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False Positive Versus False Negative in Neonate Suspected Congenital Syphilis, Case Report with Analysis for Quality Improvement Austin Bowden, OMS-3, Herbert Vasquez, MD, Mitchell Goldstein, MDPage 3	The Genetics Corner: A Mother and Child with Cleft lip and Palate Have an Atypical 1p36 Deletion that Disrupts KIF1B, a Cause of Autosomal Dominant Charcot-Marie-Tooth Disease, Type 2A1 Subhadra Ramanathan, MSc MS, Robin Dawn Clark, MDPage 118
Child Passenger Safety: Investigation into American Academy of Pediatrics Recommendations, Laws, Regulations, and Safety Testing and How They Compare to California Regulations Candace LeFlame, D.O., Anh Rebhan, D.O., M.S.Page 10	False Alarms Signal Urgency of Infant-Specific Devices Mitchell Goldstein, MD, MBA, CMLPage 125
Briefly Legal: Was Baby's Brain Damage Caused by Mismanagement of Preeclampsia? Maureen E. Sims, M.D., Barry Schiffrin, M.D.Page 18	Clinical Pearl: Inhaled Budesonide with Surfactant Decreases BPD Rates Without Affecting Neurodevelopmental Outcomes Melanie Wielicka, MD, PhD, Joseph R Hageman, MDPage 132
Best Practices for Infant and Family Developmental Care in Intensive Care: The Time Has Come Joy Browne, Ph.D., PCNS, IMH-E(IV)Page 26	Defining the Lines: Coding for the Neonatal Delivery and Admission Kate Peterson Stanley, MD, FAAPPage 135
Machine Learning Workflow – Part 1 John B. C. Tan, PhD, Fu-Sheng Chou, MD, PhDPage 36	From the National Perinatal Information Center: Raising the Bar: Elevating Breastmilk Utilization Rates for ALL Babies Elizabeth Rochin, PhD, RN, NE-BCPage 140
Reviewing the Benefits of Breastfeeding and of Providing Support for New Families Barb Himes, IBCLC, CDPage 43	Health Equity Column: Leading with Health and Racial Equity in the NICU: A Neonatologist Perspective Jenné Johns, MPH, Dalia M. Feltman MD, MA, FAAPPage 144
Burnout, Exhaustion, and ... It Is Not Just COVID Kelly Welton, RRT-NPSPage 49	Letter to the Editor: Where Are We with RSV and COVID-19? Gail Levine, MD, Mitchell Goldstein, MDPage 150
High-Frequency Oscillatory Ventilation (HFOV) New Patients, New Strategies – Same Physics Rob Graham, R.R.T./N.R.C.P.Page 58	ErratumPage 151
A Call to Action & Open Invitation Cody Miller Pyke, JD, LLM, MSBePage 64	Academic True Open Model (ATOM)Page 152
Putting a Stop to Surprise Medical Bills for New Parents Michelle Winokur, DrPH, and the AfPA Governmental Affairs Team, Alliance for Patient Access (AfPA)Page 76	Upcoming Meetings, Subscriptions and Contact InformationPage 155
I CAN Digitally Involved (I CANDI): Supporting Involvement of Children in Research Amy OhmerPage 80	Editorial BoardPage 158
High-Reliability Organizing (HRO), Decision Making, the OODA Loop, and COVID-19 Daved van Stralen, MD, FAAP, Thomas A. Mercer, RAdm, USNPage 86	Policy on Animal and Human Research, Manuscript SubmissionPage 160
Medical News, Products & Information Compiled and Reviewed by David Vasconcellos, MSIIIPage 104	Neonatology and the Arts Herbert Vasquez, MDPage 160
	NICU Baby's Bill of Rights NICU Parent NetworkPage 161
	Sunflower in Bloom Paula Whiteman, MDPage 163
	The Blue Jay Barbara Strobel-DellgerPage 164



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False Positive Versus False Negative in Neonate Suspected Congenital Syphilis, Case Report with Analysis for Quality Improvement

Austin Bowden, OMS-3, Herbert Vasquez, MD,
Mitchell Goldstein, MD

Introduction

Treponema pallidum subspecies *pallidum* is a pathogenic spirochete responsible for syphilis, a sexually transmitted infection with a characteristic clinical presentation that alternates from active to dormant stages with progressively increased severity (9). These stages are classified as primary, secondary, and tertiary syphilis; each stage has unique findings on history and physical exam (7). The *T. Pallidum* subspecies that cause syphilis is uniquely transmitted by sexual contact, while other subspecies of treponemes are transmitted by close nonvenereal contact (9).

