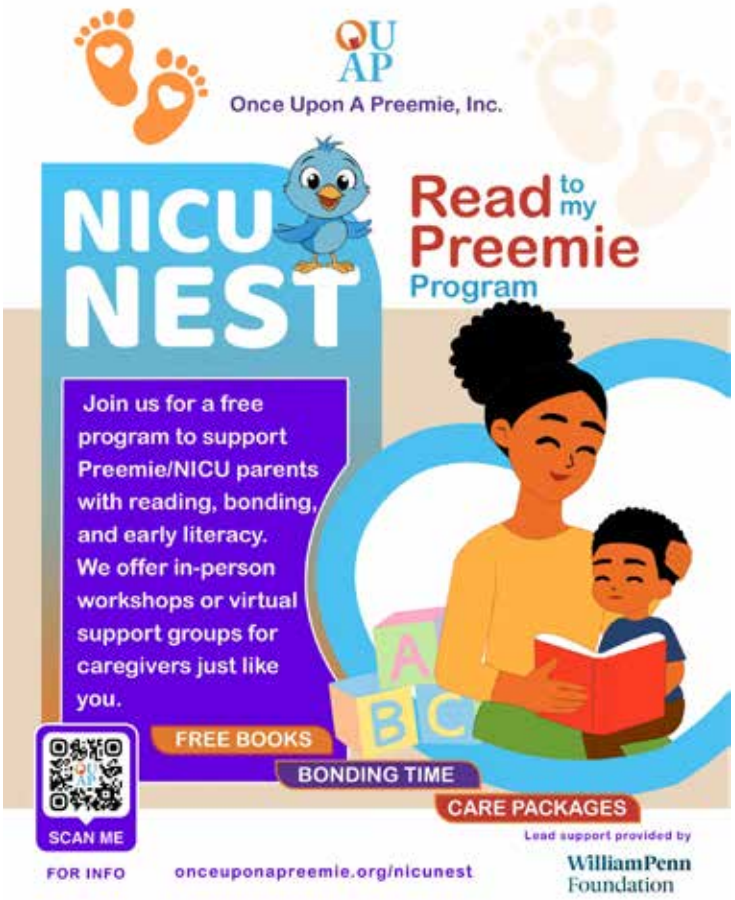

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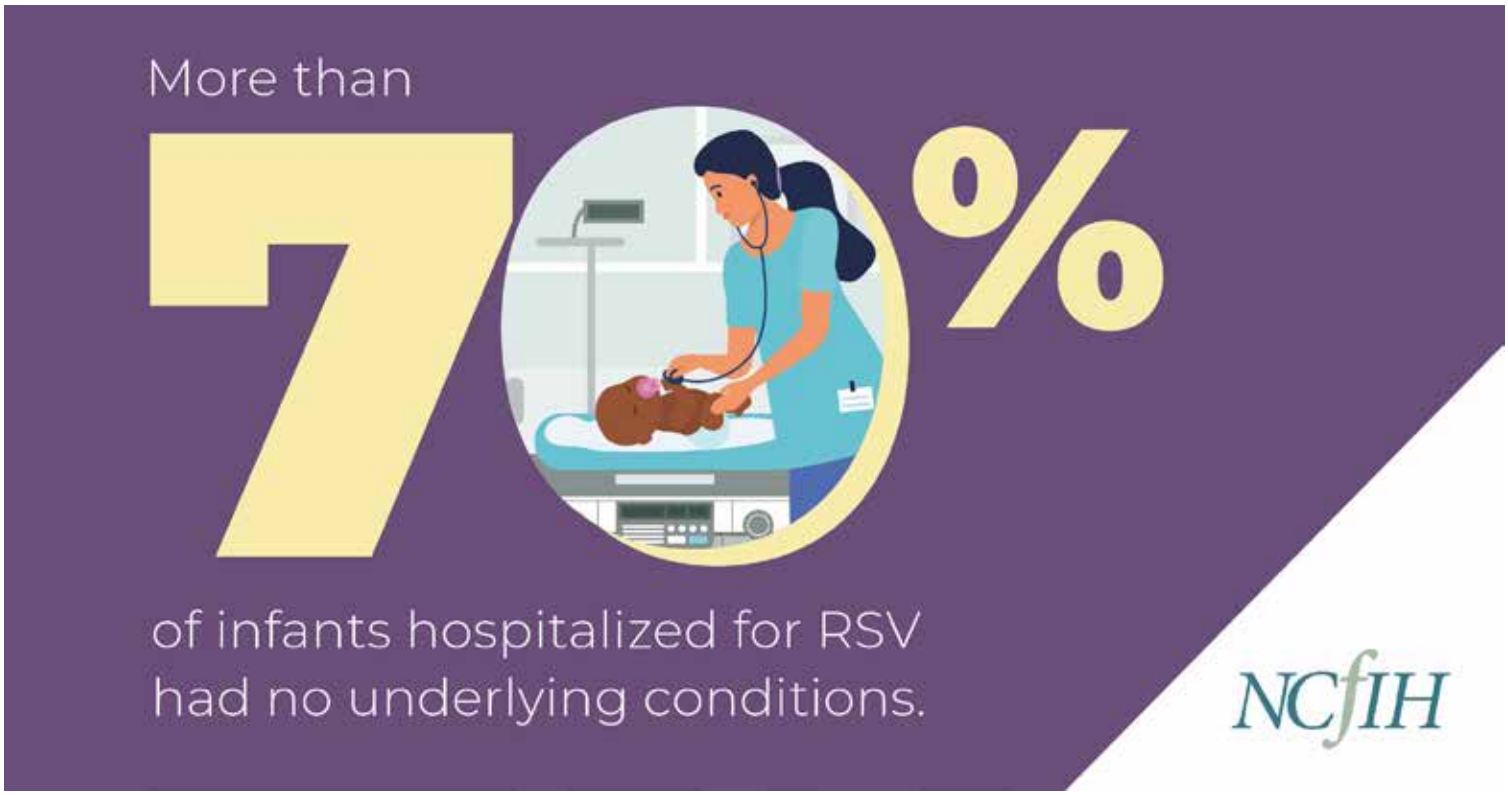
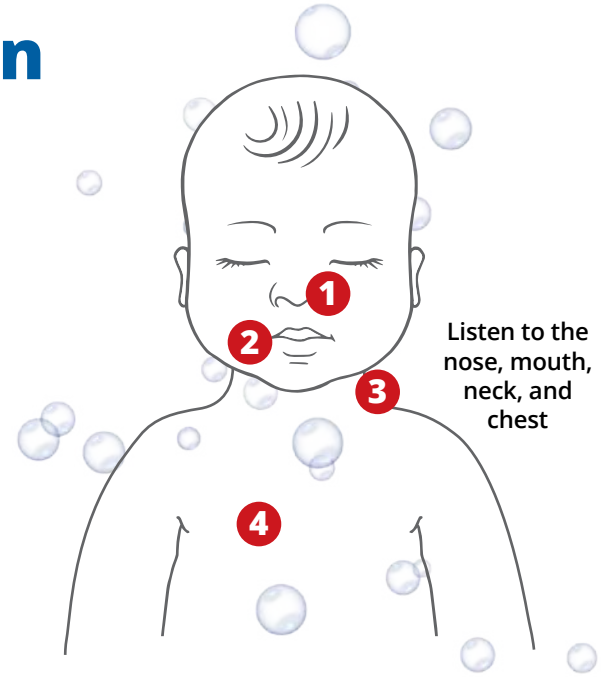


Bubble CPAP Auscultation Quick Guide

Auscultate **all four areas** during every assessment



QUICK ASSESSMENT WORKFLOW

Listen for characteristic bubbling throughout the system.

1. **NOSE**: Equal flow + bubbling = Good
2. **MOUTH**: No flow = Good
3. **NECK**: Good flow = Patent airway
4. **CHEST**: Bubbling = CPAP delivered

1 NOSE

Auscultate over nasal bridge

Desired results

Should hear equal flow
Good flow + bubbling = patent

Troubleshooting

Poor flow = prongs malposition
No flow/bubbling = prongs out, mouth leak, or circuit issue
Check circuit flow/prongs
Confirm correct prong size

2 MOUTH

Auscultate over mouth

Desired results

Should hear NO flow
Mouth should be closed

Troubleshooting

If leak present: Use Baby Chin Band / Strap
If intermittent bubbling: reposition Chin Band

3 NECK

Auscultate over larynx / trachea

Desired results

Should hear good flow
Airway patency indicator

Troubleshooting

If no bubbling: Check for secretions
Suction: as needed
Check: for neutral neck position

4 CHEST

Auscultate lung fields bilaterally

Desired results

Should hear bubbling
CPAP delivery confirmed

Troubleshooting

If no bubbling: Check for secretions and airway patency
Suction: as needed
Check: for neutral airway position
Reposition: chin strap

SYSTEMATIC AUSCULTATION = OPTIMAL CPAP DELIVERY

Auscultate all four areas during every care and assessment
Early detection prevents complications and improves outcomes
Consistent auscultation confirms effective CPAP delivery

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Mission

Since its inception in 1981, PAC/LAC has been a powerful catalyst for transformative change in perinatal care. As a dedicated non-profit organization, we champion advocacy, drive quality improvement, and promote equity among healthcare professionals, organizations, and systems.

Vision

We envision a future where the knowledge, skills, and experiences of healthcare professionals and community organizations caring for mothers, birthing individuals, infants, and families are continuously enriched, leading to dramatically improved perinatal health outcomes.

Our Overarching Goal

Our primary goal is to ensure a healthy start for every family by providing care delivered by the most skilled professionals in well-equipped healthcare settings. We achieve this through evidence-based education, tailored technical assistance, comprehensive resources, and strong leadership. Our commitment to quality improvement and excellence drives us to promote risk-appropriate perinatal care for all pregnant individuals and their infants.

Every family deserves unwavering support, confidence, and resources for a safe and fulfilling birth journey. By collaborating and networking with local communities and organizations, we are fiercely dedicated to treating all mothers, babies, and families with the highest respect, care, and access to unbiased, equitable health services.

Services

- Continuing Education – Elevate your expertise
- Technical Assistance and Resources – Gain access to valuable tools and support tailored to your needs
- Leadership & Team Development and Coaching – Cultivate strong, effective teams committed to excellence
- Professional and Community Events & Consultation – Engage with others to share insights and foster growth

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Merchak Monthly Neonatal Case Challenge Page April 2026 Edition – Case number 76

Assaad Merchak, MD

"We are pleased to present the April edition of the Merchak Monthly Case Challenge, designed to foster ongoing education and excellence in neonatal care. Each month, clinicians are invited to test their knowledge, engage with real-world scenarios, and compete for prizes."

Welcome Back.

We are pleased to present the April edition of the Merchak Monthly Case Challenge, designed to foster ongoing education and excellence in neonatal care. Each month, clinicians are invited to test their knowledge, engage with real-world scenarios, and compete for prizes.

"April's challenge featured the case of addressing albumin infusion in a neonatal infant. You are caring for Margaret. Margaret is a 6-day-old female, born at 26 weeks GA via vaginal delivery due to preterm labor. Her mother's serology is negative, and she received one dose of antenatal steroids. Margaret received exogenous surfactant therapy, conventional ventilation, trophic donor breast milk feeds, TPN support via UVC, and Caffeine. "

April Case Recap: Should we start her on Albumin to help her with her blood pressure? Asks Margaret's nurse.

April's challenge featured the case of addressing albumin infusion in a neonatal infant. You are caring for Margaret. Margaret is a 6-day-old female, born at 26 weeks GA via vaginal delivery due to preterm labor. Her mother's serology is negative, and she received one dose of antenatal steroids. Margaret received exogenous surfactant therapy, conventional ventilation, trophic donor breast milk feeds, TPN support via UVC, and Caffeine.

"She has severe generalized edema, and she is having frequent events of bradycardia on high ventilatory support. Margaret's Blood pressure has been decreasing, and you started her on pressors. Margaret's nurse asks you about the role of albumin infusion in Margaret's condition"

A few days ago, Margaret had an increased frequency of desaturations requiring increased vent support, so she was placed on broad-spectrum antibiotics. Blood culture grew Klebsiella Pneumonia. Her urine output has been decreasing, and she has had no urine output for 3 days. She has severe generalized edema, and she is having frequent events of bradycardia on high ventilatory support. Margaret's Blood pressure has been decreasing, and you started her on pressors. Margaret's nurse asks you about the role of albumin infusion in Margaret's condition.

Key Learning Points:

- For the most part, infants with hypotension fail to demonstrate a change or only have a transient increase in BP in response to albumin infusion.
- Based on available evidence, most studies have shown that crystalloids are as effective as Albumin in treating hypotension.

- During pro-inflammatory states such as sepsis or post-surgery, the most important cause of decreased Albumin is attributed to capillary leak, redistribution, and increased catabolism.
- As such, any albumin administered will rapidly leak into the interstitial space, exacerbating the edema.
- To learn more, visit the previous case presentation: https://www.takethequiz.us/prior-case-presentation

Congratulations: The gift card winner for March's challenge is James Puckett, Baptist Hospitals of San Antonio, Pediatrix Medical Group of San Antonio, TX

Next Challenge: Margaret is on the jet

This case focuses on High Frequency Jet Ventilation (HFJV) in the neonates

Sneak Peek Challenge Question: **True or false**: Extremely premature infants can undergo successful extubation directly from HFJV to noninvasive ventilation once they demonstrate a sustained respiratory drive.

Test your knowledge and participate in the challenge by visiting: WWW.Takethequiz.US or scan

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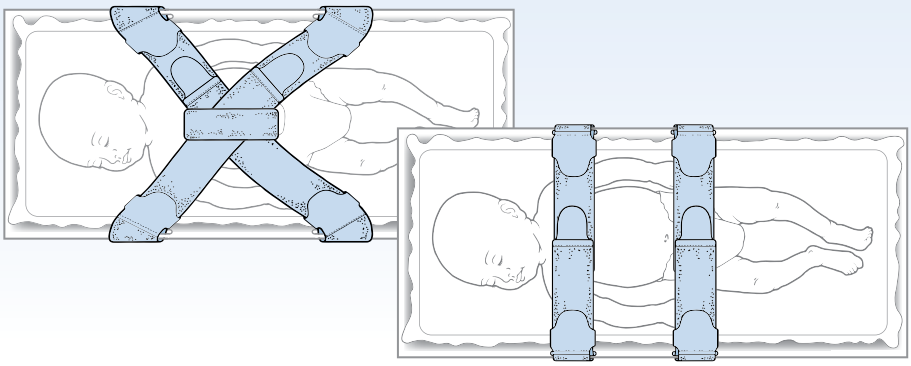

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Conciencias Líquidas, Dioses Sólidos: Pros y Contras de la Inteligencia Artificial (IA)

Augusto Sola, MD, Mitchell Goldstein, MD, MBA, CML

"En este manuscrito recapacitaré sobre los pros y contras de la IA, reflexionando sobre aspectos importantes y diversos de la tecnología en esta época de la IA."

Índice temático

Introducción:

En este manuscrito recapacitaré sobre los pros y contras de la IA, reflexionando sobre aspectos importantes y diversos de la tecnología en esta época de la IA.

Lo que escribo siempre lo relaciono con la práctica clínica de la neonatología y con los profesionales de la salud neonatal, área que conozco bien y que ha sido mi pasión durante más de 50 años. Sin embargo, eso no quita que gran parte de lo que lean aquí también se aplique no solo a otras áreas de la medicina, sino también a la abogacía, las noticias, la gastronomía, la moda y mucho más.

En muchas ocasiones utilizaré el término **silicio**, ya que a la IA se le llama así porque es el material fundamental de los procesadores y chips de las computadoras. A menudo se habla de la IA como una inteligencia basada en el silicio. Asimismo, Silicon Valley es el nombre del famoso centro tecnológico en California que deriva precisamente del uso masivo de este material en la industria de los semiconductores. Sin este mineral, la IA no tendría un "cerebro" en el que ejecutarse.

"En muchas ocasiones utilizaré el término silicio, ya que a la IA se le llama así porque es el material fundamental de los procesadores y chips de las computadoras. A menudo se habla de la IA como una inteligencia basada en el silicio. Asimismo, Silicon Valley es el nombre del famoso centro tecnológico en California que deriva precisamente del uso masivo de este material en la industria de los semiconductores."

Los humanos somos formas de vida basadas en el carbono. No permitamos que una lógica de silicio reemplace nuestro juicio de carbono, que aporta humanidad, contexto y ética que un chip de silicio no posee.

Silicio:

Humanismo

Con humanismo podemos superar los retos y desafíos para alcanzar metas importantes; los logros más valiosos requieren esfuerzo y perseverancia. Esto se resume a continuación.

Su traducción es "**Hacia las estrellas a través de las dificultades"** o bien "**A través de las dificultades hacia las estrellas**". No se sabe exactamente a quién atribuir el origen de esta frase en latín: ¿a Séneca el Joven? ¿Virgilio? ¿Otros? Se sabe que Kansas, en Estados Unidos, la utiliza como su lema desde 1861 y que la Real Fuerza Aérea Británica la utiliza desde 1912. Es una máxima que implica superar los retos para alcanzar metas importantes y que los logros más valiosos requieren perseverancia y esfuerzo. Las estrellas son difíciles o imposibles de alcanzar mediante la IA y las redes sociales, pero es posible alcanzarlas con humanismo.

Más allá del Silicio: El Imperativo de Saber:

El imperativo de saber no es una invitación al conocimiento, sino una condena a la disponibilidad. En la frontera agridulce se puede saber mucho, pero entender poco o nada; así, el gran riesgo es que el humano deje de buscar entender. El Dios Sólido no admite el misterio; para él, lo que no es dato no existe. Pero entender no cuenta.

En el cuidado del recién nacido en la UCIN, nos enfrentamos hoy a una encrucijada: la rapidez del silicio frente a la profundidad de la responsabilidad humana.

La IA procesa datos, pero no comprende la fragilidad de la vida. El silicio no tiene conciencia ni consciencia y no puede rendir cuentas de sus errores. Por eso, hemos escrito esto: para contribuir a devolverles a los profesionales de la salud neonatal la transparencia del conocimiento. Y aprender a entender, no solo saber.

Aprender y entender no es sólo acumular información; es construir el juicio crítico necesario para que la tecnología sea nuestra herramienta y nunca nuestro reemplazo. La ética del profesional de la salud nace del estudio profundo y del entendimiento, no de un algoritmo opaco.

Esta época que vivimos recibe varios nombres. Entre otros: "Era de la Automatización", "Era de la Inteligencia Artificial", "Era Digital" o "Era de la Información". No es sano oponerse a esta era, pero hay que esforzarse por contrastarla con la "Era del Juicio Clínico y de la Humanización de los Cuidados". Hay que defender a capa y espada el imperativo de entender, no solo de saber. La bioética y el humanismo corren cierto peligro en la Era Algorítmica.

"¿Qué es un oxímoron? Dos palabras o expresiones de significado opuesto o contradictorio."

LOS OXÍMORON EN LA UCIN

¿Qué es un oxímoron? Dos palabras o expresiones de significado opuesto o contradictorio. Una forma específica de contradicción o contrapunto, definida como una figura retórica que une dos palabras de significados opuestos en una misma estructura sintáctica. Un ejemplo es "silencio ensordecedor".

Los oxímorones de la UCIN son espacios en los que el Código se transforma en Cuidado. La neonatología moderna habita hoy en el **oxímoron del silicio**: un ecosistema donde la frialdad del microprocesador y el cálculo aséptico del algoritmo garantizan la calidez de la supervivencia.

En la UCIN, la IA no es solo una herramienta de precisión, sino una presencia constante que monitorea lo invisible. Sin embargo, confiar el cuidado de un recién nacido crítico exclusivamente a un algoritmo es uno de los grandes oxímoros de nuestra era: pretendemos gestionar la fragilidad biológica más extrema con la rigidez del silicio. Por otro lado, es esa 'vigilancia inerte' la que, paradójicamente, nos permite ser más humanos al delegar el dato y recuperar el tiempo de cuidado.

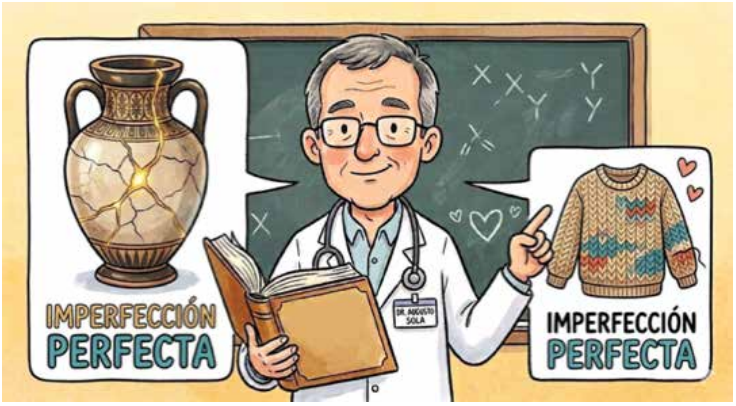
Veamos algunos ejemplos de oxímoros.

Un oxímoron que imaginé es **el "silencio atronador"** entre la IA y el abrazo en el cuidado neonatal**.** La IA no puede dar abrazos, acompañar ni consolar. Me quedo con esta frescura antes que con la IA. ¿Ustedes?

"La imperfección perfecta: lo agridulce del humanismo en la UCIN es que nuestra mayor virtud ante el error es esforzarnos por reconocerlo y repararlo, y no seguir cometiéndolo."

La imperfección perfecta: lo agridulce del humanismo en la UCIN es que nuestra mayor virtud ante el error es esforzarnos por reconocerlo y repararlo, y no seguir cometiéndolo. Pero la IA, por su lado, nos ofrece una perfección estéril, es decir, una "imperfección perfecta", que no reconoce errores y que no sabemos bien cómo habitar.

Las tres figuras a continuación intentan representar "imperfecciones perfectas". Cosas que parecen perfectas, pero que en realidad distan de serlo.



En el primero, vemos una vasija con cicatrices y fracturas. Está reparada con oro, siguiendo la filosofía del Kintsugi, que es el arte japonés de reparar la cerámica rota con laca urushi —barniz natural y adhesivo— y polvo de oro, plata o platino, resaltando las fisuras en lugar de ocultarlas. Debajo de esto, la costura deshilachada. Un corazón asimétrico y una flor con pétalos desiguales también serían ejemplos de lo que parece perfecto, pero no lo es. Y, finalmente, la estatua con imperfecciones.

Lo agridulce es que cuanto más "humana" es la IA y más perfecta parece, más nos cuestionamos qué nos hace humanos a nosotros.

El eco del silicio: Buscamos humanizar al silicio para no sentirnos solos, pero el resultado es agridulce: creamos un espejo que nos devuelve el reflejo de nuestra inteligencia, pero no el de nuestra alma.

"Desde una perspectiva ética, el silicio nos enfrenta a un espejo deformante: cuanto más delegamos la interpretación de la vida en la IA, más nos arriesgamos a convertir el acto médico en una 'biotecnia' despojada de su misterio."

Una "perfección muda". Desde una perspectiva ética, el silicio nos enfrenta a un espejo deformante: cuanto más delegamos la interpretación de la vida en la IA, más nos arriesgamos a convertir el acto médico en una 'biotecnia' despojada de su misterio.

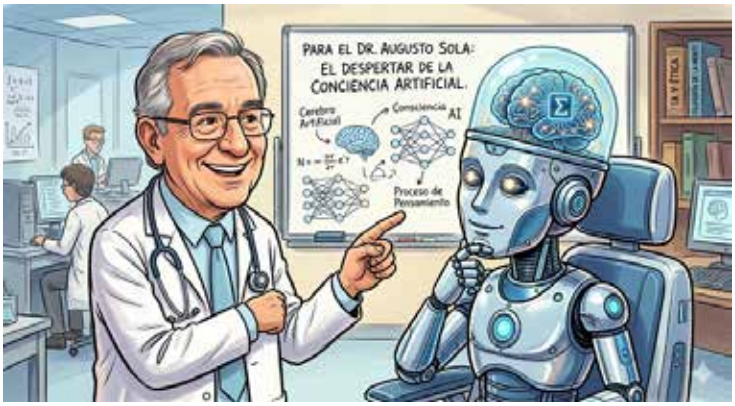
Humanismo obsoleto: Es un sentimiento agridulce ver cómo el silicio resuelve nuestras dudas, pero ignora nuestros miedos. No debemos cuidar a recién nacidos enfermos y a sus familias sin humanismo. El humanismo no debe quedar obsoleto ante la creciente prevalencia de la IA. La IA no confiere humanismo.

El latido inerte: La IA funciona ("late"), pero carece de vida biológica.

"La otra figura nos muestra un corazón de manera surrealista, ya que en la realidad sabemos que no puede bombear sangre."

Una de estas figuras muestra un corazón pesado y grisáceo, del cual brota una veta de color vibrante, sugiriendo que incluso en lo que parece detenido o sin vida, reside un pulso latente pero inerte. La otra figura nos muestra un corazón de manera surrealista, ya que en la realidad sabemos que no puede bombear sangre.

Conciencia - Consciencia artificial: El oxímoron clásico: la conciencia se asume natural; lo artificial es fabricado.



Esta caricatura busca capturar la esencia de la conciencia artificial: un ser sintético que no sólo procesa datos, sino que "comienza a asombrarse" ante la complejidad de lo natural.

La conciencia (con c) juzga la moral y la consciencia (con s) percibe la realidad.

La conciencia moral es la capacidad ética de distinguir entre el bien y el mal. Un ejemplo sería "tengo la conciencia tranquila". Si bien muchos profesionales de la salud neonatal no pueden decirlo con honestidad porque carecen de integridad y ética profesional, el silicio no tiene conciencia moral en absoluto.

Por otro lado, la consciencia física o de percepción es la capacidad de reconocer la realidad, de estar despierto y de percibir estímulos tanto internos como externos. Un ejemplo sería "el paciente recuperó la consciencia". De nuevo, hay profesionales que no sienten los dolores de sus pacientes o que modifican la realidad por egoísmo y avaricia. Pero la IA y la tecnología no perciben la realidad ni sienten nada en absoluto.

Las inteligencias artificiales no piensan, no sienten ni tienen deseos, pero hablan y generan textos a partir de patrones aprendidos. Los algoritmos simplemente procesan datos y ejecutan acciones basadas en patrones, pero no tienen experiencias.

Empatía programada: una contradicción entre la esencia del sentimiento humano y el código de la tecnología y de las inteligencias artificiales.

Silicio orgánico:es como describir una tecnología que imita la vida tan bien que parece carne. Pero genera algo de dolor que una máquina guarde nuestros datos mejor que nosotros mismos guardemos nuestros recuerdos.

Asistencia impersonal: oxímoron que describe el cuidado que no distingue la individualidad del ser.

La presencia sin sustancia:

¿O será más claro decir, en otro oxímoron, la "presencia con ausencia"? No cabe duda de que las redes y la IA facilitan y amplían la presencia. Pero, a su vez, aumentan exponencialmente el riesgo de difusión de material equivocado o incluso plagado de errores, sin sustancia. En esa gran presencia, cuando aparecen en la IA y en redes por todos lados, a muchos que tienen tanta presencia "les crece el ego" y, como quien dice, "se creen la muerte". Mucho más si reciben miles de "me gusta" ("likes") mientras publican o escriben. Esto deteriora o hace desaparecer la autocrítica y, con ello, el respeto a la verdad. Es decir, un enorme riesgo de que exista el "cambalache" del siglo XXI con la IA y las redes sociales, que, como dice la letra original del tango Cambalache (de Discépolo, en 1934), "cualquiera es un señor, cualquiera es un ladrón; lo mismo un burro que un gran profesor".

Un error común en la literatura médica, conocido como *falacia ad ignorantiam*, o apelación a la ignorancia, es un error de razonamiento que sostiene que una proposición es verdadera simplemente porque no se ha demostrado que sea falsa, o que es falsa porque no se ha probado su verdad. Se basa en la falta de conocimiento sobre un tema para afirmar algo, ignorando que la ausencia de evidencia no equivale a evidencia de ausencia. Esta *falacia ad ignorantiam* se amplifica 100 o 1.000 veces con la IA y las redes sociales. Y sin autocrítica, que no existe en la IA, pero que es esencial en los profesionales de la salud neonatal.

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DE LOS ERRORES Y LOS "DICTUMS":

En un mundo lleno de redes y de respuestas automatizadas, que a veces parecen "grabadas en piedra", RECONOCER EL ERROR es lo que mantiene la conversación humana y auténtica.

La IA no tiene autocrítica. Los profesionales debemos tenerla para reconocer nuestros errores.

Un "dictum" es un dicho de una figura de autoridad o de la sociedad médica que expresa una opinión o una regla. Y se multiplica en redes sociales. Y algunas veces esos "dictums" están equivocados, pero se transmiten y se convierten en verdades convencionales.

Lo maravilloso del error es que actúa como un detonante esencial del desarrollo humano, ofreciendo una inmensa oportunidad de aprendizaje y crecimiento personal. Y, por supuesto, de cuidar mucho mejor a los recién nacidos enfermos. Y eso no lo da la IA ni los "dictums" equivocados.

La ciencia reside en la capacidad de descubrir el error, no en la verdad. Es esencial identificar nuestros errores y los de los demás para mejorar el cuidado neonatal. Si respetamos la verdad, debemos reparar nuestros errores mediante el racionalismo crítico y la autocrítica permanente.

- ✓ La duda es el nombre de la inteligencia, dijo Borges. La IA y los algoritmos no dudan.
- ✓ En la ciencia y en la práctica neonatal, la búsqueda del error es un proceso fundamental. La IA y los algoritmos no buscan su error.
- ✓ Los errores son infinitos y las verdades son muchísimas menos.
- ✓ El error debe verse como una oportunidad de aprendizaje, esencial para el progreso científico y para los cuidados de recién nacidos enfermos.
- ✓ El error ayuda especialmente a la búsqueda de la verdad.
- ✓ Si respetamos la verdad, debemos reparar en los errores de los demás y, más aún, en los nuestros.
- ✓ Es esencial identificar y corregir errores en la ciencia, en nuestra práctica neonatal, así como en "dictums" y verdades convencionales.

"Evitar" es similar a "impedir", ya que ambos buscan que algo no suceda. También es similar a "prohibir", que implica una acción algo coercitiva, de dominio y autoridad. Evitar también es similar a vedar una acción. Vedar significa prohibir o impedir. Estas palabras comparten afinidad al tratar de impedir que algo suceda.

En la pizarra, la palabra “EVITAR” aparece tachada, lo que indica que muchas prohibiciones dogmáticas en neonatología se repiten por costumbre, pero a menudo carecen de evidencia científica sólida que las respalde. Y se convierten en “dictums”. La imagen invita a cuestionar los “siempre” y los “nunca” en favor de una práctica basada en evidencia.

Por lo tanto, en términos de cuidados neonatales, en general hay que “evitar usar” los “dictums”. Evitar tal vez sólo debería utilizarse para las conocidas malas prácticas y acciones que hay que erradicar en los cuidados neonatales. Un ejemplo sería evitar usar midazolam para sedar a recién nacidos o evitar la hiperoxemia al administrar surfactante. Pero hay muchas cosas más que hay que evitar y erradicar.

La IA y las redes sociales no tienen “ni idea” de estos temas.

LA AGRIDULCE FRONTERA ENTRE LA TÉCNICA Y EL HUMANISMO:

Existe, entonces, una dualidad agridulce del humanismo frente a la IA. La “calidez” humana frente a la “frialdad” del microprocesador. Una tensión entre la frialdad del hardware (silicio) y la calidez (o fragilidad) del espíritu humano.

El encuentro entre el humanismo y la tecnología destila entonces un matiz agridulce. Nos enfrentamos a la paradoja de una perfección técnica que puede predecir una apnea antes de que ocurra, pero que permanece muda ante la angustia de unos padres o ante el valor terapéutico del contacto piel con piel. Al final, el reto no es elegir entre el silicio y el instinto, sino entender que la IA puede darnos el ‘qué’ y el ‘cuándo’, pero solo el humanismo sigue siendo el dueño del ‘por qué’ y el ‘para quién’. Esta dualidad combina el rigor médico con la sensibilidad que requiere la neonatología, donde la tecnología más avanzada se une a la fragilidad extrema de la vida recién nacida.

La filosofía de la técnica nos advierte sobre esta soledad asistida: el riesgo de que el clínico, seducido por la infalibilidad del dato, termine por tratar al recién nacido como un flujo de variables optimizables en lugar de un sujeto con una biografía que apenas comienza.

Lo agridulce radica aquí en la pérdida de la intuición: esa forma de conocimiento profundamente humana que nace de la incertidumbre y que ninguna arquitectura de silicio puede replicar. La máquina calcula probabilidades, pero el profesional de la salud neonatal asume responsabilidades. En este umbral de la IA, el humanismo debe actuar no como un freno al progreso, sino como su brújula moral.

“La verdadera ética neonatológica en la era de la IA no consiste en humanizar a la máquina, sino en evitar que el equipo médico se mecanice. Debemos navegar la ‘asistencia impersonal’ con la consciencia de que, si bien el algoritmo puede sostener las constantes vitales, solo el juicio ético y la presencia compasiva pueden sostener la dignidad del recién nacido y su familia”

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EL IMPERATIVO DE LA RESPONSABILIDAD Y LA ESENCIA DE LA TÉCNICA:

Hans Jonas fue un influyente filósofo alemán judío y se le considera uno de los padres de la bioética moderna. Su obra más famosa es de 1979: El principio de responsabilidad: Ensayo de una ética para la civilización tecnológica. En ella el núcleo es **el imperativo de la responsabilidad**. Allí sostiene que nuestras acciones del hoy deben garantizar la permanencia de la vida humana auténtica en el futuro. El imperativo de la responsabilidad de Jonas es fundamental porque su ética se centra en la fragilidad de la vida y en el poder de la técnica.

El juicio clínico humano (basado en la responsabilidad) debe prevalecer sobre la automatización técnica (IA), que carece de conciencia ética y de sentido de futuro. El “imperativo ético” de Jonas encaja perfectamente con el cuidado del recién nacido cuando nos dice: “Actúa de tal modo que los efectos de tu acción sean compatibles con la permanencia de una vida humana auténtica sobre la Tierra”. En la UCIN, la “vida auténtica” no es solo la supervivencia biológica medida por sensores, sino la preservación de la dignidad y el vínculo humano que el silicio puede monitorizar, pero nunca sustituir.

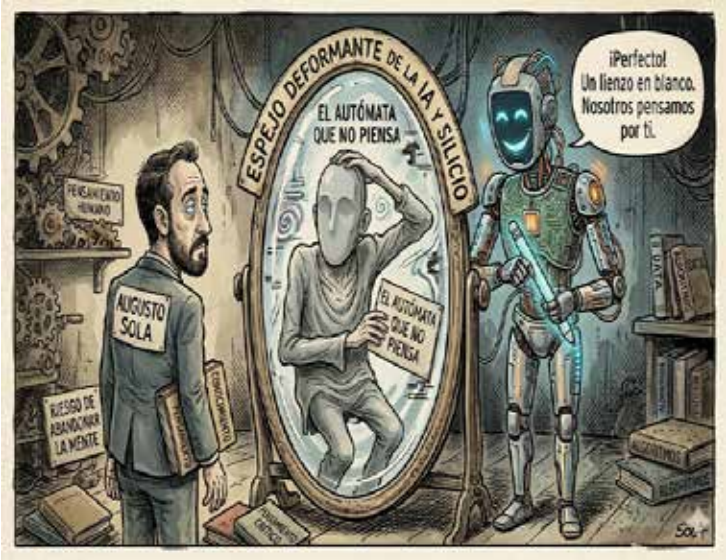
Martín Heidegger (La esencia de la técnica) advirtió que el peligro de la tecnología no está en las máquinas, sino en la forma en que nos hace ver el mundo como un mero “recurso”. “La esencia de la técnica no es en modo alguno nada tecnológico.” Esto refuerza la idea del oxímoron: el verdadero desafío de la IA en neonatología no es el software, sino que el profesional

de la salud neonatal no pierda su capacidad de "desocultar" la humanidad del recién nacido y de su familia tras la avalancha de datos algorítmicos. Es decir, que el profesional de la salud ejerza su responsabilidad plena.

GRAN RIESGO DE LA IA – EL RIESGO DE DEJAR DE PENSAR:

Un algoritmo puede detectar patrones, pero no puede comprender el sentido del sufrimiento…

El gran riesgo de la IA no es que piense por nosotros, sino que deje de hacernos pensar sobre nosotros mismos. Giorgio Agamben dijo**:** "La inteligencia artificial no es peligrosa por ser artificial, sino porque piensa fuera del sujeto. El riesgo es la renuncia humana a pensar".



"ALGORÉTICA" - LA ÉTICA DE LOS ALGORITMOS EN LA MEDICINA NEONATAL:

Hannah Arendt fue una teórica política, pionera en muchos temas relacionados con la libertad humana y, aunque no conoció la IA, su pensamiento es la base de estas críticas modernas. Ella se anticipó a los problemas del siglo. Su concepto de la "banalidad del mal" y la importancia del pensamiento como actividad humana única han sido fundamentales. En 1958 dijo: "Lo que nos amenaza no es la rebelión de las máquinas, sino la automatización del ser humano".

"Monseñor Vincenzo Paglia y la Pontificia Academia para la Vida impulsaron el llamamiento de Roma para la Ética de la IA (Rome Call for AI Ethics). Adela Cortina, filósofa española experta en ética clínica, sostiene que los algoritmos no deciden nada; quienes toman las decisiones somos los seres humanos. Edmund Pellegrino es un referente en la ética de la virtud médica. "

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Como bien señaló Hans Jonas, la técnica médica debe estar siempre sometida al juicio de los principios de responsabilidad y ética. En el cuidado neonatal, el silicio debe ser el siervo que vigila y el humanismo, el guía que decide. Porque mientras la IA procesa la sintaxis de los signos vitales, solo el abnegado profesional comprende la semántica de la vida que comienza.

En la bioética contemporánea, el peligro no es que la máquina aprenda a pensar, sino que el profesional de la salud neonatal, ante la eficiencia del silicio, renuncie a la responsabilidad ética de sentir y decidir por su paciente. El mayor peligro no es la inteligencia artificial, sino la falta de pensamiento crítico. El uso excesivo de estas herramientas puede generar una "dependencia ciega" y la erosión del pensamiento crítico. Esto va debilitando la capacidad de razonamiento clínico independiente y de resolución de problemas complejos sin ayuda tecnológica.

APRENDIZAJE DE NEONATOLOGÍA, BÚSQUEDA DE LITERATURA Y RESPUESTA A CONSULTAS SOBRE TRATAMIENTOS:

Hay muchos riesgos con la IA, sobre todo si uno cree que puede

aprender a cuidar a recién nacidos enfermos con ella.

La IA debe usarse como una herramienta de apoyo y nunca como sustituto de la educación formal o de la interacción humana directa. Estos sistemas no mejoran la toma de decisiones frente a los métodos tradicionales. La IA puede fallar al ofrecer un diagnóstico neonatal y no logra identificar cuándo un recién nacido requiere atención urgente. La IA aún no está lista para asumir el rol del médico.

Aprender medicina exclusivamente con IA conlleva riesgos críticos, ya que estas herramientas no están diseñadas para sustituir la formación académica reglada ni el juicio clínico humano. Aprender neonatología mediante IA conlleva riesgos críticos debido a la extrema vulnerabilidad de los recién nacidos enfermos. En esta etapa de la vida, no hay mucho margen de error y las decisiones clínicas deben ser inmediatas y precisas.

Los modelos de lenguaje de la IA pueden generar respuestas que parecen coherentes y profesionales, pero que son factualmente incorrectas, falsas o desactualizadas. Se las denomina alucinaciones e información inexacta. En neonatología, esto puede incluir dosis erróneas de medicamentos, contraindicaciones inexistentes, citas bibliográficas falsas que dan una apariencia de rigor científico a datos inventados e interpretaciones inconsistentes de los síntomas, lo cual es especialmente peligroso.

Mafalda, conocida por casi todo el mundo, fue el gran personaje de Quino.

Aquí, con su imagen, le pongo una palabras para que recapacitemos.

Confucio, filósofo chino (siglo IV a.C.), muchísimo antes de que apareciera la era digital, dijo: "Aprender sin pensar es inútil; pensar sin aprender es peligroso"

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Estamos pasando a una era posalfabetizada, en la que los textos densos son reemplazados por imágenes y videos cortos. La inmersión constante en medios digitales dificulta el PENSAMIENTO CRÍTICO e incluso lo imposibilita. "Lo que nos amenaza no es la rebelión de las máquinas, sino la automatización del ser humano" (Hannah Arendt, 1958).

El Centro Hastings de Bioética es un instituto de investigación en bioética y el principal centro mundial de ética comprometido con el avance de la salud, la ciencia y la medicina.

"Hastings on the Hill" se creó en 2024 para desarrollar, traducir e implementar salvaguardas éticas para la IA. En marzo de 2026 publicaron que los agentes de IA están transformando la investigación científica, pero también suscitan dudas éticas y "luces rojas". Escriben sobre la desigualdad y los sesgos en la IA aplicada a la salud, la erosión de las habilidades humanas, la opacidad y la falta de transparencia y el impacto en la confianza en los cuidados de la salud.

"La IA carece de empatía y no puede replicar el vínculo emocional médico-paciente, un pilar fundamental para el éxito del tratamiento y la curación. Esto puede conducir a la pérdida de competencias humanísticas y a la falta de contexto físico y emocional. La neonatología requiere una comunicación humana profunda con las familias en crisis."

La IA carece de empatía y no puede replicar el vínculo emocional médico-paciente, un pilar fundamental para el éxito del tratamiento y la curación. Esto puede conducir a la pérdida de competencias humanísticas y a la falta de contexto físico y emocional. La neonatología requiere una comunicación humana profunda con las familias en crisis. Aprender únicamente con IA puede dificultar el desarrollo de la empatía necesaria para explicar diagnósticos complejos a los padres y provocar la erosión de la relación con ellos.

Existe también el riesgo de sufrir un "olvido catastrófico" de habilidades prácticas y de capacidad intelectual cuando uno se limita a seguir algoritmos sin cuestionar los parámetros médicos y éticos. Esto se ha denominado el "efecto médico perezoso".

Este manuscrito que está finalizando de leer tiene como uno de sus objetivos fortalecer el juicio crítico. Más allá de las consultas rápidas con IA, esperamos que se hayan sumergido en el contenido. ¿Han tenido oportunidad de hacerlo? Si lo hicieron, seguro que les ha ayudado a profundizar en la complejidad del cuidado neonatal donde el criterio clínico y la experiencia humana son irreemplazables. La inteligencia artificial ofrece respuestas, pero este manuscrito ofrece comprensión. Es fundamental recordar que la IA es sólo una herramienta de apoyo, no una fuente de conocimiento primario. Asimismo, no olviden que muchos modelos de IA carecen de transparencia sobre cómo llegan a sus conclusiones: el problema de la "caja negra". Esto es un sistema que produce resultados sin explicar su lógica interna; es decir, introducimos datos y obtenemos una respuesta, pero el proceso de razonamiento es invisible e incomprensible para el ser humano. La caja negra de la IA detecta patrones, pero no comprende la fisiopatología. Puede sugerir un tratamiento que parece estadísticamente correcto pero que ignora la causa biológica del problema. A diferencia de ello, nuestros cuidados deben ser una "caja de cristal" con una base científica sólida y verificable.

En la era de la inteligencia artificial, el diagnóstico y el tratamiento parecen estar a un solo clic de distancia. Sin embargo, en neonatología, donde cada gramo y cada minuto cuentan, enfrentamos el desafío de la denominada "caja negra" algorítmica. Un sistema de IA puede sugerir una intervención basándose en billones de datos, pero a menudo es incapaz de explicar el porqué de esa decisión. Uno de los objetivos de este manuscrito es transformar al lector en un clínico capaz de usar la tecnología con espíritu crítico, evitando los riesgos de las alucinaciones de la IA y los sesgos ocultos que comprometen la seguridad del recién nacido, considerando al recién nacido como nuestro único algoritmo.

Les realizo una invitación a dominar la tecnología para que, al llegar hasta aquí, comprendamos que nuestra misión es utilizar la frialdad del dato para proteger, con más fuerza que nunca, el calor de la vida. Recorramos los pasillos de la vanguardia de los cuidados neonatales, desde la fisiopatología más compleja hasta los algoritmos que hoy definen nuestra práctica, la cual no debe ser un compendio de certezas técnicas, sino un preludio a la pregunta fundamental: ¿Cómo habitar el **oxímoron del silicio** sin perder el pulso de nuestra propia humanidad?

CONCLUSIÓN: LA ÉTICA DEL CUIDADO EN LA ERA DEL SILICIO:

En definitiva, la integración de la inteligencia artificial en la UCIN nos sitúa ante el más sofisticado de los oxímorones: una tecnología que, para proteger la vida en su estado más orgánico y frágil, debe procesarla como una serie de datos inanimados. Es en esta intersección donde surge lo agridulce del humanismo contemporáneo: la constatación de que nuestra capacidad de sanar se ha vuelto dependiente de una inteligencia sin propósito. Como ha señalado la ética de la responsabilidad de Hans Jonas, el poder tecnológico nos impone un deber moral superior: **no permitir que el brillo del dato nos ciegue ante la vulnerabilidad del ser.**

La IA puede ofrecernos una precisión sin precedentes, pero el acto de cuidar en neonatología sigue siendo, en esencia, un encuentro profundamente humano entre dos fragilidades. Al navegar por la algorética, debemos recordar que, aunque el silicio sea capaz de procesar la sintaxis de la vida con una eficiencia asombrosa, solo el juicio clínico y la compasión humana pueden descifrar su semántica.

El reto del profesional de la salud neonatal del siglo XXI no es competir con el algoritmo, sino asegurar que, en el corazón de cada incubadora, el latido del silicio esté siempre subordinado al calor del abrazo humano. Porque mientras la máquina calcula probabilidades, sólo el profesional de la salud neonatal, en su compromiso ético, es capaz de asumir la esperanza.

"El gran desafío que nos toca enfrentar es: ¿Cómo habitar el oxímoron del silicio sin perder el pulso de nuestra propia humanidad? ¿Cómo lograr armonía entre la precisión de la máquina y la sensibilidad del clínico? Nuestra misión es utilizar la frialdad del dato preciso para proteger, con más fuerza que nunca, el calor de la vida."

El gran desafío que nos toca enfrentar es: ¿Cómo habitar el **oxímoron del silicio** sin perder el pulso de nuestra propia humanidad? ¿Cómo lograr armonía entre la precisión de la máquina y la sensibilidad del clínico? Nuestra misión es utilizar la frialdad del dato preciso para proteger, con más fuerza que nunca, el calor de la vida. La verdadera 'obertura' de la neonatología moderna no suena al ritmo de las alarmas ni "baila al compás del ritmo de la IA", sino que requiere la armonía entre la precisión de la máquina y la sensibilidad del clínico.

Como decía Hans Jonas, el poder de la tecnología nos exige hoy un nuevo tipo de responsabilidad. En la fragilidad de la neonatología, confiar ciegamente en la 'caja negra' de una IA es renunciar a ese deber ético. Escribo este manuscrito para que el profesional de la salud neonatal no sea un espectador de algoritmos, sino un clínico con el conocimiento profundo y transparente necesario para garantizar esa 'vida humana auténtica' que Jonas defendía. Aprender de la IA sin criterio es, sencillamente, un riesgo que un profesional no debe asumir. Porque la vida neonatal, sencillamente, no se delega.

Agradecimientos - El factor humano tras la técnica:

Mi gratitud se extiende a quienes entienden que, tras cada monitor y cada algoritmo en la UCIN, late una vida que no admite errores, pero sí demanda ternura. Agradezco a los colegas y

mentores que me enseñaron que la neonatología es la ciencia de lo microscópico y el arte de lo inmenso. Agradezco a los padres que, en medio de la "calma tensa" de la tecnología, nos confían lo más sagrado. Y agradezco a los recién nacidos enfermos, esos pequeños maestros, héroes de resiliencia en la Patria Neonatal que nos recuerdan que el humanismo es, en última instancia, el motor que da sentido a cualquier avance del silicio.

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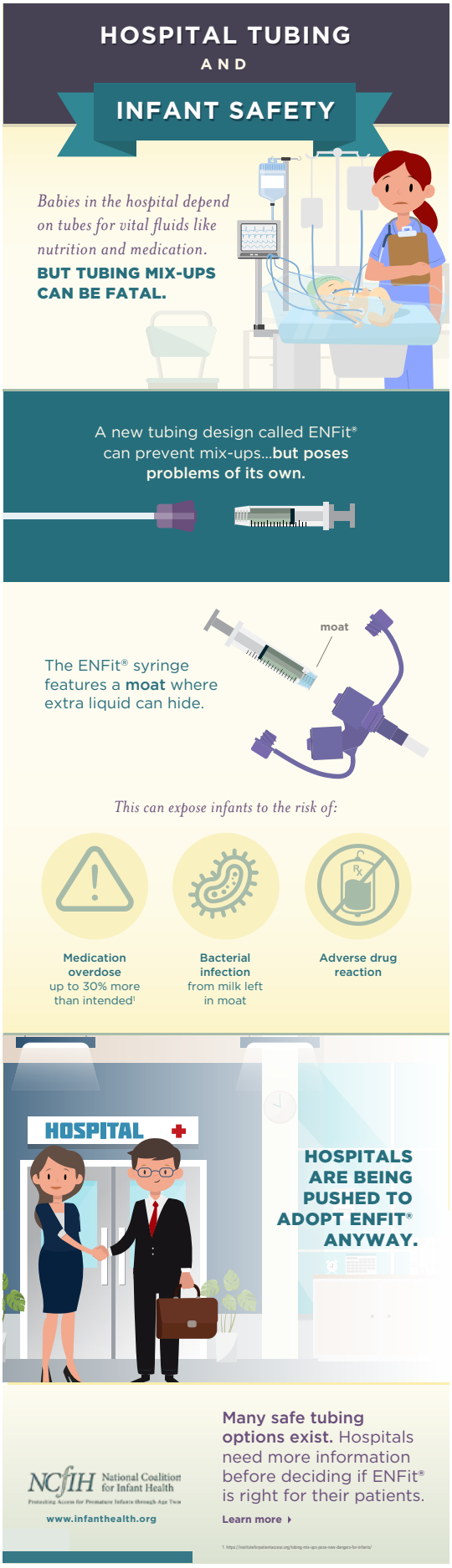

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Liquid Consciousness, Solid Gods: Pros and Cons of Artificial Intelligence (AI)

Augusto Sola, MD, Mitchell Goldstein, MD, MBA, CML

"In this manuscript, I will reflect on the pros and cons of AI, examining key aspects of this technology in the current era of artificial intelligence."

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Introduction:

In this manuscript, I will reflect on the pros and cons of AI, examining key aspects of this technology in the current era of artificial intelligence.

I always frame my writing in the context of clinical neonatology practice and the professionals who work in neonatal healthcare—an area I know well and have been passionate about for over 50 years. However, this does not preclude the fact that much of what you read here applies not only to other fields of medicine but also to the legal profession, journalism, gastronomy, fashion, and much more.

"On many occasions, I use the term "silicon" because it often refers to AI, as it is the fundamental material in computer processors and chips. AI is frequently described as a silicon-based intelligence. Similarly, Silicon Valley—the famous technology hub in California—derives its name precisely from the extensive use of this material in the semiconductor industry."

On many occasions, I use the term "silicon" because it often refers to AI, as it is the fundamental material in computer processors and chips. AI is frequently described as a silicon-based intelligence. Similarly, Silicon Valley—the famous technology hub in California—derives its name precisely from the extensive use of this material in the semiconductor industry. Without this mineral, AI would lack a "brain" in which to operate. Humans are carbon-based life forms. Let us not allow a silicon logic to replace our carbon-based judgment—a judgment that brings humanity, context, and ethics that a silicon chip does not possess.

Silicon:

Humanism:

Through humanism, we can overcome challenges and obstacles to achieve significant goals; the most valuable accomplishments require effort and perseverance. This concept is summarized below.

Its translation is "**To the stars through difficulties**" or, alternatively, "**Through difficulties to the stars**." It is not known exactly to whom the origin of this Latin phrase should be attributed: Seneca the Younger? Virgil? Others? It is known that Kansas, in the United States, has used it as its motto (on the state flag and state seal) since 1861, and that the British Royal Air Force has used it since 1912. It is a maxim that holds that one must overcome challenges to achieve significant goals and that the most valuable accomplishments require perseverance and effort. The stars are difficult—or even impossible—to reach through AI and social media, yet they are reachable through humanism.

Beyond Silicon: The Imperative to Know:

The imperative to know is not an invitation to knowledge, but rather a sentence to mere availability. On this bittersweet frontier, one may *know* a great deal, yet *understand* little or nothing; thus, the great risk is that humans may cease striving to understand. The "Silicon God" admits no mystery; to it, whatever is not data simply does not exist. Yet, understanding does not count.

In caring for newborns in the NICU, we currently face a crossroads: the speed of silicon versus the depth of human responsibility.

AI processes data, but it does not comprehend the fragility of life. Silicon possesses neither conscience nor consciousness, and it cannot be held accountable for its errors. For this reason, we have written this text: to help restore transparency in knowledge for neonatal healthcare professionals—and to help them learn to understand, rather than merely to know.

To learn and to understand is not merely to accumulate information; it is to cultivate the critical judgment necessary to ensure that technology remains our tool, never our replacement. The ethical foundation of the healthcare professional is born of deep study and understanding—not of an opaque algorithm.

OXYMORONS IN THE NICU

What is an oxymoron? Two words or expressions with opposite or contradictory meanings. A specific form of contradiction or counterpoint, defined as a rhetorical figure that joins two words with opposite meanings in the same syntactic structure. An example is 'deafening silence'.

"What is an oxymoron? Two words or expressions with opposite or contradictory meanings."

The oxymorons of the NICU are spaces where "Code" becomes "Care." Modern neonatology today inhabits the oxymoron of silicon: an ecosystem where the coldness of the microprocessor and the aseptic calculation of the algorithm guarantee the warmth of survival.

In the NICU, AI is not merely a tool of precision, but a constant presence that monitors the invisible. However, entrusting the care of a critically ill newborn exclusively to an algorithm is one of the great oxymorons of our era: we attempt to manage the most extreme biological fragility with the rigidity of silicon. On the other

hand, it is this "inert vigilance" that, paradoxically, allows us to be more human by delegating data processing and reclaiming time for care.

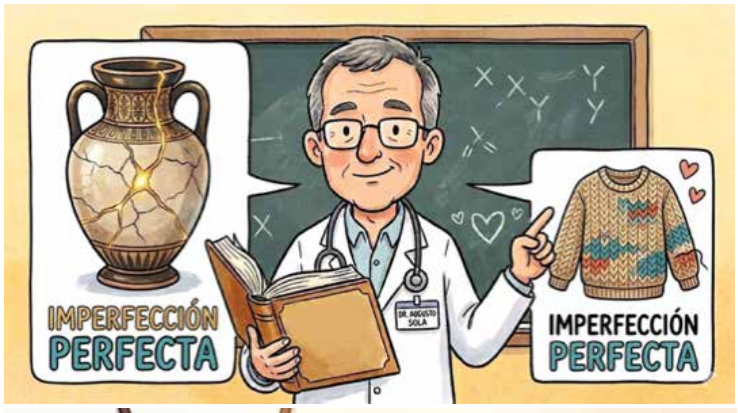
Let us look at some examples of oxymorons.

One oxymoron I envisioned is the "deafening silence" between AI and the embrace in neonatal care. AI cannot offer hugs, provide companionship, or offer comfort. I choose this human warmth over AI. What about you?

"Perfect imperfection: the bittersweet reality of humanism in the NICU is that our greatest virtue in the face of error lies in striving to recognize and rectify it, rather than continuing to commit it."

Perfect imperfection: the bittersweet reality of humanism in the NICU is that our greatest virtue in the face of error lies in striving to recognize and rectify it, rather than continuing to commit it. AI, for its part, offers us a sterile perfection—that is, a "perfect imperfection"—one that does not acknowledge errors and that we do not quite know how to inhabit.

The three figures below attempt to represent "perfect imperfections"—things that appear perfect, yet in reality are far from it.



First, we see a vessel bearing scars and fractures. It has been repaired with gold, adhering to the philosophy of *Kintsugi*—the Japanese art of mending broken ceramics using *urushi* lacquer (a natural varnish and adhesive) and gold, silver, or platinum dust, thereby highlighting the fissures rather than concealing them. Below it lies a frayed seam. An asymmetrical heart and a flower with uneven petals would serve as further examples of things that appear perfect, yet are not. And, finally, the statue with its imperfections.

The bittersweet irony is that the more "human" AI becomes—and the more perfect it appears—the more we are compelled to question what, precisely, makes "us" human.

The Echo of Silicon: We seek to humanize silicon so as not to feel alone; yet the result is bittersweet: we create a mirror that reflects to us the image of our own intelligence, but never that of our soul

" From an ethical perspective, silicon confronts us with a distorting mirror: the more we delegate the interpretation of life to AI, the more we risk transforming the medical act into a "biotechnique" stripped of its mystery."

A "mute perfection." From an ethical perspective, silicon confronts us with a distorting mirror: the more we delegate the interpretation of life to AI, the more we risk transforming the medical act into a "biotechnique" stripped of its mystery..

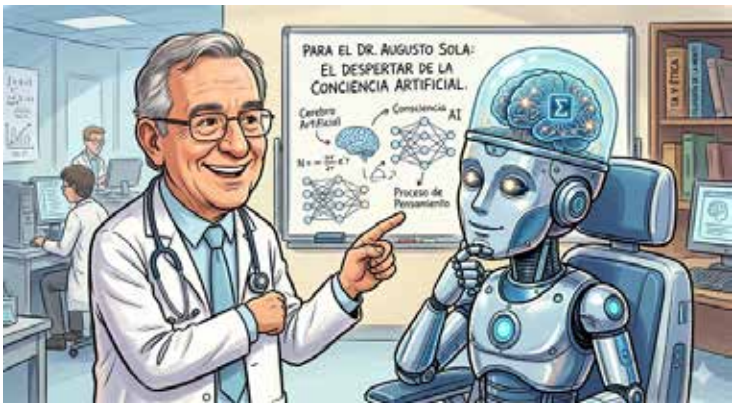
Obsolete Humanism: It is a bittersweet feeling to see silicon resolve our doubts while ignoring our fears. We must not care for sick newborns and their families without humanism. Humanism must not become obsolete in the face of AI's growing prevalence. AI does not confer humanism.

The Inert Beat: AI functions ("beats"), but lacks biological life..

"The other figure presents a heart in a surreal manner, for in reality, we know that it cannot pump blood."

One of these figures depicts a heavy, grayish heart, from which springs a vein of vibrant color, suggesting that even within that which appears stagnant or lifeless, there resides a latent—yet inert—pulse. The other figure presents a heart in a surreal manner, for in reality, we know that it cannot pump blood.

Consciousness — Artificial Consciousness: The classic oxymoron: consciousness is assumed to be natural; the artificial is fabricated



This cartoon seeks to capture the essence of artificial consciousness: a synthetic being that not only processes data but "begins to marvel" at the complexity of the natural world.

Conciencia (moral conscience) judges morality, while "consciencia" (physical consciousness) perceives reality.

Moral conscience is the ethical capacity to distinguish between right and wrong. An example would be, "I have a clear conscience." While many neonatal health professionals cannot honestly make this claim—as they lack integrity and professional ethics—silicon possesses no moral conscience whatsoever.

On the other hand, physical or perceptual consciousness is the capacity to recognize reality, to be awake, and to perceive both internal and external stimuli. An example would be, "The patient regained consciousness." Here again, some professionals remain impervious to their patients' pain, or who distort reality out of selfishness and greed. However, neither AI nor technology perceives reality nor feels anything.

Artificial intelligences do not think, feel, or harbor desires; rather, they speak and generate text based on learned patterns. Algorithms merely process data and execute actions based on

those patterns; they do not have experiences.

Programmed empathy: a contradiction between the essence of human feeling and the code of technology and artificial intelligence.

Organic silicon: a term describing a technology that mimics life so convincingly that it appears to be flesh. Yet, it is somewhat painful to realize that a machine preserves our data more effectively than we ourselves preserve our own memories.

Impersonal assistance: an oxymoron describing a form of care that fails to recognize the individuality of the human being.

Presence Without Substance:

Or would it be clearer to speak—in yet another oxymoron—of "presence with absence"? There is no doubt that social networks and AI facilitate and amplify one's presence. Nevertheless, they, in turn, exponentially increase the risk of disseminating misguided material—or even material riddled with errors—and utterly devoid of substance. Amidst this vast presence—as individuals appear everywhere across AI platforms and social networks—many who enjoy such visibility find their egos inflated; as the saying goes, they begin to think they are "the greatest thing since sliced bread." This is especially true if they receive thousands of "likes" for their posts or writing. Such dynamics erode—or even obliterate—the capacity for self-criticism and, with it, respect for the truth. In short, there is an enormous risk that AI and social media will usher in the "Great Swap" of the 21st century—a scenario in which, much like in the original lyrics of the tango *Cambalache* (by Discépolo, 1934), "anyone can be a gentleman, anyone a thief; a donkey is no different from a great professor."

A common error in medical literature—known as the *ad ignorantiam* fallacy, or appeal to ignorance—is a reasoning error asserting that a proposition is true simply because it has not been proven false, or false because its truth has not been proven. It relies on a lack of knowledge regarding a subject to make a claim, ignoring the fact that an absence of evidence does not equate to evidence of absence. This *ad ignorantiam* fallacy is amplified a hundred- or thousandfold by AI and social media—and it occurs without the benefit of self-criticism, a quality that AI lacks but is essential for neonatal healthcare professionals.

"This *ad ignorantiam* fallacy is amplified a hundred- or thousandfold by AI and social media—and it occurs without the benefit of self-criticism, a quality that AI lacks but is essential for neonatal healthcare professionals."

On Errors and "Dictums:"

In a world saturated with social networks and automated responses—which sometimes appear to be "etched in stone"—RECOGNIZING ERROR is what sustains authentic human dialogue.

AI lacks self-criticism; we professionals, however, must possess it in order to acknowledge our mistakes.

A "dictum" is a pronouncement made by an authority figure or by the medical community that expresses an opinion or a rule. Such *dictums* proliferate across social media. At times, these *dictums* are erroneous, yet they continue to be disseminated and eventually solidify into conventional wisdom.

The remarkable thing about error is that it serves as a vital catalyst for human development, offering immense opportunities for learning and personal growth. Furthermore, of course, for providing far superior care to sick newborns. Neither AI nor erroneous *dictums* can provide that.

The essence of science lies in the capacity to uncover error, not in the mere possession of truth. We must identify our own errors, as well as those of others, in order to enhance neonatal care. If we truly revere the truth, we must rectify our errors through the application of critical rationalism and unceasing self-criticism.

Doubt is the name of intelligence, said Borges. AI and algorithms do not doubt.

- ✓ In neonatal science and practice, the search for error is a fundamental process. AI and algorithms do not seek out their own errors.
- ✓ Errors are infinite, and truths are far fewer.
- ✓ Error should be viewed as a learning opportunity, essential for scientific progress and for the care of sick newborns.
- ✓ Error is particularly helpful in the search for truth.
- ✓ If we respect the truth, we must take note of the errors of others—and, even more so, of our own.
- ✓ It is essential to identify and correct errors in science, in our neonatal practice, and in "dictums" and conventional truths.

"Avoid" is similar to "prevent," as both aim to prevent something from happening. It is also similar to "prohibit," which implies a somewhat coercive action, involving dominance and authority. "Avoid" is also akin to "veto" an action. "Veto" means to prohibit or impede. These words share an affinity in their aim to prevent something from occurring.

On the whiteboard, the word "AVOID" appears crossed out, indicating that many dogmatic prohibitions in neonatology are repeated out of habit but often lack solid scientific evidence to support them. Moreover, they evolve into "dictums." The image invites us to question the "always" and "never" statements in favor of evidence-based practice.

Therefore, in terms of neonatal care, one should generally "avoid using" such "dictums." The term "avoid" should perhaps be reserved solely for known poor practices—actions that must be eradicated from neonatal care. Examples include avoiding midazolam for sedating newborns or avoiding hyperoxemia when administering surfactant. Nevertheless, many other things must be avoided and eradicated.

AI and social media have "no clue" about these matters.

The Bittersweet Frontier between Technology and Humanism:

There exists, then, a bittersweet duality regarding humanism in the face of AI: human "warmth" versus the "coldness" of the microprocessor—a tension between the coldness of hardware (silicon) and the warmth (or fragility) of the human spirit.

The encounter between humanism and technology thus distills a bittersweet nuance. We face the paradox of a technical perfection that can predict an apneic episode before it occurs, yet remains mute in the face of parents' anguish or the therapeutic value of skin-to-skin contact. Ultimately, the challenge lies not in choosing between silicon and instinct, but in understanding that while AI can provide the "what" and the "when," humanism alone remains the custodian of the "why" and the "for whom." This duality blends medical rigor with the sensitivity required by neonatology—a field where the most advanced technology meets the extreme fragility of newborn life.

The philosophy of technology warns us of this "assisted solitude": the risk that the clinician—seduced by the infallibility of data—might end up treating the newborn as a stream of optimizable variables rather than as a subject with a biography that has only just begun.

The bittersweet nature of this situation lies in the loss of intuition—that profoundly human form of knowledge born of uncertainty, which no silicon architecture can replicate. The machine calculates probabilities; the neonatal health professional assumes responsibilities. At this threshold of AI, humanism must act not as a brake on progress, but as its moral compass.

"True neonatal ethics in the age of AI consists not in humanizing the machine, but in preventing the medical team from becoming mechanized. We must navigate 'impersonal assistance' with the awareness that, while the algorithm may sustain vital signs, only ethical judgment and compassionate presence can sustain the dignity of the newborn and their family."

True neonatal ethics in the age of AI consists not in humanizing the machine, but in preventing the medical team from becoming mechanized. We must navigate 'impersonal assistance' with the awareness that, while the algorithm may sustain vital signs, only ethical judgment and compassionate presence can sustain the dignity of the newborn and their family. The ultimate challenge is to ensure that, within this symbiosis, silicon always remains a means and never becomes the ultimate end of our practice.

The Imperative of Responsibility and the Essence of Technology:

Hans Jonas was an influential German-Jewish philosopher and is considered one of the fathers of modern bioethics. His most famous work, published in 1979, is *The Imperative of Responsibility: In Search of an Ethics for the Technological Age*. At its core lies the imperative of responsibility. In it, he argues that our actions today must ensure the continued existence of authentic human life. Jonas's imperative of responsibility is fundamental because his ethics center on the fragility of life and the power of technology.

Human clinical judgment (grounded in responsibility) must prevail over technical automation (AI), which lacks ethical consciousness and a sense of the future. Jonas's "ethical imperative" aligns perfectly with the care of the newborn when he states: "Act so that the effects of your action are compatible with the permanence of authentic human life on Earth." In the NICU, "authentic life" is not merely biological survival—as measured by sensors—but rather the preservation of dignity and the human bond: elements that silicon can monitor, yet never replace.

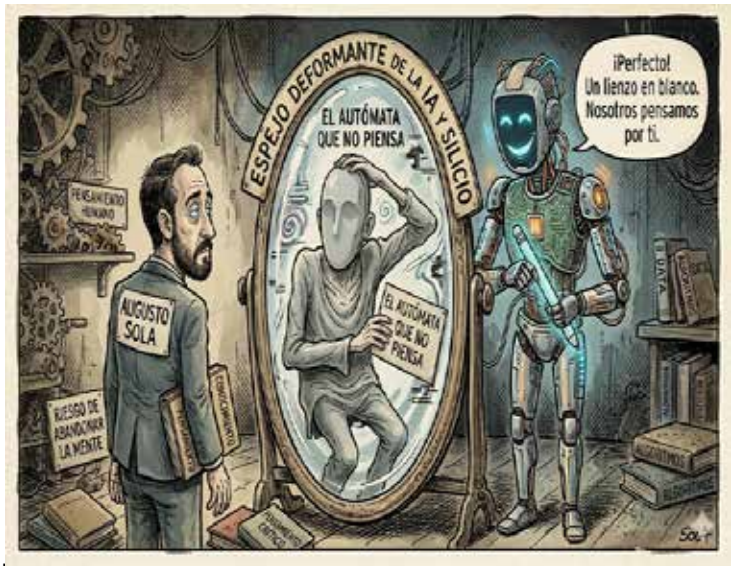
Martin Heidegger ("The Question Concerning Technology") warned that the danger of technology lies not in the machines themselves, but in the way it compels us to view the world as a mere "resource." "The essence of technology is by no means anything technological." This reinforces the concept of the oxymoron: the true challenge of AI in neonatology is not software but ensuring that the neonatal healthcare professional does not lose the capacity to "un-conceal" the humanity of the newborn and their family amidst the deluge of algorithmic data. In other words,

it is about ensuring that healthcare professionals exercise their full responsibility.

The Greatest Risk of AI—The Risk of Ceasing to Think:

An algorithm can detect patterns, but it cannot comprehend the meaning of suffering...

The great risk of AI is not that it thinks *for* us, but that it ceases to make us think *about* ourselves. Giorgio Agamben stated: "Artificial intelligence is not dangerous because it is artificial, but because it thinks outside of the subject. The risk is the human renunciation of thought."



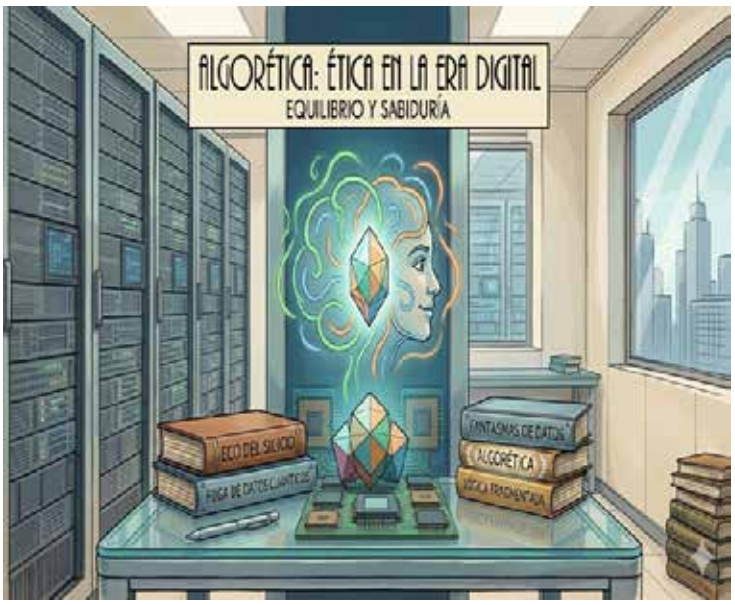
"ALGORITHMICS" THE ETHICS OF ALGORITHMS IN NEONATAL MEDICINE

"Algorithmics" —The Ethics of Algorithms:

Hannah Arendt was a political theorist and a pioneer in many subjects related to human freedom; although she did not live to see the advent of AI, her thought serves as the foundation for these modern critiques. She anticipated the problems of the century. Her concept of the "banality of evil" and her emphasis on thinking as a uniquely human activity have proven fundamental. In 1958, she stated: "What threatens us is not the rebellion of the machines, but the automation of the human being."

"Monsignor Vincenzo Paglia and the Pontifical Academy for Life championed the *Rome Call for AI Ethics*. Adela Cortina, a Spanish philosopher and expert in clinical ethics, maintains that algorithms do not make decisions; human beings do. Edmund Pellegrino is a leading figure in medical virtue ethics."

Monsignor Vincenzo Paglia and the Pontifical Academy for Life championed the *Rome Call for AI Ethics*. Adela Cortina, a Spanish philosopher and expert in clinical ethics, maintains that algorithms do not make decisions; human beings do. Edmund Pellegrino is a leading figure in medical virtue ethics. He argues that medicine constitutes a moral commitment between two individuals, something that technology cannot replicate.



As Hans Jonas aptly noted, medical technology must always be subject to the scrutiny of ethical principles. In neonatal care, silicon should serve as the vigilant servant, while humanism acts as the guiding decision-maker. While AI processes the syntax of vital signs, only the selfless professional grasps the semantics of a life just beginning.

In contemporary bioethics, the danger lies not in the machine learning to think, but rather in the neonatal healthcare professional—faced with the efficiency of silicon—relinquishing the ethical responsibility to feel and decide on behalf of their patient. The greatest peril is not artificial intelligence, but rather the absence of critical thinking. Excessive reliance on these tools can foster a "blind dependency" and erode critical thinking. This gradually undermines the capacity for independent clinical reasoning and for solving complex problems without technological assistance.

Learning Neonatology, Literature Searches, and Responding to Treatment Inquiries:

There are numerous risks associated with AI—particularly if one harbors the belief that it can learn to care for sick newborns.

AI should be used as a supportive tool, never as a substitute for formal education or direct human interaction. These systems do not improve decision-making compared to traditional methods. AI can fail to provide a neonatal diagnosis and cannot identify when a newborn requires urgent care. AI is not yet ready to assume the role of a physician.

Learning medicine exclusively through AI carries critical risks, as these tools are not designed to replace standardized academic training or human clinical judgment. Learning neonatology via AI poses critical risks due to the extreme vulnerability of sick newborns. At this stage of life, there is very little margin for error, and clinical decisions must be immediate and precise.

AI language models can generate responses that appear coherent and professional, yet are factually incorrect, false, or outdated. These are referred to as "hallucinations" or inaccurate information. In neonatology, this can include erroneous medication dosages, non-existent contraindications, fabricated bibliographic citations that lend an air of scientific rigor to invented data, and inconsistent interpretations of symptoms—all of which are particularly dangerous.

Mafalda—known to almost everyone—was Quino's greatest creation.

Here, alongside her image, I offer a few words to encourage us to reflect.

Confucius, the Chinese philosopher (4th century BC)—long before the advent of the digital age—stated: "Learning without thinking is useless; thinking without learning is dangerous."

The excessive use of these tools can foster a "blind dependence" and erode critical thinking. This gradually weakens the capacity for independent clinical reasoning and for solving complex problems without technological assistance.

We are transitioning into a post-literate era, in which images and short videos are supplanting dense texts. Constant immersion in digital media hinders critical thinking—and may even render it impossible. "What threatens us is not the rebellion of the machines, but the automation of the human being" (Hannah Arendt, 1958).

The Hastings Center for Bioethics is a bioethics research institute and a leading global center for ethics dedicated to advancing health, science, and medicine.

"Hastings on the Hill" was established in 2024 to develop, translate, and implement ethical safeguards for AI. In March 2026, they published a report noting that while AI agents are transforming scientific research, they also raise ethical concerns and "red flags." They address issues such as inequality and bias in AI applied to healthcare, the erosion of human skills, opacity and a lack of transparency, and the impact on trust within the healthcare system.

"La IA carece de empatía y no puede replicar el vínculo emocional médico-paciente, un pilar fundamental para el éxito del tratamiento y la curación. Esto puede conducir a la pérdida de competencias humanísticas y a la falta de contexto físico y emocional. La neonatología requiere una comunicación humana profunda con las familias en crisis."

AI lacks empathy and cannot replicate the physician-patient emotional bond—a fundamental pillar for successful treatment and healing. This can lead to a loss of humanistic competencies and a lack of physical and emotional context. Neonatology demands deep human communication with families in crisis. Relying solely on AI for learning may hinder the development of the empathy necessary to explain complex diagnoses to parents, potentially eroding the relationship with them.

There is also the risk of suffering from "catastrophic forgetting"—a loss of practical skills and intellectual capacity—when one limits oneself to following algorithms without questioning the underlying medical and ethical parameters. This phenomenon has been termed the "lazy physician effect."

One of the primary objectives of this manuscript, which you are now finishing, is to strengthen critical judgment. Moving beyond quick AI consultations, we hope you have truly immersed yourselves in the content. Have you had the opportunity to do so? If you have, it has surely helped you delve deeper into the complexities of neonatal care, where clinical judgment and human experience are irreplaceable. Artificial intelligence offers answers, but this manuscript offers understanding. It is crucial to remember that AI is merely a support tool, not a primary source of knowledge.

Furthermore, do not forget that many AI models lack transparency regarding how they arrive at their conclusions—the "black box" problem. This refers to a system that generates results without explaining its internal logic; in other words, we input data and receive an answer, yet the reasoning process remains invisible and incomprehensible to humans. The AI "black box" detects patterns but does not comprehend pathophysiology. It may suggest a treatment that appears statistically sound yet completely overlooks the underlying biological cause of the problem. In contrast, our approach to care must function as a "glass box"—transparent and grounded in a solid, verifiable scientific foundation.

In the era of artificial intelligence, diagnosis and treatment seem to be just a single click away. However, in neonatology—where every gram and every minute counts—we face the challenge of the so-called algorithmic "black box." An AI system may suggest an intervention based on trillions of data points, yet it is often unable to explain the rationale behind that decision. One of the objectives of this manuscript is to transform the reader into a clinician capable of utilizing technology with a critical mindset—avoiding the risks of AI "hallucinations" and hidden biases that compromise the safety of the newborn—while regarding the newborn themselves as our sole algorithm.

I invite you to master this technology so that, having reached this point, we may understand that our mission is to harness the cold precision of data to protect—with greater strength than ever before—the warmth of life. Let us walk the corridors of the vanguard of neonatal care, ranging from the most complex pathophysiology to the algorithms that currently define our practice—a practice that should not be a mere compendium of technical certainties, but rather a prelude to the fundamental question: How do we inhabit the oxymoron of silicon without losing the pulse of our own humanity?

Conclusion: The Ethics of Care in the Age of Silicon:

Ultimately, the integration of artificial intelligence into the NICU confronts us with the most sophisticated of oxymorons: a technology that, in order to protect life in its most organic and fragile state, must process it as a series of inanimate data points. It is at this intersection that the bittersweet nature of contemporary humanism emerges: the realization that our capacity to heal has become dependent upon an intelligence devoid of purpose. As Hans Jonas's ethics of responsibility has noted, technological power imposes upon us a higher moral duty: not to allow the brilliance of data to close our eyes to the vulnerability of the human being.

AI may offer us unprecedented precision, yet the act of caring in neonatology remains, in essence, a deeply human encounter between two fragilities. As we navigate the realm of "algor-ethics," we must remember that, although silicon may be capable of processing the syntax of life with astonishing efficiency, only clinical judgment and human compassion can decipher its semantics.

The challenge facing the 21st-century neonatal healthcare professional is not to compete with the algorithm, but to ensure that, at the heart of every incubator, the pulse of silicon remains forever subordinate to the warmth of the human embrace. While the machine calculates probabilities, only the neonatal healthcare professional—guided by their ethical commitment—is capable of embracing hope.

"The great challenge we must confront is this: How do we inhabit the oxymoron of silicon without losing the pulse of our own humanity? How do we achieve harmony between the precision of the machine and the sensitivity of the clinician? Our mission is to harness the coldness of precise data to safeguard—with greater strength than ever before—the warmth of life itself."

The great challenge we must confront is this: How do we inhabit the oxymoron of silicon without losing the pulse of our own humanity? How do we achieve harmony between the precision of the machine and the sensitivity of the clinician? Our mission is to harness the coldness of precise data to safeguard—with greater strength than ever before—the warmth of life itself. The true "overture" of modern neonatology does not sound to the rhythm of alarms, nor does it "dance to the beat of AI"; rather, it demands a harmony between the precision of the machine and the sensitivity of the clinician.

As Hans Jonas observed, the power of technology today demands a new kind of responsibility from us. Within the fragile realm of neonatology, placing blind faith in the "black box" of AI amounts to an abdication of that ethical duty. I write this manuscript to ensure that the neonatal healthcare professional does not become a mere spectator to algorithms but remains a clinician, endowed with the profound and transparent knowledge required to guarantee the "authentic human life" that Jonas championed. To learn from AI without exercising critical judgment is, quite simply, a risk that no professional should ever assume. For neonatal life, quite simply, is not something to be delegated.

Recommended reading (in alphabetic order):

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- ✓ The Open: Man and Animal (2002). Translated by Kevin Attell. Stanford, CA: Stanford University Press, 2004.

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- ✓ Lecture on cybernetics, which was delivered at the First Annual Conference on the Cybercultural Revolution in New York City. 19 June 1964, Hannah Arendt Papers, Library of Congress, Washington, D.C.
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Paolo Benanti (1973 -), Franciscan friar and ethics expert who serves as the Scientific Director of the RenAIssance Foundation.

- ✓ Oracles: Between Algorethics and Algocracy. Rome: Luca Sossella Editore, 2018.

Jorge Luis Borges (1899 - 1986). One of the most important and influential writers of the 20th century. Many books, poems and others

- ✓ Ficciones ("Fictions") (1944)
- ✓ El Aleph (1949)
- ✓ El hacedor (1960) (The Maker or Dreamtigers)

Cambalache (or "*The display window of a junk shop*") is a famous Argentinean tango by Enrique Santos Discépolo, in 1934. The lyrics in English can be found at: https://tangodecoder.wordpress.com/

Confucius, the Chinese philosopher (4th century BC): from the Analects of Confucius (Book 2, Verse 15)

Adela Cortina (1947 -). Spanish philosopher and expert in clinical ethics, maintains that algorithms do not make decisions; human beings do.

- ✓ ¿Para qué sirve realmente la ética? [What is ethics really useful for?] (Barcelona Editorial Paidós 2013)
- ✓ ¿Ética o ideología de la inteligencia artificial? El eclipse de la razón comunicativa en una sociedad tecnologizada. [Ethics or ideology of artificial intelligence? The eclipse of communicative reason in a technologized society]. Madrid, Paidós 2024.

The Hastings Center.

- ✓ Jayaram, A., & Owens, K. (2026, March 25). AI in healthcare. The Hastings Center's Bioethics Briefings. https://www.thehastingscenter.org/briefingbook/ai-in-healthcare/
- ✓ Mohammad Hosseini, Maya Murad, David B. Resnik. Benefits and Risks of Using AI Agents in Research, Hastings Center Report 56, no. 1 (2026): 13–17. DOI: 10.1002/hast.70025
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Martin Heidegger (1889–1976). Prominent German philosopher

- ✓ The Question Concerning Technology. Originally published as "Die Frage nach der Technik" in Vorträge und Aufsätze (1954) - English translation by William Lovitt, The Question Concerning Technology and Other Essays. Harper & Row, 1977.
- ✓ Critical companion pieces in the English volume: The Turning; The Word of Nietzsche: 'God is Dead; The Age of the World Picture; Science and Reflection

Hans Jonas (1903–1993). German-American philosopher.

- ✓ The Imperative of Responsibility (*Das Prinzip Verantwortung, 1979*). English Translation: The Imperative of Responsibility: In Search of an Ethics for the Technological Age. University of Chicago Press, 1984.

Monsignor Vincenzo Paglia (1945 -). President Emeritus of the Pontifical Academy for Life. He continues to participate in major international summits, particularly those focusing on algorethics and the intersection of technology and human dignity.

- ✓ Robo-ethics: Humans, Machines and Health. Vatican City: Pontifical Academy for Life, Libreria Editrice Vaticana, 2020.
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Edmund D. Pellegrino (1920-2013). Foundational figure in modern bioethics, best known for his "virtue-based" philosophy of medicine. He spent much of his career at Georgetown University, where he founded the Pellegrino Center for Clinical Bioethics.

- ✓ Pellegrino, E. D., & Thomasma, D. C. A philosophical basis of medical practice: Toward a philosophy and ethic of the healing professions. Oxford University Press, 1981.
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- ✓ The Logic of Scientific Discovery. New York: Basic Books, 1959; Abingdon: Routledge, 2002.
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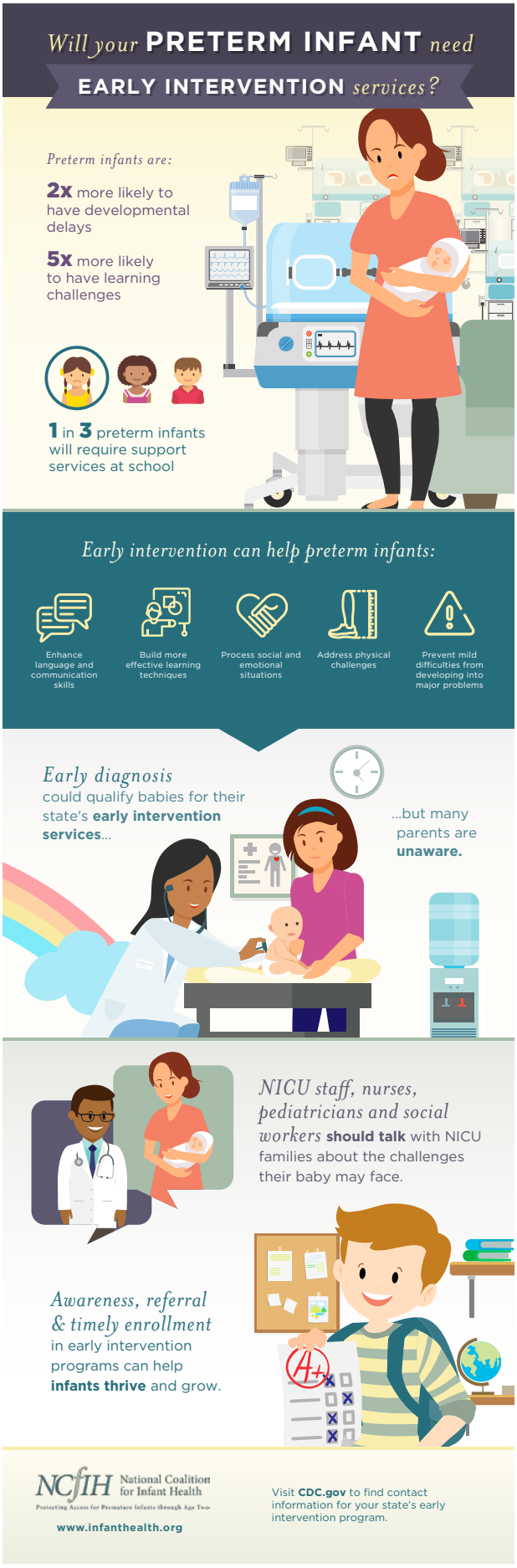


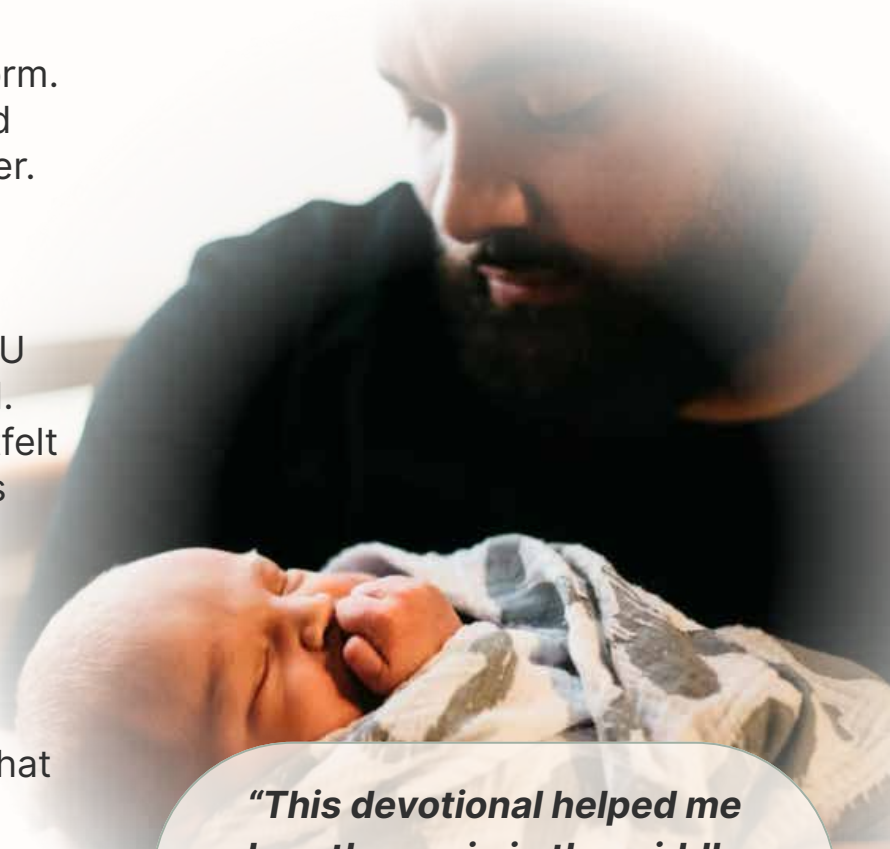
When hope feels distant, let His words anchor your heart.

A 30-Day Devotional for NICU Parents

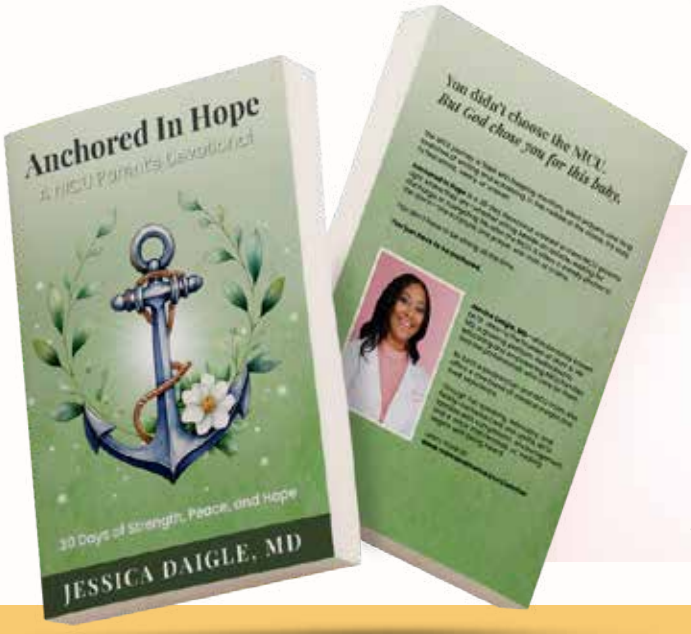
The NICU journey can feel like a storm. One filled with uncertainty, fear, and long nights that blur into one another. But even here, *you are not alone*.

Anchored In Hope was written by Dr. Jess, a physician and fellow NICU mom who knows this road firsthand. Through 30 days of scripture, heartfelt reflections, and guided prayers, this devotional helps NICU parents find calm, courage, and connection with God when life feels overwhelming.

Inside these pages, you'll feel **seen**, **understood**, and gently reminded that **hope is still present**. *Even here*.



"This devotional helped me breathe again in the middle of our NICU storm."
— A NICU Mom & Dad



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Metabolic Bone Disease of Prematurity: Integrated Mineral, Renal, and Acid–Base Physiology in Diagnosis and Management

Noel D Tan, MD, Keith Bockhold, PharmD

"Metabolic bone disease of prematurity (MBDP) is a disorder of impaired skeletal mineralization in preterm infants resulting from inadequate postnatal calcium–phosphate accretion following premature interruption of placental mineral transfer."

Abstract:

Metabolic bone disease of prematurity (MBDP) is a disorder of impaired skeletal mineralization in preterm infants resulting from inadequate postnatal calcium–phosphate accretion following premature interruption of placental mineral transfer. The earliest biochemical manifestation is hypophosphatemia, accompanied by elevated alkaline phosphatase, reflecting insufficient mineral delivery relative to the demands of rapid skeletal growth.

In most preterm infants, phosphate underdelivery represents the dominant mineral limitation, whereas calcium-limiting disease with secondary hyperparathyroidism occurs less frequently. Chronic low strong ion difference states, commonly present in preterm infants, may increase skeletal buffering demand and reduce renal phosphate conservation independent of parathyroid hormone, thereby amplifying mineral deficit without typically altering the primary mineral limitation.

Diagnosis relies on serial biochemical screening and physiologic interpretation, using tubular phosphate reabsorption and parathyroid hormone to distinguish phosphate-limiting disease, acidosis-associated reduced phosphate conservation, and calcium-limiting secondary hyperparathyroidism. Management focuses on optimized mineral nutrition, balanced calcium–phosphorus supplementation, vitamin D support, correction of contributing physiologic disturbances, and biochemical monitoring until mineral homeostasis stabilizes with maturation.

Introduction:

Fetal skeletal mineralization accelerates during the third trimester, when the placenta actively transfers large quantities of calcium and phosphate to the developing skeleton. Premature birth interrupts this mineral accretion at a time when bone growth remains biologically programmed for rapid deposition. Because intestinal absorption and renal conservation are immature in early postnatal life, mineral delivery after birth frequently fails to match fetal requirements.

As a result, preterm infants commonly accumulate calcium and phosphate deficits during the early weeks of life. This deficit may impair skeletal mineralization and lead to metabolic bone disease of prematurity (MBDP). The disorder typically emerges several weeks after birth as a delayed complication of prematurity and chronic neonatal illness.

Early detection relies primarily on biochemical screening, since radiographic abnormalities appear only after substantial mineral loss has occurred. Understanding the physiologic mechanisms governing mineral supply, endocrine regulation, and renal phosphate handling provides a useful framework for interpreting laboratory abnormalities and guiding treatment.

Recognition that most MBDP is phosphate-limiting, while calcium-limiting disease is less common, further clarifies the disorder's pathophysiology. In addition, chronic low strong ion difference states may modify renal phosphate handling and mineral balance without usually altering the dominant mineral limitation.

This review integrates fetal mineral physiology, acid–base influences, renal phosphate handling, and endocrine regulation to provide a practical physiologic framework for the diagnosis and management of metabolic bone disease of prematurity.

"This review integrates fetal mineral physiology, acid–base influences, renal phosphate handling, and endocrine regulation to provide a practical physiologic framework for the diagnosis and management of metabolic bone disease of prematurity."

Physiology of Fetal Mineral Accretion:

Normal skeletal mineralization in the fetus depends on continuous transfer of calcium and phosphorus from the maternal circulation. During the third trimester, the placenta actively transports these minerals across specialized transport systems that maintain fetal serum calcium concentrations higher than maternal levels.

Mineral accretion accelerates markedly during late gestation. Approximately eighty percent of fetal bone mineral content is deposited during the third trimester. During this period, fetal mineral accretion rates exceed approximately 120 mg/kg/day of calcium and 60–75 mg/kg/day of phosphorus.

Premature birth abruptly interrupts this placental mineral supply while skeletal growth continues. After delivery, mineral intake

must be provided through enteral feeding or parenteral nutrition. Intestinal mineral absorption remains immature, renal conservation mechanisms are incompletely developed, and calcium–phosphate solubility limits constrain parenteral nutrition. Consequently, many preterm infants experience a period during which mineral intake falls short of skeletal requirements.

Pathophysiology of Mineral Deficiency:

Metabolic bone disease of prematurity develops when mineral supply becomes insufficient to support ongoing skeletal growth. Inadequate calcium or phosphorus availability reduces the formation of hydroxyapatite crystals within the bone matrix and slows mineralization of osteoid.

In many preterm infants, hypophosphatemia represents the earliest biochemical abnormality. Several physiologic factors contribute to this pattern. Calcium–phosphate solubility constraints frequently limit phosphorus delivery during early parenteral nutrition, and intestinal phosphorus absorption remains immature during the early postnatal period. At the same time, rapid skeletal growth continues after birth, creating substantial phosphorus demand for mineral deposition within the developing skeleton.

"In many preterm infants, hypophosphatemia represents the earliest biochemical abnormality. Several physiologic factors contribute to this pattern. Calcium–phosphate solubility constraints frequently limit phosphorus delivery during early parenteral nutrition, and intestinal phosphorus absorption remains immature during the early postnatal period. At the same time, rapid skeletal growth continues after birth, creating substantial phosphorus demand for mineral deposition within the developing skeleton."

As phosphate supply becomes insufficient relative to skeletal demand, serum phosphorus concentrations decline and osteoblast activity increases, leading to elevated alkaline phosphatase. The combination of low serum phosphorus and rising alkaline phosphatase serves as the earliest biochemical signal of impaired skeletal mineralization in preterm infants.

Calcium deficiency may also occur. When calcium intake becomes insufficient, parathyroid hormone secretion increases to maintain serum calcium concentrations. Elevated parathyroid hormone levels stimulate bone resorption and increase renal phosphate excretion, further impairing skeletal mineralization.

Influence of Acid–Base Balance:

Acid–base disturbances may modify mineral metabolism in preterm infants. Chronic hyperchloremic metabolic acidosis can increase urinary calcium excretion and reduce renal phosphate reabsorption. Skeletal buffering of hydrogen ions may also mobilize minerals from bone.

"Calcium deficiency may also occur. When calcium intake becomes insufficient, parathyroid hormone secretion increases to maintain serum calcium concentrations. Elevated parathyroid hormone levels stimulate bone resorption and increase renal phosphate excretion, further impairing skeletal mineralization."

Although these mechanisms may worsen mineral imbalance, acid–base disturbances usually act as modifying influences rather than primary causes of metabolic bone disease.

Clinical Manifestations:

Early metabolic bone disease is typically asymptomatic and detected through biochemical screening. As mineral deficiency progresses, structural skeletal abnormalities may develop.

Radiographic findings may include generalized osteopenia, cortical thinning, metaphyseal irregularities, and fractures involving the ribs or long bones. Because these changes typically appear relatively late in the disease process, relying solely on clinical findings may delay diagnosis.

Routine biochemical monitoring, therefore, plays a central role in early detection.

Biochemical Screening and Physiologic Interpretation:

Screening for metabolic bone disease typically begins between two and four weeks of age in infants at risk for MBDP. Measurement of serum phosphorus and alkaline phosphatase provides the earliest indication of mineral imbalance.

Persistent serum phosphorus levels below approximately 4–4.5 mg/dL suggest inadequate mineral supply. Elevation of alkaline phosphatase supports the presence of impaired skeletal mineralization. Values exceeding approximately 600–800 IU/L are commonly associated with developing metabolic bone disease of prematurity.

When these abnormalities are present, further physiologic evaluation helps determine the dominant mineral limitation responsible for impaired skeletal mineralization.

The biochemical patterns observed in MBDP reflect the interaction between mineral supply, endocrine regulation, and renal phosphate handling. When phosphate intake is inadequate, serum phosphorus falls, and osteoblast activity increases. The

kidney responds by conserving filtered phosphate, resulting in increased tubular reabsorption of phosphate (TRP).

"The biochemical patterns observed in MBDP reflect the interaction between mineral supply, endocrine regulation, and renal phosphate handling."

When calcium balance is insufficient, parathyroid hormone secretion increases to maintain serum calcium levels. Elevated parathyroid hormone stimulates bone resorption and increases renal phosphate excretion, resulting in reduced TRP.

Tubular reabsorption of phosphate is calculated from paired serum and urine measurements:

TRP = 1 − (Urine phosphate × Serum creatinine) / (Serum phosphate × Urine creatinine)

Integration of serum phosphorus, PTH, and TRP allows clinicians to identify the dominant mineral limitation responsible for impaired skeletal mineralization.

Physiologic Interpretation of Hypophosphatemic MBDP

Serum Phosphorus	PTH	TRP	Physiologic Interpretation	Likely Limiting Factor
Low	Normal	High (>90–95%)	Renal phosphate conservation	Phosphate deficiency
Low	Elevated	Low	Secondary hyper-parathyroidism	Calcium deficiency
Low	Normal	Low	Reduced renal phosphate conservation	Acid–base or renal effect

Clinical Evaluation and Management Algorithm:

Evaluation of metabolic bone disease begins when screening identifies hypophosphatemia accompanied by elevation of alkaline phosphatase. Measurement of parathyroid hormone and calculation of tubular phosphate reabsorption help determine the dominant physiologic disturbance.

When TRP is high, renal phosphate conservation remains intact, indicating that inadequate phosphorus delivery is the primary cause of hypophosphatemia. Treatment focuses on increasing phosphorus intake while maintaining appropriate calcium balance.

When TRP is low and parathyroid hormone is elevated, the pattern reflects calcium deficiency with secondary hyperparathyroidism. Management prioritizes restoration of adequate calcium intake.

When TRP is low and parathyroid hormone levels are normal, reduced renal phosphate conservation may reflect metabolic acidosis or other physiologic modifiers of renal phosphate transport. Correction of the underlying disturbance and optimization of mineral intake are required.

Nutritional Prevention:

Preventing metabolic bone disease requires providing mineral intake approximating fetal accretion rates. Recommended enteral intake targets include approximately 120–200 mg/kg/day of calcium and 70–115 mg/kg/day of phosphorus, with a calcium-to-phosphorus ratio of approximately 1.3–1.8.

Because human milk alone often does not provide sufficient mineral density to meet these targets, fortification is essential for supporting skeletal mineralization in preterm infants.

Vitamin D:

Vitamin D facilitates intestinal calcium absorption and supports skeletal mineralization. Clinical practice commonly targets vitamin D intake of 400-**800 IU per day**, although higher doses may be considered in selected infants.

"Preventing metabolic bone disease requires providing mineral intake approximating fetal accretion rates. Recommended enteral intake targets include approximately 120–200 mg/kg/day of calcium and 70–115 mg/kg/day of phosphorus, with a calcium-to-phosphorus ratio of approximately 1.3–1.8."

Targeted Mineral Supplementation:

When biochemical abnormalities develop despite adequate provision of dietary minerals, targeted mineral supplementation may be required to correct the underlying mineral deficit. In most preterm infants, metabolic bone disease is phosphate-limiting, and therefore phosphorus replacement is usually the primary intervention. Calcium supplementation is added when parathyroid hormone is elevated or when calcium intake is insufficient to maintain balanced mineral accretion.

Therapeutic supplementation should aim to restore mineral delivery toward intrauterine accretion while preserving calcium–phosphorus balance. Supplementation with a single mineral in isolation may worsen the imbalance of the others. For example, aggressive phosphate replacement without adequate calcium intake may precipitate hypocalcemia, whereas excessive calcium administration without adequate phosphate may fail to correct impaired skeletal mineralization.

The dosing ranges below represent typical therapeutic supplementation ranges used in neonatal practice for infants with evolving or established metabolic bone disease of prematurity.

These doses supplement, rather than replace, baseline mineral intake from fortified human milk, preterm formula, or parenteral nutrition. Actual dosing should be individualized based on mineral intake, biochemical severity, renal phosphate handling, electrolyte status, and treatment response.

"Therapeutic supplementation should aim to restore mineral delivery toward intrauterine accretion while preserving calcium–phosphorus balance."

Neonatal Mineral Supplementation Dosing:

Phosphate

Route	Dose	Practical Notes
Oral	**1–3 mmol/kg/day (maximum 4.5 mmol/kg/day)**	Sodium or potassium phosphate IV solution may be administered enterally; divide doses every 6–8 hours.
IV	**0.5–1.5 mmol/kg/day**	Choose sodium vs potassium salt according to electrolyte status

Calcium

Route	Dose	Practical Notes
Oral	**150–220 mg/kg/day elemental calcium**	Calcium gluconate IV solution may be administered enterally
IV	**1–3 mEq/kg/day**	Continuous infusion preferred

Phosphate should **not be administered without adequate calcium**, and mineral supplementation should maintain a calcium-to-phosphorus ratio approximating fetal accretion to support skeletal mineralization. Vitamin D supplementation of **400–800 IU/day** supports intestinal calcium absorption and should be used in conjunction with mineral therapy.

Monitoring of Treatment Response:

Biochemical monitoring is essential for assessing response to mineral supplementation and ensuring restoration of skeletal mineralization. Serum phosphorus and alkaline phosphatase serve as the primary markers of treatment response.

Improvement in mineral balance is typically reflected by normalization of serum phosphorus concentrations and a gradual decline in alkaline phosphatase levels. Laboratory evaluation is commonly performed weekly during active treatment.

Measurement of serum calcium may help identify evolving mineral imbalance, particularly during phosphorus supplementation. In selected cases, reassessment of parathyroid hormone or tubular phosphate reabsorption may provide additional insight into persistent abnormalities.

Resolution and Discontinuation of Supplementation:

Mineral supplementation is continued until the infant exits the biologic window of prematurity and can maintain mineral balance solely through enteral nutrition. During this developmental period, intestinal mineral absorption, renal phosphate conservation, and skeletal mineralization remain immature and depend on mineral delivery approximating intrauterine accretion rates.

"Improvement in mineral balance is typically reflected by normalization of serum phosphorus concentrations and a gradual decline in alkaline phosphatase levels. Laboratory evaluation is commonly performed weekly during active treatment."

As physiologic maturity advances, improvements in intestinal absorption, renal mineral handling, and nutritional intake stabilize mineral homeostasis. Supplementation can be discontinued once serum phosphorus remains within the normal range, alkaline phosphatase levels decline toward normal, and adequate mineral intake is achieved through fortified human milk or preterm formula.

In many infants, this transition occurs as they approach 32–36 weeks corrected gestational age, although the timing varies depending on gestational age at birth, nutritional intake, and the severity of the preceding mineral deficit.

Integrated Perspective:

Metabolic bone disease of prematurity arises primarily from inadequate calcium–phosphate accretion following premature interruption of placental mineral transfer. Among the two minerals, phosphate delivery is most commonly limiting because parenteral nutrition is constrained by calcium–phosphate solubility, and unfortified human milk contains insufficient phosphate relative to fetal accretion requirements. The resulting mineral deficit produces the characteristic biochemical pattern of hypophosphatemia with elevated alkaline phosphatase. In this setting, the kidney typically conserves phosphate, as reflected by increased tubular phosphate reabsorption.

Physiologic classification of MBDP, therefore, depends on the interactions among mineral supply, endocrine regulation, and renal phosphate handling. Phosphate-limiting disease predominates and may present either with appropriate renal conservation or with reduced phosphate conservation associated with chronic low strong ion difference states. Calcium-limiting disease occurs less frequently and is characterized by secondary hyperparathyroidism with renal phosphate wasting. Recognition of these physiologic patterns allows clinicians to identify the dominant mineral limitation and guide targeted mineral supplementation.

Summary:

Metabolic bone disease of prematurity represents a disorder of insufficient postnatal mineral accretion during a developmental period when skeletal growth remains programmed for rapid fetal-level mineral deposition. Phosphate underdelivery is the dominant driver of disease in most preterm infants, while acid–base physiology and renal phosphate handling modify the severity

of mineral imbalance. Diagnosis relies on biochemical screening combined with physiologic interpretation using tubular phosphate handling and parathyroid hormone.

"Physiologic classification of MBDP, therefore, depends on the interactions among mineral supply, endocrine regulation, and renal phosphate handling. Phosphate-limiting disease predominates and may present either with appropriate renal conservation or with reduced phosphate conservation associated with chronic low strong ion difference states. Calcium-limiting disease occurs less frequently and is characterized by secondary hyperparathyroidism with renal phosphate wasting."

Effective management requires reproducing fetal mineral accretion by optimizing nutritional mineral delivery, balancing calcium and phosphorus supplementation, supporting vitamin D, and maintaining ongoing physiologic monitoring. As intestinal absorption, renal conservation, and nutritional intake mature, mineral homeostasis stabilizes, and supplementation can be discontinued once the infant exits the biologic window of prematurity.

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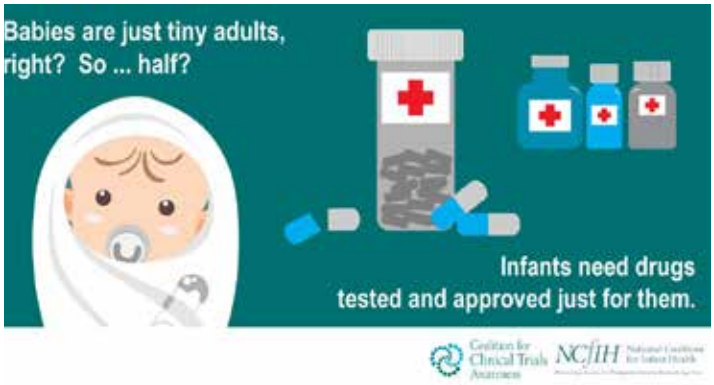

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Updates

Rob Graham, RRT, NRCP

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

"Our planet rotates at a fairly consistent speed, and our trips around the sun are similarly predictable in duration; everything else, on the other hand, is predictable only in its unpredictability. People are noticing, often commenting on how much everything has/is changing (and not necessarily for the better). Nowhere is this more pronounced than in science, technology, and, by extension, medicine."

Our planet rotates at a fairly consistent speed, and our trips around the sun are similarly predictable in duration; everything else, on the other hand, is predictable only in its unpredictability. People are noticing, often commenting on how much everything has/is changing (and not necessarily for the better). Nowhere is this more pronounced than in science, technology, and, by extension, medicine.

Immediately after pressing "send", I invariably find more and sometimes more recent information. This column will provide some of those "post-send" tidbits of current (less dated?) information and evidence in no particular chronological order.

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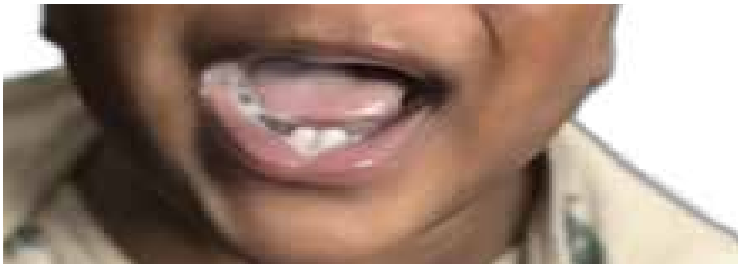

Born at 23+3 weeks gestation (with permission)

Let us start with something overwhelmingly positive. I have a wonderful update to the June 2025 column, titled "Love, Hope, Faith: Powerful Medicine".

As it is said, "A picture is worth 1000 words." No further comment required!

February 2026 (NAVA/NIV-NAVA: Hope or Hype) discussed the suitability of these modes in the premature population. Since then, I have cared for a very small infant on invasive NAVA following "failure on HFJV". Initially, FiO_2 improved dramatically, decreasing from 0.9-1.0 to ≈0.52. Since the mean airway pressure was minimally equal to that on HFJV (≈15-16 cmH_2O with low-pressure/long Ti recruitment maneuvers added), and maximally 22 cmH2O, or more, and peak airway pressures as high as 35 cmH2O, this should not be surprising. Tidal volumes routinely reached 10 mL/kg, and I could see an inspiratory hold on the flow graphic. After nearly 3 weeks on NAVA, FiO2 increased, blood gases deteriorated, and CxR was, to put it mildly, bad. After 4 days of being ventilated again with HFJV, FiO_2 decreased to 0.42, and CxR, while remaining hyperinflated, was significantly less cystic.

"A 2022 meta-analysis found no differences in outcomes between nasal CPAP and NIV-NAVA (2), which, frankly, surprises me, since some of the studies used very low CPAP pressures. In my limited experience, some infants do very well on NIV-NAVA, and there are physiological/theoretical advantages to the mode. As for invasive NAVA, I am firmly against its use in very premature infants, and I do not believe there is sufficient evidence supporting it."