“Treponema pallidum subspecies pallidum is a pathogenic spirochete responsible for syphilis, a sexually transmitted infection with a characteristic clinical presentation that alternates from active to dormant stages with progressively increased severity (9).”

T. pallidum varies from 6 to 15 μm in length and is 0.2 μm in diameter, which is relatively thin compared to other prokaryotic organisms. The spiral-shaped body is surrounded by a dual membrane system: a cytoplasmic membrane, a loosely associated outer membrane, and a thin layer of peptidoglycan between each of the membranes, analogous to gram-negative bacteria. One unique feature of this membrane is the peptidoglycan layer compared to gram-negative bacteria is its more proximal association with the inner membrane, whereas gram-negative bacteria's peptidoglycan layer is firmly linked to both membranes (5). This structural difference is theorized to be why penicillin antibiotics, which inhibit peptidoglycan linkage, are so efficacious in treating *T. pallidum* (5) (9). The endoflagella organelle is located in the periplasmic space giving *T. pallidum* a corkscrew pattern motility. It is important to note that the motility of *T. pallidum* is a major virulence factor, as it allows the dissemination of infection and seeding of multiple unrelated organ sites. This includes immune-privileged sites like the eye and epididymis, where replication can occur unimpeded by the immune system (5),(9).

Ongoing research suggests that *T. pallidum* has multiple mechanisms that it utilizes to successfully infect and propagate within a host for an extended period while avoiding eradication by the host immune system. Proteins expressed on its surface membrane allowing attachment to host cell membranes and the extracellular matrix, resulting in successful host infection after initial exposure (5). *T. pallidum* then evades detection of the immune system via

a slow cycle of replication which maintains a low antigenic threshold. It also evades detection by expressing very few antigenic proteins on its outer membrane surface and altering the epitopes of the more immunogenic antigens periodically through facilitated rearrangements of the TpRK gene (5). These factors allow *T. pallidum* to evade host immune detection and immune response, resulting in an anomalous cluster of non-specific symptoms or an entirely sub-clinical presentation (5).

Syphilis is called “the great imitator” colloquially (9) because these non-specific clinical findings are also seen in other, more common diseases deciding to test for the condition less likely. There are also many limitations with clinical testing for *T. pallidum*. There is no viable method of culturing *T. pallidum* outside of the host for diagnostic testing because the organism lacks any capacity to replicate outside of a viable host (4). *T. pallidum* nearly exceeds the limits of what can be resolved with routine light microscopy due to its thin spirochete morphology, and its unique cell wall makes visualization with gram staining a challenge. Researchers can detect treponeme samples with darkfield microscopy, silver stain microscopy, and electron microscopy; but accurately ruling out syphilis in this manner requires tissue sampling of an area with active signs of infection, and it is therefore not a good diagnostic tool for detecting *T. pallidum* during the latent phases of infection (4).

“One challenge this testing modality presents is the fluctuation of the marker values due to disease dormancy and cross-reactivity of these testing modalities with other disease states such as falsely elevated RPR in association with autoimmune antiphospholipid syndromes (4, 7).”

Given the limitations of conventional detection methodology, the predominant tests for *T. pallidum* are either serological: evaluating the host for the production of antibodies against *T. pallidum* antigens, or non-serological: indirect markers found to be elevated in association with *T. pallidum* infection (4). One challenge this testing modality presents is the fluctuation of the marker values due to disease dormancy and cross-reactivity of these testing modalities with other disease states such as falsely elevated RPR in association with autoimmune antiphospholipid syndromes (4, 7).

Difficulties with diagnosis and detection and the stigmatization of testing for sexually transmitted infections contribute to a higher prevalence of cases in the general population despite many efficacious treatments. In 2019, the US had 129,813 cases of all stages of syphilis reported, including 38,992 primary and secondary infections (6). This number has been continually increasing since 2001, with a 10% increase from 2018-2019 alone (6). Al-

though MSM populations are the most at risk for infection, there has been a marked increase in heterosexual populations, specifically the ratio of infected women (6).

Syphilis is a relevant disease in neonatology because *T. Pallidum* may transmit from mother to the immune-compromised fetus trans-placentally during pregnancy, causing a congenital infection reminiscent of late-stage syphilis and potentially fetal demise (7). The risk of this occurring is the highest during the active secondary phase of infection and lowest during the latent phase. The long-term consequences of an undetected and untreated maternal infection justify universal testing of all mothers prior to labor for syphilis (1, 7). Clinical serologic testing such as the CIA/EIA test is better suited to screen general population members, and non-serologic testing confirms the presence of infection due to each test's specificity and sensitivity relative to the general population. Serology is the more sensitive test, while non-serology is more specific for the presence of infection (4). If both tests results are positive, according to current CDC guidelines, the mother should receive penicillin G or an equivalent non-teratogenic antibiotic therapy by Intramuscular route for ten days and complete the course at least 30 days prior to delivery (1). Suppose this standard of care is not met. In that case, the neonate falls into either the category of "suspected" or "probable" congenital syphilis and should be treated appropriately with laboratory workup and Penicillin G IV. If there is a need for IV intervention and workup, the neonate will likely be admitted for care for the ten days following due to the more complex standard of care required for IV drugs in neonates (1).