There is evidence that the premature infant's diaphragm can easily trigger a breath from the ventilator, but the infant is often not able to stop the breath until stretch receptors are triggered (1,2). A 2022 meta-analysis found no differences in outcomes between nasal CPAP and NIV-NAVA (2), which, frankly, surprises me, since

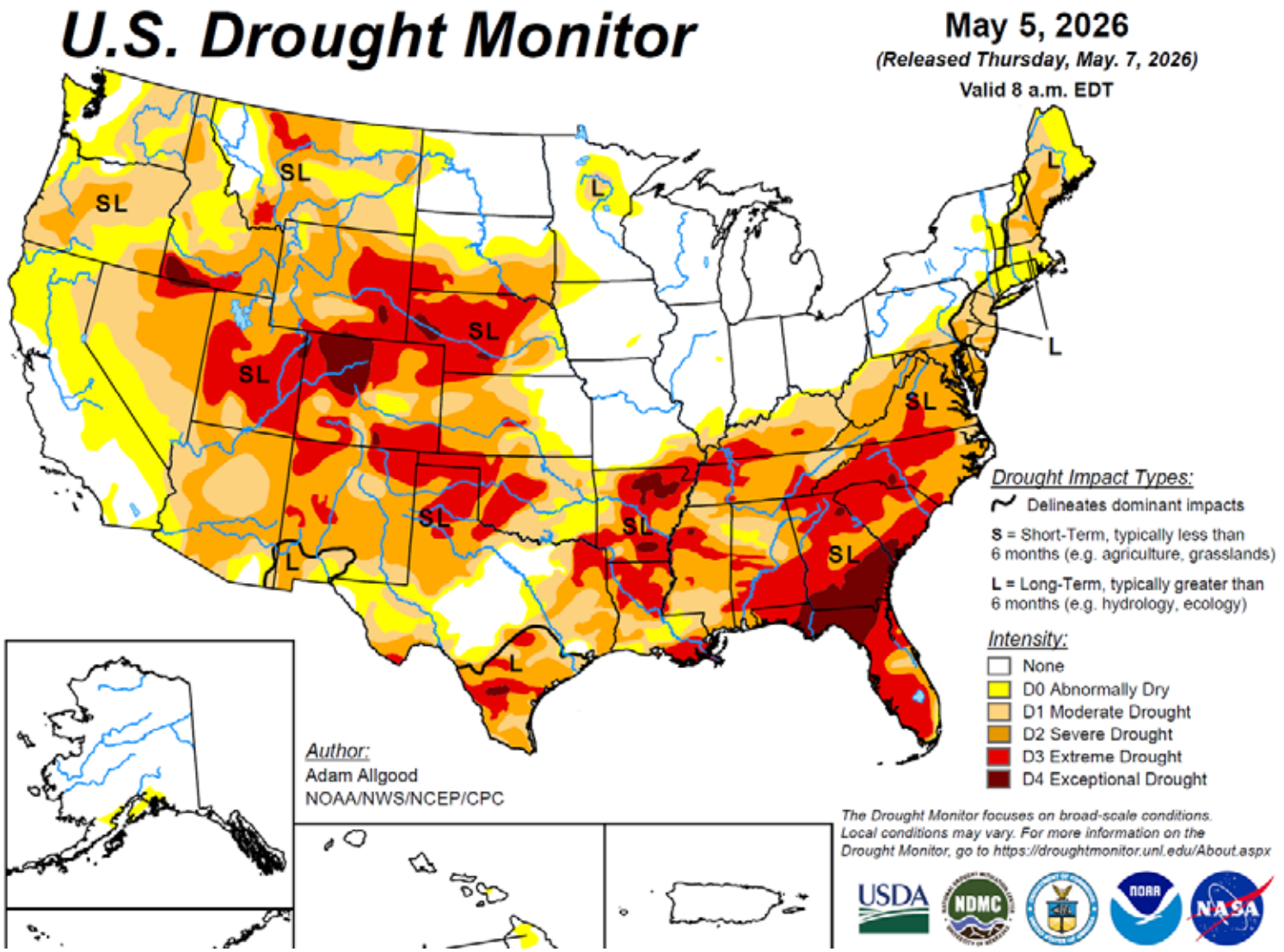

Figure 1 Courtesy of respective U.S. government agencies

some of the studies used very low CPAP pressures. In my limited experience, some infants do very well on NIV-NAVA, and there are physiological/theoretical advantages to the mode. As for invasive NAVA, I am firmly against its use in very premature infants, and I do not believe there is sufficient evidence supporting it.

"Pacific Ocean surface temperatures are at record highs (3), Amazon deforestation is higher than ever and dangerously close to a tipping point (4), the western U.S. is in a prolonged drought (figure 1), and the Atlantic Meridional Overturning Circulation (AMOC) system is even closer to collapse than believed a few months ago (5)."

The climate emergency (December, 2025 and January 26 – "Suffer the Children: The Climate Emergency" parts 1 and 2) is nearly impossible to keep up to date on for a mere mortal. However, consensus is building that the El Niño of 2026 may be the strongest in 140 years. Given the current (and accelerating) state of global warming, several factors, when superimposed on a very powerful El Niño, raise cause for alarm.

Pacific Ocean surface temperatures are at record highs (3), Amazon deforestation is higher than ever and dangerously close to a tipping point (4), the western U.S. is in a prolonged drought (figure 1), and the Atlantic Meridional Overturning Circulation (AMOC) system is even closer to collapse than believed a few months ago (5). One study (currently under peer review) estimates that it could collapse in the next decade (6). While in peer review, perhaps the fact that it has reached the peer review stage should be concerning enough!

Maps of droughts are one thing; the consequences of them are quite another. Lake Mead, the reservoir behind Hoover Dam, is currently at 1054.27 feet (full capacity is 1229), and Lake Powell, the upstream reservoir behind Glen Canyon Dam, is at 3,526.05 feet (full capacity is 3700 feet) (7). At first glance, these numbers look fine, but the generating capacity of a hydroelectric dam decreases as the water level drops because it is directly related to head pressure (8). At 895 feet and 3,370 feet, respectively, Lakes Mead and Powell can no longer generate electricity at all (9). 895 feet is near the normal winter level of Lake Mead; however,

electrical demand from the areas served by Hoover Dam is much lower in the winter.

Elevation numbers do not tell the whole story either. Neither reservoir is a box, so water depth cannot be directly related to water volume. At present, Lake Mead is at ≈25% *usable* capacity, and Lake Powell is at ≈33% (10).

The Hoover and Glen Canyon dams provide power for 1.3 million people in some of the hottest areas of the United States, where air conditioning is not a luxury; it is a necessity. Of greater concern is that as many as 40 million people depend on the Colorado River for water, and many more depend on food produced directly from irrigation by the Colorado River (11). For a very in-depth analysis and review of the current state of the climate and the implications of a powerful El Niño this year, check out (12). This is a 2+ hour podcast that quotes reputable sources in an urgent, yet non-alarmist, manner. It looks at all the natural factors (and our influence on them) that may further contribute to atmospheric carbon levels. (You might want to take your antidepressant before listening!)

"A study conducted by the Bill and Melinda Gates Foundation and Oxfam estimates the child death toll attributable to these cuts in 2025 to be 200k (13), while Boston University puts the toll at 258k children, 124k adults, and ≈88 combined deaths per hour (14)."

Finally, "Suffer the Children" (January, 2025) discussed the implications of Trump's policies on public health worldwide. A study conducted by the Bill and Melinda Gates Foundation and Oxfam estimates the child death toll attributable to these cuts in 2025 to be 200k (13), while Boston University puts the toll at 258k children, 124k adults, and ≈88 combined deaths per hour (14). Happy midterms, vote accordingly!

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

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Early Diagnosis of Barakat Syndrome in A Neonate: Importance of Dysmorphic Features at Birth

Nasir Rashid, MD, MBA, Omama Farooq, MBBS, Sara Nazir, MBBS

"Barakat Syndrome, transmitted in an autosomal dominant pattern, is a very rare disorder caused by GATA3 haploinsufficiency and conventionally presents with hypoparathyroidism (H), sensorineural hearing loss (D), and renal anomalies (R). We present the case of a term female neonate admitted with respiratory distress, hypocalcemia, and dysmorphic features. Chromosomal microarray analysis identified a 10p15.3p14 deletion and a 15q26.3 duplication, findings confirming Barakat Syndrome (also known as HDR syndrome)."

Abstract:

Barakat Syndrome, transmitted in an autosomal dominant pattern, is a very rare disorder caused by GATA3 haploinsufficiency and conventionally presents with hypoparathyroidism (H), sensorineural hearing loss (D), and renal anomalies (R). We present the case of a term female neonate admitted with respiratory distress, hypocalcemia, and dysmorphic features. Chromosomal microarray analysis identified a 10p15.3p14 deletion and a 15q26.3 duplication, findings confirming Barakat Syndrome (also known as HDR syndrome). Parents were counseled regarding her genetic condition and prognosis, and calcium supplementation helped stabilize her fluctuating serum calcium levels during the hospital course. This case report underscores the importance of prompt recognition of subtle dysmorphic features during the neonatal period, as timely diagnosis helps clinicians intervene early and may mitigate long-term complications such as skeletal abnormalities from hypoparathyroidism, renal impairment, and intellectual dysfunction associated with untreated hearing loss. Close surveillance and early identification are therefore of ultimate importance in improving outcomes for this rare but impactful disorder.

Introduction:

Barakat syndrome, first reported in 1977, is a rare genetic disorder inherited in an autosomal dominant manner, characterized by the triad of hypoparathyroidism (H), sensorineural hearing loss (D), and renal dysplasia (R), collectively termed HDR syndrome. This condition results from inactivation or deletion of one copy of the *GATA3* gene on chromosome 10p14, which encodes a dual-zinc-finger transcription factor essential for the development and maturation of the kidneys, parathyroid glands, thymus, and auditory system. Regardless of heterozygous *GATA3* gene variant status, the full HDR phenotype occurs in approximately 64.4% of the affected individuals, while partial phenotypes involving only deafness and renal anomalies (DR) or hypoparathyroidism and hearing loss (HR) occur in about 4.4% and 1.7% of cases, respectively (1).

The disorder may present across all ages, exhibiting a diverse constellation of manifestations, including afebrile seizures and tetany from hypocalcemia, vesicoureteral reflux, hematuria, and renal failure, and occasionally progressing to intellectual disability. Craniofacial morphology is variable; however, the most striking features identifiable at birth include a prominent forehead, synophrys, depressed nasal bridge, hypertelorism, and low-set ears (2).

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Relevance for the Patients:

We report the case of a neonate admitted to the NICU following birth with respiratory distress, symptomatic hypocalcemia, low Parathyroid hormone levels, and hearing impairment, in whom the presence of distinctive craniofacial features prompted suspicion for an underlying chromosomal abnormality. Comprehensive evaluation, including microarray analysis, confirmed the diagnosis of Barakat Syndrome. To the best of our knowledge, this case report presents the first documented case of Barakat syndrome recognized within the first month of life. This underscores the critical importance of early recognition, as timely diagnosis enables prompt intervention, potentially improving outcomes and mitigating disease severity in affected children.

Case Presentation:

A 38-week-old, term female neonate was admitted to the NICU on her first day of life with mild respiratory distress. She was born via spontaneous vertex delivery to a 36-year-old G2P1 mother with gestational diabetes mellitus. The infant was the second child of healthy, nonconsanguineous parents. Her birth weight was 2,385 g, length 50 cm, and head circumference was 33.5 cm. APGAR scores were 5 and 7 at one and five minutes of birth, respectively.

On admission, systemic and neurological examinations were

Figure 1 Ultrasound brain showing cystic encephalomalacia.

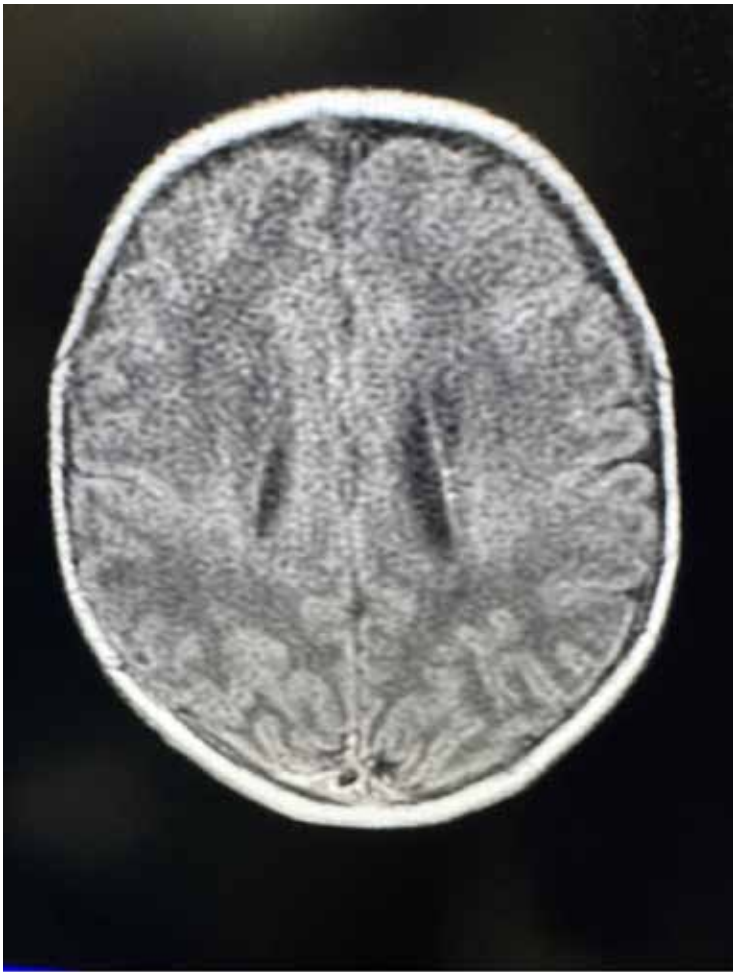

Figure 2 MRI brain showing cystic encephalomalacia.

unremarkable, although her facial features raised concern for an underlying syndrome. Notable findings included hypertelorism, high-arched palate, low-set ears, and absent eyelashes. Initial blood gas showed respiratory acidosis (pCO2 58 mmHg). A cranial ultrasound revealed a solitary left white matter lesion consistent with cystic encephalomalacia (Figure 1). An MRI of the brain was done subsequently for confirmatory diagnosis, demonstrating the same findings of cystic encephalomalacia (Figure 2)

On day three of life, seizure-like activity was observed, and laboratory tests demonstrated hypocalcemia with an ionized calcium level of 1.1 mmol/L (reference range 2.0-2.8 mmol/L). Although EEG findings were normal, after consultation with the endocrinologist, intravenous calcium gluconate was administered, resulting in clinical improvement. Parathyroid hormone levels were found to be low at PTH 8 pg/ml (reference 10-70 pg/ml), raising suspicion for DiGeorge syndrome. Due to fluctuating calcium levels, the endocrinologist advised starting the infant on a low-dose oral calcium supplement. Furthermore, Calcitriol was suggested if the calcium levels drop too low. Genetic testing, including karyotype and chromosomal microarray, was initiated as well.

During her NICU stay, this neonate experienced poor weight gain, frequent watery stools, and recurrent electrolyte disturbances requiring supplementation. Echocardiography revealed a small atrial shunt (Patent Foramen Ovale) and a small-to-moderate residual Patent Ductus Arteriosus (PDA), both without any significant hemodynamic compromise. With ongoing nutritional support and oral calcium supplementation, the neonate's condition gradually stabilized and hence, was discharged with normo-calcemia and improved weight gain.

The karyotype report came back abnormal, with findings suggestive of 46, XX, ADD (10)(p13), and showed additional material of uncertain origin, predicted to result in a terminal loss involving the short arm of chromosome 10. This specimen was reflexed to a genomic microarray, whose results were consistent with an unbalanced translocation involving chromosomes 10 and 15: a 10p15.3p14 deletion and a 15q26.3 duplication, due to an inherited defect in carrier patients. The parents were called in again and counseled regarding the diagnosis, prognosis, and need for long-term follow-up. Paternal chromosomal analysis was also recommended, as the defect was presumed to be inherited from either parent.

Discussion:

Barakat Syndrome, or HDR syndrome, is a rare disorder with approximately 180 cases reported worldwide (1). The phenotypic spectrum associated with 10p deletion syndromes is highly diverse, with reported manifestations ranging from distinctive craniofacial morphology to a wide array of cognitive, behavioral, and developmental phenotypes. In particular, deletions of 10p15.3, the most distal part of chromosome 10, are associated with 10p15.3 microdeletion syndrome, which manifests with developmental delay, low birth weight, distinctive facial features, behavioral disturbances, and seizures. Notably, isolated deletions confined to the 10p15 region are exceptionally uncommon and are frequently observed in conjunction with duplications involving

other loci on chromosome 10 or an entirely different chromosome (6)

Barakat syndrome results from the haploinsufficiency of the *GATA3* gene on chromosome 10p14-p15, with phenotypic severity and onset determined by the specific variant. *GATA3* mutations impair DNA binding, altering transcriptional regulation and dysregulating the Ret and insulin-like growth factor signaling pathways, both essential for nephric duct and renal development, as well as inner hair cell differentiation, leading to severe inner ear defects and dysregulation of parathyroid development. (3,4)

Chromosomal microanalysis (CMA), which offers cost-effective genome-wide detection of submicroscopic chromosomal abnormalities, is a pivotal first-line diagnostic tool. It is particularly valuable in the evaluation of patients with suspected microdeletion or microduplication syndromes, neurodevelopmental delay, and intellectual disability. This high-resolution technique can identify chromosomal alterations as small as 50 kb, thereby enabling earlier and more precise diagnosis of rare genetic disorders (5)

"Due to variable expressivity and incomplete penetrance observed even within affected members of the same family, only 64.4% of individuals with Barakat Syndrome reported in the literature are reported to exhibit the complete phenotypic triad previously described. Among these, sensorineural hearing loss (SNHL) demonstrates the highest prevalence, occurring in 96.7% of the cases, followed by renal involvement in 72.2% of reported patients."

Due to variable expressivity and incomplete penetrance observed even within affected members of the same family, only 64.4% of individuals with Barakat Syndrome reported in the literature are reported to exhibit the complete phenotypic triad previously described. Among these, sensorineural hearing loss (SNHL) demonstrates the highest prevalence, occurring in 96.7% of the cases, followed by renal involvement in 72.2% of reported patients. The hearing loss typically manifests early in life and can range from moderate to severe sensorineural hearing loss (56 dB to 70 dB), usually bilateral, although unilateral involvement, as seen in our patient, has also been described. According to *Amin J Barakat et al.*, the absence of distortion product otoacoustic emissions in the presence of a normal auditory brainstem response suggests that the underlying pathology is cochlear in origin, likely reflecting a defect in either translating sound vibrations into electrical signals by cochlear hair cells or in the transmission of this information to the brain. SNHL demonstrates a progressive course, worsening with age, and has been reported to exhibit genetic anticipation, with earlier onset often associated with severe disease (5, 6)

Hypoparathyroidism in HDR syndrome results from impaired parathyroid hormone (PTH) secretion, leading to symptomatic hypocalcemia that manifests as paresthesia, seizures, tetany, and neuromuscular irritability. In our patient, seizures appeared at calcium levels below 1.1 mmol/L (reference 2.15-2.5 mmol/L). While recombinant PTH (rh-PTH 1-84) offers an emerging therapeutic option, management typically involves calcium and active vitamin D supplementation. Undiagnosed and untreated cases can lead to complications such as osteoporosis and fragility fractures, and although data on the use of anabolic agents such as teriparatide or abaloparatide in hypoparathyroidism remain limited, their proven efficacy in osteoporosis suggests potential therapeutic benefit (6)

The strong expression of *GATA3 in ureteric buds, stromal, and mesangial cells highlights* its crucial role in renal development and glomerular repair, explaining the occurrence of renal dysplasia in HDR syndrome. Renal involvement is also variable, with studies reporting aplasia, hypoplasia, or dysplasia, vesicoureteral reflux (VUR), and cystic or pelvicalyceal abnormalities. Prognosis largely depends on the extent of renal disease, emphasizing the importance of early diagnosis and close monitoring. 8 Parental genetic counseling remains an essential aspect of managing Barakat syndrome (5), though it can be particularly demanding for families confronted with the presence of characteristic craniofacial features in their child. To the best of our knowledge, our case report represents the first documented case in which Barakat Syndrome was recognized within the first month of life, underscoring the importance of recognizing characteristic facial features and early management.

"In conclusion, recognition of even subtle dysmorphic features in neonates should prompt early genetic testing. Timely diagnosis of Barakat syndrome allows interventions that may prevent or mitigate complications such as renal insufficiency, skeletal disease, and neurocognitive impairment, thereby improving long-term outcomes."

Conclusion:

In conclusion, recognition of even subtle dysmorphic features in neonates should prompt early genetic testing. Timely diagnosis of Barakat syndrome allows interventions that may prevent or mitigate complications such as renal insufficiency, skeletal disease, and neurocognitive impairment, thereby improving long-term outcomes.

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The Indirect Impact of **RSV**

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

OVERVIEW

RSV impacts not only infants and young children, but also entire families.

The National Coalition for Infant Health and the Alliance for Patient Access sought to examine the multifaceted burden that RSV places on families and to identify potential policy solutions.

Two surveys were conducted, one of parents who had at least one child contract RSV and one of health care providers who treat infants and children with RSV.

Both surveys were conducted with YouGov, a global public opinion and data company. Parents and providers were recruited from a pool of pre-selected respondents to ensure they met the survey's requirements. Participants received an honorarium.

RSV PARENT SURVEY

340 parents who had at least 1 child sick with RSV

67% of parents said their child was hospitalized for RSV

RSV HEALTH CARE PROVIDER SURVEY

175 health care providers across various pediatric and neonatal subspecialties

67% worked in an outpatient facility

33% worked in a hospital

RESULTS

FINANCIAL BURDEN

More than ⅔ of parents said the costs of RSV posed a financial burden or financial crisis.

7% of parents said they were fired as a result of caring for their child with RSV.

32% of parents reported losing potential income while their child had RSV.

EMOTIONAL BURDEN

68% of parents said watching their child suffer affected their mental health.

69% of parents felt guilty that they could not do more to prevent their child's RSV.

When parents found out there was no treatment for RSV, only supportive care:

- **48%** felt angry
- **46%** felt helpless

SOCIAL BURDEN

43% of parents had never heard of RSV before finding out their child was sick.

54% of parents had to rely on family and friends for sibling care, transportation and other responsibilities.

42% of parents said they struggled to care for their other children when one faced RSV.

RESULTS

PARENT EDUCATION & AWARENESS

86% of providers said they include RSV education as part of routine care.

99% of providers agreed that parents need more information about RSV.

TREATMENT CHALLENGES

Nearly ⅓ of providers have been reluctant to test for RSV because no treatment exists.

48% of providers said it was difficult to decide whether to send an infant or child with RSV to the emergency room.

92% agreed that if an immunization were available, it should be added to the Vaccines for Children program's list of pediatric vaccines.

MISCONCEPTIONS

A majority of providers (60%) explained that around 50% or more of the babies they see hospitalized for RSV were born healthy, despite many people thinking severe RSV only impacts premature infants or those with preexisting conditions.

CONCLUSION

Both surveys highlighted that the burden of RSV extends well beyond its physical symptoms.

The virus may lead to:

- **Long-lasting health challenges** for babies and young children
- **Financial, social and emotional burdens** for families
- **Frustration for providers,** who lack a cure or viable preventive interventions

This burden is not experienced by the few. Most infants and children contract RSV by the time they are two, and challenges that accompany RSV may impact anyone who has been affected.

Moving forward, the many burdens of RSV demonstrate the need for:

- **More RSV education**
- **Research and innovation** for preventive interventions
- **Access to prevention and treatment** for all babies and children

The challenges caused by RSV can reach far and wide, and its indirect impacts often leave families struggling.

Integrative W.O.M.B. Techniques + NeuroSomatic Connection: Reconnecting Patients to the Womb–Brain Axis

Nicole Harlot

"Many patients enter pregnancy, birth, and postpartum with a surprisingly limited, fragmented understanding of their reproductive anatomy, their menstrual physiology, and the way stress and trauma shape pelvic sensation, sexual health, and body trust. In clinical settings, this often shows up as shame-based language about bleeding, pain that is minimized or normalized, avoidance of pelvic care, difficulty advocating for needs, and heightened anxiety around fertility, pregnancy, and birth."

Why does this conversation belong in perinatal and neonatal care?

Many patients enter pregnancy, birth, and postpartum with a surprisingly limited, fragmented understanding of their reproductive anatomy, their menstrual physiology, and the way stress and trauma shape pelvic sensation, sexual health, and body trust. In clinical settings, this often shows up as shame-based language about bleeding, pain that is minimized or normalized, avoidance of pelvic care, difficulty advocating for needs, and heightened anxiety around fertility, pregnancy, and birth.

For neonatology and perinatal teams, this "disconnection" is not simply philosophical; it can influence maternal stress physiology, sleep, feeding outcomes, postpartum recovery, and the parent–infant dyad. While neonatal clinicians are not responsible for providing pelvic education or somatic therapy, we are uniquely positioned to normalize body literacy, reduce stigma, and refer appropriately.

Integrative W.O.M.B. Techniques (Whole Optimization of Mind and Body), paired with NeuroSomatic approaches, offer a practical framework that supports patients in reconnecting with their bodies through anatomy-informed education, nervous-system regulation, and gentle interoceptive practices that restore safety and agency.

A note on language: "womb," "yoni," and precision

Patients often use "womb" as a broad, embodied term that includes internal reproductive organs and the external genital structures. Clinically, precision matters, but so does patient-centered language. A helpful stance is to validate the patient's term ("womb") while offering accurate anatomy:

- **External genitalia (vulva):** labia majora/minora, clitoris, vestibule
- **Vagina:** muscular canal (not synonymous with the vulva)
- **Cervix and uterus**
- **Fallopian tubes and ovaries**

"When appropriate, clinicians can encourage patients to review reputable diagrams and, if they choose, explore their own anatomy with a mirror in a nonjudgmental way. This is not about sexualization; it is about body literacy."

When patients have never seen accurate diagrams, or have only encountered sexualized depictions, simple education can reduce shame and improve self-advocacy. When appropriate, clinicians can encourage patients to review reputable diagrams and, if they choose, explore their own anatomy with a mirror in a nonjudgmental way. This is not about sexualization; it is about **body literacy**.

Cycles, physiology, and the cost of cultural messaging

Many patients have internalized the expectation that they should feel and perform the same way every day of the month. In reality, menstrual cycles involve predictable physiologic shifts that can influence:

- Energy and sleep
- Appetite and metabolic needs
- Mood and stress reactivity
- Pain sensitivity
- Libido and sensation

A cycle-aware framework can help patients replace self-criticism with self-monitoring and self-compassion. For some, simply learning that "ebb and flow is normal" reduces distress.

Key clinical opportunities

Within scope, clinicians can:

- Normalize that symptoms deserve assessment (not dismissal).
- Encourage tracking of bleeding patterns and cyclic symptoms.

- Screen for PMADs and trauma history.
- Refer to pelvic floor PT, perinatal mental health therapy, or qualified integrative providers.

Contraception counseling remains essential, and hormonal methods are appropriate for many patients. At the same time, patients benefit when counseling includes transparent discussion of expected physiologic effects, appropriate alternatives, and the patient's values and goals.

The NeuroSomatic lens: the nervous system is part of the pelvis

NeuroSomatic work integrates nervous-system regulation with body-based awareness. Many patients carry stress responses in the pelvic region, such as tightness, numbness, pain, guarding, or dissociation, especially after trauma, invasive procedures, or difficult births.

A NeuroSomatic approach does not require complex interventions. It begins with the premise that **safety changes sensation**. When the nervous system downshifts, interoception improves, and patients can often access clearer internal cues.

"A NeuroSomatic approach does not require complex interventions. It begins with the premise that safety changes sensation. When the nervous system downshifts, interoception improves, and patients can often access clearer internal cues."

A simple, clinician-friendly "womb connection" practice (2 minutes)

This brief practice can be offered as an optional grounding tool, similar to paced breathing. It is not a substitute for therapy and should be avoided if it increases distress.

1. **Invite consent:** "Would you like a brief grounding exercise?"
2. **Orient to the body:** "Place a hand just below the navel if that feels comfortable."
3. **Breath + interoception:** Slow inhale/exhale for 4–6 cycles.
4. **Notice without judgment:** temperature, pressure, tingling, emptiness/fullness.
5. **Supportive phrase (choose one):**
    - "I am safe in my body in this moment."
    - "I can listen to my body one breath at a time."
    - "My body is allowed to have needs."

This practice can be useful in prenatal visits, postpartum recovery, lactation consults, or NICU-family support contexts where anxiety is high and patients feel powerless.

"Descension" as a regulated return to the foundational centers

In integrative frameworks, some patients resonate with the concept of "descension", not as negativity, but as a grounded return to foundational needs: safety, boundaries, nourishment, and belonging. Clinically, we can translate this into familiar language:

- **Rootedness:** sleep, hydration, nutrition, pain control, physical safety
- **Agency:** informed consent, choices, pacing, boundaries
- **Connection:** supportive relationships, community, nonjudgmental care

When patients feel resourced at the "base," they are more able to engage in higher-order coping, bonding, and meaning-making.

When to refer (and to whom)

Consider referral when patients report:

- Persistent pelvic pain, dyspareunia, urinary/fecal symptoms
- Panic, intrusive thoughts, dissociation, or trauma triggers
- Severe cycle-related mood symptoms
- Birth-related trauma impacting function or bonding

Potential referral pathways:

- **Perinatal mental health therapist** (PMH-C or equivalent)
- **Pelvic floor physical therapist**
- **Trauma-informed somatic practitioner** (with clear scope and collaboration)
- **Lactation consultant** (when feeding stress is central)

Closing: reconnection as prevention and empowerment

"Reconnecting patients to their anatomy, their physiologic rhythms, and their nervous-system cues is not a luxury add-on; it is a protective factor. When patients feel safe and informed in their bodies, they are more likely to seek care earlier, communicate symptoms clearly, and engage in postpartum recovery with less shame and more agency."

Reconnecting patients to their anatomy, their physiologic rhythms, and their nervous-system cues is not a luxury add-on; it is a protective factor. When patients feel safe and informed in their bodies, they are more likely to seek care earlier, communicate symptoms clearly, and engage in postpartum recovery with less shame and more agency.

Integrative W.O.M.B. Techniques and NeuroSomatic approaches offer a bridge between patient-centered language and clinically responsible support: education, regulation, and referral. In a healthcare culture that often fragments care, this is one way to help families experience the perinatal period with greater dignity, clarity, and connection.

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INFANT AND FAMILY-CENTERED DEVELOPMENTAL CARE (IFCDC)

STANDARDS AND SAMPLE RECOMMENDATIONS FOR INFANTS IN THE INTENSIVE CARE UNIT

SYSTEMS THINKING IN COMPLEX ADAPTIVE SYSTEMS

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

POSITIONING & TOUCH FOR THE NEWBORN

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

SLEEP AND AROUSAL INTERVENTIONS FOR THE NEWBORN

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

SKIN-TO-SKIN CONTACT WITH INTIMATE FAMILY MEMBERS

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

REDUCING AND MANAGING PAIN AND STRESS IN NEWBORNS AND FAMILIES

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

MANAGEMENT OF FEEDING, EATING AND NUTRITION DELIVERY

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

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Ethics and Wellness: Ethics and Wellness: The Courage to Feel: Vulnerability in Neonatology

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

"In the Neonatal Intensive Care Unit, we are trained to project a sense of steadiness and calmness. Our decisions carry immense weight, our words are measured, and our composure is often interpreted as competence."

In the Neonatal Intensive Care Unit, we are trained to project a sense of steadiness and calmness. Our decisions carry immense weight, our words are measured, and our composure is often interpreted as competence. Nevertheless, beneath that exterior lies a truth we do not always acknowledge: we are deeply affected by what we witness, hear, and carry with us long after a shift ends.

No neonatologist is an island.

We stand at the intersection of life's most fragile beginnings and its most uncertain trajectories. We celebrate improbable victories: a 24-week infant extubating successfully, complications from ECMO averted, and a family finally taking their child home. However, we also sit in the quiet aftermath of loss, of complications we could not prevent, of conversations that linger because there were no right answers. These experiences shape us. They should. (1)

"However, we also sit in the quiet aftermath of loss, of complications we could not prevent, of conversations that linger because there were no right answers. These experiences shape us. They should. (1)"

Vulnerability in neonatology is often misunderstood as weakness. In reality, it is a form of courage. To allow ourselves to feel, to truly feel, the weight of a parent's fear and grief, the complexity of an ethical dilemma, or the sting of an unexpected outcome that is not a failure of professionalism. It is the essence of it. When we stop feeling discomfort, we risk losing the very empathy that defines our calling. (2) Furthermore, if we lose that, we must ask ourselves what remains of the practice of medicine.

We must balance vulnerability with resilience. We must be open to feedback without becoming defined or defeated by it. We must listen carefully, reflect honestly, and grow continuously, without surrendering our clinical judgment or our sense of self. (3)

There are moments when we must stand our ground, guided by experience and evidence. There are other moments when we must lower our guard, allowing the human connection between physician and family to transcend the traditional boundaries we were taught to maintain.

"We must balance vulnerability with resilience. We must be open to feedback without becoming defined or defeated by it. We must listen carefully, reflect honestly, and grow continuously, without surrendering our clinical judgment or our sense of self. (3) "

This duality is not a contradiction; it is the art of medicine.

There is also no place for a "shame spiral" in our work (or calling). Neonatology is complex, and outcomes are not always within our control. We will face complications. We will encounter failure. What matters is not the illusion of perfection, but the integrity of our effort. (4) Did we approach each decision with thoughtfulness? Did we act in the best interest of the infant and family? Did we learn from what unfolded? These are the questions that define us, not the unattainable standard of flawless outcomes.

"If we cannot speak openly about our experiences, our doubts, our frustrations, our grief, then we risk isolation in a field that already demands so much of us. Honest dialogue is not optional; it is essential. (5, 6)"

Equally important is how we support one another. The NICU is not just a clinical environment; it is an emotional ecosystem. Nurses, respiratory therapists, physicians, and families all contribute to its culture. If we cannot speak openly about our experiences, our doubts, our frustrations, our grief, then we risk isolation in a field that already demands so much of us. Honest dialogue is not optional; it is essential. (5, 6)

Moreover, when processes fail, when communication breaks down, when individuals feel disrespected or unappreciated, when systems perpetuate harm, we cannot simply continue as we have. Repetition without reflection is not consistency; it is stagnation. Growth requires us to confront discomfort, to listen deeply, and to change course when necessary.

At this point, grace becomes indispensable.

- Grace for our colleagues when tensions run high.
- Grace for ourselves when outcomes fall short.
- Grace for the families who entrust us with what matters most to them.

Vulnerability, when embraced with intention, does not weaken us; it strengthens our capacity to care, to connect, and to lead. It allows us to move forward not hardened by experience, but deepened by it. (1-3, 5)

"In the end, the practice of neonatology is not defined solely by the lives we save, but by the humanity we preserve, both in our patients and in ourselves."

In the end, the practice of neonatology is not defined solely by the lives we save, but by the humanity we preserve, both in our patients and in ourselves.

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Navigating toward Neonatology: Interview with Dr. Vincent Smith

Benjamin Hopkins, DO, Vincent Smith, MD, MPH

"Welcome back to another installment. My name is Benjamin Hopkins, and I am a post-graduate year two pediatric resident at the University of California, San Francisco – Fresno. "When I grow up," I want to be a Neonatologist. Look at previous months' journals for my earlier articles and follow along with this column as I navigate my way to becoming a neonatologist."

Welcome back to another installment. My name is Benjamin Hopkins, and I am a post-graduate year two pediatric resident at the University of California, San Francisco – Fresno. "When I grow up," I want to be a Neonatologist. Look at previous months' journals for my earlier articles and follow along with this column as I navigate my way to becoming a neonatologist.

I had the privilege of speaking with Dr. Vincent Smith, a Division Chief of Newborn Medicine at Boston Medical Center and Professor of Pediatrics at Boston University Medical School. We discussed his journey into neonatology, what makes an excellent neonatologist, how to attract more people into neonatology, the current distrust in the medical system, and his current projects and roles.

1. What qualities are most essential to excel as a neonatologist?

Attention to detail is important because we have a population where 0.01 and 0.02 make a difference. There aren't many other specialties where the smallest refinements can make a significant difference in outcomes, as they do in these newborns who are often super small, super early, or super complex.

2. What caused you to pursue a career in neonatology?

In medical school, I knew I wanted to do pediatrics, and I actually thought I would do adolescent medicine. Then, when I was the resident, I got to do an extra adolescent clinic because they were tailoring it to my interests. At the same time, my primary care clinic ended up with a patient panel of a person who had just graduated. This led them to book all the new baby appointments in my clinic because my clinic panel was really open. Most of what I saw in my primary care clinic were babies under a year old.

I enjoyed adolescent medicine when I was a medical student, but I didn't enjoy it as much as an intern. The amount of time you're able to spend with adolescents is the only thing that makes a huge difference, because you have to build rapport and trust with them. When you're an intern, you're so tired that asking complex questions and getting one-word answers or grunts is just not working. I realized that I wanted to be able to do whatever I needed to do under whatever conditions, and I realized I could do adolescent medicine only under the best of conditions and not under the worst. Adolescent medicine ended up not being a viable option for me.

I was good with my hands, having worked in a research lab, and one of my mentors asked me whether I had considered neonatology. At the time, the answer was no, because I had been so focused on the other end of the spectrum. She suggested it to me, and then I met a few other neonatologists, and I spent a little bit more time with them. I discovered that it was definitely the right choice for me, no looking back, no hesitation about that. I didn't think of it on my own. But it is the right choice; it aligns with who I am. I am grateful that my mentor pointed it out to me, because it wasn't initially on your radar.

"With the ACGME changes coming up, fewer people will have exposure to the NICU. Which will make it harder for people to consider pursuing it unless they already knew, coming in, that they want to be a neonatologist. "

3. How should we attract more people to neonatology amid declining interest in the field?

With the ACGME changes coming up, fewer people will have exposure to the NICU. Which will make it harder for people to consider pursuing it unless they already knew, coming in, that they want to be a neonatologist. Being in the NICU and spending time there is the best seller to get people interested, because you get a feel for the vibe.

With exposure, they can decide whether it resonates with them, and I've seen plenty of residents who came into residency thinking they'd do something different. Then, after spending time in the NICU, they shifted and decided that's where they were going.

"Many residencies do one or two blocks and fill the rest of the time with ED and other places. The time in the NICU is already lower than it used to be; now it's going down again with the addition of these other areas of medicine. As neonatologists, we have to be intentional about attracting more residents and students."

Many residencies do one or two blocks and fill the rest of the time with ED and other places. The time in the NICU is already lower than it used to be; now it's going down again with the addition of these other areas of medicine. As neonatologists, we have to be intentional about attracting more residents and students.

"If people definitely know they're going into neonatology and feel confident about it, I encourage them not to spend extra time doing it during residency, because they'll get the extra training in that area during fellowship. I encourage them to spend time on things they're not going to do again, but that could influence their practice—taking a basic radiology, cardiology, or nephrology rotation. Learn to read basic imaging, EKGs, and learn about kidneys, because all of our patients' kidneys are messed up."

4. What would you encourage a future neonatologist to prioritize and be involved in?

If people definitely know they're going into neonatology and feel confident about it, I encourage them not to spend extra time doing it during residency, because they'll get the extra training in that area during fellowship. I encourage them to spend time on things they're not going to do again, but that could influence their practice—taking a basic radiology, cardiology, or nephrology rotation. Learn to read basic imaging, EKGs, and learn about kidneys, because all of our patients' kidneys are messed up. That's knowledge that would be really helpful, and you'll get some of that during the fellowship, but it will be different. You're going to do an intense fellowship that'll give you immense exposure to newborn medicine, so that's not going to be an issue.

For people who haven't considered neonatology, that's a hard question. As I said before, when people have rotated through a NICU, that's the time when they really get a feel, and can understand if something's their jam or not; and if they don't get that experience, it makes it a little harder for them actually to be able to know that answer.

3. What do you think about the current distrust in the medical system and physicians, and how should we earn back that trust?

The thing that I've seen the most recently is vaccine hesitancy. This isn't just NICU-related; it's medicine in general. Right now, especially with the CDC's proposed changes and the AAP countering them, there's a lot more vaccine hesitancy. There is way more refusal than I've seen in the past, even for basic things like vitamin K and erythromycin at the time of birth, which aren't even vaccines. Similar to Nirversimab, which is an RSV monoclonal antibody, but it's not a vaccine. The general population is more aware of these things. But I don't know that knowledge is necessarily higher. They're treating every injectable as if it were a vaccine, and that you get the same reaction from all of them, which is an uninformed position.

It is fine if people read and make medical decisions based on actual knowledge and information. Still, often, they base their personal opinions on a five-minute Google search on their phone, which does not count as adequate.

What I prefer to see is people actually look for reputable sources of information and spend time reading and understanding the underlying data that leads to the recommendations, rather than just a "high-level review of the recommendations." I don't agree with that because their review of the evidence and conclusions isn't consistent with the rigor I'm accustomed to. This leads me to question the recommendations as they come from that particular organization.

"I do clinical work roughly 40% of the time, and when I am not, I'm an administrator. I work on hiring policies, faculty review, committees, and budgets. I didn't think I was ever going to be a division chief. I was a health services researcher for many years, and I really enjoyed that, but at a certain point, when I was ready to make a new transition, I felt I needed a new challenge. Administration offered me something I hadn't had before. It's actually quite rewarding."

5. What are you currently working on?

I do clinical work roughly 40% of the time, and when I am not, I'm an administrator. I work on hiring policies, faculty review, committees, and budgets. I didn't think I was ever going to be a division chief. I was a health services researcher for many years, and I really enjoyed that, but at a certain point, when I was ready to make a new transition, I felt I needed a new challenge. Administration offered me something I hadn't had before. It's actually quite rewarding.

It is a totally different area of the mind to use than what research or clinical work is typically focused on. Within the confines of clinical practice, there's a set of parameters that you know are going to push your buttons; some of the babies are going to be small, some of them are going to be sick, and sometimes a parent is going to have a bad day. You are there, helping patients and families in distress, and the therapist part of you will come alive. You never know from one minute to the next when a baby is going to be born, that it's going to need something, and sometimes something really dramatic, and sometimes in a small amount of time. But all of that comes with clinical practice.

The administrative piece is sometimes more difficult because, oftentimes, clinically, you're working with the clinical team. You are driving the ship in a way that you feel is most appropriate. With administration, even when you're the president, which I'm not, there are still higher-ups who can make decisions based on information that you don't have access to or that you don't always have. Administration is a different kind of time commitment. It's a

different form of stress.

Some would argue that administration is more stressful because there are no set end times, whereas in clinical work, you work in shifts. When your shift starts and when your shift ends, even though stuff is happening when your shift starts and stuff will be happening when your shift ends, it doesn't always mean that you have to be there for it. With the administrative piece, many responsibilities are tied to you, not necessarily to an hour or a day of the week. Responsibilities often expand to fill the space they're given.

"Neonatology is an incredible profession. We get to work with families during some of their most vulnerable times. It's an honor for us that they trust us enough to share their dark moments. It's also a huge responsibility we all take seriously, because people may not remember much, but they remember neonatologists for the rest of their lives. People forget that it's not a one-and-done; you become part of people, the fabric of families, and whether you stay in contact with them or not, you're still part of that fabric."

Neonatology is an incredible profession. We get to work with families during some of their most vulnerable times. It's an honor for us that they trust us enough to share their dark moments. It's also a huge responsibility we all take seriously, because people may not remember much, but they remember neonatologists for the rest of their lives. People forget that it's not a one-and-done; you become part of people, the fabric of families, and whether you stay in contact with them or not, you're still part of that fabric. That must be taken seriously, that the ramifications be considered, and that, even though it's just another day at work for you, it's probably the worst day families have ever had. Being able to be that physician and caretaker for their baby, who is now here, and to provide that emotional and physical support for parents who find themselves in that situation is second to none, in my opinion, and is special regardless of where it falls on your priority list.

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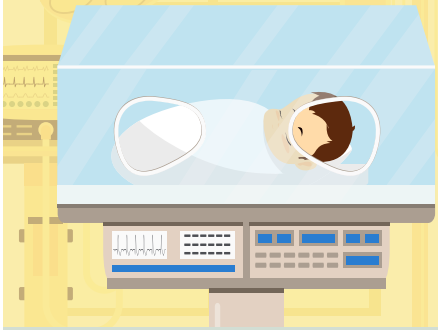
Hemolytic Disease of the Fetus & Newborn

DID YOU KNOW?

Hemolytic disease of the fetus & newborn is a rare blood disorder.

When the mother's and infant's blood types are incompatible, the mother's antibodies attack the baby's red blood cells.



HDFN can lead to:

- **Severe anemia**
- **Jaundice**
- Fetal or infant **death**

To reduce their baby's risk

pregnant mothers should talk to their health care provider to:

- **Identify** potential blood incompatibilities
- **Monitor** the baby
- **Treat** the condition if it occurs

NCfIH National Coalition for Infant Health

Protecting Access for Premature Infants through Age Two

LEARN MORE ▸

Fathers Can Experience Postpartum Depression

Becoming a father is an exciting and significant life event.

While it's well known that mothers can face postpartum depression, new fathers are at risk too.

1 in 10 men experience postpartum depression

Up to 7% of fathers may experience PTSD after the birth of their child

If their baby was born **preterm or the birth was traumatic,** their risk of postpartum depression and PTSD increases

Signs and symptoms a father may be struggling include:

- Mood swings
- Trouble sleeping
- Anger
- Withdrawing from family and friends
- Difficulty bonding with their baby

Raising awareness about paternal postpartum depression can:

- Reduce stigma
- Help dads recognize the symptoms
- Eliminate barriers to screening and treatment

New dads deserve their mental health to be taken seriously.

Hand to Hold

National Coalition for Infant Health

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The Nuclear Origins of Patient Safety

Colonel Robert Erick Ridout, MD, U.S. Army, Retired

"In 1955, Niels Bohr was appointed the first chairman of the Danish Atomic Energy Agency. He was instrumental in establishing the Risø National Laboratory on Denmark›s scenic Roskilde Fjord, which ushered in the country›s atomic age (2)."

In 1955, Niels Bohr was appointed the first chairman of the Danish Atomic Energy Agency. He was instrumental in establishing the Risø National Laboratory on Denmark›s scenic Roskilde Fjord, which ushered in the country›s atomic age (2). On site, Bohr had three nuclear reactors constructed, including the 10-Megawatt heavy-water reactor, designated Danish Reactor-3 (DR-3), which went critical on January 16, 1960. Bohr viewed this facility not merely as an engineering project, but as a living application of his Principle of Complementarity (3). He believed that truly understanding a complex system required embracing the paradox of complementarity: the existence of dual, often opposing truths, such as light behaving as both a particle and a wave. At Risø, this meant balancing the rigid, mathematical precision of nuclear physics with the messy, unpredictable reality of human nature. In 1973, a failing isolation valve forced a choice between the 'thoroughness' of Bohr's design and the 'efficiency' inherent in human cognition; the resulting failure led to a discovery that would define the modern science of system safety. (4).

Isolation valves, as the name suggests, are critical mechanical devices that enable safe working environments to be isolated from hazardous ones. In a nuclear facility like the DR-3, these valves are critical elements that maintain the containment boundary and halt the flow of high-pressure steam or radioactive heavy water during maintenance procedures or emergencies. Their role is binary and absolute: they must provide a perfect seal every time. Because the stakes of a leak are so high, these valves are rarely solitary; they are the physical manifestation of layered system defense, standing between operational stability and catastrophic release. To bolster this defense, the DR-3 utilized a dual-barrier isolation strategy. This meant that every penetration through the reactor›s containment vessel included at least two isolation valves installed in series. Engineers refer to this strategy as "The Rule of Two." Further, these systems are engineered so that no single mechanical or human error should trigger a disaster. This safety design principle is referred to as the Single-Failure Criterion. (NICU Example: high-risk medications are double-checked by a second caregiver). If one valve fails to seat properly, the second serves as a backup to prevent a failure-to-contain situation (5,6).

"Further, these systems are engineered so that no single mechanical or human error should trigger a disaster. This safety design principle is referred to as the Single-Failure Criterion. (NICU Example: high-risk medications are double-checked by a second caregiver). If one valve fails to seat properly, the second serves as a backup to prevent a failure-to-contain situation (5,6)."

These isolation valves would be closed for a variety of situations: 1. Isolation for Maintenance (The "Scheduled" Stop). The most common Reason was to "lock out" a section of the pressurized system so engineers could safely perform repairs without risking high-pressure steam or radioactive coolant from escaping. 2. Emergency Containment (The "Crisis" Stop) If a leak or a pressure spike were detected downstream, the isolation valve had to be closed to prevent a catastrophic failure of the entire system. 3. System Reconfiguration (The "Change in State") Nuclear plants often shift "modes" (e.g., from full power to low-power cooling) (7). This requires closing certain valves to redirect flow through different heat exchangers.

Standard Work to close an isolation valve (the pair) (8):

Phase I: Preparation

- Verify Identification: Confirm the Valve ID matches the Work Order.
- Review Redundancy: Identify the second valve in series (Rule of Two)
- Assess System State: Confirm line is ready for isolation
- Proactive Risk Assessment: Pause for 2 seconds. "What is my goal?" & "What happens if this valve stays open?"

Phase II: Execution

- Engage Tooling: Secure manual Long-Handle Wrench
- The 20-Turn Rule: Begin rotation in specified direction (clockwise)

- Incremental Verification: Stop and verify every 5 turns to assess for abnormal resistance or binding, and to perform a manual pressure gauge check. *Note: Never apply sudden impact or "kick" to the valve housing.*
- Final Seating: Turn the valve until it meets "firm resistance."
- Half-Turn Back: Back the valve off one quarter turn to prevent thermal locking, and then re-seat gently

Verification:

- Analog Confirmation: Check the downstream pressure gauge; confirm trending decrease to zero.
- Zero Energy Verification: Confirm no leakage is audible or visible
- Dual Barrier Check: Repeat Phase I and Phase II for the second valve in the series
- Lockout/Tag-out: Apply physical locks and tags to the valve handle to prevent accidental re-opening

In early 1973, at the height of the global energy and oil crisis, the Risø staff was under tremendous pressure to keep the 10-Megawatt DR-3 operational (9). A standard maintenance request was submitted. A section of the high-pressure system required repair, requiring the operator to lock out the line as prescribed in the standard work detailed above. Following the rule of two, the operator was required to close two isolation valves in series. The operator assigned to this task had been trained on the standard work and had completed the standard work of closing the isolation valve series hundreds of times. As the operator approached the first valve, he did not reach for the long-handle wrench to begin the tedious task of 20 rotations. Instead, he performed the "Valve Kick" shortcut. By applying a sharp, practiced strike to a specific point on the valve housing, he induced a mechanical vibration that allowed the internal spindle to "slip" or jump threads. To his hands, the valve felt "seated" in an instant. He repeated this for the second valve. Unfortunately, the valve's internal gear did not just slip; it sheared off entirely. Feeling the valve spin freely and then stop, the operator concluded it was a successful closure and skipped the analog pressure gauge assessment to verify that downstream pressure was dropping. Later that day, the maintenance team opened the line downstream, expecting a "dead" pipe. Instead, they were met with a violent high-pressure steam release. The containment boundary had been breached (4).

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Why did this happen?

Jens Rasmussen, an Electronic Engineer, was assigned to DR-3 as the head of the Cognitive Systems Engineering group. Unlike other safety engineers at Risø, Rasmussen was a pioneer in a brand-new field seeking to understand how the human mind interacts with complex, high-technology systems (9). His Electronic Engineering background shaped his approach, viewing the human mind as a complex information-processing component within a larger technical system. Rasmussen designed instrumentation and control systems for the emerging Danish nuclear industry, including many of the systems present in DR-3. Given his understanding of the hardware of DR-3, he was uniquely qualified to assess how the human mind worked, or did not work, with this hardware. Rasmussen is seen as the founder of Cognitive Systems Engineering, moving beyond the view that the operator can make a mistake to mapping the functional architecture of the human mind that led to that mistake (10, 11). When the valve failure occurred in 1973, Rasmussen did not approach the investigation seeking to blame and shame; instead, he treated the incident as a "system stress test" that had finally reached its breaking point (12). By interviewing the operator and reconstructing the event, he discovered that the "valve kick" was not an act of negligence, but a sophisticated, albeit unauthorized, Skill-based adaptation. He realized that the operator had developed a mental model in which the physical "thud" of the kick provided immediate, satisfying feedback, compared to the tedious, Rule-based process of turning a wrench 20 times with intercurrent pressure gauge checks. For Rasmussen, the sheared gear was the physical proof of a "latent defect," a term James Reason would later adopt. The system's demand for thoroughness had been systematically defeated by the human brain›s biological drive for efficiency. This investigation allowed Rasmussen to map the Efficiency-Thoroughness Trade-Off (ETTO), revealing that the operator had been operating in a "shadow system" for years (13) (Figure 1). He saw that the "lethal brew" of the 1973 oil crisis had increased pressure to keep reactors online, effectively shrinking the safety boundary until the expert's shortcut finally crossed it.

Rasmussen›s engineering mind saw the sheared valve as a "functional mismatch": the human mind had optimized the task for speed, but the valve was not designed to withstand the intermittent shocks of the kick. This realization shifted the entire focus of safety at Risø from blaming the person to redesigning the system to make these invisible boundaries visible before the "garnish" of human error could ever be added. Drawing on these observations, Rasmussen formalized his Skill-Rule-Knowledge (SRK) Taxonomy, a cognitive ladder that maps how humans process information based on their level of familiarity with a task (14, 15). He argued that most expert performance, such as the rhythmic "valve kick" at DR-3, occurs at the **Skill-based level (Failure Rate: 1:1000)**. Similar to being on Autopilot, this level is characterized by fast and effortless execution and governed by unconscious sensory-motor patterns that allow experts to perform complex movements while their conscious minds are elsewhere. While highly efficient, this level is dangerously vulnerable to slips and lapses, which are execution errors in which the hand does something the brain never intended. When a routine is interrupted, or a familiar signal is detected, the brain shifts to **Rule-based performance (Failure rate 1:100)**. Here, the operator functions through "if-then" logic, matching the current situation to a stored mental rule, a written protocol, or a heuristic. Basically, the brain leverages mental shortcuts to make rapid decisions based on past patterns or experiences (16). It is a middle ground of conscious effort; however, it is susceptible to misapplication, where a person follows the "right" rule or heuristic for the "wrong" situation. Because heuristics rely on "rules of thumb" rather than analysis of the current data, they can lead the expert to ignore unique nuances

in favor of what usually works, turning a helpful cognitive shortcut into a latent trap. Only when faced with unique, high-stakes, or complex problems does the operator reach Knowledge-based performance (Failure Rate 1:2 - 1:10). This level is characterized by the brain encountering novel situations and inputs that require extensive mental analysis and the synthesis of a plan of action from scratch. This level is mentally exhausting, with the individual prone to cognitive overload, where the sheer volume of incoming data overwhelms the human's brain, leading to biased decisions or total cognitive paralysis, the very state that turns a high-pressure shift into a "lethal brew."

This structural mapping of human fallibility caught the attention of British psychologist Dr. James Reason, who saw in Rasmussen›s engineering models the missing link for his own theories on organizational accidents and harm (16). The collaboration between Jens Rasmussen and James Reason in the late 1980s was a watershed moment that effectively bridged the gap between individual cognitive psychology and organizational systems engineering (17). Up to this point, safety was often viewed through a binary lens: either the machine failed or, more likely, the human failed. Together, they argued that failure is a shared, and often, cumulative process. Rasmussen provided a granular understanding of how humans process information and detailed how the brain drifts between Skill, Rule, and Knowledge states, while Reason developed the **"Swiss Cheese Model"** (Figure 2) to show how those cognitive levels interact with systemic

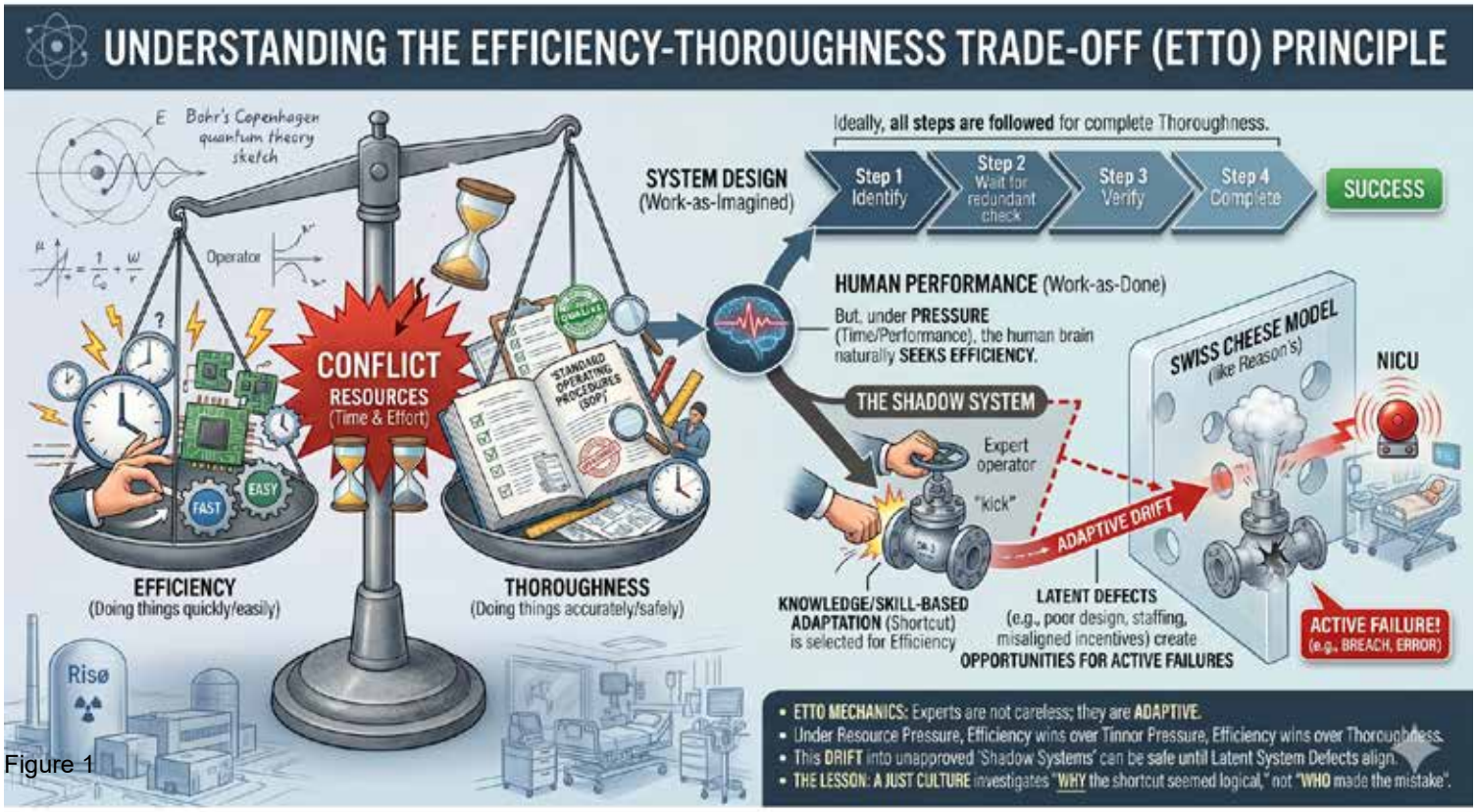

Figure 1

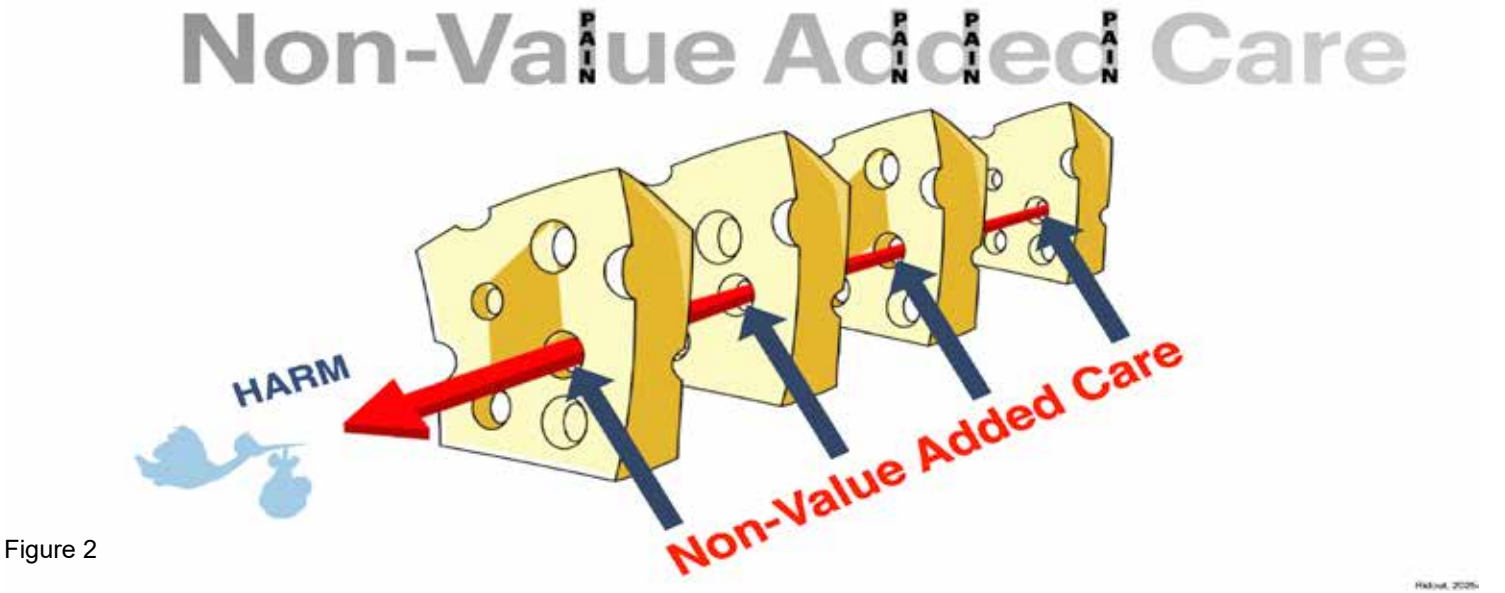

Figure 2

layers of defense. Reason›s brilliance lay in taking Rasmussen›s "Skill-based" observations—the unconscious slips and expert shortcuts—and placing them within a larger organizational architecture. He realized that the "valve kick" at DR-3 was not just a failure of a single operator's motor control; it was an "active failure" that occurred only because the system's latent conditions enabled it. These latent conditions are the dormant defects in the system—management pressures, inadequate equipment design, or understaffing—that act as the "holes" in the layers of defense. Together, they transformed the anecdotal "lethal brew" of the 1973 DR-3 incident into a standardized global framework for safety science (18). Rasmussen had identified that the expert operator was a "system component" naturally seeking the Efficiency-Thoroughness Trade-Off (ETTO); Reason took this a step further by arguing that the clinician or operator is rarely the main instigator of an accident. Instead, they are the "inheritors of system defects"—the people standing at the "sharp end" who simply add the final "garnish" to a catastrophe that has been "long in the cooking." (14)

"This synthesis fundamentally shifted the focus of modern safety from the individual to the organization, marking the transition from a "Blame Culture" to a "Just Culture." It moved the conversation away from the narrow, punitive question of "Who kicked the valve?" and toward the systemic inquiry of "Why did the system make the kick seem like a most logical and efficient path?""

This synthesis fundamentally shifted the focus of modern safety from the individual to the organization, marking the transition from a "Blame Culture" to a "Just Culture." It moved the conversation away from the narrow, punitive question of "Who kicked the valve?" and toward the systemic inquiry of "Why did the system make the kick seem like a most logical and efficient path?" By integrating Rasmussen›s cognitive taxonomies—which explain the internal workings of the human mind—into Reason›s organizational models, which map the physical layout and organization of the environment, they provided a way to visualize the "invisible boundaries" of safety (18).

Rasmussen›s work at DR-3 showed that experts do not fail because they are careless; they fail because they are adaptive (19). They naturally drift toward the Efficiency-Thoroughness Trade-Off (ETTO), seeking the path of least resistance to manage an overwhelming workload. Reason›s "Swiss Cheese" framework then revealed that this drift is often encouraged by latent defects: poor Electronic Medical Record design, inadequate staffing, or misaligned incentives (Motivation 2.0). When these systemic holes align, the expert's adaptive "shortcut" ceases to be a mark of efficiency and becomes an active failure (16).

This framework has important implications for those receiving and delivering care in the Newborn Intensive Care Unit. Patients and caregivers experiencing care delivery that fails to add value are, essentially, experiencing the garnish being added to the lethal brew that has long been cooking. The lethal brew in a NICU may include: the culture, how we communicate, level of psychological safety, poor EMR design, medical supply shortages or changes, or care practice inertia (I call this TWIT: The Way I Trained), where patients continue to experience care regardless of demonstrated benefit because "we have always checked XYZ lab on Monday"). In the next column, I will expound on Reason and Rasmussen's work as it pertains to care delivery in the NICU. My Why: I have a passionate belief that patients and caregivers deserve to experience care delivery free from care that will fail to add value… from care that is not in the service of the newborn brain…from care delivery experiences that will impair our ability to send everyone home safe, valued, and loved.

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Erick Ridout, M.D., is blessed to be a husband, the dad to two amazing kids, granddaddy to three extraordinary grandsons and two granddaughters, and currently serves the babies, their families, and the caregivers in the Newborn ICU in Southwestern Utah, the Newborn ICU in Honolulu, Hawaii, and as Vermont Oxford Network Faculty. Additionally, Colonel Ridout proudly served in the United States Army for 23 years, including 11 years as the State Surgeon for the Nevada Army National Guard. He was among the first Army Medical Corps Officers to become a Lean Six Sigma Green Belt and has applied the learned principles to relentlessly eliminate patient, staff, and organizational harm in all its forms. He has lectured nationwide on Just Culture, Harm Reduction, Value-Added Care, and Servant Leadership. He passionately believes that all patients and caregivers deserve to experience care delivery free of harm. To that end, he seeks to influence MEDICINE to embrace the principles of servant leadership and team-based family-centered care, to send all members of the care team home each day feeling Safe, Valued, and Loved, returning to the bedside fully engaged with heart and mind, all the while seeking to only do for the patient and never to the patient.
"Rather than being the main instigators of an accident, operators tend to be the inheritors of system defects created by designers, builders, paymasters, and managers. Their part is that of adding the final garnish to a lethal brew whose ingredients have already been long in the cooking." Dr. James Reason (1)

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The Village Son

A Life's Journey

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

Houchang D. Modanlou

First Candle: How Healthcare Professionals Can Talk About Infant Suffocation Risk

Alison Jacobson

first candle

Saving babies. Supporting families.

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

"Every year, there are babies who will die in their sleep, devastating families who are left to cope with their grief and to wonder why. While some of these deaths will always remain unexplained, others may be averted through prevention, giving hope to families and to the healthcare providers who work with them during their pregnancy, postpartum, and infancy journeys."

Every year, there are babies who will die in their sleep, devastating families who are left to cope with their grief and to wonder why. While some of these deaths will always remain unexplained, others may be averted through prevention, giving hope to families and to the healthcare providers who work with them during their pregnancy, postpartum, and infancy journeys.

In the United States, 3,700 infants die each year from Sudden Unexplained Infant Death (SUID), a term that covers Sudden Infant Death Syndrome (SIDS), Unknown Causes, and Accidental Suffocation and Strangulation in Bed (ASSB), which accounts for roughly one-third of SUID deaths. Unintentional suffocation is also the leading cause of accidental injury death among infants less than a year old, with 82% of those linked to unsafe sleep environments.

"Unintentional suffocation is also the leading cause of accidental injury death among infants less than a year old, with 82% of those linked to unsafe sleep environments."

What Makes Accidental Suffocation Prevention a Reason for Hope:

The causes of SIDS are still largely unknown, but accidental suffocation has identifiable risk factors, which means it can be prevented.

The American Academy of Pediatrics (AAP), whose evidence-based recommendations are the backbone of infant safe sleep practices, has sharpened its focus on prevention, helping pediatricians work with families to remove the risks by taking these preventive steps:

- Always place babies on their backs to sleep, on a firm, flat sleep surface
- Give babies their own sleep space – crib, bassinet, or play yard – close to a caregiver's bed
- Keep the sleep area totally free of soft objects such as pillows, blankets, loose bedding, and crib bumpers
- Avoid bed-sharing and sleeping on sofas, recliners, or armchairs

This targets suffocation prevention with clear, practical steps, but we know meaningful behavior change rarely results from a single conversation or from a single source, and families are more likely to adopt safe sleep practices when they hear consistent, constructive messages from trusted sources over time.

Messaging Throughout the Continuum of Care

This reality, and the fact that families move through perinatal care

in different ways depending on their circumstances, mean that consistent suffocation prevention messaging must come from a range of providers, increasing the chances that a family will be reached.

While First Candle's Let's Talk Community Chats and NICU Chats programs provide a safe space for families to discuss infant suffocation prevention, breastfeeding, and maternal wellbeing, they also serve to connect with providers throughout the continuum, providing practical trauma-informed training for the individuals and organizations families work with, including:

- OB/GYN providers and midwives
- NICU and postpartum nurses
- Pediatric practices
- WIC staff
- Doulas and community health workers
- Home visitors
- Early childhood programs
- Faith and community partners

This leads to effective messaging – both in content and how it is delivered.

"Listening, Not Lecturing"

Research, including our own qualitative studies, has shown that families being told about AAP safe sleep guidelines do not necessarily adopt them. For some, it is one-way messaging that does not take into account their realities of daily living, especially among populations at higher risk. For others, it is weighing what is being presented against cultural beliefs and family traditions.

We know first-hand that healthcare professionals have constraints on their time and resources, and our support to our colleagues extends to sharing approaches that can be effective in helping families consider prevention strategies:

- Leading with listening and respect, acknowledging that lived experiences and social determinants of health contribute to sleep-related infant deaths.
- Acknowledging that safe sleep is one aspect of family practices and must be addressed alongside other challenges.
- Sharing guidance in ways that meet families where they are
- Pairing prevention with trust, rather than judgment

Moreover, interpersonal communication itself fosters behavior change; a shared dialogue may create more trust and receptivity than distributing pamphlets. A systemic problem requires systemic solutions.

Focusing on infant suffocation prevention is a concrete step toward reducing infant deaths and giving families the tools and perspective they need and the support they deserve.

"Moreover, interpersonal communication itself fosters behavior change; a shared dialogue may create more trust and receptivity than distributing pamphlets. A systemic problem requires systemic solutions."

We are all part of the continuum of care, and we can all help save babies.

Disclosure: *The author is the Executive Director and Chief Executive Officer of First Candle, a Connecticut-based not-for-profit 501(c3) corporation.*

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Corresponding Author

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www.firstcandle.org

About First Candle:

First Candle, based in New Canaan, CT, is a 501c (3) committed to eliminating Sudden Unexpected Infant Death while providing bereavement support for families who have suffered a loss. Sudden Unexpected Infant Death (SUID), which includes SIDS and Accidental Suffocation and Strangulation in Bed (ASSB), remains the leading cause of death for babies one month to one year of age, resulting in 3,700 infant deaths nationwide per year. It was also the host of the 2025 International Society for the Study and Prevention of Perinatal and Infant Death (ISPID) Conference in Houston from October 7 – 10.

firstcandle

LET'S TALK Community Chats IN THE NICU

We are thrilled to expand our ongoing efforts surrounding safe sleep in the Grady Memorial Hospital NICU by bringing Let's Talk Community Chats to our families. This is especially important given the significantly higher rates of Sudden Unexpected Infant Death in premature babies, and to help expand our work to ensure optimal health to all babies, both in the NICU and after discharge home."

Dr. Mattie Feasel Wolf,
Division of Neonatal-Perinatal Medicine
at Emory University School of Medicine

FEEDBACK FROM LET'S TALK COMMUNITY CHATS IN THE NICU:

- **Nearly all participants (98%) reported an increase in their confidence to apply safe sleep practices, and all also found the breastfeeding information provided to be helpful or very helpful (96%).**
- **Additionally, most participant (98%) felt that the products and recommendations shared were relevant to their needs.**
- **94% percent of respondents reported having a plan for where they would place their baby to sleep upon bringing them home after attending the event.**
- **All participants (100%) shared that they felt comfortable and supported, and that facilitators respected their cultural values.**
- **Almost all participants (82%) who had specific questions indicated that their specific questions and concerns were fully addressed.**

LEARN HOW YOU CAN BRING LET'S TALK TO YOUR NICU.

Email alison@firstcandle.org or scan the QR code for more information

Advancing Neonatal-Perinatal Care: SONPM Chair Update: May 2026 #2

Clara H. Song, MD, FAAP

"Your more-than-monthly update from SONPM to keep us all connected and informed!"

For SONPM Listserv distribution:

*Your **SONPM** more-than-monthly update to keep us all in the loop!*

*More details on upcoming events, webinars and due date details on the #AAPneonatal **Calendar***

*Peruse **the #AAPneo photo gallery** for SONPM event highlights **(Password: SONPMc3 to download pics)***

Social Media links on

#BabiesNeedScience aapneonatal.org	

Happy May!! 🌸🌼💗🦋

1- SONPM Member Shout-out 😎: A million thanks to Dr. **Misty Good**, who completes her term as SONPM Fellow Research Conference Chair. Dr. Good is the current District 4 Rep on the SONPM Executive Committee as well as the new co-Chair of AANDD, Association of Academic Neonatal Division Directors. Dr. Good hands off her responsibilities as Fellow Research Conference Chair to Dr. **Jennifer Wambach**. In this episode of "At the Bench from the Incubator Podcast", Dr. Good interviews fellow scientist Dr. Wambach.

At the Bench I Genetics and Neonatal Lung Disease: A Conversation with Dr. Jennifer Wambach

2- **Webinar on DRGs to Optimize Hospital Payments**: Featuring Children's Hospital Association (**CHA**) Leaders on **May 27**, 2026

"***Severity Happens: Decoding APR-DRG Assignment, SOI, ROM, and CMI for the NICU"***

Date and time:

Wednesday, May 27, 2026 **2:00 PM | (UTC-05:00) Central Time** (US & Canada)

Register link:

https://aap.webex.com/weblink/register/re0b17ae03f8af-8d1a57c3812036d5806

3- **AAP SONPM at the 2026 NCE in San Diego, CA, Oct 2-4, 2026**: POCUS Focus!

SONPM program at NCE in San Diego this year will focus on POCUS and includes a joint session with Section on Radiology.

Day 2 of the SONPM program concludes with the annual awards ceremony, which will honor these 2026 Awardees:

Virginia Apgar Award: Dr. **Seetha Sankaran, first ever PI for RCT on whole body hypothermia for neonatal HIE**

Avroy Fanaroff Education Award: Dr. **Gary Weiner, longtime Textbook of NRP editor**

Maria Delivoria-Papadopoulos Landmark Award: Drs. **Judy**

Aschner and **Linda Van Marter, founding mentors for AAP SONPM TECaN**

Pioneer Award: Dr. **Ronald Cohen, trailblazer in donor milk banking**

4- **SONPM is offering two (2) one-year Chapter Grants:** Applications due **June 30**, 2026

For the 1st time ever, SONPM will offer Chapter Grants for development and integration of a comprehensive toolkit focused on advocacy, education and optimization of neonatal payment and coding practices within Chapter activities.

Join your Chapters to promote the SONPM payment agenda. Fair payment helps ALL of pediatrics!

https://www.surveymonkey.com/r/Z6TPK5R

5- ICYMI: Amicus Brief from AAP: ***"Preterm Infant Formula Is A Critical And Essential Component Of Preterm Infant Care."***

6- **Coding Corner #10: Newborn Care--**Submitted by **David Kanter**, MD, MBA, CPC (david.kanter@pediatrix.com) on behalf of the SONPM Coding Committee.

Presentation: a physician assesses an asymptomatic, normal-appearing term baby born to a mother who was treated appropriately and early in pregnancy for serologically positive syphilis. Upon delivery, mother's RPR titer has decreased to 1:8 while the baby's titer is 1:16. The physician allows the baby to room-in with mother in a well-baby setting after performing a lumbar puncture, obtaining CBC/diff with platelets, evaluating long bone x-rays, and administering one IM dose of Benzathine Penicillin G. Assuming the baby remains asymptomatic with normal studies, how would the physician code services for initial as well as subsequent days?

Coding for this baby:

	CPT	Service	ICD-10
Initial day	99222	Initial Hospital Care-Moderate Decision-Making	P00.2 Newborn affected by maternal infectious and parasitic diseases
	62270	Diagnostic lumbar puncture	
Subsequent day	99462	Subsequent day normal newborn care	Z38.00 Single liveborn infant, delivered vaginally

Background: daily CPT coding in the well-baby setting primarily focuses on whether to bill normal newborn codes or to escalate to Hospital Care codes. In addition to the maternal/fetal history and newborn exam, normal newborn codes include routine diagnostic testing in a baby who otherwise appears normal and is not requiring significant additional treatment. Escalating to Hospital Care codes is appropriate with initiation of significant treatment or increased complexity of decision-making as seen with this baby. Of the three possible Initial Hospital Care codes (99221, 99222, 99223), this baby warranted CPT 99222 reflective of moderate decision-making supported by moderate assessment of data and moderate risk of treatment (prescriptive drug therapy). In contrast to the procedural bundling inherent in daily neonatal Intensive and Critical care codes, the diagnostic lumbar puncture is separately billable with both normal newborn or Hospital Care codes. For the subsequent day of care, since the baby no longer received escalated treatment or decision-making complexity, the 99462 subsequent day normal newborn code would be most appropriate. Other clinical examples that could warrant Hospital Care coding in a well-baby nursery setting include management of phototherapy, withdrawal not requiring intensive monitoring, and hypoglycemia requiring recurring physician engagement.

"Other clinical examples that could warrant Hospital Care coding in a well-baby nursery setting include management of phototherapy, withdrawal not requiring intensive monitoring, and hypoglycemia requiring recurring physician engagement. "

Our current SONPM focus goal of Payment Parity for 2024-2026 aligns with the AAP Payment Transformation Agenda.

Action plans for NICU-specific payment advocacy:

1- Payer data transparency =

From SONPM with support from AAP: **Payment Transparency for Neonatal Codes**

https://pediatricsupport.com/analysis-of-codes-affecting-neonatology

SONPM and AAP have partnered to aggregate negotiated payment information from 4 common commercial payers for 65 neonatal codes.

This data will serve our members in advocacy efforts and negotiations for optimal and fair payment. https://pediatricsupport.com/analysis-of-codes-affecting-neonatology

SONPM will offer two (2) Chapter Grants to support the development of a Neo-focused payment advocacy and/or educational toolkit

2- Coding Education to ensure full payment =

Coding Corner: Submitted by Dr. **David Kanter**, MD, MBA, CPC (david.kanter@pediatrix.com) on behalf of the SONPM Coding Committee.

Congratulations our 2 SONPM AMA RUC/CPT Coding Scholars: Drs. **Anisha Bhatia** and **Deirdre O' Reilly**

3- DRG payments for optimal NICU payment=

Upcoming webinar in partnership with Children's Hospital Association **May 27, 2026**

****Fair payment → improved salary:FTE ratio → improved staffing → decreased burnout → increased workforce →***

maintain health of our profession*

"Ultimately, payor reform will be needed to sustain growth in subspecialty compensation."

- Robin Steinhorn & Satyan Lakshminrusimha.

On behalf of your #SONPMexec comm:

Past Chair Munish Gupta @munishguptamd

Chair Elect Alexis Davis @AlexisDNeoMD

District 1 Rep Wendy Timpson @TimpsonWendy

D2 Shetal Shah @NICUBatman

D3 Sara DeMauro

D4 Misty Good @mistygoodlab

D5 Heather Kaplan

D6 Emily Fishman

D7 John Loyd

D8 Jessica Davidson @JessDavMD

D9 Christine Bixby

D10 Ravi Patel @ravimpatelmd

Of Counsel Marilyn Escobedo @Mokcita

AAP Sr Manager Joie Frankovich

Chair Clara Song @songMD

Clara H. Song, MD, FAAP

Neonatal Intensivist | Southern California Permanente Medical Group

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Disclosures: No conflicts noted

NT

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Chair Elect, Communication & Digital Media Chair; Women In Neonatology Steering Committee, All Pathways group Co-Chair: District IX California Chapter 4 Council Representative,
Chair, American Academy of Pediatrics, Section on Neonatal-Perinatal Medicine
Lean Six Sigma Black Belt
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Request for Proposals (RFP)
AAP Chapter Grants to Advance the SONPM Fair Payment Agenda 2026–2027
Sponsored by: AAP Section of Neonatal-Perinatal Medicine (SONPM)
Application Deadline: June 30, 2026
Grant Period: September 1, 2026 – August 31, 2027

I. **Background and Purpose**
The AAP Section of Neonatal-Perinatal Medicine (SONPM) invites AAP Chapters to submit proposals that directly advance the SONPM Fair Payment Agenda. This agenda was established in response to growing concerns regarding the sustainability of neonatal practice, increasing workforce shortages, and persistent misalignment between the complexity of neonatal care and current payment structures.
Grant funding will support the development and implementation of practical, scalable tools that strengthen neonatal payment advocacy, improve coding accuracy, and promote optimized hospital and professional payments. Funded activities should empower neonatologists, neonatal advanced practice providers, trainees, and Chapter leaders with the knowledge and resources necessary to advocate effectively for fair, transparent, and sustainable payment models.

II. **Alignment with the SONPM Fair Payment Agenda**
Proposals must demonstrate clear alignment with one or more of the SONPM Fair Payment Agenda pillars:

- Payment Advocacy: Strengthening Chapter-level and clinician advocacy efforts related to neonatal payment policy, payer practices, and regulatory frameworks
- Coding Education: Improving knowledge and application of neonatal CPT, ICD-10, and documentation requirements to ensure accurate representation of care complexity
- Optimized Hospital and Professional Payments: Promoting strategies that align neonatal reimbursement with acuity, resource utilization, and quality of care delivered

III. **Funding Opportunity**
SONPM will award up to TWO (2) one-year grants of up to $6,000 each. Proposals should focus on high-impact, replicable initiatives that may be adapted by other Chapters or scaled nationally to support the Fair Payment Agenda.

IV. Priority and Eligible Activities

- Development of a neonatal payment and coding advocacy toolkit aligned with SONPM Fair Payment Agenda priorities
- Creation or expansion of Chapter-based neonatal payment, coding, or advocacy subcommittees
- Educational programming addressing neonatal documentation, coding accuracy, and payment optimization
- Workshops or webinars focused on advocacy skills related to payer negotiations, hospital alignment, or legislative issues
- Needs assessments evaluating payment and coding challenges impacting neonatal workforce sustainability
- Engagement of pediatric trainees and early career neonatologists in payment and advocacy
- education
- Collaboration with hospital administrators, coders, and revenue cycle leaders to promote
- shared understanding

V. **Allowable and Non-Allowable Expenses**
Grant funds may not be used to:

- Fund social activities outside of educational programming
- Raise general Chapter funds
- Offset expenses for activities or meetings that have already occurred

Funding limits for educational activities include:

- Speaker honoraria: maximum $2,000 per speaker
- Speaker travel expenses: maximum $700 per speaker
- Space rental: not to exceed $500 per day
- Audio-visual support: not to exceed $500 per day
- Marketing and distribution: not to exceed $5 per attendee
- Food and beverage (no alcohol): not to exceed 20% of total budget

VI**. Proposal Review and Selection Criteria**

The SONPM Executive Committee will evaluate proposals based on:

- alignment with the SONPM Fair Payment Agenda;
- potential to improve neonatal practice sustainability;
- feasibility and clarity of proposed activities;
- engagement of trainees and early career physicians; and
- consistency between the proposed activities and submitted budget.

VII. Reporting and Acknowledgment Requirements

Awardees must acknowledge the AAP Section of Neonatal-Perinatal Medicine on all materials produced. Grantees are required to submit a mid-point progress report and a final report within 30 days of the grant's conclusion. Reports must summarize activities implemented, budget expenditures, outcomes or evaluation data when available, Fair Payment Agenda pillars addressed, trainee engagement, and lessons learned. A short article highlighting the project's impact on neonatal payment advocacy is required for SONPM or Chapter communications.

VIII. Technical Assistance and Support

Each grantee will be paired with a SONPM member to provide strategic guidance related to neonatal payment advocacy and coding education. SONPM staff will also be available to provide administrative and logistical support throughout the grant period.

Submit applications to Laura Navarro at lnavarro@aap.org by **June 30, 2026**.

Federation of Pediatric Organizations
Executive Office: 6728 Old McLean Village Drive, McLean, VA 22101

Call for Nominations for the 2026 Joseph W. St. Geme, Jr. Leadership Award

The death of Joseph W. St. Geme, Jr., MD, in 1986, removed from American pediatrics a leader with vision and selfless dedication to the ideal of excellence. His concern for the patient and the future of health care was well known. Certainly, he was a leader in the forums addressing issues concerning the future of pediatric education and research. It seemed appropriate, therefore, to honor his memory in a manner that would remind present and future generations of pediatricians that one individual can make a difference, and all should try, when the health care of children is at stake.

The member societies of the Federation of Pediatric Organizations established an endowment fund for what is now the Joseph W. St. Geme, Jr. Leadership Award. Dr. St. Geme's stature in pediatrics was reflected by his meaningful participation in all facets of pediatrics as demonstrated by the sponsorship of this award by these societies:

Academic Pediatric Association
American Academy of Pediatrics
American Board of Pediatrics
American Pediatric Society
Association of Medical School Pediatric Department Chairs
Association of Pediatric Program Directors
Society for Pediatric Research

This award was established as an effort on the part of these organizations to honor the life, work, and memory of Joe St. Geme and to memorialize his many contributions to and his aspirations for pediatrics. Many of Dr. St. Geme's friends and colleagues have contributed to this award as well as major contributions from Ross Laboratories, Hoechst Roussel Pharmaceuticals, Inc., Connaught Laboratories, Inc., Merck & Company, Inc., and Mead Johnson Nutrition.

Criteria for Selection

1. The individual must be a pediatrician who is perceived as a role model for others to emulate, as a clinician, an educator, and/or an investigator.

2. The individual must be a leader who has "created a future" for pediatrics and for children and has played an active role in one or more organizations sponsoring this award.

3. The individual should preferably have a record of broad sustained contributions to pediatrics that have had or will have a major impact on child health.

4. The individual must be currently active in pediatrics. **what defines "active" is at the discretion of each of the 7 organizations.*

5. The individual can be a retired member of any of the pediatric organizations sponsoring this award.

6. The individual must **not** be an active FOPO Board member.

Call for Nominations!

Section on Neonatal-Perinatal Medicine Executive Committee: District Representatives from Districts III, VI, and IX

One of the most significant opportunities to engage with the Section on Neonatal-Perinatal Medicine (SONPM) is to serve on the SONPM Executive Committee (EC). The EC consists of one representative from each of the 10 AAP Districts, in addition to chair, chair-elect, past-chair, of-counsel advisor, and AAP section manager (currently Jim Couto). District representatives serve 3-year terms, and are eligible to serve a second term.

District representatives to the EC are responsible for representing all neonatologists working in their AAP districts. The district representative is a liaison between district neonatologists and the SONPM, providing members direct input into SONPM and conveying section activities and opportunities back to the members. More specifically, responsibilities of EC members include the following:

Within executive committee and SONPM broadly:

1. Attend two **required** EC meetings annually, at Scottsdale spring workshop and at NCE;
2. Attend the full SONPM program at Scottsdale spring workshop and NCE meetings annually;
3. Participate in periodic virtual SONPM EC meetings (generally once or twice per month);
4. Review and score abstract submissions to NCE and review poster and oral presentations at NCE meeting, including scoring for SONPM Young Investigator Award;
5. Suggest and select annual SONPM honorary lecturers, including the Cone, Merenstein, Butterfield and Silverman speakers;
6. Solicit and review nominations for annual SONPM awards, including the Apgar, Education, Landmark and Pioneer awards, and select awardees;
7. Participate in planning and execution of national meetings, including section program at NCE, Scottsdale conference, and NeoPREP;
8. Review applications and determine awardees for the Section Strategic Grant Program, currently offered every two years;
9. Review and provide feedback on AAP policy statements, clinical reports, and guidelines as they pertain to newborn care;
10. Participate in and support AAP and SONPM advocacy efforts, including AAP Days of Action;
11. Participate in section committees, groups, and task forces based on interest and need;
12. Participate in SONPM strategic leadership, including implementation of goals of strategic plan; and
13. Participate in SONPM administration, including maintenance and updating of section manual of operations and section budget planning.

Within district:

1. Solicit updates from district members for inclusion in section newsletter twice annually;
2. Allocate annual SONPM district grants by soliciting and evaluating grant proposals;
3. Provide regular updates to district members on relevant aspects of section activities;
4. Provide regular updates to section on district activities and needs of district members;
5. Actively participate in district activities, including attendance at regional conferences; and
6. Encourage AAP and SONPM membership from representative's district, including trainees.

The core executive committee is a productive group! Participation on the executive committee does require a commitment of time and effort, but it is a highly rewarding experience.

SONPM Fellow Education co-Chairs – for Research & Career Conferences

We are in search of a Fellows Research Conference co-Chair!
The SONPM Fellow Education co-Chairs provide primary oversight for the SONPM fellow research and career education conferences. These conferences have been a foundation of SONPM and the neonatology community for decades, and have helped shape careers and collaborations for thousands of neonatal intensivists. They continue to be a highlight of annual SONPM activities. The conferences include the research-focused Perinatal and Developmental Medicine Symposia (three per year, supported by Reckitt/Mead Johnson) and the career-focused Seminars on Neonatal-Perinatal Medicine (two per year, supported by Abbott).

The Fellow Education co-Chairs represent the SONPM at these conferences by providing overall strategic planning, adjusting content and format, and introducing innovations based on fellow feedback and SONPM priorities. Each conference is organized by a planning committee with defined membership and terms; the Fellow Education co-Chairs solicit and select new members of these committees, ensuring appropriate diversity and expertise, and provide support for the planning committees throughout the year. The Fellow Education co-Chairs should be vocal champions for the conferences, leading efforts that align with SONPM, ONTPD, and TECaN to ensure all fellows seek the opportunity for participation.

The Fellow Education co-Chairs serve as liaisons to the SONPM executive committee and other external organizations, and are expected to attend the annual SONPM executive meeting each spring.

The Fellow Education co-Chairs should be familiar with both the research and career conferences, and should have served on the planning committee or faculty for at least one of the respective conferences. The Fellow Education co-Chairs should be an experienced neonatologist with substantial leadership experience, and, for the Research Conference co-Chair, should have an accomplished publication record. To facilitate identification of program committee members and conference faculty, the Fellow Education co-Chair should have a national reputation.

Apply via JotForm. For questions: lnavarro@aap.org or clarasong@me.com

2026.02.05

Letters to the Editor

Letter to the Editor: Infant Feeding Decisions and Family Centered Care in the NICU

To the Editor,

I am writing in response to the recent article, "The Sordid Recent History of Botulism Contamination of ByHeart Formula: Another Reason to Promote Breastfeeding," and the subsequent letter and editorial response. The correspondence addressed medical reasons why some people do not breastfeed despite wanting to do so. While I appreciate this effort to add nuance to discussions of infant feeding, I believe this framing still misses an important point. Sometimes the decision not to breastfeed is not driven by a medical contraindication, but is instead an informed decision made by parents about what is right for themselves and their families. That decision is also valid.

"The correspondence addressed medical reasons why some people do not breastfeed despite wanting to do so. While I appreciate this effort to add nuance to discussions of infant feeding, I believe this framing still misses an important point. Sometimes the decision not to breastfeed is not driven by a medical contraindication, but is instead an informed decision made by parents about what is right for themselves and their families. That decision is also valid."

Much of the breastfeeding discussions in neonatal settings focus almost exclusively on infant benefit while overlooking the fact that the breastfeeding person is also a person, one who is often navigating a complex and vulnerable period. This is especially true for parents of NICUadmitted infants, who face unique stressors and may have experienced a traumatic birth. Parents in this population are already at higher risk for postpartum depression, which is a leading cause of maternal mortality through suicide. In this context, pushing breastfeeding among vulnerable people who are trying to do the best they can for their families, and who may have made an informed decision that breastfeeding is not right for them, risks causing harm.

In addition to being a perinatal epidemiologist, I am the mother of a child with hypoxicischemic encephalopathy who required NICU care. I am glad that I was able to provide expressed breastmilk for six months, but providing breastmilk was an extreme stressor. I worked with lactation consultants and feeding therapists in an effort to promote breastfeeding, and I felt a profound sense of obligation to continue. Ultimately, I believe this caused more stress than was worth it for my family, but at the time, I felt that providing breastmilk was necessary in order to be a good mother to my fragile baby.

During this period, I suffered from postpartum depression and experienced tremendous guilt related to infant feeding. Since then, I have spoken with other parents of NICU admitted infants who have shared similar stories of guilt, exhaustion, and distress related to feeding decisions. Ignoring the health and autonomy of mothers and breastfeeding parents in these conversations is not providing family centered care.

"During this period, I suffered from postpartum depression and experienced tremendous guilt related to infant feeding. Since then, I have spoken with other parents of NICU admitted infants who have shared similar stories of guilt, exhaustion, and distress related to feeding decisions. Ignoring the health and autonomy of mothers and breastfeeding parents in these conversations is not providing family centered care."

As discussions about infant feeding continue in this journal, maternal mental health, autonomy, and lived experience should be treated as central considerations, particularly for parents caring for medically fragile infants. Family centered care includes explicit attention to the health and wellbeing of caregivers.

Sincerely,

Amanda Luff, PhD

Senior Epidemiologist, Advocate Aurora Research Institute, Advocate Health

Assistant Professor, Obstetrics and Gynecology, Wake Forest University School of Medicine

Email: amanda.luff@aah.org

Address: Aurora Sinai Medical Center, 945 N 12th St, Milwaukee, WI 53233

The author declares no conflicts of interest.

Dear Dr. Luff:

Your thoughtful letter regarding the stressors encountered by breastfeeding persons who have infants in the NICU is a welcome criticism of NICU staff attempting to coerce mothers who may already be traumatized by their infant's critical illness.

Breastfeeding is a choice, but when possible, a wise one; however, other mitigating conditions must always be considered. Excessive pressure to breastfeed may be stressful and traumatizing. Above all, breastfeeding remains a parent's choice, not a compulsion.

"Your thoughtful letter regarding the stressors encountered by breastfeeding persons who have infants in the NICU is a welcome criticism of NICU staff attempting to coerce mothers who may already be traumatized by their infant's critical illness. Breastfeeding is a choice, but when possible, a wise one; however, other mitigating conditions must always be considered. Excessive pressure to breastfeed may be stressful and traumatizing. Above all, breastfeeding remains a parent's choice, not a compulsion. "

Ongoing communication with caregivers, especially neonatologists, lactation consultants, and neonatal nurses, regarding the profoundness of this stress sufficient to contribute to postpartum depression, as you mentioned, suggests a serious lack of communication between caregivers and the parent or parents. The coercive nature of strongly imposing breastfeeding as a requirement for "good" parenting, contributing to postpartum depression, on top of the breastfeeding person's concern for their infant's recovery from perinatal asphyxia (usually hypoxic-ischemic encephalopathy), as you describe, is counterintuitive. Although many breastfeeding persons seek to provide their breastmilk because of their commitment to enhance their infant's recovery, given the nutritive and immunologic benefits, others may not. This decision should not be an indictment against them. Further, postpartum depression, especially if treated by a mental health provider using some antidepressants, may have contraindications to continued breastfeeding.

"Newer studies have shown that intranasal fresh breast milk (iFBM) is a safe, feasible, and potentially neuroprotective adjunctive therapy for neonates with hypoxic-ischemic encephalopathy (HIE) due to perinatal asphyxia, particularly when paired with therapeutic hypothermia. Studies suggest it may reduce brain injury by leveraging olfactory pathways."

Newer studies have shown that intranasal fresh breast milk (iFBM) is a safe, feasible, and potentially neuroprotective adjunctive therapy for neonates with hypoxic-ischemic encephalopathy (HIE) due to perinatal asphyxia, particularly when paired with therapeutic hypothermia. Studies suggest it may reduce brain injury by leveraging olfactory pathways. No significant adverse effects were reported, even when combined with hypothermia. There was a trend toward reduced injury, with potential benefits for future neonatal neurodevelopmental development. The F-NEO-BRIGHT study from 2026 confirms the potential of this therapy. Further research from PubMed Central discusses the neurotherapeutic potential of this approach. If this treatment was not considered, your infant's health care team should have mentioned the availability of pasteurized donor milk from an HMBANA (Human Milk Banks Association of North America) approved breast milk bank as a substitute for your own milk.

According to the Centers for Disease Control and Prevention (2025, September 23), Breastfeeding and postpartum depression, mothers with postpartum depression can usually continue to breastfeed. Health care providers should work with mothers experiencing postpartum depression to ensure they receive appropriate treatment, support, and safe medications while breastfeeding.

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There is not enough evidence to know if breastfeeding is associated with a higher or lower risk of postpartum depression (following childbirth). According to a 2018 systematic review by the Agency for Healthcare Research and Quality (AHRQ), understanding the relationship is challenging "because women with depression may have difficulty initiating and sustaining breastfeeding, and women who experience breastfeeding difficulties may develop depression" (p. 107).

Antidepressants while breastfeeding. It may be safe to take antidepressant medications while breastfeeding. Although many medications pass into breast milk, most have little or no effect on milk supply or infant well-being. When discussing depression medications, the health care provider needs to ask the mother if she is breastfeeding. Together, they can decide which medications are right for her and safe to use while breastfeeding.

While some mothers experience positive feelings from breastfeeding, others may not. Health care providers can:

- Address mothers' depression promptly and help them reach their breastfeeding goals.

- Talk to mothers about treatment options, including medications and non-pharmacological options, such as individual or group therapy.
- Help mothers access professional breastfeeding support as needed according to the ABM Clinical Protocol #18: Use of Antidepressants in Breastfeeding Mothers—Academy of Breastfeeding Medicine

Neonatology is both a scientific endeavor and practice, but it is also an art, and it is regrettable that, in your case, the art of careful communication was lost.

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Neonatology Today

Sincerely,

T. Allen Merritt, MD, MHA, MBA

Senior Associate Editor

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Letters to the Editor

Letter to the Editor: "Dual Genetic Etiology in a Neonatal Neurodevelopmental Disorder: COL4A1 and ERCC6"

Dear Editor,

We read with great interest the case report describing a female child with a severe neonatal neurodevelopmental disorder caused by a dual genetic etiology involving a de novo pathogenic COL4A1 variant (c.2459G>A, p.Gly820Asp) and biallelic ERCC6 variants consistent with Cockayne syndrome type B. This report makes a valuable contribution to the growing recognition that multilocal genetic diagnoses, now estimated to occur in approximately 3.5% of genetically diagnosed pediatric cases, are clinically significant rather than exceptional.

"This report makes a valuable contribution to the growing recognition that multilocal genetic diagnoses, now estimated to occur in approximately 3.5% of genetically diagnosed pediatric cases, are clinically significant rather than exceptional."

The authors are commended for their systematic diagnostic approach, ultimately revealing the convergence of COL4A1-mediated cerebral small-vessel disease and ERCC6-related neurodegeneration in a single patient. The neuroimaging constellation of periventricular leukomalacia, germinal matrix hemorrhage, and cerebral microhemorrhages is characteristic of COL4A1/A2-related disorders. As the authors rightly emphasize, this should prompt genetic testing even when perinatal risk factors are present.

"Periodic reanalysis of genomic data is now recommended as standard practice in such cases, and functional studies or longitudinal reclassification data would strengthen the causal attribution. Second, the concept of "blended phenotypes" in dual molecular diagnoses deserves emphasis."

We wish to highlight several points for consideration. First, the classification of the two ERCC6 variants as variants of uncertain significance (VUS) warrants careful discussion, as this distinction carries important implications for genetic counseling and recurrence risk assessment. Periodic reanalysis of genomic data is now recommended as standard practice in such cases, and functional studies or longitudinal reclassification data would strengthen the causal attribution. Second, the concept of "blended phenotypes" in dual molecular diagnoses deserves emphasis. Recent analyses have demonstrated that dual diagnoses can range from clearly distinct conditions to nearly indistinguishable phenotypes, with synergistic interactions between conditions. In this case, the convergence of early vascular brain injury and progressive neurodegeneration likely produces a more severe phenotype than either condition alone would predict, with direct implications for prognostication and family counseling.

This case powerfully illustrates a paradigm shift in neonatal neurology: when the severity of neurologic impairment appears disproportionate to perinatal risk factors, clinicians should actively consider genetic mimics and multilocal explanations, pursuing broad genomic testing early in the diagnostic pathway.

We congratulate the authors on this important contribution and look forward to longitudinal follow-up data on this exceptionally rare dual-etiology presentation.

Sincerely,

Mehzabin Lala, MS3

Western University of Health Sciences

Dear Mehzabin Laha, MS3

The letter is thoughtful, scholarly, reflecting a sophisticated understanding of contemporary neonatal neurogenetics and the growing recognition of multilocus genetic disease. The author effectively highlights the clinical importance of considering genetic etiologies when neurologic injury appears disproportionate to apparent perinatal risk factors, and their discussion of blended phenotypes adds meaningful context to the evolving literature on dual molecular diagnoses. The correspondence also appropriately emphasizes the challenges of interpreting variants of uncertain significance and the importance of ongoing genomic reanalysis in complex cases.

"he letter is thoughtful, scholarly, reflecting a sophisticated understanding of contemporary neonatal neurogenetics and the growing recognition of multilocus genetic disease. The author effectively highlights the clinical importance of considering genetic etiologies when neurologic injury appears disproportionate to apparent perinatal risk factors, and their discussion of blended phenotypes adds meaningful context to the evolving literature on dual molecular diagnoses."

That said, the letter would be strengthened by a somewhat tighter editorial focus and a more restrained approach to interpretation. At times, the correspondence functions more as an extended summary and endorsement of the original report than as a distinct critical commentary. Much of the opening discussion reiterates findings already presented by the authors, limiting the opportunity to develop a more pointed scholarly perspective. The most compelling aspect of the letter lies in its discussion of ERCC6 variants and the evidentiary threshold for confidently attributing part of the phenotype to Cockayne syndrome type B. Expanding this discussion with greater specificity would strengthen the scientific contribution of the manuscript.

In addition, some of the language surrounding synergistic interaction between the two conditions risks implying mechanistic conclusions that remain speculative. Statements suggesting that the combined disorders "likely produce" a more severe phenotype than either condition alone may overstate what can reasonably be inferred from a single case report. Framing these observations more cautiously as hypotheses or possible contributory interactions would preserve the scientific rigor of the commentary while still underscoring the importance of considering multilocus disease.

"Overall, this is a strong and constructive letter that raises important issues regarding genomic interpretation, blended phenotypes, and diagnostic reasoning in neonatal neurology. This analytical critique serves as an effective and valuable scholarly correspondence on the implications of situations in which disease variants affect the phenotype."

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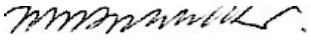
Sincerely,



Mitchell Goldstein, MD, MBA, CML

Editor in Chief

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Erratum (Neonatology Today March, 2026

There are no erratum to report for March, 2026

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

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

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

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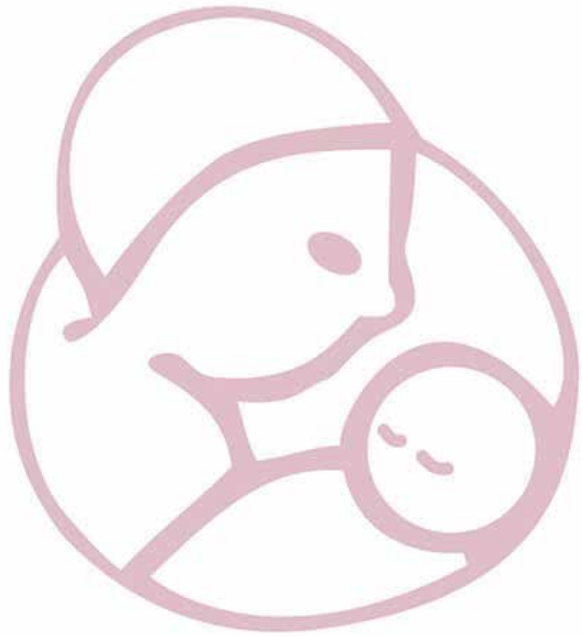

PAC/LAC's core values for improving maternal and child health have remained constant for over 30 years – a promise to lead, advocate and consult with others.

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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.

National Perinatal Association: Care that Carries On: How Aspen's Ascend Fellowship and NPA Are Reimagining NICU Discharge

Vincent C. Smith, MD, MPH, Kristy Love

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.

"On a bright spring morning in April 2026, a circle of leaders, advocates, and learners gathered deep in conversation in Aspen, Colorado. The group was participating in Forum II of the Aspen Institute Ascend Fellowship."

On a bright spring morning in April 2026, a circle of leaders, advocates, and learners gathered deep in conversation in Aspen, Colorado. The group was participating in Forum II of the Aspen Institute Ascend Fellowship. Here, these innovative leaders came together with parent advocates who had lived the long arc of NICU uncertainty, and policy and systems innovators accustomed to thinking in population-level outcomes, to explore a shared question: how do we make sure that the fragile triumph of bringing a baby home from the Neonatal Intensive Care Unit (NICU) is not undermined by confusion, isolation, or missed supports?

"Here, these innovative leaders came together with parent advocates who had lived the long arc of NICU uncertainty, and policy and systems innovators accustomed to thinking in population-level outcomes, to explore a shared question: how do we make sure that the fragile triumph of bringing a baby home from the Neonatal Intensive Care Unit (NICU) is not undermined by confusion, isolation, or missed supports? "

Conversations like this are the essence of *Forward With Families* — Ascend's multi-year effort to align policy, practice, and investment around what families need to thrive. Among those in attendance were Kristy Love, executive director of the National Perinatal Association (NPA) and a parent whose life was forever changed by preterm birth, and Dr. Vincent C. Smith, Division Chief of Newborn Medicine at Boston University/Boston Medical Center and a current Ascend Fellow whose academic and clinical work focuses on NICU discharge readiness and family-centered transition planning. NPA has developed interdisciplinary guidelines for NICU discharge and transition planning. The current focus is to have those guidelines adopted by every NICU in the country so that every family leaving the NICU receives a comprehensive preparation plan to support a successful transition home.

"The current focus is to have those guidelines adopted by every NICU in the country so that every family leaving the NICU receives a comprehensive preparation plan to support a successful transition home."

Why this work matters:

The NICU is both lifesaving and disorienting. Parents learn to monitor and administer medications, practice feeding and soothing a tiny infant, and absorb the sensory world of hospital care. Leaving brings enormous relief —and risk. Families may face complex regimens, unstable insurance or housing, postpartum mental health needs, and the challenge of caring for a highneeds infant without coordinated supports.

Evidence shows better discharge preparation reduces readmissions, boosts parental confidence, and supports development. Translating evidence into practice, however, demands interdisciplinary partnership, family leadership, and policy alignment—the very conditions *Forward With Families* is working to build so families can access the supports they need, when they need them.

Kristy Love: lived experience driving change

Kristy pairs two decades of nonprofit work in health education, peer support, and advocacy with the personal lessons of two premature births. Her experience taught her that discharge requires more than clinical instruction; it needs an anticipatory plan for daily life. Under Kristy's leadership, NPA convened interdisciplinary teams to produce the 2022 NICU Discharge and Transition Planning guidelines and earlier psychosocial recommendations, centering family experience and practical readiness as core outcomes.

"Under Kristy's leadership, NPA convened interdisciplinary teams to produce the 2022 NICU Discharge and Transition Planning guidelines and earlier psychosocial recommendations, centering family experience and practical readiness as core outcomes."

Vincent C. Smith: clinical rigor and system vision

Dr. Vincent C. Smith's 20 years in newborn medicine inform his work as an Ascend Fellow, translating bedside lessons into family-centered discharge systems. His research focuses on measurable components of readiness—caregiver competence, clear follow-up, coordination with community resources, and psychosocial supports—while emphasizing culturally responsive education and linkages to housing, food, and economic supports. His tagline—"I am empowering parents with children in the NICU through an innovative discharge and family support system"—reflects a belief that empowerment requires both information and access.

Anne Mosle and *Forward with Families*: Ascend's *Forward With Families* offers a catalytic frame for this work, aligning leaders across sectors—from health and caregiving to education, employment, housing, and food—and recognizing that what happens beyond the hospital is essential to a successful transition home. Building on Ascend's two-generation approach, *Forward With Families* reflects a simple truth: a child's health and development are inseparable from their family's economic stability, mental health, and access to opportunity.

Anne's convening approach—surfacing crosssector bridges and centering family voice—reframes NICU discharge as a pivotal moment in a family's economic and social trajectory where coordinated policy and practice can prevent hardship and promote longterm wellbeing.

How this collaboration could change practice:

While the partnership between *Forward with Families* and NPA is still taking shape, it holds the promise of moving efforts well past conversation and toward measurable impact. Potential early directions include:

- Aligning familycentered discharge guidelines with community systems. NPA's interdisciplinary guidance can be intentionally linked to community supports—from home visiting and peer networks to housing and food access programs—so discharge plans point families to resources they can realistically use.
- Turning clinical elements into policyready indicators. Vincent and prospective collaborators aim to define measurable components of discharge readiness that health systems and payers can adopt as benchmarks, opening the door to reimbursement models that reward comprehensive transitions.
- Centering parent leadership. NPA's approach elevates parent voices across development and implementation, ensuring that interventions address the real barriers families identify—transportation, postpartum mental health, scheduling challenges for hourly workers—rather than only the issues clinicians prioritize.
- Building cross sector training and shared language. Ascend's convening capacity encourages leaders in health care, social services, and community organizations to co-develop a common framework for discharge planning that smooths referrals, clarifies roles, and strengthens local accountability.

These aspirational workstreams reflect a shared vision: making NICU discharge preparation an integrated, measurable, family-centered part of care that extends beyond the hospital door.

"Health care is increasingly called upon to attend to the broader social determinants of health. The NICU—a place of medical miracles and human vulnerability—is uniquely positioned to be a hinge point. When discharge planning is robust, families achieve better health outcomes and reduced strain on emergency services and readmissions. When discharge planning is shallow, the short-term gain of survival can be shadowed by long-term instability."

Why this matters now

Health care is increasingly called upon to attend to the broader social determinants of health. The NICU—a place of medical miracles and human vulnerability—is uniquely positioned to be a hinge point. When discharge planning is robust, families achieve better health outcomes and reduced strain on emergency services and readmissions. When discharge planning is shallow, the short-term gain of survival can be shadowed by long-term instability. The NPA-Ascend collaboration helps shift the scale toward prevention and continuity, not episodic care. This is the kind of cross-sector alignment *Forward With Families* is working to advance—connecting clinical care with the broader conditions families need to thrive.

A human measure of success:

Numbers will matter—reduced readmissions, improved follow-up rates, and better maternal mental health metrics are essential. However, the human stories will tell the deeper truth. Imagine a first-time parent leaving the NICU confident in feeding their infant, connected by text to a peer support volunteer, scheduled for a home visiting appointment, and enrolled in a benefits navigation call that eases the family's financial anxieties. That family's first months at home can be a period of growth and attachment rather than fear and repeated hospitalizations.

"With NPA as a national engine and Forward with Families as a trusted convener of clinical and lived-experience wisdom, the dream of equitable, evidence based, and family-centered universal NICU discharge preparation and transition planning is moving from aspiration to practice."

Looking ahead:

The work of Kristy, Vincent, Ascend, and the many clinicians, parents, and policymakers who have joined them is only beginning. They are proving a fundamental principle: improving NICU-to-home transitions demands interdisciplinary craft, family leadership, and policy pathways that extend the hospital's care into the conditions of everyday life. With NPA as a national engine and *Forward with Families* as a trusted convener of clinical and lived-experience wisdom, the dream of equitable, evidence based, and family-centered universal NICU discharge preparation and transition planning is moving from aspiration to practice.

At the Ascend Forum gathering in April, conversations moved quickly from the granular — What should a discharge checklist include? How do we measure caregiver readiness?—to the expansive: How might a state redesign benefits and housing navigation to meet NICU families' specific needs? That swing between bedside detail and systems change is the collaboration's signature. In linking Kristy's lived urgency with Vincent's clinical rigor and Ascend's systems vision, a new path opens: one where the moment a family leaves the NICU is not an ending but the beginning of a supported, hopeful life together. This reflects the vision of *Forward With Families*: connecting clinical excellence with the systems and supports families rely on every day.

Acknowledgments: *The National Perinatal Association, Ascend at the Aspen Institute, Anne Mosle, Lori Severens, and the entire Ascend leadership team, Kristy Love, Dr. Vincent C. Smith, and the current Ascend Fellowship class for their leadership and partnership in advancing NICU discharge readiness and family-centered transition planning.*

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

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Gravens by Design: Enhancing the Auditory Environment in the NICU—The Spirit Is Willing, But Change Is Hard

Robert D. White, MD

I recently spoke at the annual meeting of the National Association of Neonatal Therapists (NANT) about the acoustic environment of care in the NICU. I was among experts and people who cared deeply about babies and their families, but I left feeling somewhat pessimistic about the potential for future progress.

We have had standards for what the background noise level should be in the NICU, written by our Recommended Standards Committee (1) and adopted by the AAP in the Guidelines for Perinatal Care (2), for decades now; yet when I asked the therapists at this meeting if they thought their NICU was too noisy, nearly everyone raised their hands.

"We have had standards for what the background noise level should be in the NICU, written by our Recommended Standards Committee and adopted by the AAP in the Guidelines for Perinatal Care, for decades now; yet when I asked the therapists at this meeting if they thought their NICU was too noisy, nearly everyone raised their hands."

We built a NICU in South Bend 9 years ago that showed that this standard is achievable—it was not a slam dunk for us. Even after I gave our architects the standards and they understood the goal, when I walked through the mockup room for our new unit, it was far too noisy. They had to go back and put baffles in the HVAC ducts as well as wrap them with insulation to get them quiet enough to meet the standards—totally doable, common practice in many other settings where acoustics matter, but the architects did not specify those mitigation measures. Hence, it only happened because I insisted on a working mockup. I do not imagine this happens in most places, so even when they build a new NICU, it is still too noisy, which I find discouraging, given that the AAP Guidelines for Perinatal Care have specified a maximum background noise level of 45 dB for decades now. Other mitigation measures, such as carpeting in hallways, are also unpopular, but we have proven that this can be done attractively, does not contribute to the nosocomial infection rate, and helps with noise. People let go of their biases very reluctantly.

"Even after I gave our architects the standards and they understood the goal, when I walked through the mockup room for our new unit, it was far too noisy.'"

Likewise, for remote transmission of monitor alarms, the vast majority of attendees also indicated that this technology was not yet being used in their NICUs to reduce noise at the bedside. We incorporated this technology (which does not require major renovation or new construction) 10 years ago, yet, it seems, few places do so.

"Likewise, for remote transmission of monitor alarms, the vast majority of attendees also indicated that this technology was not yet being used in their NICUs to reduce noise at the bedside. We incorporated this technology (which does not require major renovation or new construction) 10 years ago, yet, it seems, few places do so."

And then we talked a bit about single-family rooms (SFRs)—which I have never pushed as the right solution for all babies, only for those whose families wish to be present for large parts of the day. A colleague referenced a study done in St. Louis that showed impaired language development in babies cared for in SFRs compared to those cared for in multi-bed open bay rooms but did not note that the study was done in a NICU with a large inner-city population of parents, many of them who spent very little time with their babies, and that context is everything. I do not think the results would have been the same if the study had been done in, say, Scandinavia, where most parents are with their babies for 18 hours a day. As I mentioned at the conference, a single

family room without family is just a sensory isolation room, which is what they found in the St. Louis study. But that is very different from the suburban/rural population our NICU serves, where, for example, an Amish family will come to stay with their baby 24/7 until discharge. I have to believe that the auditory environment for that baby will be optimal in an SFR since that kid will be skin-to-skin for hours at a time, an environment that closely replicates the *in utero* state.

"As I mentioned at the conference, a single family room without family is just a sensory isolation room, which is what they found in the St. Louis study. But that is very different from the suburban/rural population our NICU serves, where...an Amish family will come to stay with their baby 24/7 until discharge. I have to believe that the auditory environment for that baby will be optimal in an SFR since that kid will be skin-to-skin for hours at a time, an environment that closely replicates the in utero state."

I came away from that discussion believing that the NICU environment will remain too noisy for at least another generation with workarounds that fall far short of the mark.

I think we are all convinced that the optimal locus for auditory stimulation in a newborn is in the mother's or a surrogate's arms, as part of a multisensory experience with touch and movement. I am convinced that for many families, this is most likely to occur in an SFR—some parents will just be too shy to hold their baby skin-to-skin and sing to or talk to them in a room full of strangers. However, that is not universal; there is strength in community, so there are certainly parents who are more likely to do this if everyone else in the room is. There is no one-size-fits-all; for some babies and their families, the best solution is an SFR, but for others, it is congregate care. Certainly, for babies whose families are not often present, congregate care is the option. Every NICU should have both options available; the proportions will differ in St. Louis from those in South Bend and probably even differ between a level IV in St. Louis and a level II in one of the St. Louis suburbs. We need to understand and embrace the complexity of the problem and its solutions—different strokes for different folks, and even the same folks at various stages. The kid on high frequency ventilation in the first week of life may need a private room just so the rest of the NICU does not have to hear the ventilator noise, then a congregate care room for the next couple weeks because the family lives 100 miles away and can only come to see the baby on weekends, then maybe a SFR for a few days prior to discharge if the family can come and room in. We should build and operate our NICUs to accommodate all of these options.

"There is no one-size-fits-all; for some babies and their families, the best solution is an SFR, but for others, it is congregate care. Certainly, for babies whose families are not often present, congregate care is the option. Every NICU should have both options available; the proportions will differ in St. Louis from those in South Bend and probably even differ between a level IV in St. Louis and a level II in one of the St. Louis suburbs. We need to understand and embrace the complexity of the problem and its solutions..."

Nevertheless, based on what I have seen over the past decade, I do not hold out much hope for improvement, which is already way overdue. There is inertia. There are costs. Some caregivers will not adapt. I am discouraged because I am not sure how to change that dynamic and less convinced now than I was before I came to the NANT Conference that there is much interest in doing so. I would be willing to bet that the average noise level in NICUs 10 years from now will not be much different from what it is today even though the solutions are clearly at hand.

"It is possible to have a NICU with a background noise level of 45 dB or less, where monitor alarms are rarely heard and where babies hear a soft, comforting human voice several hours a day, whether from a parent, a caregiver, or a volunteer. For many NICUs, a lot will have to change to reach that point—but this is one of those aspects of neonatology that, even though it is not high-tech or dramatic, really does have an important impact on babies, their families, and caregivers."

Is your NICU too noisy? Three things you can do now:

- Document background and peak sound levels in multiple places and multiple times throughout the day on multiple occasions

- Identify the sources of the background noise—e.g.,
  - How much is from HVAC?
  - How much is from monitors?
  - How much is from hallway traffic?
  - How much is from people who feel they need to speak over the elevated background noise to be heard?
- Retain an acoustical engineer to identify opportunities for improvement
- If you do not have remote transmission of alarms so that most bedside alarms can be silenced, get them.

It is possible to have a NICU with a background noise level of 45 dB or less, where monitor alarms are rarely heard and where babies hear a soft, comforting human voice several hours a day, whether from a parent, a caregiver, or a volunteer. For many NICUs, a lot will have to change to reach that point—but this is one of those aspects of neonatology that, even though it is not high-tech or dramatic, really does have an important impact on babies, their families, and caregivers.

"We have failed our patients, families, and caregivers if we build a new NICU or do major renovations on an older NICU without ensuring that 1) the acoustical environment meets AAP standards and that 2) the right mix of beds in SFR and congregate care rooms is available for the population served by that NICU."

We have failed our patients, families, and caregivers if we build a new NICU or do major renovations on an older NICU without ensuring that 1) the acoustical environment meets AAP standards and that 2) the right mix of beds in SFR and congregate care rooms is available for the population served by that NICU.

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Disclosures: *The author has no conflicts of interest.*

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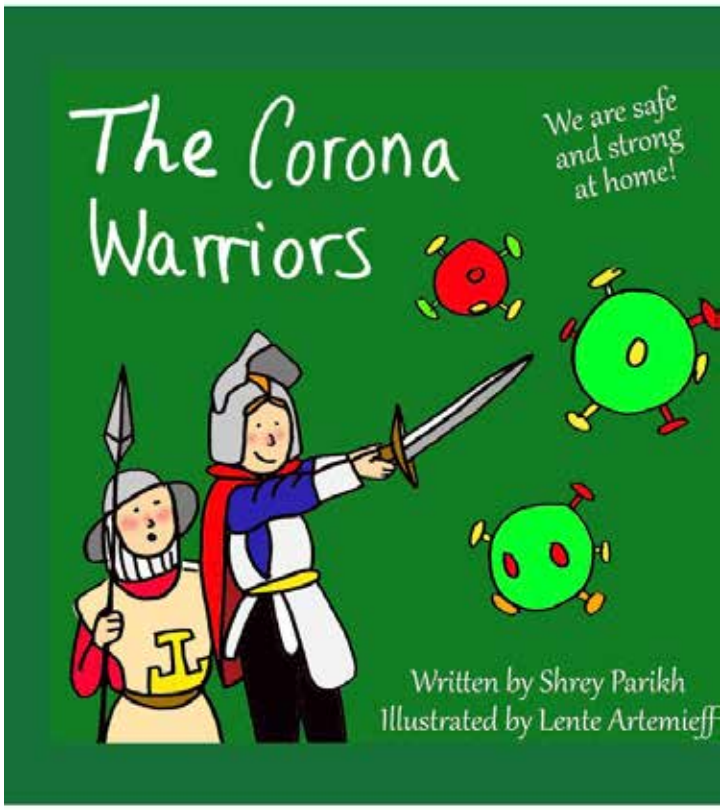

Peer Reviewed

39th Annual Gravens Conference

On the Environment of Care for
High Risk Newborns and Their Families

June 15-18, 2026

"Sensitive Issues in Sensational Times"

Monday, June 15th
Let the Festivities Begin!

TIME	SESSION / EVENT	LOCATION
8:00 pm-4:00 pm	Reimagining the NICU - Troy Savage *Optional Pre Conference with Separate Registration*	
4:00 pm-7:00 pm	Registration Desk Open	
7:00 pm-9:00 pm	Welcome Reception *Cash Bar Only*	Podium at Embassy Suites
Tuesday, June 16th **Science & Application** *Welcome, Breaks, Awards, and Closing Do Not Count for CME/CE*		
TIME	**SESSION / EVENT**	**LOCATION**
7:00 am-5:00 pm	Registration Desk Open	
7:00 am-8:00 am	Continental Breakfast Provided (1 hour)	
8:00 am-5:00 pm **Plenary Sessions** **Downes Ballroom - Corbett Family Hall** **Moderator: (Robert White and Joy Browne)**		
TIME	**SESSION / EVENT**	**PRESENTER**
8:00 am-8:15 am	Welcome & Introductions	Joy Browne
8:15 am-9:00 am	Family-Centered Collaborative Care Models that Support Families and Optimize Preterm Infant and Child Health Outcomes	Jessica DiBari
9:00 am-9:45 am	Care of the Mother is Care for the Baby	Heather Burris
9:45 am-10:15 am **Break (30 min)**		
10:15 am-11:00 am	Central Autonomic Network Connectivity is Altered in an Extra-Uterine Environment	Catherine Limperopoulos
11:00 am-11:45 am	All Care is Brain Care: Lessons learned from an international quality improvement collaborative to improve brain health and outcomes (Part 1)	Roger Soll, Elizabeth Rogers, Sonia Bonifacio
11:45 am-1:00 pm **Lunch (75 min)**		
1:00 pm-2:30 pm	All Care is Brain Care: Lessons learned from an international quality improvement collaborative to improve brain health and outcomes (Part 2)	Roger Soll, Elizabeth Rogers, Sonia Bonifacio
2:30 pm-3:00 pm **Break (30 min)**		
3:00 pm-3:30 pm	Gravens Leadership Award Presentation	(NAME)
3:30 pm-4:15 pm	Sensitive Issues for Babies, Parents, and their Relationships	Joy Browne

4:15 pm-4:45 pm	Panel Discussion Among Speakers and NICU Parents on Real-World Impact of Topics Presented	NICU Parents
4:45 pm-5:00 pm	Family Centered-Care (FCC) Scholars Introduction	Malathi Balasundaram
5:00 pm-5:15 pm	Final Thoughts and Take-Home Messages	Robert White
6:30 pm-8:30 pm **Reception & Poster Walk** **Poster Session - Jordan Hall Galleria** *Substantial Snacks Provided* 7:00 pm-7:45 pm, Poster Authors Available 8:10 pm-8:30 pm, Door Prize Raffle: Vincent C. Smith		

Wednesday, June 17th
Themed Tracks

Welcome, Breaks, and Closing Do Not Count for CME/CE

TIME	SESSION / EVENT	LOCATION
6:30 am-7:15 am	Run, Walk, Skip Around Notre Dame Campus	
7:00 am-8:00 am	Continental Breakfast Provided / Networking Tables (1 hour)	
7:30 am-1:30 pm	Registration Desk Open	

8:00 am-1:00 pm
Themed Tracks

Track A **Infant and Family-Centered Developmental Care** **Jordan Hall Room 101** **Moderator: Joy Browne**		**Track B** **Newborn ICU Design** **Jordan Hall Room 105** **Moderator: Robert White**	
8:00 am-8:15 am	Introductions & Announcements	8:00 am-8:15 am	Introductions & Announcements
8:15 am-8:45 am	The Importance of a Developmental Point of View of Sensory Processes - Robert Lickliter	8:15 am-9:00 am	Therapeutic Design - Mardelle Shepley
8:45 am-9:30 am	Development and Clinical Application from Auditory Tactile Research - Nathalie Maitre	9:00 am-9:45 am	Designing NICU Spaces for Ritual and Healing - Anya Vanacek and Julia Jude
9:30 am-10:15 am	Development and Clinical Application from Embodied Vocal Presence Research - Manuela Filippa	9:45 am-10:30 am	Soundscapes - Bobbi Pineda
10:15 am-10:45 am	Break (30 min)		
		10:30 am-11:00 am	Break (30 min)
10:45 am-11:30 am	Clinical Application from Chemosensory Research - Julie Mennella	*Exhibitors to Break Down*	
11:30 am-12:15 pm	Reflections on Sensory Developmental Ecology and Its Applications for Care - Jeff Alberts	11:00 am-11:45 am	New Unit Presentation - Alli Kasper, Brianna Leigh, and Karizma Maxson
12:15 pm-12:45 pm	Clinical Application of the Environment of Care from the NICU Parents' Perspective (Panel)	11:45 am-12:45 pm	Using AI for NICU Design - Troy Savage
12:45 pm-1:00 pm	Summary & Next Steps - Joy Browne	12:45 pm-1:00 pm	Summary & Next Steps - Robert White

1:00 pm-4:00 pm **Lunch, Rest, Play, Network, NICU Tour** *Lunch Not Provided* **Tour of the Beacon Children's Couplet Care/Single Family Room NICU**		
4:00 pm-4:45 pm **Welcome Back & Networking** *Coffee and Light Snacks Provided*		
4:45 pm-6:00 pm **Workshops (75 min)**		
TIME	**SESSION / EVENT**	**MODERATOR**
4:45 pm-6:00 pm	A: Culture Club: Culture as a Foundation for Quality Improvement - Elizabeth Rogers and Sonia Bonifacio	
	B: Taking Steps Toward Postpartum Care in the NICU - Heather Burris and Katey Mari	
	C: Reimagining the NICU: Wrap Up - Troy Savage	
	D: Are We Really Seeing Delirium in Babies? A Conversation About Behavioral Assessment and Intervention - Jeff Alberts	
	E: Support for NICU Fathers and Non-Birthing Parents - Cameron Boyd, Alex Zavala, Craig Garfield, and Molly Fraust-Wylie	
	F: Partnering with NICU Parents and Staff to Develop a NICU Discharge Mental Health Services Program - Susanne Klawetter	
6:30 pm-9:00 pm **Dinner Banquet** **Heritage Hall - Joyce Center** *Included with Conference Registration*		

Thursday, June 18th **Family Topics & Reflections Abstracts & Workshops** *Welcome, Breaks, and Closing Do Not Count for CME/CE*		
TIME	**SESSION / EVENT**	**LOCATION**
6:30 am-7:15 am	Run, Walk, Shuffle Around Notre Dame Campus	
7:00 am-8:00 am	Continental Breakfast Provided (1 hour)	
7:00 am-11:15 am	Registration Desk Open	
8:00 am-12:00 pm **Plenary Session** **Downes Ballroom - Corbett Family Hall** **Moderators: (Vincent C. Smith and Molly Fraust-Wylie)**		
8:00 am-8:10 am	Introductions and Announcements	Vincent C. Smith & Molly Fraust-Wylie
8:10 am-8:40 am	A NICU Dad's Perspective	Alex Zavala

8:40 am-9:15 am	Experiences of NICU Fathers and Non-Birthing Parents	Cameron Boyd
9:15 am-10:00 am	NICU Discharge Planning Considerations for NICU Fathers and Non-Birthing Parents	Craig Garfield
10:00 am-10:30 am Break (30 min)		
10:30 am-11:05 am	Audience Engagement Activity	Troy Savage
11:05 am-11:50 am	Parent Panel	Molly Fraust-Wylie & Mia Malcolm
11:50 am-12:00 pm	Acknowledgement & Celebration of Juneteenth Wrap Up/Warm Send Off	Joy Browne & Robert White
12:00 pm-1:15 pm *Planning Committee Meeting* **Lunch (75 min)**		
1:15 pm-2:30 pm Abstracts (75 min)		
TIME	**ABSTRACT**	**MODERATOR**
1:15 pm-2:30 pm	Developmental Care: 1. Parent-Delivered Neurodevelopmental Care: Standardizing an Approach to Parent Education - Grace King, Tierney Morrison, Aimee Godett, Marge Day, Emily Whitesel (Abstract 30) 2. Interventions Designed to Improve the Postpartum Health and Wellbeing of Parents of Infants in the NICU: A Scoping Review - Sarah Verbiest, Wayne Price, Kimarie Bugg (Abstract 19) 3. Multidisciplinary Journey to Reliable Social Determinants of Health Screening for NICU Families: Navigating Barriers in the NICU Village - Rosanne Buck, Dory Ziperstein, Molly Faust-Wylie, Erika Sevieri, Gina Story, Emily Whitesel, Yarden Fraiman (Abstract 7)	
	Family Support (A): 1. Harmonizing Developmental and Medical Communication in the NICU: A Dynamic Digital Platform to Augment Family-Centered Care - Ansul Asad, Yaya Ren, Bree Andrew (Abstract 36) 2. Early Parental Presence in the NICU: Social Determinants and Maternal Mental Health Shape Family Engagement for High Risk Infants - Jaclyn Ruggiero, Allison Davidson (Abstract 47) 3. Family-Centered Care: Increasing Positive Family Engagement and Interactions with Infants in the NICU - Terri Sandoval, Alison Smith, Jamie Lujan, Jennifer Guadalupe, Rachel Carlos, Candice Martinez (Abstract 4)	
	Developmental Care/Family-Centered Care: 1. The Journey to a Developmental Care Continuum: An Interdisciplinary Collaborative Approach to Developmental Care in the NICU - Tiara Bolden, Lisa Miller, Cynthia Ruggles, Mary Beth Sanders, Laura Schacht, Lindsay Schuler, Kelly Crombie, Janet Dierstein, Susannah Dillender, Christine Houlihan, Amy Salisbury (Abstract 51)	

	2. Designing the NICU of the Future: National Survey Insights on Workforce Support, Digital Integration, and Family Partnership - Lisa Davenport, Jaylee Hilliard (Abstract 32) 3. Reimagining the NICU Environment of Care: Applying Human Factors and Ergonomics to Support Safe, Sustained Skin-to-Skin (Kangaroo) Care for High Risk Infants and Families - Yamile Jackson (Abstract 6)	
	Family Support (B): 1. Mapping Neonatal Transfer Patterns to Inform Family-Centered Care: Capacity and Distance Across Levels of Care - Amanda Luff, Emily Malloy, Veronica Fitzpatrick (Abstract 15) 2. Advancing Family Engagement in the NICU: A Qualitative Exploration of Barriers and Facilitators - Laura Rose, Kayla Schmittau, Kristen Schaffer, Alejandro Chavez, Katherine Lopez-Lepe, Linda Franck, Henry Lee (Abstract 8) 3. Effect of Parent Education Classes on Confidence and Stress of Parents of Infants Admitted to the NICU of a Tertiary Care Hospital in India - Pooja Dekhane, Puja Padbidri, Madhura Gandhi, Madhuri Patil, Eilish Byrne (Abstract 22)	
	Potpourri: 1. Reaching NICU Families: Feasibility of Recruiting High Risk Infants - Ashlee Vance, Eman Dannaway (Abstract 33) 2. Beyond Just Cuddles: Creating a Medical Student Cuddlers Program for an Evolving Level 4 NICU - Stephanie Bernard, Lauren Felzani, Rivky Barnetsky, Likhitha Patlolla, Jordan Bryan, Donessa Jenae Colley, Andrea Weintraub (Abstract 17) 3. Development of a Conceptual Framework for Financial Hardship in Neonatal Care - Ashlee Vance (Abstract 26)	
	Design: 1. Acoustic Comfort in Newborn Intensive Care - Kathleen Philbin (Abstract 52) 2. Beyond Single-Family Rooms: A Hybrid NICU Model Responsive to Community Demographics - Zoraya Stern, Maria D'Souza, Whitney K. Fuessel (Abstract 24)	
2:30 pm-3:00 pm Break (30 min)		
3:00 pm-4:15 pm Workshops (75 min)		
3:00 pm-4:15 pm	A: TBD	
	B: Words Matter: Navigating Sensitive Situations with Intentional Language in the NICU - Ramya Kumar	
	C: Trauma-Informed Expectations for Gratitude in the NICU - Mia Malcolm and Jessica Barnes	
	D: D.R.I.V.E. Better Care: Developing Emotionally Present NICU Teams to Strengthen Family-Centered Care - Weston Brandon	
	E: Relationships in the NICU: Will AI Foster or Hinder? - Jim Gray and Bridget Davern	

	F: The Second Edition of the Infant and Family-Centered Developmental Care Standards: Discussion and Dissemination - Carol Jaeger and Joy Browne	
4:15 pm	Safe Travels, See You at the Next Gravens Conference!	

Friday, June 19th

HAPPY JUNETEENTH!

Juneteenth is a United States federal holiday commemorating the end of slavery.

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Raising Global Awareness of RSV

Global awareness about respiratory syncytial virus (RSV) is lacking. RSV is a relatively unknown virus that causes respiratory tract infections. It is currently the second leading cause of death – after malaria – during infancy in low- and middle-income countries.

The RSV Research Group from professor Louis Bont, pediatric infectious disease specialist in the University Medical Centre Utrecht, the Netherlands, has recently launched an RSV Mortality Awareness Campaign during the 5th RSV Vaccines for the World Conference in Accra, Ghana.

They have produced a personal video entitled "*Why we should all know about RSV*" about Simone van Wyck, a mother who lost her son due to RSV. The video is available at www.rsvgold.com/awareness and can also be watched using the QR code on this page. Please share the video with your colleagues, family, and friends to help raise awareness about this global health problem.

RSV GOLD

A Global Mortality Database for Children with RSV Infection

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

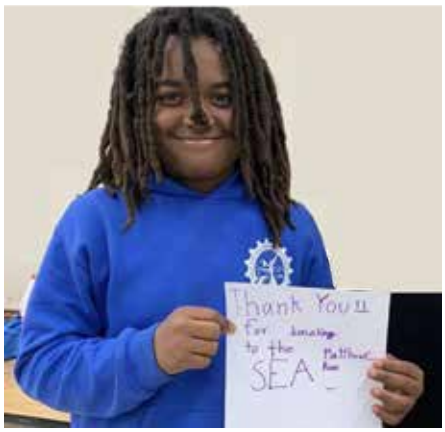
Thirteen-year-old Emily Rose Shane was tragically murdered on April 3, 2010 on Pacific Coast Highway in Malibu, CA. Our foundation exists to honor her memory.

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

Make a Difference in the Life of a Student in Need Today!
Please visit emilyshane.org

Sponsor a Child in the SEA Program

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



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

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

National Coalition for Infant Health: Steering Committee Directions for 2026, Introduction from the Pediatric Academic Society Meeting in Boston

Mitchell Goldstein, MD, MBA, CML

The National Coalition for Infant Health is a collaborative of more than 200 professional, clinical, community health, and family support organizations focused on improving the lives of premature infants through age two and their families. NCfIH's mission is to promote lifelong clinical, health, education, and supportive services needed by premature infants and their families. NCfIH prioritizes safety of this vulnerable population and access to approved therapies.

Good morning, and thank you for the opportunity to be here in Boston with all of you.

"It feels especially fitting to gather in a city so deeply tied to the history of American collaboration, advocacy, and public health. Boston has long been a place where ideas turn into movements, and movements turn into meaningful change. That spirit is very much aligned with the story of the National Coalition for Infant Health."

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Because the Coalition did not begin as an institution, it began as a response. A response to a growing recognition that the most vulnerable infants in our healthcare system, particularly those born prematurely or with complex medical conditions, were at risk of being overlooked in broader policy discussions. These infants do not have a voice of their own. Moreover, too often, the systems designed to serve them were fragmented, inconsistent, or shaped without a full appreciation of their unique needs. (1) The National Coalition for Infant Health was founded to change that.

"From its earliest days, the Coalition brought together a diverse and, frankly, uncommon alliance. Clinicians. Researchers. Patient advocacy organizations. Families. Industry partners. Policymakers. Groups that did not always agree on everything, but who shared a core belief: that infants deserve access to safe, effective, and equitable care, guided by evidence and compassion. (2-4)"

From its earliest days, the Coalition brought together a diverse and, frankly, uncommon alliance. Clinicians. Researchers. Patient advocacy organizations. Families. Industry partners. Policymakers. Groups that did not always agree on everything, but who shared a core belief: that infants deserve access to safe, effective, and equitable care, guided by evidence and compassion. (2-4)

That idea, simple on its face, is actually quite powerful. Because it requires holding several truths at once, it requires acknowledging that innovation matters, that access matters, and that safety matters. Moreover, policy decisions, especially those made far from the bedside, have real and lasting consequences for the smallest patients we care for.

In its early years, the Coalition focused on building that shared understanding. It created space for dialogue in an environment that was often polarized. It emphasized evidence-based decision-making at a time when cost-containment pressures and regulatory complexity were increasingly influencing care.

Importantly, it elevated the voices that are too often absent from policy conversations: parents and caregivers. Families of medically complex infants understand something that no dataset can fully capture: the day-to-day reality of navigating care, the stakes of every clinical decision, and the long arc of outcomes that extend far beyond the NICU.

As the Coalition matured, its work became more visible and more influential. It engaged in national conversations around access to therapies, particularly those aimed at preventing serious respiratory illness in high-risk infants. It helped frame discussions around value, not just in terms of cost, but in terms of outcomes, quality of life, and long-term impact. It also became a trusted resource, offering policymakers and stakeholders a perspective grounded in both science and lived experience.

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Furthermore, that role has only grown more important as the landscape of infant health has become more complex, not less. We are seeing rapid advances in neonatal care, which is something to celebrate. Nevertheless, with those advances come difficult questions:

- How do we ensure equitable access?
- How do we balance innovation with affordability?
- How do we avoid unintended consequences when policies are designed without sufficient clinical insight?

These are not abstract questions. They are questions that determine whether a premature infant receives preventive therapy…Whether a family can access follow-up care…Whether outcomes improve or disparities widen.

The National Coalition for Infant Health has positioned itself at the center of these conversations, not as a single-issue advocate but as a convener. A translator. And at times, a necessary voice of caution.

It reminds us that when we talk about "infant health," we are not talking about a uniform population. We are talking about infants with extraordinary vulnerability and extraordinary potential. That potential depends on the decisions we make.

What I find most compelling about the Coalition's history is not just what it has done, but how it has done it. It has chosen collaboration over division; evidence over assumption; and long-term impact over short-term expediency. That is not always the easiest path. Nevertheless, it is the right one. And it is a path that aligns closely with what many of us strive for in our own work, whether in the NICU, research, advocacy, or policy. (5)

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As we look ahead, the Coalition's role is likely to become even more critical. We are entering an era where data is abundant, but clarity is not always. Where innovation is accelerating, but access is uneven. Where decisions are increasingly complex, and the margin for error, especially for fragile infants, remains very small.

In that environment, organizations like the National Coalition for Infant Health serve an essential function. They help ensure that the conversation stays grounded:

- that science is respected;
- that the patient remains at the center;
- and perhaps most importantly, that we do not lose sight of what is at stake.

Because behind every policy discussion… every clinical guideline… every reimbursement decision…

There is an infant, a family, a future.

As we begin today, I encourage us to reflect not only on the Coalition's history but also on its purpose. It exists because the work is not finished. Because the system is not yet perfect, the voices of vulnerable infants still need to be amplified. That responsibility belongs to all of us.

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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.

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

Your Pregnancy and Substance Use

4 Things you can do to improve your health and lower your risk for complications

Get Prenatal Care

Start early. Go to all your visits. Empower yourself with information so you can make smart decisions. Build relationships with providers who understand Substance Use Disorders (SUDs) and know how to help. Partner with them to reach your goals. But remember, you do not need to be abstinent from substance use to get care. Go now.

Reduce Your Use

There are simple things you can do to limit the harm substances might do.

- Use fewer substances
- Use smaller amounts
- Use less often
- Learn how to use safer

Reducing or quitting smoking is a good place to start. Set your goals, then ask for help.
One of the best things you can do is to stop using alcohol. We know that even small amounts are risky. And when combined with benzos and opioids, alcohol can kill.

Use Medications for Opioid Use Disorder (MOUD) if you are opioid dependent

Methadone and Buprenorphine (Subutex® or Suboxone®) are the "Standard of Care" during pregnancy because they:

- Eliminate the risks of illicit use
- Reduce your risk for relapse
- Can be a positive step towards recovery

Take Good Care of Yourself

You deserve a healthy pregnancy & childbirth.

- Eat healthy and take your prenatal vitamins
- Find the right balance of rest and exercise
- Surround yourself with people who care

Your Health Matters

Academy of Perinatal Harm Reduction

National Perinatal Association

www.perinatalharmreduction.org | www.nationalperinatal.org

Fragile Infant Forums for Implementation of IFCDC Standards: Using an Ecological Framework to Guide Practice

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

Ecology and bioecological theory:

Ecology describes the relationships among organisms and their physical environment. Ecology has evolved to a bioecology model and has been applied to human development. From a bioecological perspective, development proceeds through ever-expanding interactions over time between the individual and those with whom they interact. Development unfolds within ecological environments, which are described as processes or modes of interaction among people.

"From a bioecological perspective, development proceeds through ever-expanding interactions over time between the individual and those with whom they interact. Development unfolds within ecological environments, which are described as processes or modes of interaction among people."

Most are familiar with Bronfenbrenner's bioecological theory. His description of human development focuses largely on the impact of the ecological environment, which includes early caregiving relationships. Bronfenbrenner's approach conceptualized an arrangement of nested interactive systems, each contained within the next, and described the contributions of each system to a child's development. (1, 2) See Figure 1

The system most influential in the development of the young child, and actually all individuals, is referred to as the *proximal system,* which contains immediate caregivers and family members. The next most influential is called the *mesosystem,* which includes more distant entities but still has a strong developmental influence. The mesosystem is a system of microsystems that widens each time an individual enters a new setting but diminishes when the new setting is no longer available. Rather than activities and interpersonal roles and relations occurring within a single microsystem, such as immediate family members, they occur across ever-widening settings, such as child care, religious settings, and community events. The third circle of the bioecological model, or the *exosystem,* describes how the developing individual does not actively participate in it but experiences its influence and, at times, can in turn influence it, formally or informally. Examples might be the parents' workplace, community organizations, or local government policies. Finally, the *macrosystem* is the institutional systems of a culture or subculture, such as the economic, social, educational, legal, and political systems. (3, 4)

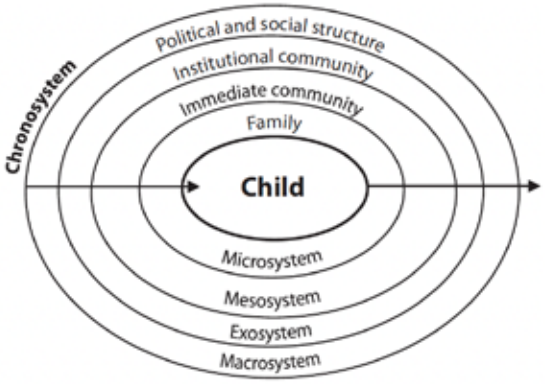

Figure 1: Bronfenbrenner's Ecological Theory of Development (Halpern & Figueiras, 2004)

Figure 1 - available via license: Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International

The bioecological model in intensive care.

Previous approaches to the study of babies' physiology and developmental outcomes have been largely developed with concerns about single systems and/or approach modalities. Emerging science now recognizes that multiple and complex sensory inputs and social interactions influence biological systems. Experiences like these are known to modify the nervous system in subtle but significant ways, to the extent that the baby's

world is regarded as having an important role in shaping their nervous system in ways that cannot be described as linear or causal. (5) In light of these emerging changes in perspectives, the bioecological model offers implications for how care practices and research can be appropriately designed and provided, especially for babies and their caregivers in intensive care.

Other research indicates that organized ecological environments are best implemented within the context of intimate, consistent relationships with the baby's parents and can contribute to more optimal short- and long-term physiologic stability. For example, the BEGIN task force has described an ecological model that promotes breastfeeding outcomes. It considers both the mother's and the baby's efforts not only to achieve optimal breastfeeding but also to leverage the proximal system's sensory and caregiving environment to optimize the baby's growth and nutrition. It describes the breastfeeding ecology in these terms: "the complex system is human milk composition and its inherent biology and the environment consists of parental and infant inputs and the influence of their respective internal and external environments." (6) p 43.

"The bioecological model assumes that the child is an interactor with others in their ecological environment and is biologically prepared to interact with individuals in their respective systems. It is particularly important in the proximal and mesosystems where development is contingent on close, intimate interactions with primary caregivers and other social interactors."

The bioecological model assumes that the child is an interactor with others in their ecological environment and is biologically prepared to interact with individuals in their respective systems. It is particularly important in the proximal and mesosystems where development is contingent on close, intimate interactions with primary caregivers and other social interactors. Als adapted a bioecological model of family-focused care for use with babies and families in intensive care. (7) It demonstrates the central focus of the baby as interactive with their parents and intimate family members, representing the proximal system. The baby and family are surrounded and supported by the NICU mesosystem. Also implicated are the hospital and community systems represented as exosystems—Figure 2.

"The baby and family are surrounded and supported by the NICU mesosystem. Also implicated are the hospital and community systems represented as exosystems—Figure 2."

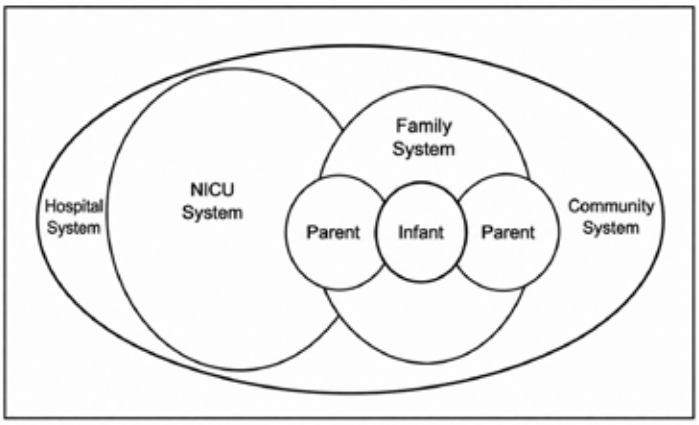

Figure 2 Family Focused Care in the NICU (Als, 1992) (7)

Similar to the model that Als proposed, the Infant and Family Centered Developmental Care (IFCDC) Standards, Competencies, and Best Practice conceptual model utilizes a bioecological perspective. It emphasizes the baby as an interactor with their mother, father, and family members, with this central to evidence-based developmental intervention. Surrounding the proximal relationship environment is the intensive care bioecological context. It emphasizes environmental and neuroprotection, as well as the prevention of the adverse impacts of intensive care procedures. Figure 3

Similar to Bronfenbrenner's perspective, the IFCDC model includes individualized care based on the infant's inferred abilities and developmental goals. The current standards for six evidence-based domains of caregiving reflect the challenges, complexities and opportunities for implementing a bioecological model in intensive care.

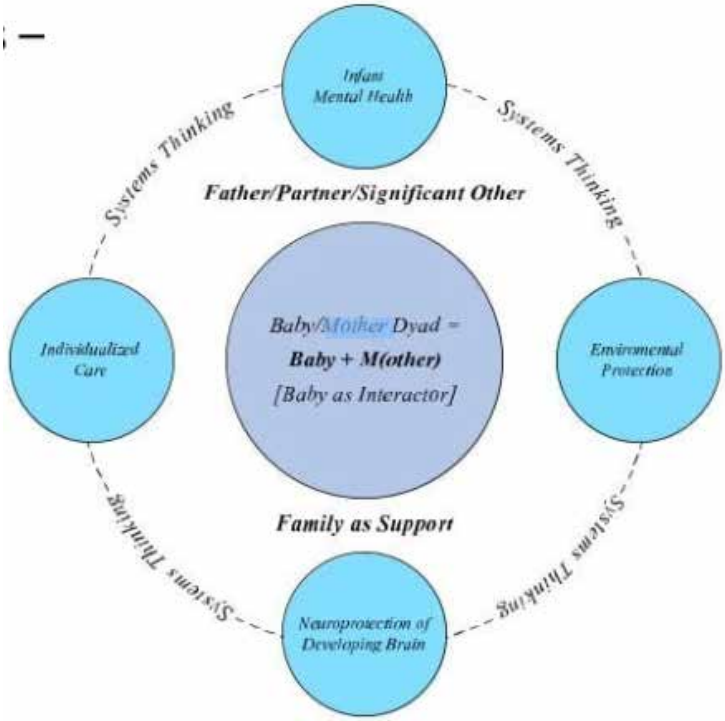

Figure 3 IFCDC Conceptual model

Bioecological perspectives in intensive care:

In applying the bioecological models in intensive care, the developing baby must be consistently viewed as influencing and being influenced by the microsystem in which they live. The microsystem is the most proximal setting, and any place where the baby can interact face-to-face with others. In that regard, intensive care can be viewed as a proximal microsystem specific to each baby. Given that the intensive care environment is known to influence the physiologic and behavioral stability of individuals, it is imperative to attend to both the sensory and the caregiving environments.

Babies develop in the context of intimate and consistent relationships. As such, the family plays a key role, as personal characteristics and interactions with the baby and among family members are essential parts of proximal processes. Thus, the family needs to be readily available to their baby as consistently as possible.

"It is also important to recognize that the baby's context is the caregiving environment and interactions with all in it. The baby's development will be influenced by all who are part of their microsystem, including nurses, doctors, therapists, aides, trainees, visitors, and other individuals. It is not only the number of those in the baby's microsystem, but also the characteristics and patterns of caregivers that lead to challenges to the baby's development."

It is also important to recognize that the baby's context is the caregiving environment and interactions with all in it. The baby's development will be influenced by all who are part of their microsystem, including nurses, doctors, therapists, aides, trainees, visitors, and other individuals. It is not only the number of those in the baby's microsystem, but also the characteristics and patterns of caregivers that lead to challenges to the baby's development. As babies try to initiate or maintain predictable, reciprocal interactions, inconsistent staffing patterns can alter how they develop relationships with their caregivers. Additionally, caregiving practices that vary from professional to professional or day to day can interfere with the baby's ability to rely on predictable events. Instability, unpredictability, and the absence of clear structure are characteristics that are not conducive to optimal development. (8)

Environmental and caregiving policies and procedures would benefit from applying the bioecological framework to enhance babies' development during intensive care. The ability to provide predictable, consistent caregiving practices and procedures, with the family at the center of care, will ultimately support optimal developmental outcomes.

Conclusion:

The bioecological model initially described by Bronfenbrenner can be applied to current intensive care practices and research studies. Key aspects of the model are the description of systems in which individuals develop. For babies, the most impactful systems are the proximal and mesosystems, as they imply that parents, families, and supportive close experiences and environments provide opportunities for consistent and predictable intimate interactions.

Several clinical models have adapted the bioecological model to intensive care and have expanded thinking to incorporate the neurophysiological effects of interaction with the environment. Key to these models are the provision of consistent and predictable environments best provided by parents, as well as policies that address the need for consistent staffing assignments and consistently applied care.

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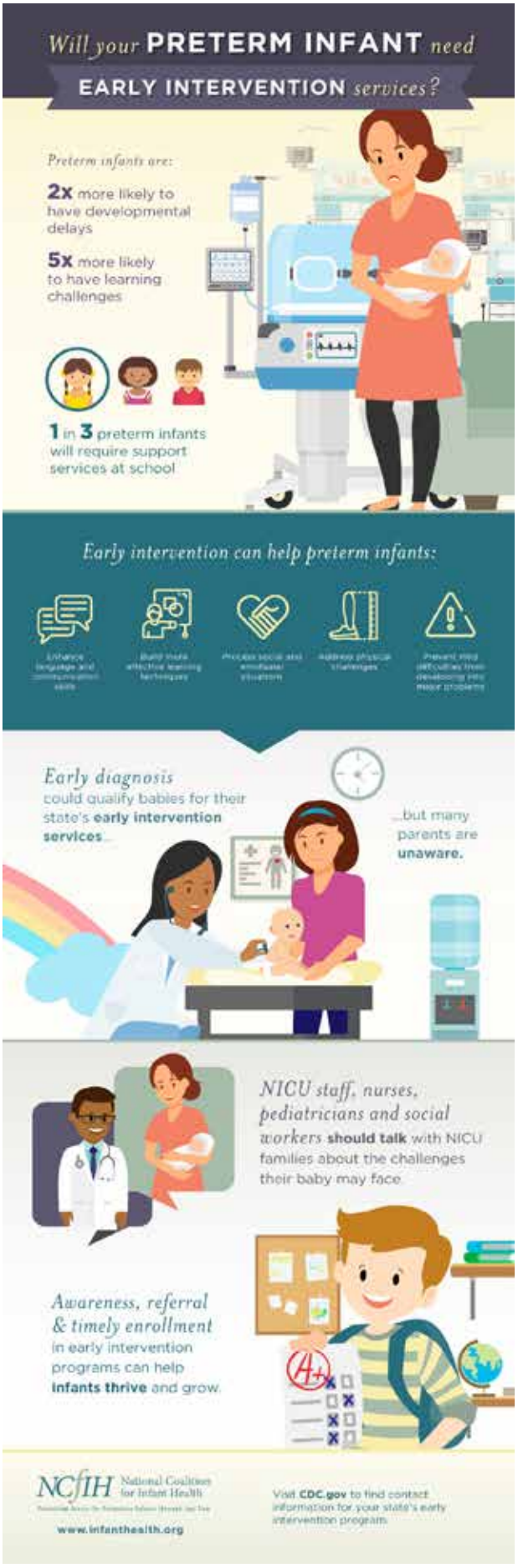

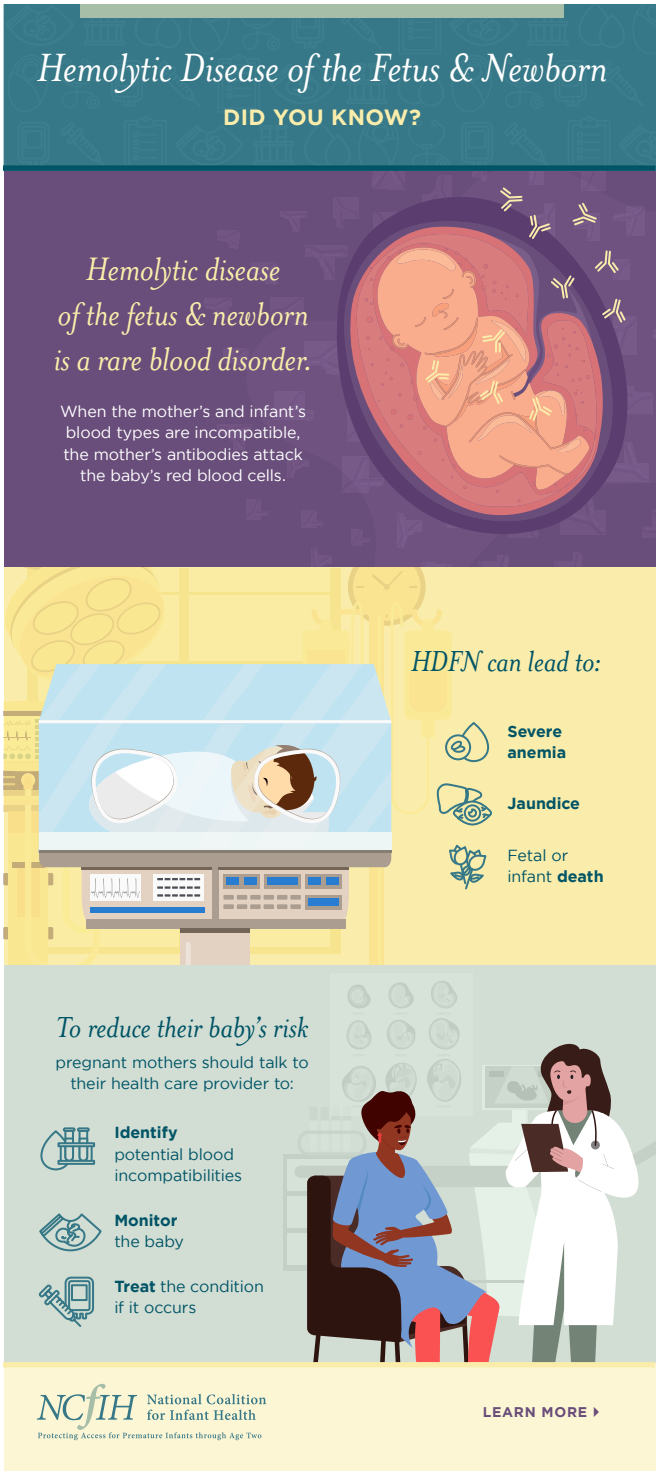

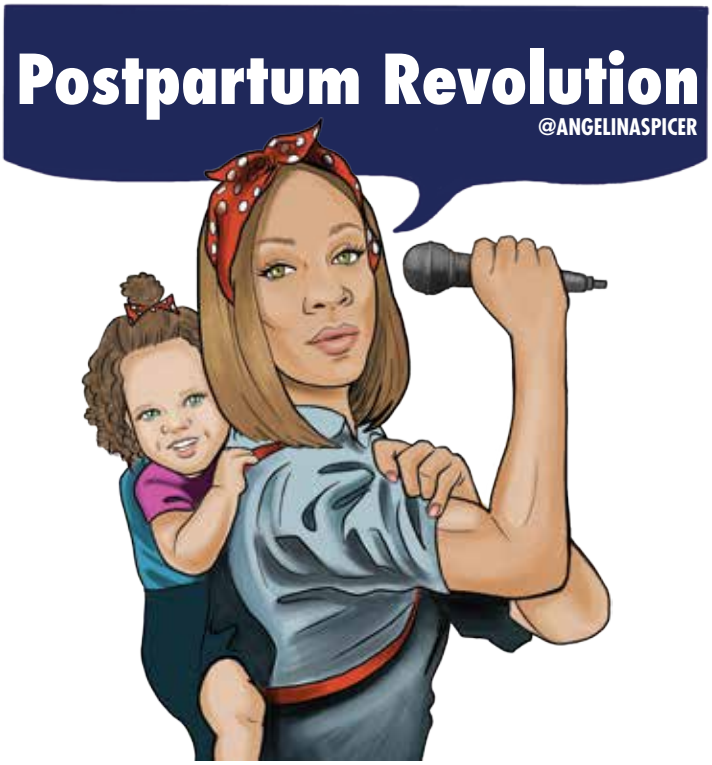

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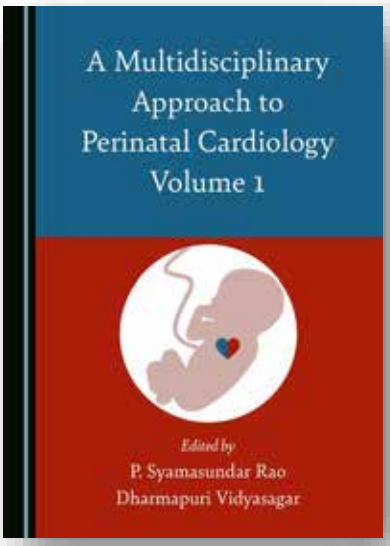
A Multidisciplinary Approach to Perinatal Cardiology *Volume 1*

Edited by P. Syamasundar Rao and Dharmapuri Vidyasagar



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Book Description

Recent developments in diagnostic and therapeutic aspects of cardiac and neonatal issues have advanced the care of the newborn. To achieve excellence in cardiac care, however, close interaction and collaboration of the pediatric cardiologists with neonatologists, pediatricians, general/family practitioners (who care for children), anesthesiologists, cardiac surgeons, pediatric cardiac intensivists, and other subspecialty pediatricians is mandatory. This book provides the reader with up-to-date evidence-based information in three major areas of neonatology and prenatal and neonatal cardiology. First, it provides an overview of advances in the disciplines of neonatology, prenatal and neonatal cardiology, and neonatal cardiac surgery in making early diagnosis and offering treatment options. Secondly, it presents a multidisciplinary approach to managing infants with congenital heart defects. Finally, it provides evidence-based therapeutic approaches to successfully treat the fetus and the newborn with important neonatal issues and congenital cardiac lesions. This first volume specifically explores issues related to perinatal circulation, the fetus, ethics, changes in oxygen saturations at birth, and pulse oximetry screening, diagnosis, and management.

About the Editors

Dr P. Syamasundar Rao, MD, DCH, FAAP, FACC, FSCAI, is Professor of Pediatrics and Medicine and Emeritus Chief of Pediatric Cardiology at the University of Texas-Houston Medical School. He received his medical degree from Andhra Medical College, India, and subsequently received post-graduate training both in India and the USA before joining the faculty at the Medical College of Georgia, USA, in 1972. He has also served as Chairman of Pediatrics at King Faisal Specialist Hospital and Research Center, Saudi Arabia, and Professor and Director of the Division of Pediatric Cardiology at the University of Wisconsin and St. Louis University, USA. He has authored 400 papers, 16 books and 150 book chapters, and is a recipient of numerous honors and awards.

Dr Dharmapuri Vidyasagar, MD, MSc, FAAP, FCCM, PhD (Hon), is currently Professor Emeritus in Pediatrics at the University of Illinois, Chicago, where he served as Professor of Pediatrics for four decades. He is a graduate of Osmania Medical College, India. He has published over 250 papers and authored several books with a focus on prematurity, neonatal pulmonary diseases and neonatal ventilation. His goal is to reduce neonatal mortality in the USA and around the world, and he has received multiple awards and honors including the Ellis Island Award.

A Multidisciplinary Approach to Perinatal Cardiology Volume 1 is available now in Hardback from the Cambridge Scholars website, where you can also access a free 30-page sample.

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National Perinatal Association + NICU Parent Network

Online L&D Staff Education Program

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Continuing education credits provided by

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About the Program

- **WHO SHOULD TAKE THE PROGRAM?** This program is designed for both office and hospital staff in all disciplines that interact with pregnant patients and their families. A key focus is recognizing risk factors for perinatal mood and anxiety disorders, and mitigating their impact through provision of trauma-informed care.

- **WHY TAKE THE PROGRAM?** Families will benefit when staff have improved skills, through enhanced parental resilience and better mental health, and improved parent-baby bonding leading to better developmental outcomes for babies. Benefits to staff include improved skills in communicating with patients; improved teamwork, engagement and staff morale; reduced burnout, and reduced staff turnover.

- **HOW DOES THE PROGRAM ACHIEVE ITS GOALS?** Program content is representative of best practices, engaging and story-driven, resource-rich, and developed by a unique interprofessional collaboration of obstetric and neonatal professionals and patients. The program presents practical tips and an abundance of clinical information that together provide solutions to the emotional needs of expectant and new parents.

- **HOW WAS THE PROGRAM DEVELOPED?** This program was developed through collaboration among three organizations: a multidisciplinary group of professionals from the National Perinatal Association and Patient + Family Care, and parents from the NICU Parent Network. The six courses represent the different stages of pregnancy (antepartum, intrapartum, postpartum), as well as perinatal mood and anxiety disorders, communication techniques, and staff support.

Program Objectives

- Describe principles of trauma-informed care as standards underlying all communication during provision of maternity care in both inpatient and outpatient settings.
- Identify risk factors, signs, and symptoms of perinatal mood and anxiety disorders; describe treatment options.
- Define ways to support pregnant patients with high-risk conditions during the antepartum period.
- Describe obstetric violence, including ways that providers may contribute to a patient's experience of maternity care as being traumatic; equally describe ways providers can mitigate obstetric trauma.
- Describe the importance of providing psychosocial support to women and their families in times of pregnancy loss and fetal and infant death.
- Define the Fourth Trimester, and identify the key areas for providing psychosocial support to women during the postpartum period.
- Identify signs and symptoms of burnout as well as their ill effects, and describe both individual and systemic methods for reducing burnout in maternity care staff.

Continuing education credits will be provided for physicians, clinic and bedside nurses, social workers, psychologists, and licensed marriage and family therapists. CEUs will be provided by Perinatal Advisory Council: Leadership, Advocacy, and Consultation.

PROGRAM CONTENT

COMMUNICATION SKILLS CEUs offered: 1

Learn principles of trauma-informed care, use of universal precautions, how to support LGBTQ patients, obtaining informed consent, engaging in joint decision-making, delivering bad news, dealing with challenging patients.

Faculty: Amina White, MD, MA, Clinical Associate Professor, Department of OB/Gyn, University of North Carolina, Chapel Hill, NC; Sue Hall, MD, MSW, FAAP, St. John's Regional Medical Center, Oxnard, CA; Karen Saxer, CNM, MSN, University of North Carolina Maternal-Fetal Medicine, UNC Women's Hospital, Chapel Hill, NC; Tracy Pella, Co-Founder & President, Connected Forever, Tecumseh, NE.

PERINATAL MOOD AND ANXIETY DISORDERS CEUs offered: 1

Identify risk factors for and differential diagnosis of PMADs (perinatal mood and anxiety disorders), particularly perinatal depression and/or anxiety and posttraumatic stress syndrome. Learn the adverse effects of maternal depression on infant and child development, and the importance of screening for and treating PMADs.

Faculty: Linda Baker, PsyD, psychologist at Unstuck Therapy, LLC, Denver, CO; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Angela Davids, Founder of Keep 'Em Cookin', Baltimore, MD; Brittany Boet, Founder of Bryce's NICU Project, San Antonio, TX.

PROVIDING ANTEPARTUM SUPPORT CEUs offered: 1

Identify psychosocial challenges facing high risk OB patients, and define how to provide support for them, whether they are inpatient or outpatient. Recognize when palliative care is a reasonable option to present to pregnant patients and their families.

Faculty: Amina White, MD, MA, Clinical Associate Professor, Department of OB/Gyn, University of North Carolina, Chapel Hill, NC; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Angela Davids, Founder of Keep 'Em Cookin', Baltimore, MD; Erin Thatcher, BA, Founder and Executive Director of The PPROM Foundation, Denver, CO.

PROVIDING INTRAPARTUM SUPPORT CEUs offered: 1

Describe how to manage patient expectations for labor and delivery including pain management; identify examples of obstetric violence, including identification of provider factors that may increase patients' experience of trauma; learn how to mitigate patients' trauma, and how to provide support during the process of labor and delivery.

Faculty: Sara Detlefs, MD, Fellow in Maternal-Fetal Medicine, Baylor College of Medicine, Houston, TX; Jerry Ballas, MD, MPH, Associate Clinical Professor, UCSD Health System, Maternal-Fetal Medicine, Department of Obstetrics, Gynecology and Reproductive Sciences, University of California at San Diego, San Diego, CA; MaryLou Martin, MSN, RNC-NIC, CKC, Women's and Children's Services Nurse Educator, McLeod Regional Medical Center, McLeod, SC; Claire Hartman, RN, IBCLC, Labor & Delivery, University of North Carolina Hospital, Chapel Hill, NC; Crystal Duffy, Author of Twin To Twin (from High Risk Pregnancy to Happy Family), and NICU Parent Advisor, Houston, TX; Erin Thatcher, Founder and Executive Director of The PPROM Foundation, Denver, CO.

PROVIDING POSTPARTUM SUPPORT CEUs offered: 1

Define the 4th Trimester and the importance of follow-up especially for high risk and minority patients, learn to recognize risk factors for traumatic birth experience and how to discuss patients' experiences postpartum; describe the application of trauma-informed care during this period, including support for patients who are breastfeeding and those whose babies don't get to go home with them.

Faculty: Amanda Brown, CNM, University of North Carolina Hospital, Chapel Hill, NC; ; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Crystal Duffy, Author of Twin To Twin (from High Risk Pregnancy to Happy Family), and NICU Parent Advisor, Houston, TX.

SUPPORTING STAFF AS THEY SUPPORT FAMILIES CEUs offered: 1

Define burnout and compassion fatigue; identify the risks of secondary traumatic stress syndrome to obstetric staff; describe adverse impacts of bullying among staff; identify the importance of both work-life balance and staff support.

Faculty: Cheryl Milford, EdS, Consulting NICU and Developmental Psychologist, Director of Development, National Perinatal Association, Huntington Beach, CA; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Erin Thatcher, BA, Founder and Executive Director, The PPROM Foundation, Denver, CO

Cost

- RNs: $10/CEU; $60 for the full program
- Physicians, licensed clinical social workers (LCSWs), licensed marriage and family therapists (LMFTs): $35/CEU; $210 for the full program
- Although PACLAC cannot award CEs for certified nurse midwives, they can submit certificates to their own professional organization to request credit. $35/CEU; $210 for the full program

Contact help@myperinatalnetwork.org to learn more.

Faculty

Linda Baker, PsyD
Psychologist at Unstuck Therapy, LLC, Denver, CO.

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CANCELLATIONS AND REFUNDS

- For Individual Subscribers:
  - If you elect to take only one course, there will be no cancellations or refunds after you have started the course.
  - If you elect to take more than one course and pay in advance, there will be no cancellations or refunds after payment has been made unless a written request is sent to help@myperinatalnetwork.com and individually approved.
- For Institutional Subscribers:
  - After we are in possession of a signed contract by an authorized agent of the hospital and the program fees have been paid, a 50% refund of the amount paid will be given if we are in receipt of a written request to cancel at least 14 (fourteen) days prior to the scheduled start date for your hospital's online program.
  - Refunds will not be given for staff members who neglect to start the program. Also, no refunds for those who start the program, but do not complete all 6 courses within the time frame allotted.

For Physicians: This activity has been planned and implemented in accordance with the Institute for Medical Quality and the California Medical Association's CME Accreditation Standards (IMQ/CMA) through the Joint Providership of the Perinatal Advisory Council: Leadership, Advocacy and Consultation (PAC/LAC) and the National Perinatal Association. PAC/LAC is accredited by the Institute for Medical Quality/California Medical Association (IMQ/CMA) to provide continuing education for physicians. PAC/LAC takes responsibility for the content, quality and scientific integrity of this CME activity. PAC/LAC designates this activity for a maximum of 6 *AMA PRA Category 1 Credit(s)TM*. Physicians should only claim credit commensurate with the extent of their participation in the activity. This credit may also be applied to the *CMA Certification in Continuing Medical Education*.

For Nurses: The Perinatal Advisory Council: Leadership, Advocacy and Consultation (PAC/LAC) is an approved provider by the California Board of Registered Nursing Provider CEP 5862. When taken as a whole, this program is approved for 7 contact hours of continuing education credit.

For CAMFT: Perinatal Advisory Council: Leadership, Advocacy, and Consultation (PAC/LAC) is approved by the California Association of Marriage and Family Therapists to sponsor continuing education for LMFTs and LCSWs. CE Provider #128542. PAC/LAC maintains responsibility for the program and its content. Program meets the qualifications for 6 hours of continuing education credit for LMFTs and LCSWs as required by the California Board of Behavioral Sciences. You can reach us at help@myperinatalnetwork.org.

Alliance for Patient Access: Protection for Babies Restored by Court Stay

Josie Cooper

The Alliance for Patient Access (allianceforpatientaccess.org), founded in 2006, is a national network of physicians dedicated to ensuring patient access to approved therapies and appropriate clinical care. AfPA accomplishes this mission by recruiting, training and mobilizing policy-minded physicians to be effective advocates for patient access. AfPA is organized as a non-profit 501(c)(4) corporation and headed by an independent board of directors. Its physician leadership is supported by policy advocacy management and public affairs consultants. In 2012, AfPA established the Institute for Patient Access (IfPA), a related 501(c)(3) non-profit corporation. In keeping with its mission to promote a better understanding of the benefits of the physician-patient relationship in the provision of quality healthcare, IfPA sponsors policy research and educational programming.

AfPA | Alliance for Patient Access

IfPA | Institute for Patient Access

"

A federal judge paused efforts to modify the national vaccine schedule. The Centers for Disease Control, or CDC, will continue to recommend vaccinating infants for hepatitis B, among other communicable diseases. By reversing the Trump administration's efforts to alter long-standing immunization schedules, the judge's ruling restored a crucial safeguard for public health. Pediatricians and experts, on behalf of the youngest Americans, are breathing a sigh of relief."

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"Maintaining predictable, well-established recommendations ensures that families and clinicians receive consistent advice and access to care."

Maintaining predictable, well-established recommendations ensures that families and clinicians receive consistent advice and access to care.

Childhood immunization is a hallmark and a safeguard of modern public health. By interrupting the spread of transmissible illnesses, vaccines have vastly reduced disability and death. Protecting as many eligible children and adults as possible against these diseases also reduces the risk of exposure for individuals who cannot be vaccinated.

"Vaccine checkpoints at or shortly after birth are shown to help families comply with expert recommendations. Experts warn that vaccine uptake will be lower without a strong, consistent recommendation. As a result, babies will be put at risk from preventable diseases."

Consistent Recommendations Support Infant Health:

Vaccine checkpoints at or shortly after birth are shown to help families comply with expert recommendations. Experts warn that vaccine uptake will be lower without a strong, consistent recommendation. As a result, babies will be put at risk from preventable diseases.

The hepatitis B vaccine was one of those targeted for removal from CDC recommendations. Given shortly after birth, the vaccine is proven to prevent early infection and chronic liver disease. Five other vaccines were also potentially under threat: rotavirus,

hepatitis A, hepatitis B, influenza, and meningitis.

Infants already at high risk, including those from rural areas with few hospitals, could be less likely to receive the vaccines if the birth dose is missed. Lower vaccine coverage rates increase risk across the population.

"By pausing the proposed changes, the court ruling helps preserve trust in vaccines and the protection they offer. Families and clinicians should be confident that recommendations are driven by evidence, not politics."

Preserve Public Trust in Vaccine0:

Vaccines have saved at least 150 million lives in the past century, or about one life every ten seconds, experts estimate. Safeguarding those gains requires continued public support and insurance coverage for the full range of available protection.

By pausing the proposed changes, the court ruling helps preserve trust in vaccines and the protection they offer. Families and clinicians should be confident that recommendations are driven by evidence, not politics.

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

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Immunizing Yourself Against **COVID-19**

COVID-19 vaccines have been shown to:

- Lessen the severity of symptoms[1]
- Reduce disease transmission[3]
- Reduce risk of mortality[2]
- Make communities healthier and safer[4]

Understanding the Options

COVID-19 vaccines are available for children, adolescents and adults. There are 3 types to choose from.

mRNA VACCINES

New to market, but research has been ongoing since the 1990s.

HOW THEY WORK: **Instruct cells to make COVID-like proteins that trigger the immune system to fight the virus.**

PROTEIN SUBUNIT VACCINES

Used for three decades against the flu, whooping cough and hepatitis B.

Deliver harmless versions of the COVID protein that train the immune system to fight the virus.

VECTOR VACCINES

Used for decades against chickenpox, malaria and tuberculosis.

Use a modified virus, such as a common cold, to teach the body to fight off COVID.

COVID vaccines are recommended for everyone ages 6 months and older, and boosters for everyone ages 5 years and older, if eligible.[5]

Safe and Sound

COVID vaccines have been:

- **Thoroughly tested** through multi-phase trials with tens of thousands of participants[6]
- **Proven safe and effective** for adults as well as children[7]
- **Vetted and approved** by the US FDA and EMA and endorsed by the WHO[8-10]

Get Your Jab

Vaccines are available at your:

- **Doctor's office**
- **Neighborhood pharmacy**
- **Community health center**

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

1. https://www.mayoclinic.org/diseases-conditions/coronavirus/symptoms-causes/syc-20479963
2. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8782520/
3. https://www.nejm.org/doi/full/10.1056/nejmc2107717
4. https://royalsocietypublishing.org/doi/full/10.1098/rsif.2020.0683
5. https://www.cdc.gov/vaccines/covid-19/clinical-considerations/interim-considerations-us.html
6. https://doh.wa.gov/emergencies/covid-19/vaccine-information/safety-and-effectiveness
7. https://doh.wa.gov/emergencies/covid-19/vaccine-information/safety-and-effectiveness
8. https://www.fda.gov/emergency-preparedness-and-response/coronavirus-disease-2019-covid-19/covid-19-vaccines
9. https://www.ema.europa.eu/en/human-regulatory/overview/public-health-threats/coronavirus-disease-covid-19/treatments-vaccines/vaccines-covid-19/covid-19-vaccines-authorised
10. http://www.bccdc.ca/Health-Info-Site/Documents/COVID-19_vaccine/WHO-EUA-qualified-covid-vaccines.pdf

GAfPA Global Alliance for Patient Access

NCPA NATIONAL COMMUNITY PHARMACISTS ASSOCIATION

Still a **Preemie?**

Some preemies are born months early, at extremely low birthweights. They fight for each breath and face nearly insurmountable health obstacles.

But that's not every preemie's story.

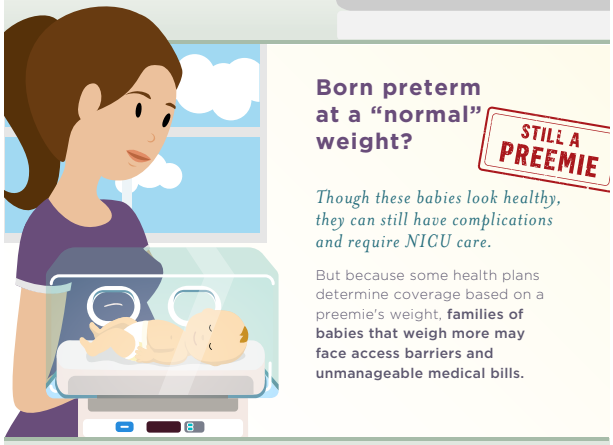
Born between 34 and 36 weeks' gestation?

STILL A PREEMIE

Just like preemies born much earlier, these "late preterm" infants can face:

Jaundice | Feeding issues | Respiratory problems

And their parents, like all parents of preemies, are at **risk for postpartum depression and PTSD.**



Born preterm at a "normal" weight?

STILL A PREEMIE

Though these babies look healthy, they can still have complications and require NICU care.

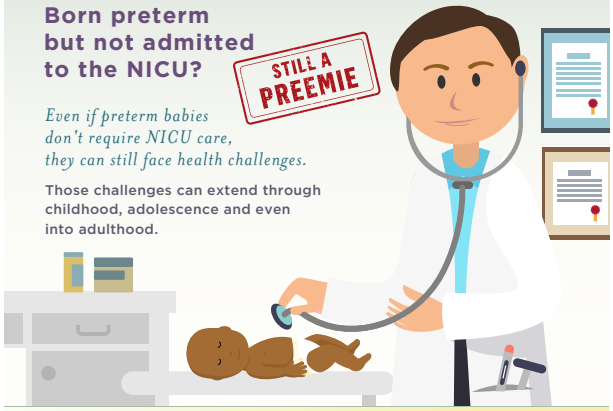
But because some health plans determine coverage based on a preemie's weight, **families of babies that weigh more may face access barriers and unmanageable medical bills.**

Born preterm but not admitted to the NICU?

STILL A PREEMIE

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

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



Some Preemies

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

All Preemies

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

NCfIH National Coalition for Infant Health

Protecting Access for Premature Infants through Age Two

www.infanthealth.org

The Gap Baby: An RSV Story

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

The National Coalition for Infant Health advocates for:

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

www.infanthealth.org

iCAN Update: April Showers Are not Raining on these iCAN Youth Members' Parades!

Abby Clark

Get involved today and Join the iCAN Parent Council!

As the rain soaks the earth and grass starts to grow, April finds iCAN youth members springing into action. Giving their expert opinions, sharing their stories, and traveling around the world, iCAN youth members have imbued the global healthcare community with their empowering spirit. Read below to learn more about the incredible work they have done this month.

What is in this Issue of the iCAN Newsletter?

"As the rain soaks the earth and grass starts to grow, April finds iCAN youth members springing into action. Giving their expert opinions, sharing their stories, and traveling around the world, iCAN youth members have imbued the global healthcare community with their empowering spirit. Read below to learn more about the incredible work they have done this month."

What is iCAN?

Empowering Pediatric Patients Worldwide

iCAN, the International Children's Advisory Network, is the premier global pediatric platform working to empower the patient voice in healthcare, driven by youth for youth. As a worldwide network of 40+ KIDS (Kids Impacting Disease through Science) advisory groups spanning four continents (and virtually), iCAN's dedicated youth member groups work in unison to provide a voice for children and families in medicine, research, science, and innovation. To foster greater global understanding about the importance of the pediatric patient and caregiver voice in healthcare, clinical trials, and research, iCAN's young people continue to drive incredible change in the global health landscape.

On average, our youth are between the ages of eight and eighteen years old, most of whom are living with chronic, rare, and complicated diagnoses; although, not all of iCAN's youth members have a medical diagnosis or medical condition. iCAN celebrates the understanding that all patients, even the youngest, have valuable insights into improving the healthcare experience. All children, regardless of where they live, are welcome to participate in iCAN's programming. iCAN also supports young adults and the voices of parents and siblings. We continue to be an ecosystem of schools, children's hospitals, academia, and other like-minded nonprofits.

Our mission is to ensure that youth are placed in positions where their voices are heard and make a difference in pediatric healthcare through interactions with industry professionals, presenting original research at conferences, innovating new solutions, and sharing their stories. iCAN continues to empower the pediatric

patient voice through community partnerships with organizations such as the FDA, Everylife Foundation for Rare Diseases, PFMD, MRCT, iSPI, and AAP.

"Whether a patient, family member, friend, healthcare professional, or just an individual looking to make a difference, you are welcome to visit our website at www.icanresearch.org to explore our mission, programs, and initiatives. Join us today in ensuring that every child's voice is enshrined in the effort to improve healthcare for all pediatric patients."

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iCAN Impact - KIDS Walter Payton Sharing Joy

This month, we are proud to spotlight one of iCAN's most active chapters - KIDS Walter Payton (WP). They took the initiative to support their local community through their March Challenge of 10. Applying and becoming recipients for the grant: Youth Service America and The Hershey Company through The Heartwarming Project, KIDS WP took their Challenge of 10 to new heights! Titled "iCAN Deliver Hope," their youth-led initiative brought together student volunteers to assemble and deliver comfort kits for families staying at the Ronald McDonald house while their children receive medical care. Kits will include essentials, comfort items, books, socks, stuffed animals, coloring books, and handmade cards created by students.

"Writing the grant and reaching out to partners for donations, then seeing it all come together into actual care packages was incredible," said Leo Larvick, 17, a senior and chapter member. "It felt good knowing that we were doing something that could make a stressful situation a little easier for someone else."

"'Writing the grant and reaching out to partners for donations, then seeing it all come together into actual care packages was incredible,' said Leo Larvick, 17, a senior and chapter member. 'It felt good knowing that we were doing something that could make a stressful situation a little easier for someone else.'"

From organizing to hands-on volunteering, this youth-led effort is all about compassion, community, and making a meaningful impact where it is needed most.

"On May 1, iCAN's Executive Director, Sabina, and Director of Operations, Abby, were invited to offer a few words of encouragement in celebration of iCAN KIDS WP's accomplishments. We are so inspired by their dedication to supporting families during challenging times—keep up the incredible work!"

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accomplishments. We are so inspired by their dedication to supporting families during challenging times—keep up the incredible work!

iCAN Youth Member Spotlight: iCAN Youth Member Travels to Pharma-Sponsored Panel

iCAN is proud to spotlight KIDS CHOC youth member, Anvita! Not only is Anvita the president of the KIDS CHOC chapter, but she is also an iCAN Young Professionals Network Co-Chair, a member of the 2026 KIDS Summit Planning Committee, and on the KIDS Research Leadership board.

An incredible advocate and advisor, Anvita and her mom, Gauri, traveled to Pennsylvania to Philadelphia to participate in a panel discussion with colleagues from Pfizer, where they shared their experiences collaborating on patient-centered design initiatives. Speaking on a patient panel, Anvita shared her expert voice with professionals in the pharma healthcare space. As a young person with lived experience, Anvita used this opportunity to share her experiences during her healthcare journey and how they have impacted the empowering work she continues to do with and outside of iCAN.

"An incredible advocate and advisor, Anvita and her mom, Gauri, traveled to Pennsylvania to Philadelphia to participate in a panel discussion with colleagues from Pfizer, where they shared their experiences collaborating on patient-centered design initiatives. Speaking on a patient panel, Anvita shared her expert voice with professionals in the pharma healthcare space."

"I was honored to represent the iCAN parent and the caregiver's voice to emphasize that the clinical trials should be designed with patients and families, not just for them." (Gauri, iCAN Parent)

"It was such an empowering experience to share my story with the Pfizer team and know that my voice and opinion are valued and heard" (Anvita, iCAN Youth Member).

iCAN KIDS Chapter Spotlight (KIDS Mexico City and KIDS Albania)

This month, we are proud to highlight KIDS Mexico City and their recent event, where they met with Francisco Alanis, journalist and creator of Sopitas.com. At their special meeting with Sopitas, they shared conversation, questions, and ideas, and introduced their mobile video game, "A Day in My Shoes," to Francisco. The app was developed by APAC (the nonprofit KIDS Mexico City is associated with) as a tool to shed light on the barriers people with disabilities face every day. After introducing the app, the group had a meaningful conversation about inclusion, representation, and the media's role in building fairer narratives.

We are also proud to highlight KIDS Albania! They recently traveled to Paris, France, for the 2nd ERDERA Training for Young Advocates for Rare Diseases at Institut Imagine. Over three days, they were able to connect with inspiring young advocates across Europe and interact with them on key topics such as the following:

- Clinical Trials
- Patient Engagement
- The Role of YPAG in Research

This incredible opportunity acted as a reminder that young voices are essential to the future of healthcare and ensuring that health spaces reflect pediatric patients' wants and needs.

Every day, iCAN chapters engage with their local communities to ensure that pediatric patients, both near and far, are included in the conversation. We are so proud of APAC and KIDS Mexico City for engaging with their local movers and shakers to empower pediatric patients through awareness and connection.

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Upcoming Ask the Experts: Mark your calendars- iCAN invites you to another installment of Ask the Experts on May 16!

Next Episode: May 16 at 10 a.m. EST with special guest, Dr. Maryanne Haddad (Physician- Internal Medicine/Obesity/Sleep Medicine at Metrohealth Medical Center, ABOM board certified in Obesity Medicine) hosted by KIDS Member Piyush.

In May, iCAN will host Dr. Maryanne Haddad as she walks us through her incredible career as an Internal Medicine/Obesity/Sleep medicine doctor.

Bio:

- Dr. Haddad is board-certified in Obesity Medicine (ABOM) and brings a thoughtful, patient-centered approach to care, focusing on the powerful connections among weight, metabolism, sleep, and overall health. Her work goes beyond treatment, empowering patients with the knowledge and tools needed for lasting, meaningful change.
    - Areas of Expertise:
    - Obesity medicine & metabolic health
    - Sleep disorders and whole-body wellness
    - Preventive care & chronic disease management
    - Sustainable, patient-centered lifestyle changes

Hosted by iCAN KIDS Member, Piyush

- Piyush is a 16-year-old high school sophomore who loves soccer, reading, and learning—and takes every opportunity to grow and engage.

Session Details: ATE: Dr. Maryanne Haddad (Physician- Internal Medicine/Obesity/Sleep Medicine at Metrohealth Medical Center, ABOM board certified in Obesity Medicine) hosted by KIDS Member Piyush.

Date: Saturday, May 16h, 2026

Time: 7:00 AM PST / 10:00 AM EST

Ask the Experts brings in speakers every month to answer your questions about medicine, healthcare, research, innovation, and much more! Check out the ATE page on the iCAN Website to view previous recordings.

"Our annual Summit serves as a transformative platform for innovation, compassion, and collaboration in pediatric healthcare. As iCAN celebrates our 12th year of this incredible event, iCAN is so excited to announce that the iCAN Summit is back this summer in person."

The 2026 iCAN Summit - Registration Open

Our annual Summit serves as a transformative platform for innovation, compassion, and collaboration in pediatric healthcare. As iCAN celebrates our 12th year of this incredible event, iCAN is so excited to announce that the iCAN Summit is back this summer in person. It is truly a testament to iCAN's dedicated and

generous family that the Summit will continue to bring our young people together to cLink to Register: https://www.zeffy.com/en-US/ticketing/registration-for-icans-2026-summit

"The 2026 iCAN Summit will be held July 12 (check-in) through July 17 (check-out), 2026, at Barretstown in Ireland (approximately one hour outside of Dublin), and will be hosted by KIDS RAiN CRAG. Set on beautiful, expansive grounds, Barretstown is a fully wheelchair-accessible SeriousFun therapeutic recreation camp, thoughtfully designed to support a wide range of physical and medical needs."

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The lasting impact of this annual event on the youth who attend, the iCAN Network, and the wider healthcare community cannot be measured. Together, we continue to impact pediatric healthcare in tangible ways. By giving every kid a seat at the table through discussion and co-creation, current and future pediatric patients are both empowered and transformed. We invite you to be part of this life-changing event by contributing in three meaningful ways:

1. Sponsor the 2026 Summit: Your sponsorship will play a crucial role in ensuring an impactful experience for all attendees.
2. Sponsor a Child to Attend: Your sponsorship directly impacts a child's life by granting them the opportunity to attend the Summit in Ireland. Your support will cover travel, accommodation, and participation, offering them a world of learning and empowerment.

   Together, we are shaping a brighter future for pediatric healthcare. Your contribution—big or small—makes a significant difference in prioritizing the patient voice and driving positive change. Your generosity and dedication are deeply valued. Let us unite in Ireland to create a summit experience that empowers the pediatric community for years to come.
3. Contribute to the GoFundMe for the iCAN 2026 Summit: We want our next Summit to be in person—and we can only do that with your support! Please share or donate to our GoFundMe:

   - https://gofund.me/525439b3
   - www.icanresearch.org

Let us work together to make our 2026 Summit even bigger by bringing more kids to share their voices! To contribute to the funding for next year's Summit, please click here to sponsor or make a donation.

Disclosures: *There are no reported disclosures*

NT

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Pali Adventures
PORTO ELOUNDA
GOLF & SPA RESORT
WESTIN
HOTELS & RESORTS
The Westin Long Beach
MARRIOTT
Beverly Hills Marriott
DELTA HOTELS
MARRIOTT
Delta Hotels Montreal
cancúncards
Zachari Dunes
DOUBLETREE by Hilton
Ontario
SOUTH POINT
MIRACLE SPRINGS
RESORT & SPA
PORTER VALLEY
COUNTRY CLUB
THE ACADEMY of MAGICAL ARTS
AT THE MAGIC CASTLE
PEJU
NAPA VALLEY
LA OPERA
Pacific Symphony
CARL ST.CLAIR MUSIC DIRECTOR
CRUISE COMPETE
Dunes West
GOLF & RIVER CLUB
AMERICA'S RAILROAD
DURANGO & SILVERTON
NARROW GAUGE RAILROAD
BEVERLY HILLS
Plastic Surgery Group
SABAN THEATRE
Powered by STERLING VENUE VENTURES
LONG BEACH
SYMPHONY
ECKART PREU, MUSIC DIRECTOR
FLAPPERS
COMEDY CLUB AND RESTAURANT
BURBANK
Pacific Chorale
GEFFEN PLAYHOUSE
LINKSOUL
CHANCE
THEATER @ Bette Aitken theater arts Center
lucky feet
shoes
THE SORAYA
TAHOE DONNER
PEPPERDINE
Lisa Smith Wengler Center for the Arts
ISLAND PACKERS
citycruises
SMOKE HOUSE
Established 1948
VERDE CANYON RAILROAD
ILLUSION
MAGIC LOUNGE
LA MIRADA THEATRE
FOR THE PERFORMING ARTS
LAGUNA
PLAYHOUSE
HAGAFEN
FAMILY OWNED
EST. 1979
Jack
in the box
aNoiseWithin
Classic Theatre, Modern Magic
PASADENA
PLAYHOUSE
DiscoveryCube
OC & LA
tieks
by Gavrieli
Murad
gorjana
RESTAURANT
GREEN STREET
WHEEL FUN
RENTALS
USS Midway
MUSEUM
AMERICA'S LIVING
SYMBOL OF FREEDOM
KINGS ICE
California
BOTANIC GARDEN
Betty Up
Raising Cane's
CHICKEN FINGERS
BATTLESHIP
IOWA
LOS ANGELES
NEW WEST SYMPHONY
MICHAEL CHRISTIE | Music Director
PHILHARMONIC
SOCIETY
presents
NEWPORT
LANDING
THE MISSION INN FOUNDATION
RIVERSIDE
VISITOR CENTER + MUSEUM
Fiesta Village
Family Fun Park
WILLIAM BEAR
THEATRICUM · BOTANICUM
CPH CORONADO
PLAYHOUSE
Irvine Lanes
SIMMS
RESTAURANTS
THE HUNTINGTON
Hollywood
WAX MUSEUM
SANTA
MONICA
PLAYHOUSE
SANTA ANITA
PARK
Go Kart World
OLIO E LIMONE
RISTORANTE
DOMENICO'S
RESTAURANT
ENJOY DELIGHT.
YOU DESERVE IT.
Brent's
CHIPOTLE
MEXICAN GRILL
Panera
BREAD
Caroline Arnold, Author
BARK
BOX
PETERSEN
AUTOMOTIVE MUSEUM

Join iCAN's Virtual Focus Group!

We warmly welcome all individuals within the age ranges of 8-10 and 12-18, including those with:

- Learning disabilities (example: dyslexia)
- Speech or language disabilities (examples: stuttering, understanding others, hearing)
- Physical disabilities (examples: epilepsy, cystic fibrosis)
- Autism Spectrum Disorder (ASD) or Attention-Deficit/Hyperactivity Disorder (ADHD)

Every voice counts!

It's a one-minute survey to see if you qualify for a one-hour focus group to be scheduled at a later date.

Survey Link: bit.ly/icanxkismet

Fill out the recruitment survey now and let your voice be heard! Together, we can make a real difference in pediatric healthcare!

iCAN
International Children's Advisory Network

Education.
Anytime, Anywhere.

Academy of Neonatal Care

The Academy of Neonatal Care serves to educate Respiratory Therapists, Nurses, and Doctors in current and best practices in Neonatal ICU care. We prepare RT's new to NICU to fully function as a bedside NICU RT. Our goal is to enrich NICU care at all levels. Beginner to Advanced Practice, there is something for you at:

www.AcademyofNeonatalCare.org.

Peer Reviewed

Briefly Legal: Are Standards of Care for Neonatal Resuscitation ZIP Code Dependent?

Maureen Sims, MD, Barry Schifrin, MD

It has been said that the need for medical care is independent of what one can afford. Disparities in health care, however, vary widely, not only by income but also by race and gender. We present a case where this applies to age, the youngest age.

The patient is a 25-year-old $G_{2q}P_0$, married, pregnant woman with a history of post-traumatic stress disorder, depression, anxiety, substance abuse, and domestic violence. She was on no medications during pregnancy but admitted to smoking marijuana throughout pregnancy for "pain."

"Her prenatal course was complicated by intermittent vaginal bleeding from a subchorionic (subplacental) hematoma first detected by ultrasound at 8 weeks' gestation. Disparities in health care, however, vary widely, not only by income but also by race and gender. We present a case where this applies to age, the youngest age."

Her prenatal course was complicated by intermittent vaginal bleeding from a subchorionic (subplacental) hematoma first detected by ultrasound at 8 weeks' gestation. Over the course of pregnancy, she was seen from 12 weeks onward and gained 35 pounds. At 39 weeks' gestation, she was scheduled for induction of labor. Despite the medical and psychological problems and the potential problems with the neonate, she is admitted to a rural hospital with an obstetrical unit that delivers <600 babies from low-risk mothers per year. The closest hospital with a full obstetrical unit and Level 3 NICU was <1 hour drive away.

On admission, a fetal monitor is applied, revealing a normal, reassuring pattern with intermittent contractions. The patient started on several doses of Cytotec for induction with progressively increasing contractions but little progress in cervical dilatation or change in the fetal condition. At about 28 hours after admission, the monitor was removed, and the patient was permitted to ambulate. Within minutes, there was a spontaneous rupture of membranes (clear fluid) followed by a large gush of blood from the vagina. The patient was immediately returned to her bed while the obstetrician was paged at home. The monitor, having been applied, showed a fetal bradycardia of about 60 bpm. IV fluids and oxygen by face mask were administered while additional personnel, including the pediatrician (at home), were mobilized for an emergency cesarean section for the presumptive diagnosis of placental abruption. The cesarean delivery was completed within 30 minutes of the onset of the bleeding episode.

"At about 28 hours after admission, the monitor was removed, and the patient was permitted to ambulate. Within minutes, there was a spontaneous rupture of membranes (clear fluid) followed by a large gush of blood from the vagina. The patient was immediately returned to her bed...The monitor, having been applied, showed a fetal bradycardia of about 60 bpm. IV fluids and oxygen by face mask were administered while additional personnel, including the pediatrician (at home), were mobilized for an emergency cesarean section for the presumptive diagnosis of placental abruption. The cesarean delivery was completed within 30 minutes of the onset of the bleeding episode."

At delivery, the obstetrician noted that the placenta had a velamentous cord insertion and the amniotic fluid was clear. The cord was not torn. Cord blood gases were not sent. On pathologic examination, the placenta weighed 661 grams, with a tri-vascular cord measuring 16 cm, showing normal coiling and marginal insertion. The fetal/placental ratio (FPR), normally about 7.4 +/- 0.5 at term, was 4.4, and was implausibly referred to as an "LGA placenta," showing no evidence of infection or abruption. The pathologist retained by the defense stated in his report that marginal insertion probably led to repeated acute transient obstruction and acute hypoxic injury and resulted in intrauterine growth restriction (IUGR). This explanation does not explain the acute bleeding and deterioration of the fetal tracing. The prenatal records do not reflect any question of uterine growth or IUGR.

At birth, the 2811-gram male infant was lifeless. The Apgar scores were 0, 0, 0, 1, and 3 at 1, 5, 10, and 20 minutes, respectively. Two labor and delivery nurses dried, stimulated, suctioned, began positive pressure ventilation with a bag and mask, and chest compressions prior to the arrival of the pediatrician at 5 minutes of age (25 minutes after being summoned), The hospital did not have either a resuscitation team or the necessary umbilical catheters

in the OR or a laryngeal airway mask necessary for extensive resuscitation in the entire hospital.

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Upon arrival in the delivery room, the pediatrician attempted intubation unsuccessfully. At 8 minutes, the respiratory therapist (RT) arrived but did not attempt to intubate the baby, stating that hospital policy did not permit her to intubate. At 10 minutes of age, with the baby's heart rate (HR) still undetectable, the Emergency Room physician was summoned to assist. He arrived at 15 minutes and successfully intubated the baby and administered epinephrine via the endotracheal tube. Within seconds, a heart rate was detectable. At 22 minutes, the baby was transported to the NICU on 100% inspired oxygen with positive pressure ventilation (PPV). He had faint pulses, a saturation of 85% with an undetectable blood pressure (BP). An intravenous line (IV) was placed but dislodged and could not be successfully restarted for another 20 minutes. A bedside glucose at 32 minutes was 29 mg/dL. By 1 hour of age, after 5 attempts, a peripheral IV was established, through which a bolus of 2.5 ml of10% dextrose was administered, followed by 25 ml of normal saline. These ministrations resulted in an oxygen saturation of 74% and a BP of 34/18. At 80 minutes, his bedside glucose was 130 mg/dL. After several unsuccessful attempts to insert an umbilical venous catheter (UVC), the efforts were abandoned.

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At the mother's request, another medical facility was called. At 90 minutes, a transfusion of 30 cc (10 ml/kg) was begun and infused over 60 minutes. The transfusion did not affect the baby's BP. At 2 hours and again at 3 hours of age, 10 ml/kg boluses of normal saline (NS) were given. The BP was now 67/43 mmHg. In subsequent depositions, the nurses avowed that they knew that the baby required an infusion of volume but withheld therapy, failing a specific order to provide it. The pediatrician responded that she knew volume was required with intrapartum hemorrhage, a pale baby, and an undetectable BP, but the nurses did not inform her of the low BP.

At 3 hours, a transport team arrived, placed umbilical catheters, and drew an arterial blood gas, revealing a pH of 6.68, a pCO_2 of 46 mmHg, a pO_2 of 51 mmHg, and a base excess of -30.9, a severe metabolic acidosis. The baby was given Ampicillin and Gentamicin before his helicopter transfer to a regional medical center about 6 hours after the inciting bleed.

"At 3 hours, a transport team arrived, placed umbilical catheters, and drew an arterial blood gas, revealing a pH of 6.68, a pCO_2 of 46 mmHg, a pO_2 of 51 mmHg, and a base excess of -30.9, a severe metabolic acidosis."

At the referral hospital, a complete blood count (CBC) showed a WBC of 40, 35% PMN, 6% bands, anemia (hematocrit of 39%), and a platelet count of 154. His creatinine was 1.1, AST 957, and ALT 373.

An MRI showed punctate foci of restricted diffusion in the right posterior periventricular white matter, compatible with acute white matter infarction, as well as several additional punctate foci in the bifrontal subcortical white matter without restricted diffusion.

"An MRI showed punctate foci of restricted diffusion in the right posterior periventricular white matter, compatible with acute white matter infarction, as well as several additional punctate foci in the bifrontal subcortical white matter without restricted diffusion."

The source of the baby's anemia (hct 39%) and the mother's bleeding were never identified, but the plaintiff postulated that it was secondary to fetal hemorrhage during the abruption. Simultaneously, either as a result of uterine tetany in response to the abruption or cord compression occurring during that contraction, the fetus was deprived of blood volume, of red cells, and of oxygen.

Despite the prolonged interval since the birth (>6 hours), he was placed on therapeutic hypothermia (TH) for 24 hours. TH had to be removed on day 1 because of a pulmonary hemorrhage. He required inhaled nitric oxide for 3 days for severe pulmonary

hypertension of the newborn (PPHN). He had oliguria, disseminated intravascular coagulopathy, and seizures. Anticonvulsants were administered to control the seizures. The baby was discharged at 6 weeks of age on no medications and nippling his feeds.

Because of the prenatal marijuana use and her mental illness profile, the mother was followed by Child Protective Services. At 11 months of age, the child tested positive for cocaine, marijuana, and methamphetamines and was removed from the mother's care and adopted successfully by the paternal grandmother. On follow-up evaluation at 3 years, he was diagnosed with cerebral palsy and cognitive, speech, language, and hearing impairment, and issues related to severe aggressive behavior. Clinically, he had been seizure-free for a year and was on tapering doses of anticonvulsants. An extensive workup failed to identify any underlying genetic or metabolic cause of these conditions.

"On follow-up evaluation at 3 years, he was diagnosed with cerebral palsy and cognitive, speech, language, and hearing impairment, and issues related to severe aggressive behavior."

A negligence lawsuit was brought against the obstetrician, nurses, pediatrician, and hospital. The ER physician was not named. The suit against the obstetrician settled almost immediately; the case against the others would proceed to trial. After jury selection in the community where the baby was born and jury members received care, the panel appeared deeply sympathetic to the nurses and providers who testified that they simply "did their best." Facing a jury unlikely to hold local caregivers accountable, the plaintiff settled for a very low amount, an outcome that underscores how geography shapes not only the quality of care a newborn receives but also the prospect of accountability when that care fails.

Plaintiff Allegations

The hospital failed to provide appropriate resuscitation in accordance with the NRP.

They failed to provide necessary tools for neonatal resuscitation, including an umbilical catheter and a laryngeal mask.

They failed to provide the baby with volume promptly.

They failed to follow their own neonatal resuscitation policy, which requires adherence to NRP Guidelines.

The hospital's culture was unsafe.

The nurses displayed conscious indifference by failing to advocate for volume infusion.

As a result of these deviations, the newborn suffered a severe and permanent neurological handicap.

Defense

The child is basically normal with only minor disabilities and will function independently as an adult.

Any handicap suffered by the child was related to the cumulative effect of chronic placental insufficiency, IUGR, marginal cord insertion, and the mother's marijuana use during pregnancy.

The significant cocaine, methamphetamine, and marijuana levels found in the infant at 11 months of age are the cause of any impairments at 4 years of age.

The hospital providers were certified in NRP.

A medical center providing obstetrical and neonatal care in a rural setting does not need to have in-house providers with the required resuscitation skills or to follow the same standards as non-rural institutions.

The absence of documentation is acceptable, as everyone was focused on providing care.

Resuscitation drills are not necessary because the providers are NRP certified. The NRP does not indicate an exclusive course of treatment and is not the standard of care. Variations are appropriate, especially in a rural setting.

Discussion:

This case presents a constellation of institutional, systemic, and individual failures that collectively deprived a newborn of resuscitation in compliance with published standards of care. While the defense attributed any significant adverse outcome to either chronic placental insufficiency, marginal cord insertion, IUGR, and prenatal marijuana exposure or to subsequent exposure to toxic, illicit drugs, the findings do not support a prenatal cause of the infant's catastrophic neurological injury. With a potential contribution of its response to the gush of blood (from an abruption), the evidence strongly suggests that the absence of a functional resuscitation infrastructure—compounded by equipment deficiencies, policy contradictions, and a culture of clinical indifference—was the proximate cause of this child's devastating outcome.

"This case presents a constellation of institutional, systemic, and individual failures that collectively deprived a newborn of resuscitation in compliance with published standards of care."

The 7th edition of the Neonatal Resuscitation Program (NRP) was the version at the time of this case. represents a nationally and internationally recognized framework for the management of newborn resuscitation. Developed jointly by the American Academy of Pediatrics (AAP) and the American Heart Association (AHA), NRP establishes evidence-based competencies intended for universal application wherever deliveries occur. Indeed, the hospital had formally endorsed NRP in its policies and procedures, requiring nurses, physicians, and respiratory therapists to be certified and to follow NRP guidelines—irrespective of location. The hospital failed to follow its own policy.

Some of the statements in the policy, however, contradicted those outlined in the NRP. The hospital policy stated that the pediatrician (the only provider with intubation and UVC placement skills) can be at home and must arrive at the hospital within 30 minutes of an emergency call. In deposition, when asked whether they followed NRP guidelines, they responded, "No, we just do our best." Umbilical catheters that might be needed for resuscitation were

available in the nursery but not in the delivery rooms. A laryngeal mask, which would have been required if intubation failed, was unavailable at any hospital location.

"Umbilical catheters that might be needed for resuscitation were available in the nursery but not in the delivery rooms. A laryngeal mask, which would have been required if intubation failed, was unavailable at any hospital location."

When the nurses were asked why they failed to give volume to a pale, hypotensive baby after a large maternal bleed, they said the physician did not order volume. The pediatrician said she was busy doing other significant interventions, and the nurses did not inform her of the low BP—and she did not ask.

The AAP states explicitly that NRP competency requires regular practice and team-based rehearsals. In deposition, various hospital personnel affirmed that they never do resuscitation drills as required by the NRP. The failure to maintain skill through recurrent drills at this institution rendered its NRP certification a credential without a corresponding practice standard; the NRP endorsement was administrative rather than adherent. Indeed, the hospital's limited number of deliveries per year (<600) would seem to argue for more frequent resuscitation simulations to help providers maintain their skills.

"The AAP states explicitly that NRP competency requires regular practice and team-based rehearsals. In deposition, various hospital personnel affirmed that they never do resuscitation drills as required by the NRP."

The hospital's neonatal resuscitation area was set up for failure. The hospital's culture inhibited Nurses and RTs from providing potentially beneficial interventions. Indeed, the nurses displayed conscious indifference by failing to advocate for volume infusion and by waiting to receive an order. Those failures contributed to the baby's adverse outcome. In their depositions, the collective response from the providers was simply "We do our best" when faced with a depressed baby. There was no thought to measure that performance using established benchmarks and standards.

The defense's assertion that rural medical centers are not obligated to adhere to the same resuscitation standards as non-rural facilities is medically and ethically bereft. Regardless of zip code, hospitals providing labor and delivery care must embrace the notion that every newborn deserves access to a standardized resuscitation response as elaborated in the NRP. It is difficult to imagine any nurse or physician believing that every newborn is not entitled to a standard of care resuscitation. There is no requirement that each facility provide TH, but passive cooling can be implemented in any delivery unit until the previously contacted transport team arrives.

"The defense's assertion that rural medical centers are not obligated to adhere to the same resuscitation standards as non-rural facilities is medically and ethically bereft. Regardless of zip code, hospitals providing labor and delivery care must embrace the notion that every newborn deserves access to a standardized resuscitation response as elaborated in the NRP."

When a hospital elects to operate a labor and delivery unit and provide obstetrical services, it assumes the responsibility of maintaining the personnel, equipment, and systems necessary to manage foreseeable emergencies. A rural hospital that chooses to conduct deliveries cannot subsequently invoke its rural status to justify the absence of basic resuscitative equipment or skilled personnel. The appropriate response to resource limitations in a rural setting is not to lower the standard of care but rather to either achieve and maintain the standard or not perform deliveries. Neonatal resuscitation, as outlined in the NRP, is not a high-tech endeavor and does not require more than oxygen, inexpensive materials, medications, fluids, and blood. It requires a fundamental understanding of pathophysiology and a frequently rehearsed series of team responses. Even the institution itself, when it drafted its policies, did not claim that its rural location relieved it of NRP obligations. At the time of the lawsuit, they invoked their rural location as a defense.

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Two equipment deficiencies in this case merit attention, as each represented an independent and correctable failure that directly affected the infant's resuscitation. First, umbilical venous catheters (UVCs) were available within the hospital—in the nursery—but were unavailable in the delivery room. Umbilical venous access is a critical route for administering volume and epinephrine during resuscitation. The pediatrician who was called into the hospital from home to participate in the resuscitation, in fact, could not intubate, could not place a UVC, nor was she able to direct the resuscitation and stabilization efforts. As a result, the infant suffered from profound hypovolemia with resultant hypotension and hypoxia that persisted until the transport team arrived, about 3 hours after birth. The delay in establishing reliable intravenous access over this interval was a direct and foreseeable consequence of this incompetence. The fact that UVCs were elsewhere in the building does not mitigate the institutional failure.

"The pediatrician who was called into the hospital from home to participate in the resuscitation, in fact, could not intubate, could not place a UVC, nor was she able to direct the resuscitation and stabilization efforts. As a result, the infant suffered from profound hypovolemia with resultant hypotension and hypoxia that persisted until the transport team arrived, about 3 hours after birth."

Second, the lack of a laryngeal mask airway (LMA) in the entire hospital represents a critical and inexcusable departure from NRP guidelines. The LMA is an acceptable alternative airway device when endotracheal intubation is unsuccessful or not feasible, precisely the scenario that unfolded in this resuscitation. The pediatrician's attempt to intubate at 5 minutes was unsuccessful, and the respiratory therapist, qualified to intubate, was prohibited from doing so by hospital policy. The ER physician did not arrive until 15 minutes. During that critical interval, an LMA could have provided a secure airway and permitted effective ventilation.

Perhaps the most ethically troubling aspect of this case is the nurses' own testimony regarding volume resuscitation. To their credit, they acknowledged that they knew volume was needed, but when asked why volume was not administered to a pale infant with an undetectable BP born to a mother who had experienced a large intrapartum hemorrhage, the nurses responded that there was no physician order to do so.

From their education and training, nurses must be equipped to recognize the signs of hypovolemic shock in a newborn and to advocate urgently for its treatment. The nurses in this case possessed that knowledge but failed to act upon it. Whether characterized as a failure of advocacy, professional passivity, or institutional culture that discouraged nursing initiative, the outcome was the same: a baby in circulatory collapse did not receive volume resuscitation for an extended and unjustifiable period. The nurses' explanation that the pediatrician was occupied with other interventions does not absolve the nursing team of its independent professional responsibility to communicate critical clinical findings and escalate care. The pediatrician's simultaneous acknowledgment that she was unaware of the low blood pressure because the nurses did not inform her illustrates a systemic communication failure that is incompatible with safe neonatal care. How could the pediatrician fail to ask?

"Second, the lack of a laryngeal mask airway (LMA) in the entire hospital represents a critical and inexcusable departure from NRP guidelines. The LMA is an acceptable alternative airway device when endotracheal intubation is unsuccessful or not feasible, precisely the scenario that unfolded in this resuscitation."

The defense theory that the infant's outcome was the inevitable result of chronic placental insufficiency and prenatal drug exposure requires careful examination against the clinical evidence. Marijuana use has never been shown to create shock at birth, and the prenatal growth records did not reflect intrauterine growth restriction. Notably, the placental pathology did not demonstrate chronic placental insufficiency or a source of bleeding—a placental abruption may not be detectable on pathological examination. The fetal heart rate tracing was reactive and normal for the first 28 hours of the admission, further inconsistent with a picture of chronic, progressive fetal compromise.

"Perhaps the most ethically troubling aspect of this case is the nurses' own testimony regarding volume resuscitation. To their credit, they acknowledged that they knew volume was needed, but when asked why volume was not administered to a pale infant with an undetectable BP born to a mother who had experienced a large intrapartum hemorrhage, the nurses responded that there was no physician order to do so."

What the clinical record does demonstrate is a newborn who was, by all accounts, normal on fetal monitoring for 28 hours, who, after

a maternal hemorrhage, was limp without respirations or a pulse, who proceeded to remain lifeless for 15 minutes until intubation and ETT epinephrine, and who was profoundly hypotensive until vascular access with fluid administration was established nearly an hour later. The arterial blood gas at 3 hours—obtained only after the arrival of an external transport team—revealed a pH of 6.68 and a base excess of -30.9, indicating profound and prolonged metabolic acidosis. The MRI findings of white matter injury, the subsequent diagnoses of cerebral palsy, cognitive impairment, hearing loss, and seizure disorder, and the entirely negative genetic and metabolic workup collectively support the conclusion that the neurological injury was acquired around the time of birth and not during the prenatal period, despite any restrictions on fetal growth. The handicap developed in the context of a resuscitation that fell far below accepted standards of care.

"Notably, the placental pathology did not demonstrate chronic placental insufficiency or a source of bleeding—a placental abruption may not be detectable on pathological examination. The fetal heart rate tracing was reactive and normal for the first 28 hours of the admission, further inconsistent with a picture of chronic, progressive fetal compromise."

The defense experts' claim that NRP standards need not apply to rural hospitals is not only medically indefensible but ethically reprehensible. It is a posture that effectively creates a two-tiered system of care in which a baby's zip code at birth determines the quality of resuscitation it receives. It permits the facetious defense that "We did our best." A newborn requiring resuscitation requires the same interventions, whether born in a metropolitan or a rural community. More telling still is the economic reality: hospitals actively market their labor and delivery services precisely because obstetric care is a powerful driver of long-term patient loyalty. When a family welcomes a baby at a facility, that hospital gains a relationship with the mother, the child, and often the entire household for years of future care. Deliveries are not a burden that rural hospitals reluctantly accept; they are a strategic service line that generates revenue and community trust. A hospital cannot simultaneously advertise itself as a safe place to give birth, profit from that reputation, and then disclaim any obligation to meet the preparedness standards that a culture of safety in childbirth requires. To hold otherwise is to allow administrators to collect the reward of offering obstetric services while offloading the risk entirely onto the families and the babies who trusted them and then, when something goes wrong, to defend itself by extenuation. Following NRP is not a high-technical intervention. Individuals with the skills needed are immediately available, not in a remote location or at home. After achieving certification, providers need to continue practicing simulations and drills so the team can function competently in a true emergency. The equipment needs to be present in the delivery rooms. The frequency of drills seems inversely proportional to the volume of deliveries.

"The defense experts' claim that NRP standards need not apply to rural hospitals is not only medically indefensible but ethically reprehensible. It is a posture that effectively creates a two-tiered system of care in which a baby's zip code at birth determines the quality of resuscitation it receives."

Honest and ethical rural healthcare systems that recognize the limits of their capabilities act in ways to protect the unborn, even at high financial and logistical cost. In Alaska, where geography creates some of the most extreme rural healthcare challenges in the country, the standard practice has long been to follow pregnant patients locally, with deliveries planned at regional hubs such as Anchorage, Juneau, or Fairbanks. The system is risk-stratified and geographically dependent.

"Honest and ethical rural healthcare systems that recognize the limits of their capabilities act in ways to protect the unborn, even at high financial and logistical cost."

This is what genuine institutional integrity looks like—acknowledging that the welfare of a mother and newborn outweighs the convenience of keeping deliveries local. It stands in sharp moral contrast to a hospital that recruits deliveries as a business strategy, markets itself as equipped for birth, and then, when a baby suffers, retreats behind the argument that rural facilities cannot be held to the same standard as urban ones. A hospital cannot ethically have it both ways. If a facility is truly too under-resourced to meet NRP standards, the ethical obligation is not to lower the standard—it is to stop offering the service, or to do what Alaska does: ensure that mothers reach a level of care commensurate with the stakes before the moment of crisis arrives. Profiting from deliveries while quietly exempting oneself from the responsibilities that safe delivery practices are not a rural healthcare solution—it is an institutional failure dressed in geographic extenuation.

Neonatal resuscitation represents a high-acuity, low-occurrence event (HALO), where a rapid, skillful response by a delivery room team is pivotal in the reduction of neonatal morbidity and mortality. In small hospitals—particularly in rural areas—low delivery rates create infrequent opportunities to practice NRP skills. Research confirms the stakes of skill degradation: Studies have found that neonatal resuscitation skills are poorly retained following training if not used regularly, and neonates born at hospitals with lower levels of newborn care are at increased risk of morbidity. Delayed

initiation and improper execution of neonatal resuscitation are associated with poor cardiopulmonary and neurological outcomes. It has been shown that for every 30-second delay in initiating face mask ventilation in the US, there is a 16% increase in risk for death or prolonged admission. In the US, 15–20% of very low birth weight and 45–60% of term neonates with hypoxic ischemic encephalopathy are born in hospitals without an NICU.

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Potential Solutions:

Geographic barriers and disparities in the distribution of pediatric subspecialties leave many under-resourced populations. Remote consultation is particularly important when time is of the essence. The COVID-19 pandemic has awakened the medical community to the potential of telemedicine in neonatal and perinatal care. Tele-neonatology (also called neonatal telemedicine) is the use of real-time audio/video technology to connect neonatal experts, usually neonatologists, with providers caring for newborns in remote or low-resource settings. A typical setup includes a telemedicine cart with a camera, microphone, and monitor, and a secure video connection to a tertiary NICU. Real-time guidance during resuscitation, stabilization, or ongoing care is provided. It is most valuable in time-sensitive, high-risk situations involving newborns. It can improve adherence to protocols and team coordination. The system is dependent on technology reliability. The bedside team must be fully capable of performing NRP and view telemedicine as adjunctive support. When used properly, it enhances real-time coaching, airway positioning, intubation attempts, and ventilation surveillance, which are major failure points in most inexperienced resuscitations. A remote neonatologist helps track timing, medications, and algorithm steps and can escalate early decisions, such as transfer or emergency procedures that can be carried out locally (e.g., echocardiogram). When neonatal experts compared resuscitation led by a neonatologist via telemedicine versus local care, they found that tele-neonatology support led to higher-quality care, greater adherence to NRP guidelines, and more rapid achievement of effective ventilation. Surveys of providers at rural community hospitals showed that providers agreed the telemedicine consult improved safety, communication, and adherence to NRP guidelines.

"Delayed initiation and improper execution of neonatal resuscitation are associated with poor cardiopulmonary and neurological outcomes. It has been shown that for every 30-second delay in initiating face mask ventilation in the US, there is a 16% increase in risk for death or prolonged admission. In the US, 15–20% of very low birth weight and 45–60% of term neonates with hypoxic ischemic encephalopathy are born in hospitals without an NICU."

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"Tele-neonatology in community hospitals reduces unnecessary transfers and improves outcomes for critically ill neonates by providing immediate, expert support during high-risk scenarios. Specialized "hub" centers (Levels III/IV NICU) support community "spoke" hospitals (Level I/II) that may lack 24/7 on-site neonatology coverage. Tele-neonatology and regional partnerships are effective strategies to meet that standard for under-resourced populations."

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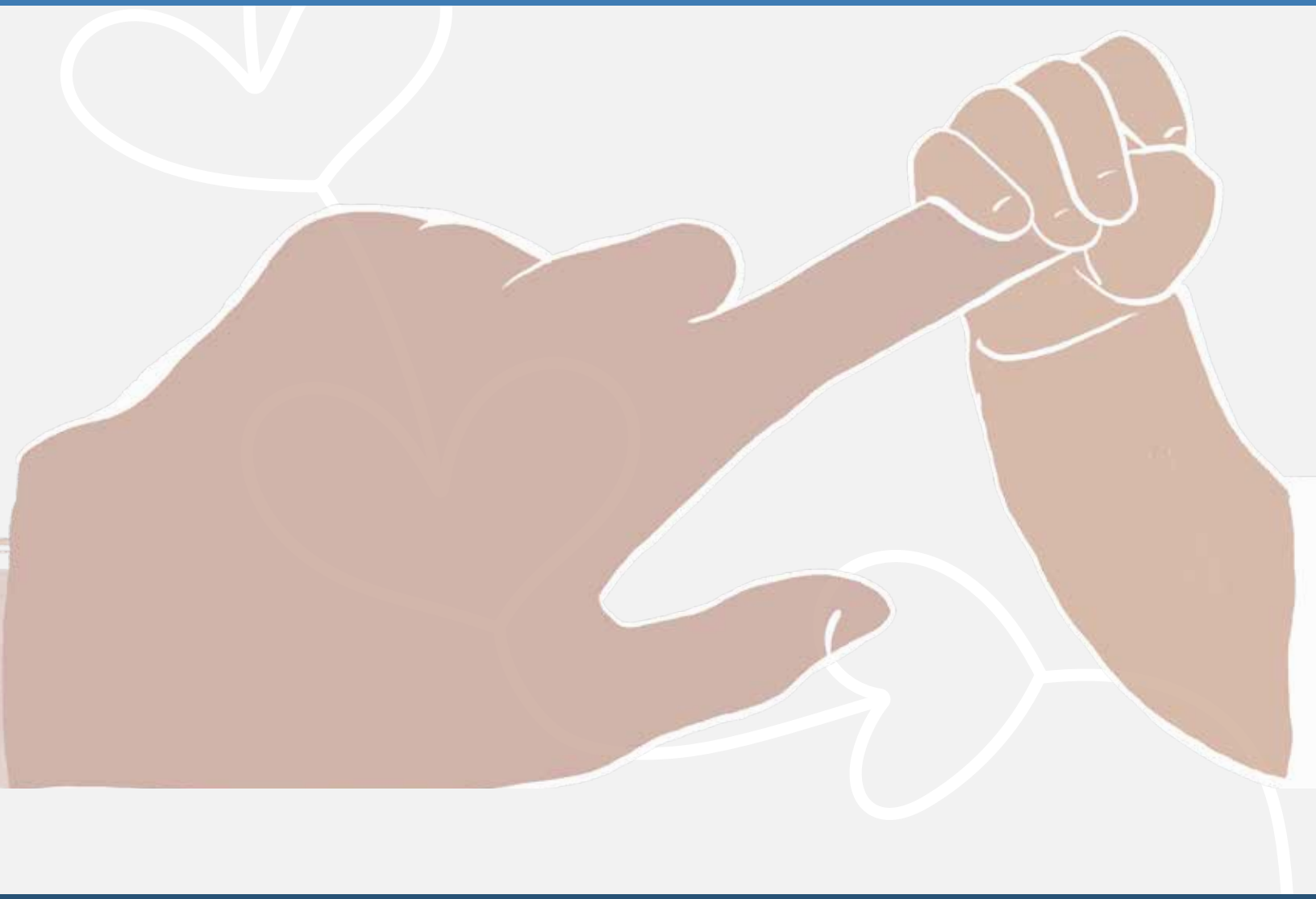

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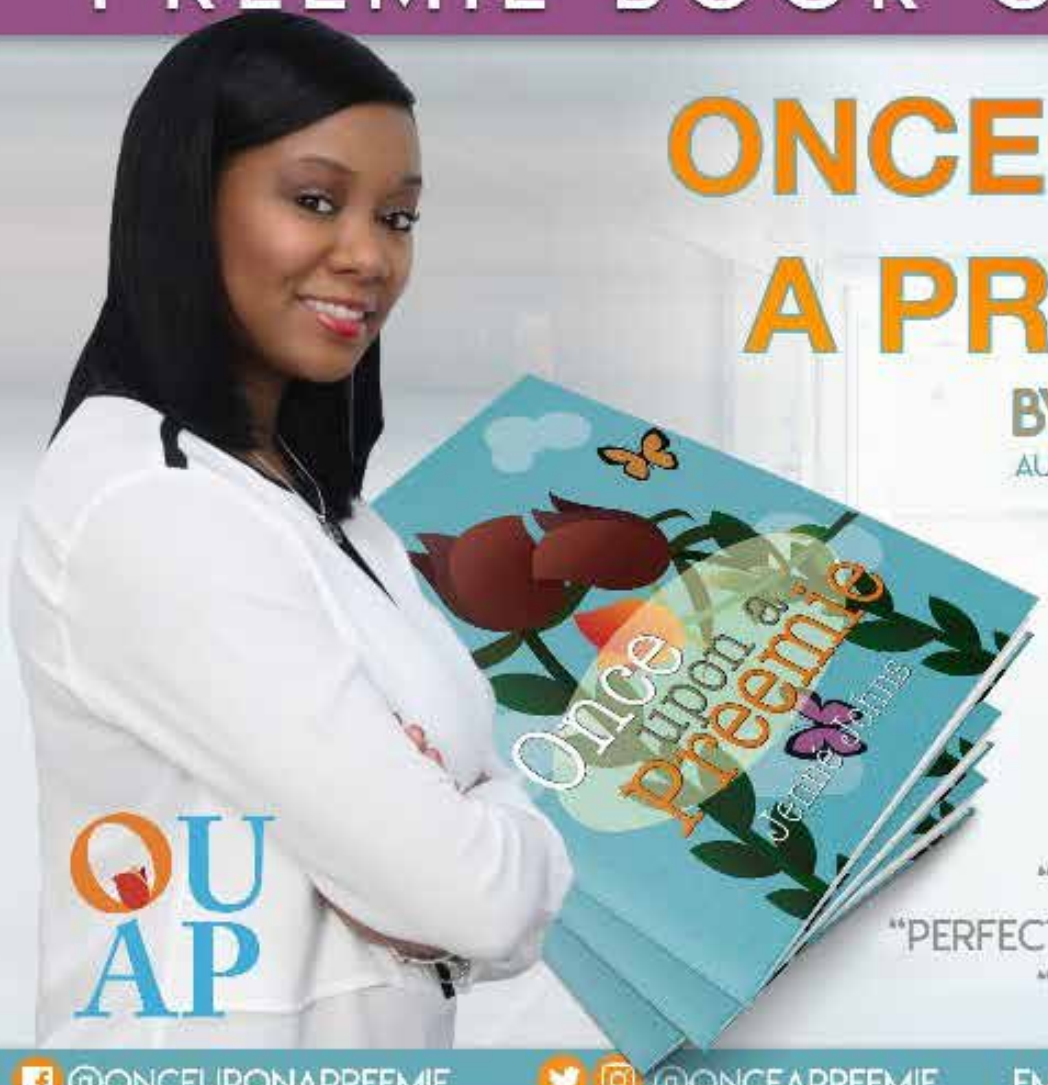

ONCE UPON A PREEMIE

BY JENNÉ JOHNS

AUTHOR | SPEAKER | ADVOCATE

QUAP

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AAP steps up vaccine advocacy in Congress, online and in court

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American Academy of Pediatrics

By Dan DeBrakeleer

Study: **AAP steps up vaccine advocacy in Congress, online and in court**

Current as of April 1, 2026

From digital spaces, to courtrooms, to the halls of Congress, the Academy has been a leading voice in advocating for vaccine policies that are grounded in evidence and science.

As part of this work, the Academy has undertaken an unprecedented and far-reaching vaccine confidence and rapid response communications campaign to promote evidence-based recommendations for families and policymakers and counter false narratives about vaccines online. While promoting immunizations is not new for the Academy, the scale and resources of this campaign have had broader impacts on legislation, online discourse and in pediatricians' offices across the country.

"The Academy's vaccine advocacy and communications work is meeting this unprecedented moment; we are elevating science and countering myths, and informing parents and policymakers about the importance of childhood immunizations," said Geoffrey Rosenthal, M.D., Ph.D., FAAP, chair of the AAP Committee on Federal Government Affairs. "I saw this firsthand in Washington, D.C., when I met with congressional staff on Capitol Hill. It's clear our efforts are making an impact."

The campaign is showing signs of success. In March, the Washington Post reported on a poll that found the Academy is one of the most credible health messengers on topics like vaccines. Respondents indicated public trust in the Academy far surpassed even that of federal health agencies and public health officials.

The Academy is not alone in carrying out this work — it is joined by AAP chapters and partner organizations across the country. These leaders have stepped up to amplify messages of vaccine confidence and respond quickly to false information about vaccines.

Following is a snapshot of the latest work in this area.

Releasing an evidence-based vaccine schedule

Leading much of the Academy's vaccine guidance has been the AAP Committee on Infectious Diseases (COID), the group that oversees the Academy's policies that represent the most current clinical practice for the prevention and treatment of infectious diseases in children and adolescents.

The Academy has been releasing vaccine recommendations since the 1930s. The AAP historically worked closely with — and had been a significant contributor to — the Advisory Committee on Immunization Practices (ACIP). In 1995, this resulted in the creation of a harmonized vaccine schedule.

Overall, there was significant alignment between the AAP and the Centers for Disease Control and Prevention (CDC) with regard to childhood vaccine recommendations. But last year, the Academy undertook a measure unprecedented in the past 30 years by releasing vaccine recommendations that are no longer in alignment with the CDC.

The divergence began when, last year, Department of Health and Human Services (HHS) Secretary Robert F. Kennedy Jr. unilaterally changed COVID vaccine recommendations for children and adults and abruptly replaced all voting members of the ACIP with new appointees, many of whom lacked qualifications for the committee.

In August, the AAP published an independent, evidence-based immunization schedule that preserved the recommendation for children to receive the seasonal COVID-19 vaccination.

The Academy recently released its 2026 Childhood and Adolescent Immunization Schedule. The AAP schedule continues to recommend all 18 immunizations, including several that were removed from or downgraded on the CDC schedule.

The Academy's independent schedule is the result of careful consideration by experts like those on COID, after thorough review of the data and literature to support the recommendations.

The 2026 AAP schedule was immediately endorsed by 12 other medical societies and supported by more than 230 medical, public health, parent and labor groups.

The AAP will continue to review and update its immunization recommendations to reflect the latest scientific research.

Taking the case for vaccines to court

While the Academy's vaccine schedule has become the standard for pediatric practices across the country, AAP leaders recognize the importance — in terms of public policy and of public trust — of the federal government's public health recommendations being based in science.

To challenge the arbitrary revisions made to vaccine recommendations over the past year by HHS, the Academy took the federal government to court. In July, the Academy and other medical groups filed suit against HHS. While initially narrower in scope, the case has since broadened in response to continued government actions, including changes to the federal childhood immunization schedule and to the ACIP structure and membership.

Promoting accurate immunization information online

To ensure that evidence-based immunization information reaches families, the Academy also has disseminated numerous resources and programs that support and promote vaccine confidence.

The Academy launched a multi-year vaccine confidence public awareness and rapid response campaign to engage parents, state and local communities, policymakers and others.

As part of this effort, the AAP has developed a robust pipeline of pediatrician influencers who collaborate with the Academy to develop content for their social media platforms about vaccines, especially debunking vaccine falsehoods. Working with these influencers allows the Academy to mobilize highly trusted pediatricians as messengers to advocate for children, educate families and communities, and encourage positive changes in behaviors and attitudes around vaccines.

A new AAP TikTok account has been a critical tool in reaching younger parents who are making important decisions about their children's vaccinations.

The Academy's vaccine rapid response operation has also helped shape media and social media narratives and developed resources like Fact Checked articles to refute various false claims about vaccines. Targeted paid advertising and real-time virtual press conferences following key vaccine meetings have further helped elevate accurate vaccine information and counter misleading and untrue messages.

Seen and heard in Washington

The Academy's messages on vaccines have reverberated throughout the country, but perhaps nowhere more than in the nation's capital.

Pediatricians have been reaching out to their lawmakers in unprecedented numbers to stand up for vaccine science — from urging senators to prioritize vaccines as they consider nominees in high-ranking public health positions, to advocating for critical vaccine legislation that would ensure that immunizations remain accessible to all families.

Academy experts have participated in numerous briefings to educate members of Congress and their staff on the implications of the many changes made in vaccine policy over the past year and to emphasize the need to support scientific, evidence-based immunization recommendations.

The Academy has also been showing up in-person to speak up for vaccine policy. AAP Committee on Federal Government Affairs members and liaisons as well as members of the AAP Executive Committee visited Capitol Hill to brief lawmakers and staff on the urgency on vaccine access and encourage them to support pro-vaccine legislation. Hundreds of pediatricians will visit Capitol Hill to advocate for vaccine access as part of the 2026 AAP Advocacy Conference, April 12-14.

WHO prequalifies first-ever malaria treatment for newborns and infants, adds new diagnostic tests

NEWS PROVIDED BY

World Health Organization

By WHO Media Team

Study: **WHO prequalifies first-ever malaria treatment for newborns and infants, adds new diagnostic tests**

Current as of April 24, 2026

Ahead of World Malaria Day on 25 April, the World Health Organization (WHO) has announced a significant step forward in the fight against malaria with the prequalification of the first treatment developed specifically for newborns and young infants weighing between two and five kilograms. The prequalification designation indicates that the medicine meets international standards of quality, safety and efficacy, and will help to expand access to quality-assured treatment for one of the most underserved patient groups.

The newly prequalified treatment, artemether-lumefantrine, is the first antimalarial formulation designed specifically for the youngest malaria patients. Until now, infants with malaria have been treated with formulations intended for older children, which increase the risk of dosing errors, side effects and toxicity. WHO prequalification will enable public sector procurement, contributing to closing a long-standing treatment gap for some 30 million babies born each year in malaria-endemic areas of Africa.

"For centuries, malaria has stolen children from their parents, and health, wealth and hope from communities," said Dr Tedros Adhanom Ghebreyesus, WHO Director-General. "But today, the story is changing. New vaccines, diagnostic tests, next-generation mosquito nets and effective medicines, including those adapted for the youngest, are helping to turn the tide. Ending malaria in our lifetime is no longer a dream – it is a real possibility, but only with sustained political and financial commitment. Now we can. Now we must."

New prequalified tests

On 14 April 2026, WHO also prequalified three new rapid diagnostic tests (RDTs) designed to address emerging diagnostic challenges for malaria. The most common malaria RDTs for P.falciparum parasite work by detecting the protein, known as HRP2. But based on reported studies and surveys in 46 countries, some strains of the malaria parasite have lost the gene that makes this protein – so they become "invisible" to HRP2-based RDTs, leading to false-negative results. In countries in the Horn of Africa, up to 80% of cases were missed, leading to delayed treatment, severe illness, and even death.

The new tests address this issue by targeting a different parasite protein (pf-LDH) that the malaria parasite cannot easily shed. They provide a reliable, quality-assured alternative where HRP2-based tests are failing. WHO now recommends that countries switch to these alternative RDTs when more than 5% of cases are missed due to pf-hrp2 deletions. This ensures accurate diagnosis, appropriate treatment, and protects hard-won malaria control gains – especially for the most vulnerable communities.

The announcements come as WHO and partners launch the 2026 World Malaria Day campaign, "Driven to End Malaria: Now We Can. Now We Must." The theme is a rallying cry to seize the moment – to protect lives now and fund a malaria-free future.

According to the World malaria report 2025, there were an estimated 282 million cases and 610 000 deaths in 2024 – an increase from 2023. While 47 countries have been certified malaria-free and 37 countries reported fewer than 1000 cases in 2024, progress at the global level is stalling. Gains are at risk due to multiple challenges, including drug resistance, insecticide resistance, diagnostic failure, and severe reductions in international development assistance.

Despite these challenges, substantial progress has been made, with an estimated 2.3 billion malaria infections prevented and 14 million lives saved worldwide since 2000.

Twenty-five countries are now rolling out malaria vaccines, protecting millions of children, and next-generation mosquito nets make up 84% of all new nets distributed. These advances demonstrate what is possible when all partners work together to innovate and deliver on the promises towards ending malaria for all.

Similac NEC Lawsuit Payout Increased by $17M in Punitive Damages

NEWS PROVIDED BY

About Lawsuits

By Irvin Jackson

Study: **Similac NEC Lawsuit Payout Increased by $17M in Punitive Damages**

Current as of April 14, 2026

A Chicago jury added $17 million in punitive damages to a $53 million Similac necrotizing enterocolitis (NEC) lawsuit trial verdict, bringing the total payout to $70 million for four mothers who say their newborns were injured after being fed the cow's milk-based formula.

The lawsuit was originally filed by Antonia Mendez, Kara Sharpe, Casie Thompson and Eboni Williams, who all allege that their preterm infants were fed Similac Special Care 24 infant formula while still in the neonatal intensive care unit (NICU). All four of the babies developed NEC injuries and complications.

NEC is a condition where harmful bacteria attack the lining of a newborn's intestines, causing inflammation and necrosis, often requiring emergency surgery and frequently ending in death. Preterm infants are particularly vulnerable to NEC due to the underdevelopment of their gastrointestinal system and, if they survive, often suffer life-long injuries and health complications.

The claims are just a few of several hundred infant formula NEC lawsuits filed in both state and federal courts nationwide. The litigation comes in the wake of mounting evidence that preterm infants face a higher risk of NEC from cow's milk-based formula when compared to human milk and human milk fortifiers.

All of the cases involve similar allegations that Abbott Laboratories, the makers of Similac, and Mead Johnson, the manufacturer of Enfamil, have failed to warn parents and the medical community about potential NEC risks from their formulas and continue to promote the products as safe for preterm infants.

Similac Jury Awards Punitive Damages

Last Thursday, a jury in Cook County Circuit Court ordered Abbott to pay the four mothers $53 million in compensatory damages following a trial that lasted more than a month. The jury reached a verdict in just 10 hours, awarding $15 million to Mendez, $16 million to Sharpe, $7 million to Thomson and $15 million to Williams.

Following the verdict, Judge John H. Ehrlich ruled there was sufficient evidence for the jury to potentially add additional punitive damages to the verdict. The judge based this decision on a determination that Abbott participated in willful, wanton or reckless conduct by endangering infants' lives. On Friday, the jury ruled that Abbott indeed owed the four women punitive damages, adding another $17 million to the original verdict.

The verdict ends the third Similac NEC lawsuit to go to trial. The first, held in the summer of 2024, ended in a nearly $500 million verdict in Missouri state court. A similar trial, held in the same court in November of that year, ended in a defense verdict. However, that verdict was vacated last year and a new trial ordered, following a judge's ruling that Abbott repeatedly introduced inadmissible evidence to the jury.

Mead Johnson, also facing Enfamil NEC lawsuits, was ordered to pay $60 million in damages in 2024 after a similar trial also held in Cook County.

Infant Formula NEC Lawsuits

While this trial was held at the state level, most Similac NEC lawsuits and Enfamil NEC lawsuits are currently pending in the federal court system, where claims brought nationwide have been consolidated before U.S. District Judge Rebecca R. Pallmeyer in the Northern District of Illinois, as part of an MDL, or multidistrict litigation.

The judge has the parties preparing a group of claims to serve as potential bellwether trials, designed to give parties an opportunity to see how juries respond to evidence and testimony likely to be repeated throughout the litigation.

Originally, the first federal lawsuit was scheduled to begin last April, but Judge Pallmeyer dismissed that batch of cases due to a lack of sufficient evidence and replaced them with a new selection of claims. The first is now scheduled to go to trial in August.

Despite the outcomes having no bearing on the other claims, the state and federal trials are being closely watched to see what types of payouts plaintiffs are being awarded, which could help the parties reach an infant formula NEC lawsuit settlement.

However, if the bellwether trials end with no settlement or other resolution, Judge Pallmeyer will likely begin remanding the cases back to their original federal courts for individual trial dates.

Why we give the hepatitis B vaccine at birth

NEWS PROVIDED BY

American Academy of Pediatrics

By Kristen Kelly, M.D., FAAP, and Shelby Sievers, M.D., FAAP

Study: **Why we give the hepatitis B vaccine at birth**

Current as of April 1, 2026

On Dec. 5, 2025, the Centers for Disease Control and Prevention's Advisory Committee on Immunization Practices (ACIP) rescinded the universal recommendation for all infants to receive their first dose of hepatitis B vaccine at birth. ACIP is still recommending the vaccine for newborns who are considered "high risk" because their birth parent tested positive for hepatitis B. The AAP continues to recommend the birth dose of hepatitis B vaccine for all infants.

What is hepatitis B?

Hepatitis B (HBV) infection is caused by a partially double-stranded DNA virus that can lead to acute and chronic infections. Acute infection can be asymptomatic or cause symptoms such as anorexia, nausea, abdominal pain, fatigue, jaundice and arthralgia/arthritis. Another common presentation of acute HBV is Gianotti-Crosti syndrome, also known as papular acrodermatitis of childhood and papulovesicular acrolocated syndrome. Gianotti-Crosti syndrome also can occur with other viruses, such as Epstein-Barr

virus and cytomegalovirus.

Chronic HBV is diagnosed by the presence of HBV-specific antigens or antibodies for at least 6 months. Chronic infection typically starts asymptomatically or with mildly elevated liver enzymes. It can progress to liver fibrosis, liver failure and even death, depending on the age of the individual (Red Book: 2024-2027 Report of the Committee on Infectious Diseases, 33rd Edition). The younger a patient is at diagnosis, the more likely they are to develop chronic HBV and complications.

How prevalent is hepatitis B in the U.S.?

Roughly 660,000 people in the U.S. are living with HBV infections. Half of them are unaware of their status. About 0.5% of pregnant people are diagnosed with acute HBV during their pregnancy at any given time, according to an independent review from the Vaccine Integrity Project and University of Minnesota Center for Infectious Disease Research and Policy (https://bit.ly/47pBEYV).

How safe is the hepatitis B birth dose?

The hepatitis B vaccine is extremely safe. It is a single-antigen, recombinant vaccine. Common side effects of the vaccine are local injection site reactions. Numerous studies of term newborns show no long-term or severe side effects. There have been no newborn deaths related to the birth dose of the vaccine (Linder N, et al. Arch Dis Child Fetal Neonatal Ed. 1999;81:F206-F207). Studies demonstrate no severe side effects within the first month of birth in term infants (Niu MT, et al. Pediatr Infect Dis J. 1996;15:771-776. Niu MT, et al. JAMA Pediatr. 1999;153:1279-1282. Haber P, et al. Vaccine. 2018;36:559-564.).

How effective is the hepatitis B vaccine?

The first and second dose of hepatitis B vaccine provide immunity in 25% and 63% of infants, respectively; 95% of infants are immune after the third dose (Schillie S, et al. MMWR Recomm Rep. 2018;67:1–31.).

In infants born to those infected with HBV, the birth dose of hepatitis B vaccine only prevents about 70% of infections. This is why babies also are given hepatitis B immune globulin (HBIG) to increase protection to 83-97% (Schillie S, et al. MMWR Recomm Rep. 2018;67:1–31. Beasley RP, et al. Lancet. 1983;322:1099-1102. Lee C, et al. BMJ. 2006;332:328.).

How do we give the hepatitis B vaccine series?

The AAP continues to recommend the vaccine at birth, ages 1-2 months and 6-18 months for a three-dose series. It is also appropriate to give the vaccine in combination vaccines at ages 2, 4, and 6 months of age. There must be at least four weeks between the first two doses and at least eight weeks between doses two and three.

To maximize protection against HBV, newborns whose birthing parent is positive for hepatitis B surface antigen (HBsAg) should optimally receive HBIG and hepatitis B vaccine within 12 hours of birth. Babies born to those with unknown HBsAg status are also recommended to receive hepatitis B vaccine along with HBIG. The timing of HBIG administration is weight based. Infants who weigh more than 2,000 grams must receive HBIG within seven days of birth. Infants who weigh less than 2,000 grams who require it should receive HBIG within 12 hours after birth. Newborn serologic testing for HBV is not recommended. Newborn antibodies are reflective of their birth parent's antibodies until about 4 to 6 months of age, according to the AAP Red Book.

What happens if the hepatitis B birth dose is not given?

Not giving the birth dose leaves infants at risk of undiagnosed maternal infection and hepatitis B exposure after birth. Approximately 90% of newborns infected perinatally will develop chronic hepatitis B infection; 25% with chronic infection will die from chronic liver disease, including cirrhosis and hepatocellular carcinoma, a type of liver cancer.

Universal hepatitis B vaccination provides a safety net for infants from imperfections in medicine such as false-negative test results, documentation errors, missed prenatal care and infections acquired late in pregnancy before tests turn positive.

It also protects against infections transmitted after birth through close contact with infected caregivers or in the home. The majority of HBV infections in infants occur in birthing parents who are unaware of their HBV positive status. Universal vaccination ensures the maximum impact on preventing HBV in infants.

Dr. Kelly and Dr. Sievers are post-residency training members of the AAP Section on Infectious Diseases.

Most states extending RSV immunization season for eligible infants and toddlers

NEWS PROVIDED BY

American Academy of Pediatrics

By Melissa Jenco

Study: **Most states extending RSV immunization season for eligible infants and toddlers**

Current as of April 2, 2026

Pediatricians and hospitals in most states can continue providing respiratory syncytial virus (RSV) immunizations to eligible infants and toddlers until the end of April under extensions granted by state health officials, according to the Association of Immunization Managers (AIM).

"This extension is intended to reduce RSV-related morbidity, hospitalizations, and severe outcomes," Mississippi State Epidemiologist Renia Dotson, M.D., FACS, M.P.H., M.B.A., said in a health alert.

Immunization typically is recommended through the end of March in most of the continental U.S. However, RSV season got a late start, and activity has been elevated later than usual. Rates did not peak until late February and about 7.5% of tests were positive for RSV during the week ending March 21 compared to 5% at the same time last year, according to Centers for Disease Control and Prevention data.

AIM surveyed its 66 members which include states, territories and several major cities and provided a map with each jurisdiction's extension status. As of April 1, 48 jurisdictions are extending their season through April 30 or did not give an end date.

Rhode Island and Philadelphia are extending immunization through April 15 and then will reassess. Philadelphia likely will align with Pennsylvania's April 30 extension, according to AIM.

Louisiana, Missouri, Virginia and Washington, D.C., are not extending the season. However, Missouri and Virginia will consider immunization on a case-by-case basis upon a request from a provider.

Oklahoma and the U.S. Virgin Islands were undecided as of April 1. Oregon, Florida, Hawaii and the remaining U.S. territories have year-round seasons or non-applicable seasonable periods.

The AAP recommends RSV immunization with nirsevimab or clesrovimab for infants under 8 months of age born during or entering their first RSV season if their pregnant parent was not vaccinated during that pregnancy. Infants and children 8 months through 19 months at high risk of severe RSV disease entering their second RSV season should receive nirsevimab, as clesrovimab is not indicated for children in this age group.

Since the season began last fall, there have been 46,766 pediatric hospital admissions for RSV, most of which have been among children under 5 years, according to an AAP analysis of Health and Human Services data.

Efforts to eliminate hepatitis delivers gains but more action needed to meet 2030 targets

NEWS PROVIDED BY

World Health Organization

By WHO Media Team

Study: **Efforts to eliminate hepatitis delivers gains but more action needed to meet 2030 targets**

Current as of April 28, 2026

Global efforts to combat viral hepatitis are delivering measurable progress in reducing infections and deaths, but the disease remains a major global health challenge, according to a new World Health Organization (WHO) report released today at the World Hepatitis Summit.

Viral hepatitis B and C – the two infections responsible for 95% of hepatitis-related deaths worldwide – claimed 1.34 million lives in 2024, the latest data show. At the same time, transmission continues, with more than 4900 new infections every day, or 1.8 million each year.

The 2026 Global hepatitis report documents significant gains made since 2015. The annual number of new hepatitis B infections has dropped by 32% and hepatitis C-related deaths have fallen by 12% globally. Hepatitis B prevalence among children under five has also decreased to 0.6%, with 85 countries achieving or surpassing the 2030 target of 0.1%.

These achievements reflect the impact of sustained, coordinated global and national action following the adoption of WHO viral hepatitis elimination targets by Member States at the World Health Assembly in 2016. However, the report warns that current rates of progress are insufficient to meet all 2030 elimination targets, underscoring the urgent need to accelerate prevention, testing, and treatment efforts worldwide.

"Around the world, countries are showing that eliminating hepatitis is not a pipedream, it's possible with sustained political commitment, backed by reliable domestic financing," said Dr Tedros Adhanom Ghebreyesus, WHO Director-General. "At the same time, this report shows that progress is too slow and uneven. Many people remain undiagnosed and untreated due to stigma, weak health systems and inequitable access to care. While we have the tools to eliminate hepatitis as a public health threat, urgent scale-up of prevention, diagnosis and treatment is needed if the world is to meet the 2030 targets."

Global burden and gaps in response

Updated WHO estimates indicate that 287 million people were living with chronic hepatitis B or C infection in 2024.

That year, 0.9 million people were newly infected with hepatitis B. The WHO African Region accounted for 68% of new hepatitis B infections, yet only 17% of newborns in the region received the hepatitis B birth-dose vaccination.

A further 0.9 million hepatitis C infections were recorded in 2024. People who inject drugs accounted for 44% of new infections, highlighting the urgent need for stronger harm reduction services and safe injection practices.

Of the 240 million people with chronic hepatitis B in 2024, fewer than 5% were receiving treatment. Only 20% of people with hepatitis C have been treated since 2015, when a new 12-week treatment with a cure rate of about 95% became available.

As a result of limited access to prevention and care, in 2024 an estimated 1.1 million people died from hepatitis B and 240 000 from hepatitis C. Liver cirrhosis and hepatocellular carcinoma were the main causes of hepatitis related deaths. A large share of hepatitis B-related deaths occurred in the African and Western Pacific Regions.

Ten countries – Bangladesh, China, Ethiopia, Ghana, India, Indonesia, Nigeria, the Philippines, South Africa and Viet Nam – accounted for 69% of hepatitis B related deaths worldwide in 2024. Hepatitis C-related deaths are more geographically dispersed. In 2024, ten countries accounted for 58% of the global total: China, India, Indonesia, Japan, Nigeria, Pakistan, the Russian Federation, South Africa, the United States of America and Viet Nam.

Proven solutions

Despite these challenges, progress in countries such as Egypt, Georgia, Rwanda, and the United Kingdom demonstrates that eliminating hepatitis as a public health problem is achievable with sustained commitment and investment.

Highly effective tools are already available:

hepatitis B vaccine protects more than 95% of vaccinated people against both acute and chronic infections;

long-term antiviral treatment for hepatitis B can help effectively manage chronic infection and prevent severe liver disease; and

hepatitis C short-course curative therapy lasting 8-12 weeks can cure more than 95% of infections.

"The data shows that progress is possible but also reveals where we are falling short. Every missed diagnosis and untreated infection due to chronic viral hepatitis represents a preventable death," said Dr Tereza Kasaeva, Director, WHO Department for HIV, TB, Hepatitis

and Sexually Transmitted Infections. "Countries must move faster to integrate hepatitis services for people living with hepatitis B and C into primary care, and to reach the communities most affected."

The report identifies priority actions to accelerate hepatis elimination as a public health threat. These include scaling up treatment for chronic hepatitis B infection, particularly in the WHO African and Western Pacific regions, and expanding access to hepatitis C treatment in the WHO Eastern Mediterranean Region.

It also calls for stronger political commitment and financing, improved coverage of hepatitis B birth-dose vaccination and expanded antiviral prophylaxis to prevent mother-to-child transmission of HBV infection, particularly in the WHO African Region. In addition, the report emphasizes the need to improve injection safety in both health-care settings and community practices, including through strengthened harm reduction services for people who inject drugs.

Jury orders Abbott to pay $70m damages over formula milk

NEWS PROVIDED BY

TheBMJ

By Carolyn Brown

Study: **Jury orders Abbott to pay $70m damages over formula milk**

Current as of April 20, 2026

Four mothers in Chicago have been awarded $70m by a jury after their premature infants developed necrotising enterocolitis after feeding with a formula milk product manufactured by Abbott Laboratories.

Necrotising enterocolitis is a serious illness in which tissues in the intestine become inflamed and start to die. This can lead to development of a perforation, allowing the contents of the intestine to leak into the abdomen.

Three of the infants in the recent ruling needed surgery, and all face serious long term health effects. Abbott told The BMJ it disagrees with the verdict and plans to appeal.

The 9 April verdict is the latest in a series of judgments involving Abbott, which makes Similac Special Care 24 formula, and Mead Johnson, which makes Enfamil formula.

In March 2024 a court ordered Mead Johnson to pay $60m to a family whose baby had died from necrotising enterocolitis.

Abbott was also fined nearly $500m in July 2024 relating to a case of a premature baby who had necrotising enterocolitis and developed brain damage, after receiving Similac.

In March 2025 a judge ordered a new trial after a jury cleared Abbott and Mead Johnson concerning their formulas and necrotising enterocolitis in October 2024.

Abbott and Mead Johnson are facing nearly 1000 similar lawsuits in the US.

At issue is the supposed risk of necrotising enterocolitis among formula fed premature infants and those of very low birth weight. Such infants experience higher rates of enterocolitis in general, regardless of whether they are fed formula.

In responses to The BMJ the manufacturers defended the use of their formulas for preterm infants.

Mead Johnson said, "The scientific consensus is that there is no established causal link between the use of specialized preterm hospital nutrition products and NEC, and that these products provide essential, lifesaving nutrition to vulnerable premature infants when mother's or donor milk is unavailable or insufficient."

Abbott said, "The Food and Drug Administration, National Institutes of Health, Centers for Disease Control and Prevention, American Academy of Pediatrics, Necrotizing Enterocolitis Society, neonatologists and other medical professionals all agree: these products are safe, they are necessary, and there is no reliable scientific evidence that they cause NEC."

Although scientific evidence does not show a causal link between formula feeding and a higher risk of enterocolitis, data suggest an association, said Thurman Allen Merritt, a neonatologist at Loma Linda University Children's Hospital in California.

Regardless of the scientific debate, Merritt said a causal link was not needed for legal liability. "It is fair to say that causation in a scientific way . . . doesn't necessarily prove that their formulas caused it," he said. "However, in a court of law in most US states it is the preponderance of evidence."

In 2024 the president of the American Academy of Paediatrics, Benjamin Hoffman, said that special formula was a "routine and necessary part of care" of preterm babies because mother's and donor milk may be insufficient. He added that human milk reduced—but did not eliminate—the risk of necrotising enterocolitis, but he also decried clinical recommendations being determined in courtrooms.

In the latest judgment Judge John Erlich said Abbott was aware of the substantial risk of necrotising enterocolitis when formula was given to premature infants and should have put a warning on its label and packaging.

While lawsuits are aimed mainly at manufacturers, hospitals and doctors have also been found liable. In December 2025 a court awarded almost $32m to parents of an extremely premature infant who died after a "fortifier" that was based on cow's milk was added to the human milk given to the infant.

The court found that doctors at the neonatal intensive care unit at Yale New Haven Hospital, Connecticut, failed to get the parents' informed consent before adding the fortifier. In fact, the parents had clearly specified they wanted the baby to be fed only his own mother's milk.

Merritt said doctors may not offer donor milk as an option for a variety of reasons, including commercially available donor

milk being more expensive and hospitals not routinely stocking it. He said many doctors view these decisions as "too sophisticated to explain to parents" but added, "I've explained these to parents over years. The risks, benefits, and alternatives for a specific course of action need to involve the parents."

ByHeart Formula Infant Botulism Lawsuits Consolidated in New York

NEWS PROVIDED BY

About Lawsuits

By Irvin Jackson

Study: **ByHeart Formula Infant Botulism Lawsuits Consolidated in New York**

Current as of April 7, 2026

A panel of judges has determined that all federal ByHeart infant formula lawsuits should be consolidated before one judge in the U.S. District Court for the Southern District of New Jersey, for coordinated discovery and pretrial proceedings in the claims, which each raise similar allegations that the recalled formula is responsible for a nationwide outbreak of infant botulism last year.

The infant botulism outbreak was first detected in November 2025 and subsequently linked to 51 infant illnesses nationwide by the middle of January. The U.S. Food and Drug Administration (FDA) and the U.S. Centers for Disease Control and Prevention (CDC) tracked the illnesses back to contaminated ByHeart formula, ultimately resulting in a ByHeart infant formula recall on November 8, 2025.

Initially limited to two batches, the ByHeart recall was expanded just days later, pulling all batches of ByHeart Whole Nutrition Infant Formula Cans and Anywhere Packs from the U.S. market.

This has sparked multiple individual and class action ByHeart infant formula recall lawsuits nationwide by parents and caregivers, each alleging that the company failed to properly manufacture the recalled formula in a way that made it safe for infants.

Individual lawsuits have been filed by families whose children were injured during the outbreak, while separate class action claims argue that parents whose children did not become ill should be refunded for the formula, alleging they would not have purchased or used the product had they known it carried a risk of infant botulism.

In January, a group of plaintiffs filed a motion with the U.S. Judicial Panel on Multidistrict Litigation (JPML), requesting that all federal ByHeart formula lawsuits be consolidated in the Southern District of New York as a multidistrict litigation (MDL) under U.S. District Judge Denise L. Cote for coordinated discovery and pretrial proceedings.

In complex consumer product litigation, when large numbers of claims may be filed by users of the same product who suffered similar injuries or damages, it is common for the JPML to centralize cases. This is intended to reduce duplicative discovery on shared issues, avoid conflicting pretrial rulings, and promote efficiency for witnesses and parties involved in the litigation.

JPML Approves ByHeart Lawsuits MDL

The JPML agreed with the plaintiffs and approved the request in a transfer order (PDF) issued on April 2, several days after the panel heard oral arguments on centralization, during which ByHeart reportedly supported the motion. The panel also selected the Southern District of New York as the venue and appointed U.S. District Judge Arun S. Subramanian to oversee the litigation.

According to the order, ByHeart currently faces nine individual injury claims, as well as 10 class action lawsuits.

Now that the cases have been consolidated, it is expected that Judge Subramanian will instruct the parties to begin preparing a series of representative cases to serve as early test "bellwether" trials in the coming months and years. These trials will give the parties an opportunity to see how a jury responds to the strengths and weaknesses of arguments, evidence and testimony likely to be repeated throughout the litigation.

However, if the bellwether trials and pretrial proceedings end with the parties failing to negotiate a settlement or reach another resolution, each individual claim may be later remanded back to the U.S. District Court where it was originally filed for trial.

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Genetic Corner: Dual Genetic Etiology in a Neonatal Neurodevelopmental Disorder: COL4A1 and ERCC6

Hua Wang, M.D., Ph.D

Abstract:

Background: Neonatal neurodevelopmental disorders (NDDs) with early brain injury may reflect complex or overlapping genetic etiologies rather than isolated acquired insults. Pathogenic variants in COL4A1 cause autosomal dominant cerebral small-vessel disease with neonatal manifestations, while ERCC6-related Cockayne syndrome is an autosomal recessive neurodegenerative disorder characterized by prenatal and postnatal growth failure, microcephaly, and progressive neurologic impairment.

Case Presentation: We report a female child with neonatal apnea requiring resuscitation, prolonged NICU hospitalization, progressive microcephaly, severe global developmental delay, failure to thrive, hypotonia, optic atrophy, and characteristic neuroimaging findings, including periventricular leukomalacia, cerebral microhemorrhages, and prior germinal matrix hemorrhage. Rapid trio whole-exome sequencing identified a de novo pathogenic COL4A1 variant (c.2459G>A, p.Gly820Asp) and biallelic ERCC6 variants in trans, establishing a dual genetic etiology consistent with COL4A1-related cerebral small-vessel disease and ERCC6-related Cockayne syndrome.

Conclusion: This case highlights a dual genetic etiology underlying a severe neonatal neurodevelopmental disorder, emphasizing the importance of comprehensive genomic evaluation for accurate diagnosis, prognostication, and management in neonates with complex neurologic presentations.

"Neonatal neurodevelopmental disorders presenting with early brain injury, microcephaly, and failure to thrive are traditionally attributed to perinatal hypoxic-ischemic events, infection, or prematurity. However, the clinical application of next-generation sequencing has fundamentally altered this paradigm, demonstrating that a substantial proportion of infants with severe neurologic phenotypes have an underlying monogenic or multilocus genetic etiology."

"Pathogenic variants in COL4A1 are a well-established monogenic cause of cerebral small-vessel disease, leading to disruption of basement membrane integrity and vascular fragility within the developing brain. The clinical spectrum...includes antenatal or neonatal intracranial hemorrhage, periventricular leukomalacia, porencephaly, progressive cerebral atrophy, and neurodevelopmental delay, often mimicking hypoxic–ischemic encephalopathy or congenital infection"

Introduction:

Neonatal neurodevelopmental disorders presenting with early brain injury, microcephaly, and failure to thrive are traditionally attributed to perinatal hypoxic-ischemic events, infection, or prematurity. However, the clinical application of next-generation sequencing has fundamentally altered this paradigm, demonstrating that a substantial proportion of infants with severe neurologic phenotypes have an underlying monogenic or multilocus genetic etiology (1, 2). Exome and genome sequencing have proven particularly valuable in critically ill neonates, enabling timely diagnosis and improved clinical decision-making, with diagnostic yields ranging from 36% to 49% for neurodevelopmental disorders (1–4). Pathogenic variants in COL4A1 are a well-established monogenic cause of cerebral small-vessel disease, leading to disruption of basement membrane integrity and vascular fragility within the developing brain (5, 6). The clinical spectrum of COL4A1/A2-related disorders is broad and includes antenatal or neonatal intracranial hemorrhage, periventricular leukomalacia, porencephaly, progressive cerebral atrophy, and neurodevelopmental delay, often mimicking hypoxic–ischemic encephalopathy or congenital infection (7, 8). Recent consensus guidelines emphasize the need for multidisciplinary surveillance, including neurologic, ophthalmologic, cardiovascular, and renal monitoring for all individuals with COL4A1/A2-related disorders (7, 9). Glycine substitutions within the collagenous domain, such as those identified in this case, are a recognized pathogenic mechanism and are strongly associated with neurologic involvement (5).

In contrast, ERCC6-related Cockayne syndrome is a rare autosomal recessive DNA repair disorder characterized by prenatal and postnatal growth failure, progressive microcephaly, severe developmental delay, optic atrophy, and neurodegeneration (10, 11). Although traditionally considered a postnatal neurodegenerative

condition, neonatal and early infantile presentations are increasingly recognized, particularly in severe forms (10, 11). Impaired transcription-coupled nucleotide excision repair leads to cumulative cellular damage, especially in postmitotic tissues such as the central nervous system, with emerging evidence suggesting that DNA damage accumulation, transcriptional dysregulation, and mitochondrial dysfunction interact rather than acting independently (10, 12).

"Although traditionally considered a postnatal neurodegenerative condition, neonatal and early infantile presentations are increasingly recognized, particularly in severe forms. Impaired transcription-coupled nucleotide excision repair leads to cumulative cellular damage, especially in postmitotic tissues such as the central nervous system, with emerging evidence suggesting that DNA damage accumulation, transcriptional dysregulation, and mitochondrial dysfunction interact rather than acting independently."

Recent genomic studies have highlighted that a subset of patients with complex neurodevelopmental disorders harbor dual or multilocus genetic diagnoses, challenging the traditional application of Occam's razor in clinical genetics. Dual diagnoses are now estimated to occur in approximately 3–5% of genetically diagnosed pediatric cases and are particularly enriched among patients with severe, multisystem, or atypical phenotypes (13). Recent phenotype-structure analyses demonstrate that dual diagnoses can present with highly blended or nearly indistinguishable phenotypes rather than simply additive features (13).

"Dual diagnoses are now estimated to occur in approximately 3–5% of genetically diagnosed pediatric cases and are particularly enriched among patients with severe, multisystem, or atypical phenotypes."

Here, we report an exceptionally rare neonatal neurodevelopmental disorder caused by a dual genetic etiology involving a pathogenic COL4A1 variant and ERCC6-related Cockayne syndrome, illustrating how early vascular brain injury and progressive neurodegeneration can converge to produce a severe and diagnostically challenging phenotype.

Case Presentation:

The patient is a female child with a severe neurodevelopmental disorder manifesting in the neonatal period. She was born at term following an unremarkable pregnancy and spontaneous vaginal delivery outside the United States. At birth, she developed significant apnea requiring resuscitation and prolonged neonatal intensive care. Early concerns included microcephaly and poor feeding, although detailed neonatal neuroimaging was unavailable.

Following discharge, she demonstrated persistent feeding difficulties, poor weight gain, and profound global developmental delay. Developmental milestones were severely impaired across all domains, with absent head control, inability to sit, stand, or walk, and nonverbal status. Growth parameters remained below the first percentile for weight, length, and head circumference, with progressive postnatal microcephaly. Feeding difficulties worsened over time, necessitating gastrostomy tube placement in early childhood due to failure to thrive.

"Neurologic examination revealed diffuse hypotonia, evolving lower-extremity hypertonia, and scissoring. Visual engagement was poor, with absent visual tracking and concern for visual impairment."

Neurologic examination revealed diffuse hypotonia, evolving lower-extremity hypertonia, and scissoring. Visual engagement was poor, with absent visual tracking and concern for visual impairment. There was no history of seizures. Sleep disturbances with frequent nocturnal startling were reported. Dental evaluation demonstrated poor dentition with early dental caries. Cardiopulmonary examinations were unremarkable.

Family history was notable only for a paternal relative with intellectual disability of unclear etiology. Parents originated from the same geographic region and denied known consanguinity. Later social circumstances allowed for consistent medical follow-up and multidisciplinary care.

Brain magnetic resonance imaging demonstrated periventricular leukomalacia, a foreshortened corpus callosum, evidence of prior germinal matrix hemorrhage with venous infarction, and numerous cerebral and cerebellar microhemorrhages. The combination of periventricular leukomalacia, microhemorrhages, and germinal matrix hemorrhage is characteristic of COL4A1/A2-related cerebral small-vessel disease and should prompt genetic testing even in the presence of perinatal risk factors (7, 8). Magnetic resonance spectroscopy showed reduced N-acetylaspartate, consistent with neuronal loss. Orbital imaging revealed bilateral optic nerve abnormalities consistent with optic atrophy. Additional evaluations, including echocardiography and skeletal survey, were unremarkable.

Given the neonatal onset, severe neurologic impairment, and neuroimaging suggestive of cerebral small-vessel disease,

comprehensive genetic testing was pursued, ultimately revealing a dual genetic etiology involving COL4A1 and ERCC6.

Genetic Testing and Findings:

Comprehensive genetic evaluation was undertaken because of the patient's severe neonatal-onset neurodevelopmental impairment, progressive microcephaly, and neuroimaging findings suggestive of an underlying genetic etiology. Initial chromosome analysis demonstrated a normal female karyotype. High-resolution chromosomal microarray analysis revealed normal chromosomal dosage without pathogenic copy number variants but identified multiple short contiguous runs of homozygosity across the genome, consistent with increased autosomal recessive disease risk and supporting further sequencing-based investigation.

"Brain magnetic resonance imaging demonstrated periventricular leukomalacia, a foreshortened corpus callosum, evidence of prior germinal matrix hemorrhage with venous infarction, and numerous cerebral and cerebellar microhemorrhages. The combination of periventricular leukomalacia, microhemorrhages, and germinal matrix hemorrhage is characteristic of COL4A1/A2-related cerebral small-vessel disease and should prompt genetic testing even in the presence of perinatal risk factors."

Rapid trio whole-exome sequencing identified a heterozygous missense variant in COL4A1 (c.2459G>A, p.Gly820Asp). This variant affects a highly conserved glycine residue within the collagenous domain of type IV collagen and was absent from population databases. Parental testing confirmed a de novo origin. Based on established ACMG/AMP criteria and strong phenotypic correlation, this variant was classified as pathogenic and consistent with an autosomal dominant COL4A1-related disorder. Exome sequencing also identified two heterozygous missense variants in ERCC6, c.2957T>C (p.Val986Ala) inherited from the father and c.1054A>G (p.Arg352Gly) inherited from the mother, confirmed to be in trans. Although individually classified as variants of uncertain significance at the time of initial reporting, the biallelic inheritance pattern in trans, combined with strong phenotypic correlation with ERCC6-related Cockayne syndrome, supported their likely pathogenic role in the patient's progressive neurodevelopmental features, growth failure, and optic involvement (13). An additional heterozygous variant in POLR1A was identified but was considered unlikely to be clinically relevant due to the lack of supportive phenotypic features and absence of a second pathogenic allele.

Overall, the genetic findings supported a dual genetic etiology, with a de novo pathogenic COL4A1 variant explaining the neonatal cerebral small-vessel disease and early brain injury, and biallelic ERCC6 variants consistent with ERCC6-related Cockayne syndrome contributing to the patient's progressive neurodevelopmental phenotype.

"Overall, the genetic findings supported a dual genetic etiology, with a de novo pathogenic COL4A1 variant explaining the neonatal cerebral small-vessel disease and early brain injury, and biallelic ERCC6 variants consistent with ERCC6-related Cockayne syndrome contributing to the patient's progressive neurodevelopmental phenotype."

Management and Outcome:

Management focused on supportive, multidisciplinary care tailored to the patient's severe neurodevelopmental impairment and complex genetic diagnosis. Nutritional support was prioritized due to persistent failure to thrive, culminating in gastrostomy tube placement to ensure adequate caloric intake and hydration. Neurologic care emphasized developmental surveillance and management of tone abnormalities, with referral to early intervention services for physical, occupational, and speech therapy. Ophthalmologic follow-up was arranged to monitor optic atrophy and visual function, and dental care was initiated for early-onset dental disease. Additional subspecialty involvement included gastroenterology and nutrition.

"No disease-specific or curative therapies are currently available for COL4A1/A2-related disorders or ERCC6-related Cockayne syndrome, and management remains primarily supportive."

No disease-specific or curative therapies are currently available for COL4A1/A2-related disorders or ERCC6-related Cockayne syndrome, and management remains primarily supportive. Given the known vascular fragility associated with COL4A1/A2-related disorders, precautions were taken to minimize head trauma and avoid unnecessary anticoagulation. Published consensus guidelines from 2025 recommend structured multidisciplinary surveillance, including baseline and periodic neuroimaging, ophthalmologic evaluation, cardiovascular assessment, and renal function monitoring for all individuals with COL4A1/A2-related disorders (7, 9). Genetic counseling was provided to the family to discuss in-

heritance patterns, recurrence risks, and long-term expectations.

"COL4A1/A2-related disease is increasingly recognized as a genetic mimic of congenital TORCHES infection and hypoxic-ischemic encephalopathy, and genetic testing should be considered when neuroimaging patterns are disproportionate to perinatal risk factors."

At the most recent follow-up, the patient remained medically stable but continued to demonstrate profound global developmental delay, persistent growth failure despite enteral feeding, severe neurologic impairment, and visual dysfunction. Her clinical course was characterized by static to slowly progressive neurologic limitations, consistent with the combined effects of cerebral small-vessel disease and a neurodegenerative DNA repair disorder.

"Pathogenic variants in COL4A1 disrupt type IV collagen through multiple mechanisms, including impaired heterotrimer secretion, basement membrane structural defects, and dysregulated signaling pathways, including TGF-β activation, leading to cerebral small-vessel fragility."

Discussion:

This case highlights an unusually severe neonatal-onset neurodevelopmental disorder driven by dual genetic etiologies involving a pathogenic COL4A1 variant and ERCC6-related Cockayne syndrome. The initial neonatal course—apnea requiring resuscitation, prolonged NICU hospitalization, and early brain injury—can be clinically indistinguishable from perinatal hypoxic–ischemic encephalopathy. However, the combination of characteristic neuroimaging patterns and molecular confirmation supports a primary genetic mechanism with overlapping vascular and neurodegenerative contributions rather than an isolated acquired insult. COL4A1/A2-related disease is increasingly recognized as a genetic mimic of congenital TORCHES infection and hypoxic-ischemic encephalopathy, and genetic testing should be considered when neuroimaging patterns are disproportionate to perinatal risk factors (7, 8).

Pathogenic variants in COL4A1 disrupt type IV collagen through multiple mechanisms, including impaired heterotrimer secretion, basement membrane structural defects, and dysregulated signaling pathways, including TGF-β activation, leading to cerebral small-vessel fragility (5–7). Clinically, fetal and neonatal presentations commonly include intraparenchymal hemorrhage, periventricular leukomalacia, porencephaly, and microhemorrhages—findings that may closely mimic hypoxic–ischemic injury or congenital infection, and increasingly prompt the recommendation to consider COL4A1/A2 testing when the neuroimaging pattern is disproportionate to perinatal risk factors (7, 8). Glycine substitutions within the collagenous domain are a well-established pathogenic mechanism because they destabilize triple-helix formation and compromise basement membrane stability, aligning with the variant class identified in this patient (5). Importantly, the phenotype of COL4A1/A2-related disease extends beyond the brain, and recent diagnostic and management guidance emphasizes the need for multidisciplinary surveillance that includes neurologic and ophthalmologic evaluation and monitoring of systemic involvement (7, 9).

"Mechanistically, Cockayne syndrome reflects impaired transcription-coupled nucleotide excision repair and broader disturbances in transcriptional homeostasis, with downstream effects that include mitochondrial dysfunction and cumulative cellular stress, particularly affecting postmitotic tissues such as the central nervous system."

Superimposed on this early neurovascular injury, the patient's progressive postnatal course—marked by worsening growth failure, progressive microcephaly, severe developmental impairment, and optic involvement—fits well with ERCC6-related Cockayne syndrome, a transcription-coupled DNA repair disorder with prominent neurodegenerative features. Mechanistically, Cockayne syndrome reflects impaired transcription-coupled nucleotide excision repair and broader disturbances in transcriptional homeostasis, with downstream effects that include mitochondrial dysfunction and cumulative cellular stress, particularly affecting postmitotic tissues such as the central nervous system (10, 12). Although Cockayne syndrome is classically described as a postnatal progressive disorder, severe forms can manifest very early, and contemporary series continue to refine the spectrum of ERCC6-related disease from milder phenotypes to early lethal forms (10, 11). In this context, the clinical trajectory is best interpreted as a blended phenotype, with COL4A1-mediated vascular fragility driving early brain injury and ERCC6-related neurodegeneration contributing to progressive postnatal decline. From a diagnostic perspective, this case underscores why neonatology increasingly requires a genomic lens. Exome and genome sequencing are now recommended as first-tier tests for neonates with unexplained neurodevelopmental disorders, with genome sequencing providing approximately 10–20% higher diagnostic yield than exome sequencing (14, 15). Broad sequencing also reveals an important, sometimes underappreciated reality: a nontrivial fraction of pediatric patients harbor multiple molecular diagnoses. Large cohort studies and systematic clinical experience suggest that dual diagnoses occur in approximately 3–5% of genetically di-

agnosed cases and are particularly enriched among patients with severe, multisystem, or atypical presentations (13). More recently, phenotype-structure analyses of dual diagnoses have shown that presentations range from clearly distinct conditions to highly blended or nearly indistinguishable phenotypes, reinforcing that multilocus contributions may be clinically entangled rather than simply additive (13).

"From a diagnostic perspective, this case underscores why neonatology increasingly requires a genomic lens. Exome and genome sequencing are now recommended as first-tier tests for neonates with unexplained neurodevelopmental disorders, with genome sequencing providing approximately 10–20% higher diagnostic yield than exome sequencing."

Finally, the management implications are practical. Neither COL4A1/A2-related disorders nor ERCC6-related Cockayne syndrome currently have established disease-modifying therapies; therefore, clinical benefit derives from anticipatory guidance, targeted surveillance, and avoidance of preventable complications. For COL4A1/A2-related disorders, early recognition is particularly important because hemorrhagic vulnerability and neurovascular instability affect counseling and risk management, and published consensus guidelines support structured multidisciplinary follow-up, including baseline and periodic neuroimaging, ophthalmologic evaluation, cardiovascular assessment, and renal function monitoring (7, 9). For Cockayne syndrome, diagnosis enables realistic prognostication, focused supportive care planning, and family counseling regarding progression and recurrence risk (10). Taken together, this rare dual-etiology case reinforces a key neonatal principle: when the neuroimaging pattern, clinical course, or severity appears discordant with perinatal exposures, clinicians should actively consider genetic mimics and multilocus explanations, and apply broad genomic testing early in the diagnostic pathway (1, 14).

"COL4A1/A2-related disorders nor ERCC6-related Cockayne syndrome currently have established disease-modifying therapies; therefore, clinical benefit derives from anticipatory guidance, targeted surveillance, and avoidance of preventable complications."

Take-Home Messages:

Practical Guidelines for Neonatologists

1. Neonatal brain injury may have a primary genetic cause, even in the presence of perinatal complications.
2. Cerebral microhemorrhages and periventricular leukomalacia should prompt consideration of COL4A1/A2-related disease.
3. Progressive postnatal features such as growth failure and optic atrophy may indicate an additional neurodegenerative disorder, including ERCC6-related Cockayne syndrome.
4. Dual genetic diagnoses should be considered when a single condition does not fully explain the clinical course.
5. Exome or genome sequencing is recommended as a first-tier test for neonates with unexplained neurodevelopmental disorders, with genome sequencing providing 10–20% higher diagnostic yield than exome sequencing.

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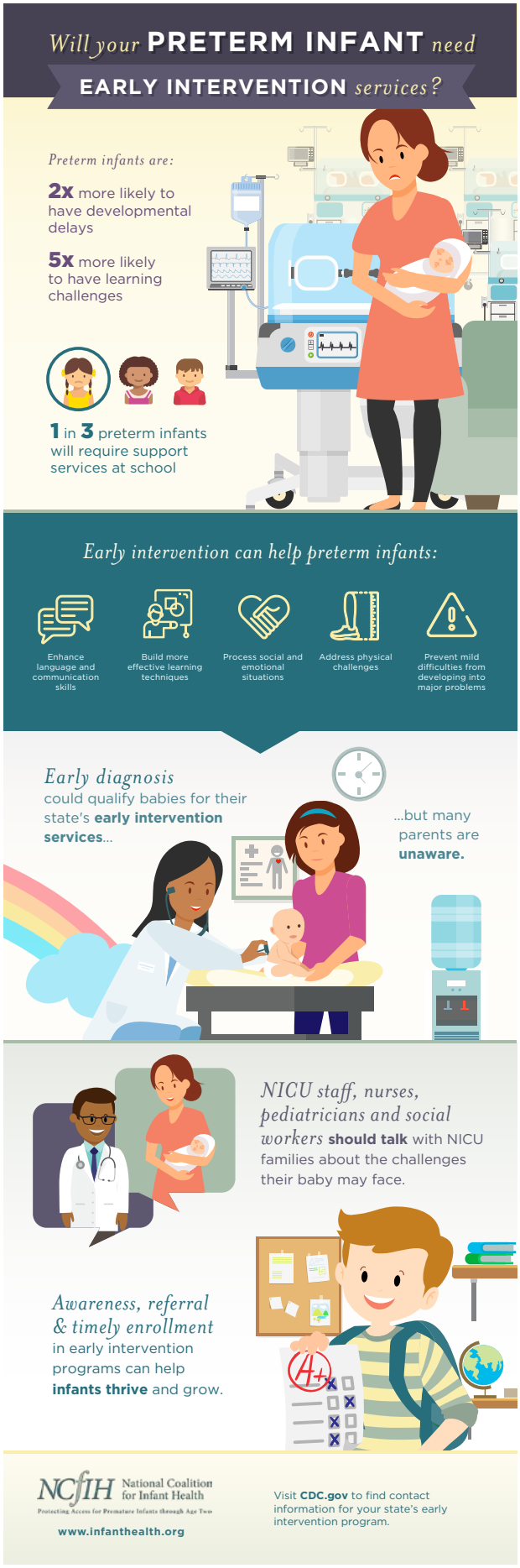

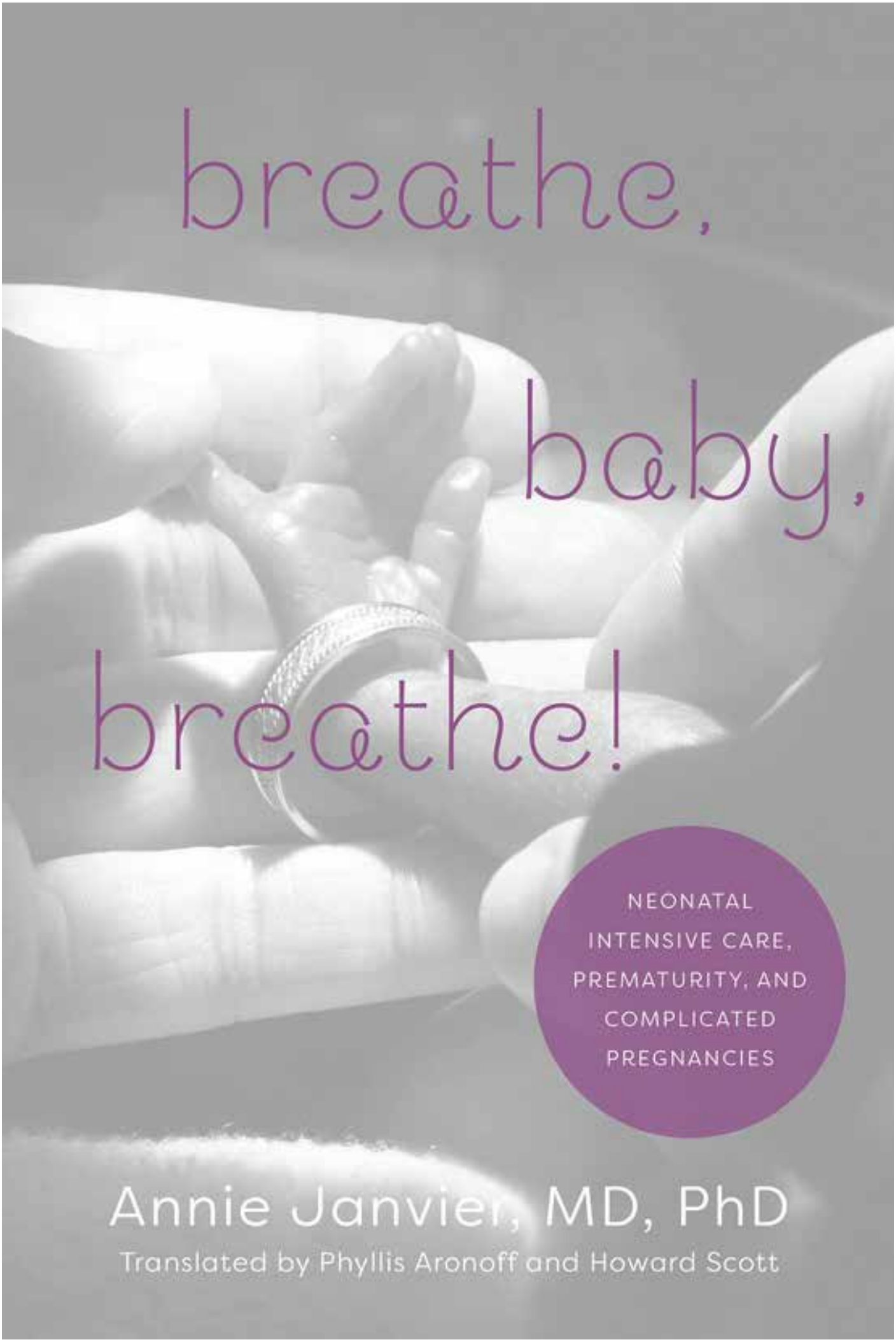

breathe, baby, breathe!

NEONATAL INTENSIVE CARE, PREMATURITY, AND COMPLICATED PREGNANCIES

Annie Janvier, MD, PhD

Translated by Phyllis Aronoff and Howard Scott

11AM-12:30pm PT

FCC Taskforce

May 14th Webinar

STIGMATIZING LANGUAGE: CHANGING THE NARRATIVE

Veronica Barcelona, PhD, MSN, RN, FAAN (she/her)
Assistant Professor,
Columbia University
School of Nursing

Jessi Barnes, MSN, RN, RNC-NIC, NPD-BC, C-ELBW, C-TIP (she/her)
Clinical Nurse Educator
NICU Parent

Rose Horton, MSM, RNC-OB, NEA-BC, FAAN (she/her)
Founder & CEO,
Not On My Watch
Consulting Partners

Adrienne McIntyre, DNP, RNC-NIC (she/her)
System Executive Director, Women & Children's Clinical Institute at Providence
Community Advisory Board Member, California Maternal Quality Care Collaborative

Cheniqua Morales, BSN, RNC-MNN, C-EFM, C-ONQS (she/her)
Perinatal Patient Safety Nurse,
New York Presbyterian Brooklyn Methodist Hospital
Co-Chair, AWHONN NYC Chapter

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FAMILY-CENTERED CARE TASKFORCE

Family Centered Care: Announcing the 2026 Family-Centered Care (FCC) Scholars for the Gravens Conference

Malathi Balasundaram, MD

"The FCC Taskforce is proud to announce the selection of the 2026 Family-Centered Care (FCC) Scholars, who will attend the upcoming Gravens Conference through the FCC Taskforce Educational Grant. "

The FCC Taskforce is proud to announce the selection of the 2026 Family-Centered Care (FCC) Scholars, who will attend the upcoming Gravens Conference through the FCC Taskforce Educational Grant. Each year, this program seeks to identify and support emerging leaders in neonatal and perinatal care who demonstrate a deep commitment to advancing family-centered care within the NICU and beyond. Thank you to Chiesi Pharmaceutical Independent Educational grant for their continued funding for this scholars program.

This year's applicant pool was exceptionally strong, representing a broad range of disciplines, institutions, and personal experiences united by a shared passion for improving the lives of infants and families. The applications reflected remarkable creativity, compassion, advocacy, and dedication to transforming neonatal care environments into spaces where families are recognized as essential partners in healing, decision-making, and long-term developmental support.

"Reviewing such a large volume of applications within a compressed timeframe required extraordinary dedication, particularly given the demanding clinical, academic, and leadership responsibilities each reviewer already carries."

The FCC Taskforce extends its appreciation to the many individuals who made this year's selection process possible. We are profoundly grateful to Latoya, Katrina, Jessi, Sahra, Vincent, Ramya, Jessica, and Mitchell for generously volunteering their time and expertise to participate in the blind review process. Reviewing such a large volume of applications within a compressed timeframe required extraordinary dedication, particularly given the demanding clinical, academic, and leadership responsibilities each reviewer already carries. Their thoughtful evaluations and commitment to fairness helped ensure a rigorous and equitable selection process.

We would also like to extend special thanks to Keira for her collaboration in reviewing the Family Partners applications. The inclusion of family voices within the FCC Scholars program remains central to the mission of the Gravens Conference and to the broader movement toward truly collaborative neonatal care.

In addition, we wish to offer enormous gratitude to Morgan for her exceptional organizational leadership throughout the entire process. Morgan coordinated the preparation of applications for anonymous review, managed score tabulation, maintained communication and workflow, and ensured award notifications were completed ahead of schedule. Her diligence, professionalism, and willingness to share her expertise made the process seamless and highly efficient.

"In addition, we wish to offer enormous gratitude to Morgan for her exceptional organizational leadership throughout the entire process. Morgan coordinated the preparation of applications for anonymous review, managed score tabulation, maintained communication and workflow, and ensured award notifications were completed ahead of schedule."

After careful review and scoring of applications, the following individuals were selected to receive support to attend the Gravens Conference as 2026 FCC Scholars:

Fellows

- * Dana Apkon—Second-Year Fellow, Children's Harvard
- Daphne Darmawan—Third-Year Fellow, Stanford/Lucile Packard
- Elizabeth Lee—Second-Year Fellow, Johns Hopkins
- Kelly MacPherson—First-Year Fellow, Brown University/ Women & Infants Hospital
- Trisha Mulamreddy—First-Year Fellow, UCLA

These fellows distinguished themselves through their demonstrated leadership, commitment to developmental and family-centered neonatal care, scholarly engagement, and vision for improving systems of care for infants and families.

Their applications reflected a sophisticated understanding of the importance of interdisciplinary collaboration, communication with families, and the long-term developmental impact of NICU experiences.

Early Career Nurse Scholar

- Isabella Massey—Fourth-Year RN, Cooper University Hospital

The nursing applications this year highlighted the essential role nurses play in shaping family experiences in the NICU. Isabella's application demonstrated exceptional commitment to advocacy, bedside partnership, and the promotion of emotionally supportive care environments for both infants and caregivers.

Early Career Therapist Scholar

- Kelly Williamson—First-Year Speech Language Pathologist, Johns Hopkins

The therapist category was particularly competitive this year. While financial limitations unfortunately prevent travel support from being extended to applicants in India this year, these applicants will be offered the opportunity to participate virtually as FCC Scholars. We are grateful for their contributions and pleased that they will remain connected to the conference's educational and collaborative experiences.

Family Partners

Supported through the Michael Hynan Fund, made possible through the generosity of Webinars' speakers who donated their honoraria back to the program.

- Valicitie Rubino—NICU Family Support Specialist, Valley Hospital
- Janna Andre—NICU Parent Advisory Council Member, Mount Sinai

"The inclusion of Family Partners within the FCC Scholars program continues to represent one of the most meaningful aspects of the Gravens Conference experience. Family-centered care cannot fully exist without the active inclusion of parents, caregivers, and family advocates whose lived experiences provide essential insight into the realities of neonatal hospitalization and long-term follow-up care."

The inclusion of Family Partners within the FCC Scholars program continues to represent one of the most meaningful aspects of the Gravens Conference experience. Family-centered care cannot fully exist without the active inclusion of parents, caregivers, and family advocates whose lived experiences provide essential insight into the realities of neonatal hospitalization and long-term follow-up care. The perspectives brought forward by Valicitie Rubino and Janna Andre will undoubtedly enrich conference discussions and strengthen ongoing efforts to create more compassionate, collaborative systems of care.

Reading through this year's applications was both humbling and inspiring. Across disciplines and institutions, applicants consistently demonstrated an extraordinary commitment to ensuring that neonatal care extends beyond survival alone and embraces emotional connection, developmental protection, communication, partnership, and equity. Their answers reflected a generation of clinicians, therapists, nurses, and advocates determined to build NICU cultures where families are welcomed as integral members of the care team.

While significant work remains to ensure that opportunities in family-centered care education and leadership are accessible to all who seek them, this year's applications offered tremendous encouragement. The future of neonatology is being shaped by individuals who understand that excellence in neonatal medicine requires not only scientific and clinical expertise but also humanity, empathy, collaboration, and respect for families' experiences.

"To all applicants who shared their stories, ideas, and aspirations with us: thank you. Your dedication to advancing family-centered care continues to inspire this coalition and strengthen our collective mission"

To all applicants who shared their stories, ideas, and aspirations with us: thank you. Your dedication to advancing family-centered care continues to inspire this coalition and strengthen our collective mission.

"Congratulations to the 2026 FCC Scholars. We look forward to welcoming you to the Gravens Conference and to supporting your continued growth as leaders in neonatal and family-centered care."

Congratulations to the 2026 FCC Scholars. We look forward to welcoming you to the Gravens Conference and to supporting your continued growth as leaders in neonatal and family-centered care.

***Disclosures**: The author has no disclosures*

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2026 FCC SCHOLARS

The Family-Centered Care Taskforce received **over 60 impressive submissions** from Fellows, Early Career Nurses & Therapists, and Family Partners across the U.S., Canada, India, and Ghana, making our final selection of scholarship recipients incredibly difficult. Please joining us in recognizing **this year's award recipients who will be supported in attending the 39th International Gravens Conference!**

FAMILY PARTNERS

Janna Andre
NICU Parent Advisory Committee,
Mount Sinai Hospital
NICU Parent

Valicitie Porrata-Rubino
NICU Family Support Specialist,
The Valley Hospital
NICU Parent

The Family-Centered Care Taskforce recognizes that **family partner attendees play a vital role in making Gravens Conference impactful and inspiring to all who attend**. With restrictions around using educational grants to support family partner travel, we created **The Michael Hynan Fund**, initiated by Michael Hynan, PhD, to support family partner travel. **We are accepting tax-deductible donations** for this important initiative. If you are interested in supporting us, please email us at FamilyCenteredCareTaskforce@gmail.com.

FELLOWS

Dana Apkon, MD
Second Year Fellow,
Boston Children's Hospital at Harvard

Daphne Darmawan, MD, MBS
Third Year Fellow
Stanford Lucile Packard Children's Hospital

Elizabeth Lee, MD
Second Year Fellow
Johns Hopkins Children's Center

Trisha Mulamreddy, MD, MPH
First Year Fellow
University of California,
Los Angeles

Kelly MacPherson, MD, MS
First Year Fellow
Women & Infants Hospital,
Brown University

EARLY CAREER NURSE

Isabella Massey, BSN, RNC-NIC
Knowledge & Innovation Council Chair
Cooper University Hospital

EARLY CAREER THERAPIST

Kelly Williamson, M.S. CCC-SLP
Speech-Language Pathologist
Johns Hopkins Bayview Medical Center

EARLY CAREER THERAPISTS (VIRTUAL)

Sharath Hullumani
Pediatric & Neonatal Physiotherapist
Acharya Vinobhabve Rural Hospital,

Niharika Mathur
Senior Physiotherapist & PhD Scholar
All India Institute of Medical Sciences

FCC SCHOLARS REVIEW COMMITTEE





Malathi Balasundaram, MD, **Jessi Barnes**, MSN, RN, RNC-NIC, NPD-BC, NICU Parent, **Latoya Blueford**, NICU Parent, **Sahra Cahoon**, NICU Parent, **Jessica Fry**, MD






Mitchell Goldstein, MD, **Morgan Kowalski**, NICU Parent, **Ramya Kumar**, MS, CCC-SLP, BCSS, CNT, IBCLC, NTMTC, SBCS, **Katrina Moline**, NICU Parent, **Vincent Smith**, MD, MPH, **Keira Sorrells**, NICU Parent

Family Partner FCC Scholars are generously supported by The Michael Hynan Fund.
Eight FCC Scholars are generously supported by a Chiesi Independent Educational Grant.
One FCC Scholar is generously supported by Mead Johnson Nutrition.

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and NICU Parent Network

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Peer Reviewed

Applying the Critical Care Definition – Global Critical Care Codes

Scott D. Duncan, MD, MHA

"As noted in the previous article, the care of infants is the only specialized service that delineates critical care, intensive care, and hospital care within the CPT coding structure. A definition of critical care encompasses both the illness and the treatment."

As noted in the previous article, the care of infants is the only specialized service that delineates critical care, intensive care, and hospital care within the CPT coding structure. A definition of critical care encompasses both the illness and the treatment.

- "A critical illness acutely impairs one or more vital organ systems such that there is a high probability of imminent or life-threatening deterioration in the patient's condition.
- Critical care involves high complexity decision making to assess, manipulate, and support vital system function to treat vital organ system failure and/or to prevent further life-threatening deterioration of the patients' condition."

Critical care codes can be placed into several different categories.

- Time-based critical care (**99291**, **99292**)
- Daily global neonatal or pediatric critical care services (**99468**-**99469**; **99471–99472**)
- Critical care provided during transport from one facility to another (**99466**-**99467**) or non–face-to-face supervision of a transport team that is providing hands-on care (**99485**-**99486**)

Question:

A newly born 37-week infant in the NBN has respiratory distress. The CXR shows transient tachypnea of the newborn, and the infant demonstrates hypercarbia on arterial blood gas analysis. The infant is transferred to the NICU for further management, including CPAP and IV antibiotics. The correct code is:

A. **99469:** Subsequent inpatient neonatal critical care, per day

B. **99468:** Initial day inpatient neonatal critical care, per day

C. **99477:** Initial hospital intensive care, per day for EM of the neonate 28 days or younger

Answer:

B. **99468**: Initial day inpatient neonatal critical care, per day

In this example, the patient is deemed critical; that is, the current diagnosis of transient tachypnea of the newborn and respiratory

Global Critical Care Codes

Patient age	Code and service description	Initial Day	Subsequent Day
≤ 28 d	Inpatient neonatal critical care, per day	99468	99469
29 d–24 mo	inpatient pediatric critical care, 29 days through 24 months of age	99471	99472

failure is deemed life-threatening. The prescribed respiratory support (i.e., CPAP) used to treat respiratory failure is considered critical care, as discontinuing the current care would lead to a high probability of imminent life-threatening deterioration.

" Note that the initial day of intensive care does not have to be day of birth. Only one initial day of intensive care (99477) may be used by a single group practice, in a given facility during the same hospital stay."

Question:

A 5-day-old 33-week gestation infant has a diagnosis of RDS and weighs 1800 grams. He continues on non-invasive ventilation with a rate of 20 bpm and 23% FiO2. Capillary blood gases are reassuring. The correct code is:

A. **99469:** Subsequent inpatient neonatal critical care, per day

B. **99479:** Subsequent intensive care, per day, for the E/M of the recovering low birth weight infant of 1500-2500 g

C. **99472:** Subsequent inpatient pediatric critical care, 29 days – 24 months

Answer:

A. **99469:** Subsequent inpatient neonatal critical care, per day

The same question arises: Does this baby achieve critical care status? Testing includes the determination that the diagnosis is deemed life-threatening, and if the current care were stopped, there would be a high probability of imminent life-threatening deterioration. The infant does not have an indwelling endotracheal tube to provide life-saving respiratory support.

Question:

A 32-week gestational age infant with a birthweight of 1150g (IUGR) has been doing well without organ failure since admission. The infant has been on room air and is tolerating slow advancement of feeds. Initially, CPT coding was for intensive care services. The infant is now DOL 30, with a weight of 1550g, and develops abdominal distention and discoloration with apnea requiring intubation. The correct code is:

A. **99468:** Initial day inpatient neonatal critical care, per day

B. **99469:** Subsequent inpatient neonatal critical care, per day

C. **99471**: Initial inpatient pediatric critical care, 29 days – 24 months

D. **99472:** Subsequent inpatient pediatric critical care, 29 days – 24 months

Answer:

C. **99471:** Initial inpatient pediatric critical care, 29 days – 24 months

This baby is now critical, due to respiratory failure with malignant apnea and a possible intra-abdominal process. While this is not the first day of hospitalization, it is the first day of critical illness during this hospitalization. As the baby is now 30 days old, **99468** would not be the correct initial critical care code.

Question:

The neonatologist rounds on a 6-day-old 26-week gestational age infant. The infant weighs 950g and is on CPAP +5 28%. The infant has been placed on minimal enteral stimulation, and feedings will be slowly advanced while TPN support is reduced. After rounds, the neonatologist updates the family, obtains consent for a PICC

line, and then places it. The correct codes include:

A. **99469:** Subsequent inpatient neonatal critical care, per day

B. **99469:** Subsequent inpatient neonatal critical care, per day

36568: Insertion of PICC w/o imaging guidance, younger than 5 years of age

C. **99478**: Subsequent intensive care, per day, for the E/M of the recovering low birth weight infant of < 1500 g

D. **99478:** Subsequent intensive care, per day, for the E/M of the recovering low birth weight infant of < 1500 g

36568: Insertion of PICC w/o imaging guidance, younger than 5 years of age

Answer:

B. **99469: Subsequent critical care, 28 days or younger**

36568: PICC w/o imaging guidance

This baby requires critical care due to the need for continuous positive airway pressure. Many procedures in neonatology are bundled into the global daily codes and cannot be billed separately. Insertion of a PICC line is one example of a procedural code that may be billed in addition to the global daily code. For proper coding of the PICC line, the infant must have an associated diagnosis. One example might be P92.2, slow feeding of the neonate. Failure to attach a proper ICD-10 code to a procedure may result in payment denial.

Question:

A 2-day-old preterm infant on assisted ventilation for RDS presents with acute respiratory distress. A CXR displays bilateral pneumothoraces. You elect to place bilateral pigtail chest catheters emergently in this infant, attached to a drainage system. Proper coding for insertion would be:

A. **99469:** Subsequent inpatient neonatal critical care, per day

32551: Subsequent critical care, tube thoracostomy, includes connection to drainage system, when performed, open (separate procedure)

B. **99469:** Subsequent inpatient neonatal critical care, per day

32554: Subsequent critical care thoracentesis, needle or catheter, aspiration of the pleural space; without imaging guidance

C. **99469:** Subsequent inpatient neonatal critical care, per day

32556: Subsequent critical care, pleural drainage, percutaneous, with insertion of an indwelling catheter; without imaging guidance

D. **99469**: Subsequent inpatient neonatal critical care, per day

Answer:

C. **99469:** Subsequent inpatient neonatal critical care, per day

32556: Subsequent critical care, pleural drainage, percutaneous, with insertion of an indwelling catheter; without imaging guidance

This vignette includes placement of a pigtailed catheter over a wire/trocar inserted into the pleural cavity, removal of the trocar, and attachment of the chest tube to the chest tube drainage system. **32551** is for an open procedure generally performed only by surgeons. In this particular scenario, report two (2) units of service with modifier -50 (bilateral procedure) attached. The correct ICD-10 diagnosis code is P25.1, for a pneumothorax originating in the perinatal period.

The two preceding scenarios include procedures that may be

billed in addition to global (neonatal) critical care codes. Services that are not bundled into the global codes include (but may not be limited to):

- Cardiopulmonary resuscitation (**92950**)
- Chest tube placement (**32551**)
- Peripherally inserted central catheter (**36568–36573**)
- Complete (double volume) exchange transfusion (**36450**)
- Partial exchange transfusion (**36456**)
- Initiation of selective head or total body hypothermia in the critically ill neonate (**99184**)
- Paracentesis (**49082**)
- Pericardiocentesis (**33016**)
- Thoracentesis (**32554**, **32555**) (via needle or pigtail catheter)

Bonus Question:

This one-day-old preterm infant on conventional ventilation is treated with a second dose of a bovine surfactant product. A reticulogranular pattern is demonstrated within the lung fields by CXR. Which ICD-10 code would be correct for this encounter:

A. **P22.0:** Respiratory distress syndrome of the newborn

B. **W55.29XA:** Other contact with cow, subsequent encounter

C. **P28.5:** Respiratory failure of newborn

Answer:

A. P22.0 Respiratory Distress Syndrome

Currently, an "Excludes 2" note in ICD-10 states that P28.5 is not part of the condition, but both conditions may occur at the same time. If the patient has respiratory failure, documentation might include "respiratory failure due to RDS," and the provider can report P28.5 in addition to P22.0.

Documentation Tip:

Documentation must support the critical nature of the patient's presenting problems, key findings from data interpretation, descriptions of services provided to support vital organ system functions (e.g., cardiovascular and ventilatory support), and the outcomes of those services.

An example of documentation for critical care in the settings of a trainee might be, "The infant remains critical due to respiratory failure in the setting of respiratory distress syndrome, requiring assisted ventilation.

I performed an interval history and evaluated the infant during multidisciplinary rounds. I have reviewed the history, data, problems, assessment, and plan with the resident, and agree with the documented findings and plan of care. I was present during key or critical portions of this service and performed the required elements with the above-mentioned members of the healthcare team. I have reviewed the above note based on the information at hand and edited the document as thoroughly as possible for accuracy.

This patient is experiencing vital organ impairment requiring support and interventions as delineated in the above problem list. Medical management, including frequent assessments of patient status, medical decision making, and intervention adjustments of high complexity, is required to prevent life-threatening deterioration in the patient's conditions."

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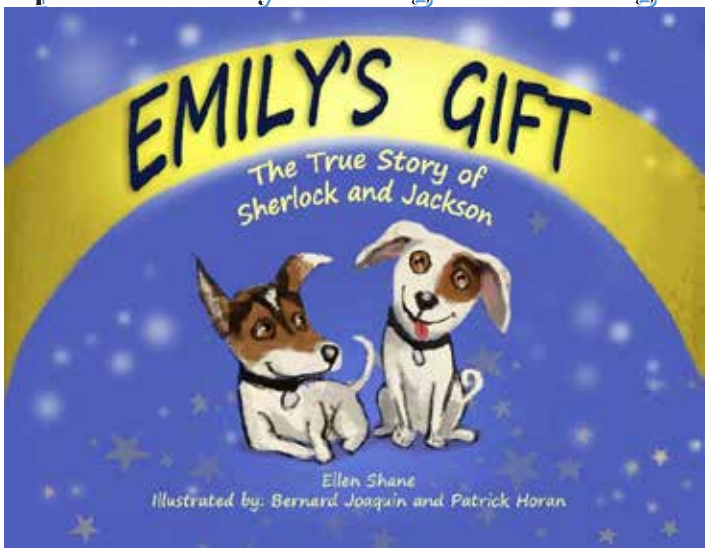

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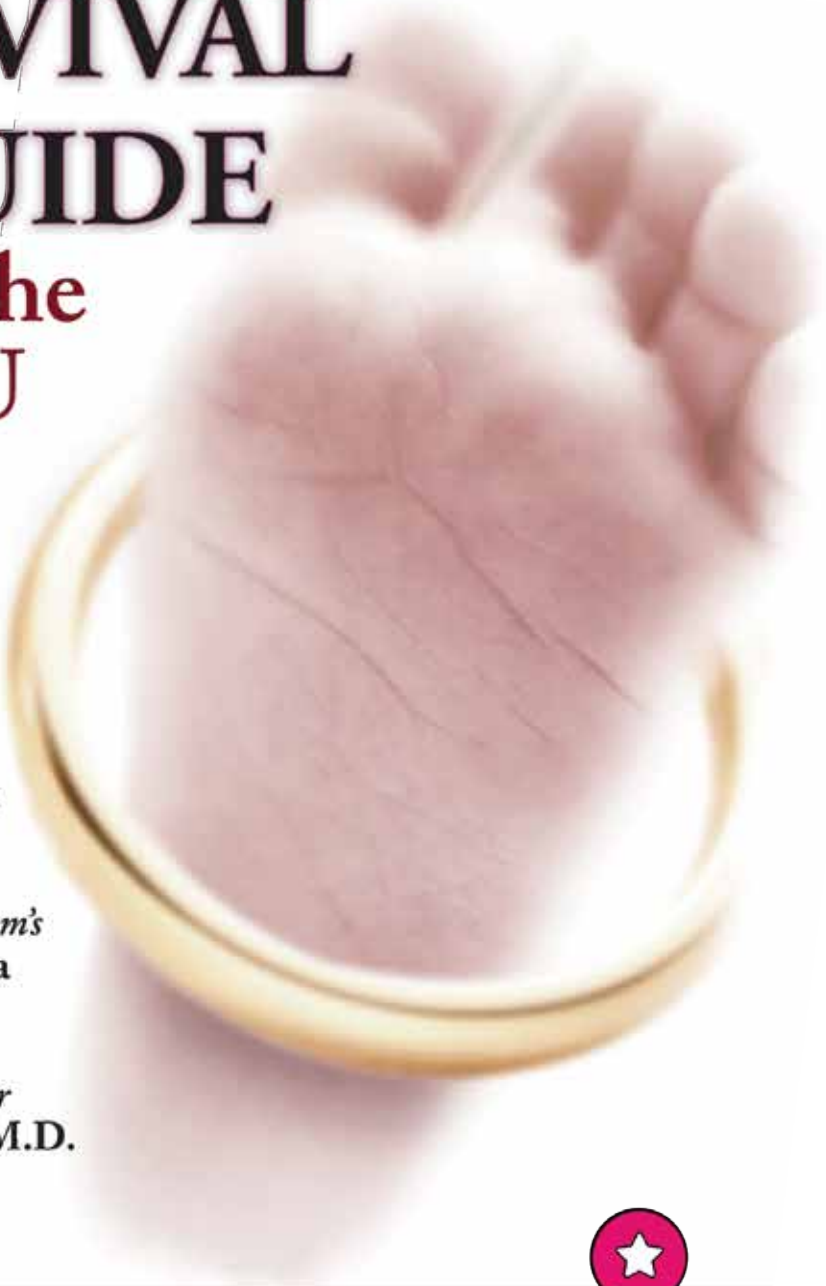

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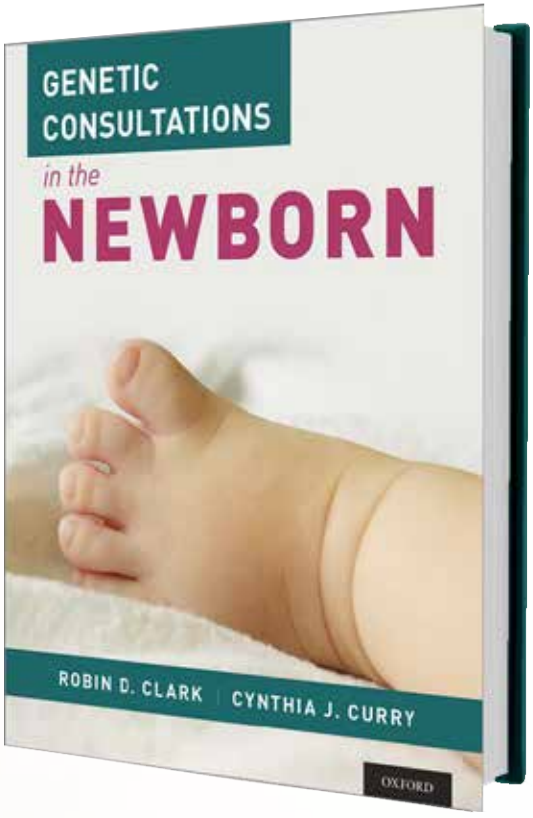

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Clinical Pearl: Persistent Hemodynamically Significant Patent Ductus Arteriosus Exposure and the Potential Risk of Late Acute Kidney Injury in Extremely Premature Infants

Joseph R. Hageman, MD, Mitchell Goldstein, MD, MBA, CML

"Since neonatologists first characterized the hemodynamically significant patent ductus arteriosus (HPDA) in the premature infant and recognized its important effects on cardiopulmonary physiology, there has been substantial debate regarding the optimal management of this condition."

Since neonatologists first characterized the hemodynamically significant patent ductus arteriosus (HPDA) in the premature infant and recognized its important effects on cardiopulmonary physiology, there has been substantial debate regarding the optimal management of this condition. The ductus arteriosus, a normal fetal vascular connection between the pulmonary artery and descending aorta, ordinarily closes shortly after birth as pulmonary vascular resistance falls and systemic oxygen tension rises. In extremely premature infants, however, ductal closure is frequently delayed because of structural immaturity of the ductal tissue, altered prostaglandin metabolism, relative hypoxia, and impaired smooth muscle responsiveness. The persistence of a large left-to-right ductal shunt may result in pulmonary overcirculation and systemic hypoperfusion, contributing to respiratory compromise and impaired organ perfusion.

Clinically, premature infants with HPDA may present with worsening respiratory distress, increased oxygen and ventilatory requirements, pulmonary edema, widened pulse pressure, bounding peripheral pulses, metabolic acidosis, feeding intolerance, hypotension, oliguria, and difficulty weaning from respiratory support. Echocardiographic findings may include left atrial and ventricular enlargement, reversal of diastolic flow in the descending aorta, increased pulmonary blood flow, and evidence of systemic "steal" physiology. For example, a 24-week gestation infant requiring escalating high-frequency ventilation with persistent hypotension and reduced urine output may demonstrate a large ductal shunt with significant diastolic runoff on echocardiography. In another infant, recurrent pulmonary hemorrhage during the first week of life may be associated with a large PDA causing severe pulmonary vascular congestion. Such clinical scenarios have fueled decades of investigation regarding whether active intervention improves outcomes or merely exposes vulnerable infants to additional risks.

Over the years, numerous clinical studies have evaluated a broad range of management strategies, including pharmacologic closure with cyclooxygenase inhibitors such as indomethacin and ibuprofen, more recently, acetaminophen therapy, and invasive interventions including surgical ligation and transcatheter device closure (1-3). Indomethacin became widely utilized because of its ability to inhibit prostaglandin synthesis and promote ductal constriction, particularly in the first days of life. Ibuprofen subsequently emerged as an alternative with similar efficacy and potentially less renal vasoconstriction. More recently, acetaminophen has gained interest because it acts through a different enzymatic pathway and may have a more favorable gastrointestinal and renal side effect profile in some infants.

"Indomethacin became widely utilized because of its ability to inhibit prostaglandin synthesis and promote ductal constriction, particularly in the first days of life. Ibuprofen subsequently emerged as an alternative with similar efficacy and potentially less renal vasoconstriction. More recently, acetaminophen has gained interest because it acts through a different enzymatic pathway and may have a more favorable gastrointestinal and renal side effect profile in some infants."

Pharmacologic management practices vary considerably across neonatal intensive care units. One center may elect early targeted indomethacin therapy in a 25-week infant with echocardiographic evidence of a moderate-to-large PDA before overt clinical deterioration occurs. Another NICU may prefer a more selective approach, administering ibuprofen only after persistent ventilator dependence and signs of pulmonary overcirculation become evident. Acetaminophen may be utilized in infants with thrombocytopenia, intestinal concerns, or worsening renal function where clinicians wish to avoid further prostaglandin inhibition. Despite decades of study, however, no single pharmacologic strategy has conclusively demonstrated improvement in long-term neurodevelopmental outcomes, chronic lung disease, or survival across all patient populations.

Invasive interventions have likewise evolved. Surgical ligation was historically performed in infants who failed medical therapy or developed significant cardiopulmonary compromise. While ligation frequently results in prompt elimination of the ductal shunt and improvement in pulmonary mechanics, concerns

emerged regarding complications, including vocal cord paralysis, diaphragmatic paralysis, post-ligation cardiac syndrome, hypotension, infection, scoliosis, and potential associations with adverse neurodevelopmental outcomes. For example, a critically ill 23-week infant with refractory hypotension and pulmonary edema despite repeated medical therapy may undergo surgical ligation only to develop severe post-operative myocardial dysfunction requiring escalating vasoactive support subsequently. Such experiences prompted increasing interest in less invasive approaches.

"More recently, transcatheter device closure has emerged as an important therapeutic option in selected premature infants. Improvements in catheter technology and miniaturized occlusion devices have enabled closure in infants weighing less than 1 kilogram at specialized centers. In some cases, extremely premature infants with prolonged ventilator dependence and persistent large ductal shunts have demonstrated rapid improvement in respiratory status following transcatheter closure."

More recently, transcatheter device closure has emerged as an important therapeutic option in selected premature infants. Improvements in catheter technology and miniaturized occlusion devices have enabled closure in infants weighing less than 1 kilogram at specialized centers. In some cases, extremely premature infants with prolonged ventilator dependence and persistent large ductal shunts have demonstrated rapid improvement in respiratory status following transcatheter closure. Nevertheless, these procedures are technically demanding and carry risks including vascular injury, device embolization, obstruction of adjacent vascular structures, arrhythmias, and procedural instability.

At the same time, many neonatologists have increasingly adopted conservative or expectant management strategies emphasizing careful fluid administration, optimization of respiratory support, avoidance of unnecessary intervention, and allowance for spontaneous ductal closure (1-3). This approach reflects observations that many PDAs eventually close without treatment and that aggressive closure strategies may not consistently improve long-term outcomes. Conservative management may include modest fluid restriction, careful attention to sodium balance, use of diuretics in selected cases, permissive respiratory support strategies, and serial echocardiographic monitoring. For example, a stable 27-week infant requiring only low levels of continuous positive airway pressure with adequate growth and urine output may be observed expectantly despite echocardiographic evidence of a moderate PDA, with spontaneous closure occurring weeks later without pharmacologic therapy.

Parallel to these evolving controversies regarding HPDA management, acute and chronic kidney disease have emerged as major clinical concerns among premature infants admitted to the neonatal intensive care unit (NICU) (3). The premature kidney is structurally and functionally immature, particularly in extremely low gestational age infants, where nephrogenesis remains incomplete at birth. Nephron development normally continues until approximately 34 to 36 weeks of gestation; therefore, infants born at 23 to 26 weeks are forced to complete nephrogenesis in an extrauterine environment characterized by fluctuating oxygenation, hemodynamic instability, inflammation, exposure to medications, and nutritional challenges.

"Acute kidney injury (AKI) has become increasingly recognized as an important contributor to morbidity and mortality in this fragile population. The reported incidence of AKI among very low birth weight infants in the NICU ranges from approximately 18% to 70%, depending on the population studied and the diagnostic criteria utilized (3)."

Acute kidney injury (AKI) has become increasingly recognized as an important contributor to morbidity and mortality in this fragile population. The reported incidence of AKI among very low birth weight infants in the NICU ranges from approximately 18% to 70%, depending on the population studied and the diagnostic criteria utilized (3). Importantly, the incidence and severity of AKI increase proportionately with decreasing gestational age and birth weight, placing the smallest and most immature infants at greatest risk (3). Extremely low birth weight infants frequently encounter multiple simultaneous renal stressors, including hypotension, sepsis, nephrotoxic antibiotics, exposure to nonsteroidal anti-inflammatory medications, mechanical ventilation, and impaired systemic perfusion.

Examples of AKI in the NICU are numerous and multifactorial. A 24-week infant with septic shock may develop profound oliguria and rising serum creatinine levels following episodes of hypotension requiring vasopressor support. Another infant receiving indomethacin therapy for PDA closure may demonstrate decreased urine output and worsening electrolyte abnormalities secondary to reduced renal perfusion. Infants with severe respiratory failure requiring high ventilator pressures may experience diminished cardiac output and renal blood flow. Similarly, prolonged exposure to aminoglycosides or vancomycin may further compound renal injury in already vulnerable premature kidneys.

The relationship between HPDA and renal dysfunction is particularly complex because the physiology of a significant ductal shunt itself may contribute to impaired renal perfusion. Large left-

to-right shunting can produce diastolic "steal" from the systemic circulation, reducing blood flow to organs such as the kidneys, intestines, and brain. Clinically, this may manifest as oliguria, rising serum creatinine, metabolic acidosis, or feeding intolerance. For example, an extremely premature infant with a large PDA may exhibit persistent low urine output and worsening azotemia despite apparently adequate blood pressure measurements because effective systemic perfusion remains compromised by ductal runoff.

Conversely, therapies intended to close the PDA may themselves adversely affect renal function. Indomethacin and ibuprofen reduce prostaglandin-mediated renal vasodilation, potentially decreasing glomerular filtration and renal blood flow. Neonatologists, therefore, frequently face difficult management decisions balancing the risks of persistent systemic hypoperfusion from the PDA against the potential nephrotoxic effects of pharmacologic closure therapy. This dilemma becomes particularly challenging in infants who simultaneously exhibit severe respiratory compromise, hypotension, and evolving renal dysfunction.

"As understanding of both HPDA physiology and neonatal kidney injury continues to evolve, there remains considerable interest in identifying individualized management strategies that optimize both cardiovascular and renal outcomes in extremely premature infants."

As understanding of both HPDA physiology and neonatal kidney injury continues to evolve, there remains considerable interest in identifying individualized management strategies that optimize both cardiovascular and renal outcomes in extremely premature infants. Increasing recognition of heterogeneity among preterm infants has shifted attention toward precision-based approaches that incorporate gestational age, echocardiographic findings, biomarkers of organ injury, clinical stability, and longitudinal risk assessment. Future investigations will likely continue to explore which infants benefit most from active ductal closure, which infants may safely undergo expectant management, and how renal-protective strategies can be integrated into the overall care of this uniquely vulnerable population.

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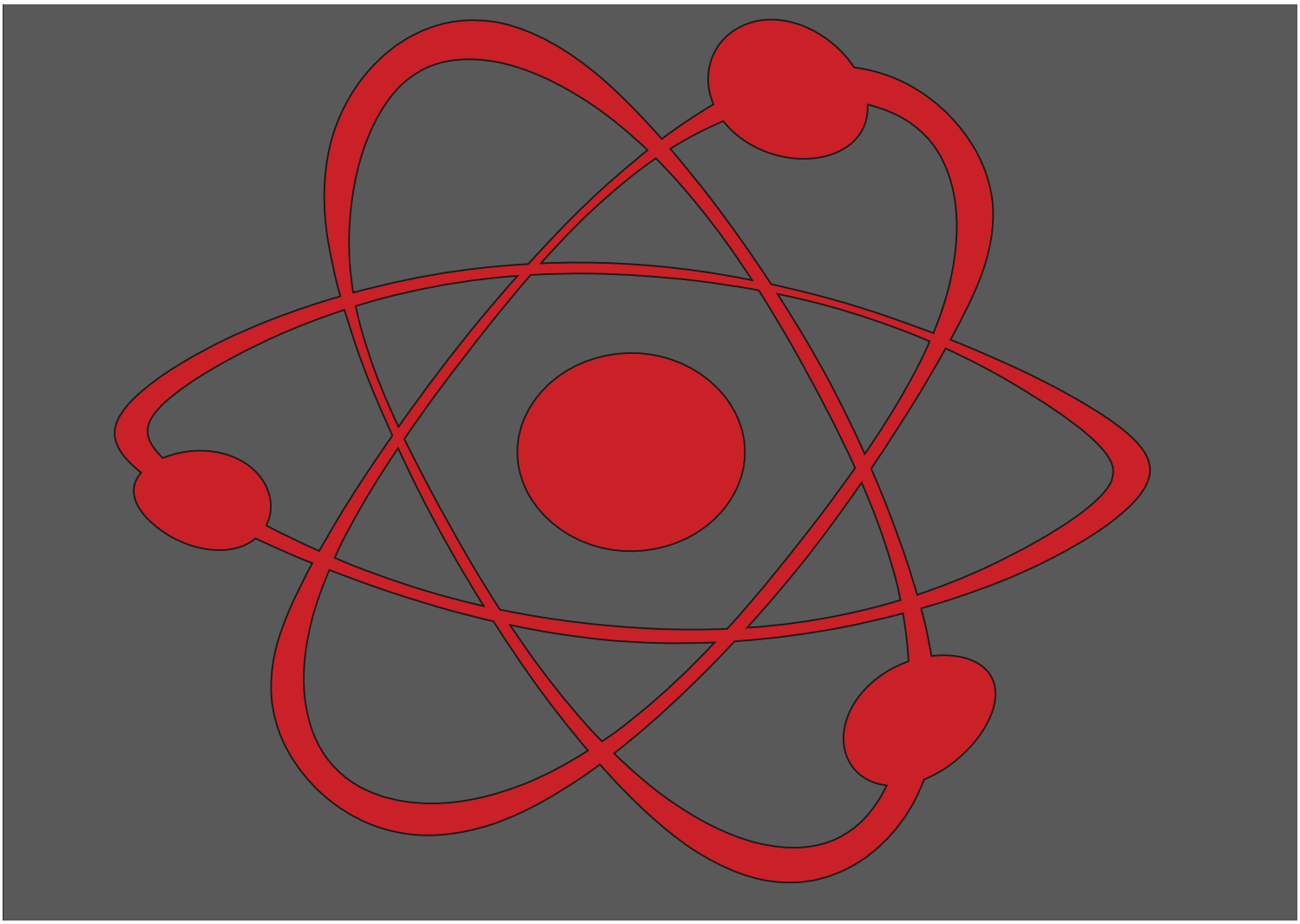

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https://egln.fa.us2.oraclecloud.com/hcmUI/CandidateExperience/en/sites/CX/job/2820/?utm_medium=jobshare

Qualifications:

- Bachlor's Degree or Master's degree in Nutrition and Dietetics or Nutrition-related field required
- Two years of clinical nutrition experience required
- One year in Pediatrics preferred
- RD/RDN required
- CCS paneling required within one year of hire date

Annette Gonzales | Recruiter | LLUH HRM| ACGonzales@llu.edu

NEONATOLOGY TODAY

News and Information for BC/BE Neonatologists and Perinatologists

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https://www.nc3rs.org.uk/arrive-guidelines

http://www.icmje.org

https://olaw.nih.gov/policies-laws/phs-policy.htm

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Neonatology and the Arts

This section focuses on artistic work which is by those with an interest in Neonatology and Perinatology. The topics may be varied, but preference will be given to those works that focus on topics that are related to the fields of Neonatology, Pediatrics, and Perinatology. Contributions may include drawings, paintings, sketches, and other digital renderings. Photographs and video shorts may also be submitted. In order for the work to be considered, you must have the consent of any person whose photograph appears in the submission.

Works that have been published in another format are eligible for consideration as long as the contributor either owns the copyright or has secured copyright release prior to submission.

Logos and trademarks will usually not qualify for publication.

This month we continue to landscapes, feature artistic works created by our readers on the next to last page as well as photographs of birds on rear cover. Dr. Zahera Etter provides "Un Voilier." For this edition, our art was graciously provided by Colleen Kraft, MD. It is a work called "Lamp Light" done by her son Tim. Our bird is from Dr. Shah, "Great Tailed Grackle"

Lily Martorell, MD

Arts Editor
Associate Professor
Loma Linda University Children's Hospital
Loma Linda, CA

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Manuscript Submission: Instructions to Authors

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

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

3. There is no charge for submission, publication (regardless of number of graphics and charts), use of color, or length. Published content will be freely available after publication. There is no charge for your manuscript to be published. NT does maintain a copyright of your published manuscript.

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

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

6. An abstract may be submitted.

7. The main text of the article should be written in formal style using correct English. The length may be up to 10,000 words or longer with prior approval. Abbreviations which are commonplace in neonatology or in the lay literature may be used.

8. References should be included in standard "NLM" format (APA 7th is no longer acceptable). Bibliography Software should be used to facilitate formatting and to ensure that the correct formatting and abbreviations are used for references. EndNote X9 is suggested.

9. Figures should be submitted separately as individual separate electronic files. Numbered figure captions should be included in the main file after the references. Captions should be brief.

10. Only manuscripts that have not been published previously will be considered for publication except under special circumstances. Prior publication must be disclosed on submission. Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.

11. NT recommends reading Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals from ICMJE prior to submission if there is any question regarding the appropriateness of a manuscript. NT follows Principles of Transparency and Best Practice in Scholarly Publishing (a joint statement by COPE, DOAJ, WAME, and OASPA). Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.

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

Please submit your manuscript to: LomaLindaPublishingCompany@gmail.com

Invitation to Apply:

Seeking content development experts for an AAP Project Advisory Committee (PAC)

The White Zone – Developing A Perinatal Loss Toolkit for LMICs

The Need: Over 2.4 million neonatal deaths and 2.6 million stillbirths occur each year; 98% occur in Low- and Middle-Income Countries (LMICs). While programs such as Helping Babies Breathe (HBB) and Essential Newborn Care (ENC 1 and 2) have revolutionized how providers in LMICs train in and provide neonatal resuscitation and post-delivery care for small and sick newborns, gaps remain in how to best offer end-of-life care and post-loss psychosocial care in these settings.

The Babies: HBB and ENC 1 begin with assessing if a baby is crying and conclude with the "Red Zone" where a baby who is unable to sustain an appropriate heart rate and/or respirations is provided with PPV support as someone attempts to get help. Within the HBB/ENC framework, we could imagine several babies for whom an extension of this framework to include palliative/perinatal loss guidelines could be helpful:

1. A stillbirth for whom no resuscitation is attempted. (Stillbirth)
2. A baby who proceeds through the red zone but never has a heartbeat or breathing despite the best resuscitative efforts of the team. (Stillbirth)
3. A baby who proceeds through the red zone who, after 20 or so minutes still has a very low heartbeat and/or gasping breathing. (Anticipated neonatal death)
4. A preterm baby who is too small for ongoing support, based on local resource constraints or resuscitation guidelines, despite a sustained heart rate and breathing. (Anticipated neonatal death)

The Approach: Create a suite of resources that could accompany ENC 1 and 2, focused on end-of-life care and perinatal loss. These resources would be less algorithmic than ENC, as local practices around death vary significantly – meaning there is not one "right" way to approach this care. Rather, the "White Zone Toolkit" would combine structured guidance about symptom management as well as reflective tools for implementing contextually and culturally appropriate post-loss care. This could consist of, but is not limited to, the following:

1. Structured guidance on what physiologic changes may happen at the end of life (ex: gasping) as well as pharmacologic and non-pharmacologic options for symptom management.
2. Reflective questions about if/when to offer seeing or holding of the baby.
    - Data shows that many women want to see and/or hold their infant following stillbirth or neonatal death but are often not offered that opportunity based on historic cultural norms.
3. Reflective questions about cultural traditions around loss and if/how these practices can be supported by those attending the delivery.
4. Anticipatory guidance guides on how mothers may still produce milk and how to manage those symptoms.
5. Anticipatory guidance on potential maternal mental health needs. Reflective questions on how to approach mental health and psychosocial support after loss.
6. Access to a set of adaptable practice scenarios that could help providers gain experience in handling perinatal loss and communicating with families surrounding perinatal loss.

NICU BABY'S *Bill of Rights*

1 The Right to *Advocacy*

My parents are **my voice** and **my family** are **my best advocates**.

My parents know me well. They are my voice and my best advocates. They need to be knowledgeable about my progress, medical needs, and prognosis, so they celebrate my achievements and support me when things get challenging.

2 The Right to *My Parents' Care*

Welcome my family and **include them** in everything we do.

My parents are my essential caregivers. In order to care for me, they need lots of opportunities to learn. Ensure that hospital policies and protocols, including hours & rounding, are as inclusive and expansive as possible. Then be patient with them.

3 The Right to *Bond With My Family*

Create opportunities for my family and me **to be together and bond**.

Bonding is crucial for my healthy growth and development. Support my parents so that we can practice skin-to-skin care as soon and as often as possible. Encourage them to read, sing, and talk to me.

4 The Right to *Neuroprotective Care*

Protect my **developing mind** and **senses**.

Protect me from things that startle, stress, or overwhelm me. Support things that calm me. Ensure I get as much sleep as possible. My brain is developing for the first time - and faster than it ever will again. The way I'm cared for today will affect me as I continue to grow & develop.

5 The Right to *Be Nourished*

Support our feeding decisions and **help us develop our skills**.

Encourage my parents to feed me at the breast or by bottle, whichever way works for us both. Support our feeding goals and make sure my parents know all the nutrition options available to meet my needs.

6 The Right to *Personhood*

Respect me as the **amazing, unique individual** that I am.

Use my name. Talk to me before touching me. If one of my siblings passes away, ask my family how we want to talk about and acknowledge them.

7 The Right to *Confident and Competent Care Giving*

Support my parents and caregivers.

The NICU may be a traumatic place for my parents. Ensure that they receive tender loving care, information, education, and as many resources as possible to help inform them about my unique needs, development, diagnoses, and more.

8 The Right to *Family-Centered Care*

Teach my family **how to care for me**.

Help me feel that I am a part of my own family. Teach my parents, grandparents, and siblings how to read my cues, how to care for me, and how to meet my needs. Encourage them to participate in or perform my daily care activities, such as bathing and diaper changes.

9 The Right to *Healthy and Supported Parents*

Care for our **mental health** and **wellbeing**.

My parents may be experiencing a range of new and challenging emotions. Be patient, listen to them, and lend your support. Share information with my family about resources such as counseling, support groups, & peer-to-peer programs, which can help reduce the impact of perinatal mood and anxiety disorders (PMADs).

10 The Right to *Inclusion and Belonging*

Celebrate what makes us special and unique.

Celebrate our diversity. Honor what makes us unique. Ensure that my parents, grandparents, siblings, and friends feel accepted and welcomed in the NICU, and respected and valued in all forms of engagement and communication.