The standard of care for "suspected" and "probable" congenital syphilis involves additional testing with Blood cell and platelet studies, electrolyte status evaluation, assessment of long bones for abnormalities via X-ray, serology studies, ophthalmologic evaluation of eyes for chorioretinitis and corneal keratitis, evaluation for rash or mucocutaneous lesions, assessment of liver and spleen size for possible hepatomegaly/hepatosplenomegaly, a lumbar puncture to assess for spirochetes invasion of the CNS and chest X-ray to evaluate for pneumonia alba or other abnormal findings (1). Guidelines recommend an additional confirmatory serology test for the mother with lower clinical suspicion to rule out false-positive findings (1-7). However, current medical literature guidelines do not provide much guidance regarding treating a patient who has a negative repeat serology test in conjunction with a positive serology finding prior. The current standard of practice is to treat both mother and neonate as per CDC guidelines regardless of clinical suspicion or follow-up serology testing results. This ultimately begs why additional testing is done if it provides no change to the course of treatment.

This case report summarizes the events of a patient encounter where this occurred while retrospectively assessing the clinical course. A protocol for hospitals to implement to address indeterminate testing events and what goals should be met before discharge to mitigate psychological stress caused by a false positive test for a stigmatized sexually transmitted infection is provided.

Patient Case

History:

Patient H (baby) was an infant of Hispanic descent born prematurely at 36 1/7 weeks EDC to a 37-year-old G5 P2 mother with gestational diabetes mellitus. She admitted to a rash during her

pregnancy and a history of sudden fetal demise ending her last pregnancy. Prenatal testing showed positive RPR and EIA serology test results, and the patient's mother was diagnosed with probable syphilis. Other findings of the congenital infection panel were negative; Group B Strep rapid test was negative. Both mother and baby were Rhesus positive, and Coombs test was negative. The mother received one injection of penicillin G by Intramuscular route but could not complete treatment as per CDC guidelines due to her entering labor prematurely, which quickly progressed to vaginal delivery.

“This case report summarizes the events of a patient encounter where this occurred while retrospectively assessing the clinical course. A protocol for hospitals to implement to address indeterminate testing events and what goals should be met before discharge to mitigate psychological stress caused by a false positive test for a stigmatized sexually transmitted infection is provided.”

Physical Exam and Test Results

Patient H was born without complications, 2730 grams at the time of birth. APGAR scores were 9 at 1 min and 9 at 5 min. Head was 32 cm in circumference, and abdominal girth was 28 cm; patient H's weight for length and head size for length were appropriate. There were no neurological abnormalities on the physical exam, and the patient was appropriately responsive to all light, sound, and touch-based stimuli without any evidence of seizures. There were no mucocutaneous lesions, no rashes, no evidence of hepatosplenomegaly. Patient H's vitals were appropriate for age, and the patient was afebrile. Chest X-ray showed no evidence of pneumonia alba or any concern of neonatal respiratory distress syndrome. Clinically, the patient demonstrated no symptoms of congenital syphilis. The only concerning finding was bilateral distal femoral metaphyseal lucency on X-ray of the long bones, but these findings were borderline and contained multiple imaging artifacts. Complete blood count and comprehensive metabolic panel laboratory studies showed no electrolyte imbalance, leukocytosis, or anemia, and head ultrasound showed no hemorrhage or ventricular abnormalities.

Treatment Course

Although the providers had low clinical suspicion, it was decided that this case should be treated like a congenital syphilis case, given the current guidelines. Contact precautions were initiated, and a 10-day course of Penicillin G IV 100,000 u/kg/day required admission to the NICU for administration. The department of public health was also consulted and notified regarding this case. Other laboratory workup was unremarkable for congenital syphilis, including a negative FTA Abs serology study. Ophthalmologic evaluation on the 7th day of life was unremarkable, with no corneal keratitis or chorioretinitis found on examination. The absence of

any other findings besides the possible long bone abnormalities was enough to justify withholding an invasive lumbar puncture procedure, as per neonatologist documentation, unless neurological symptoms or fever developed during care.

Although non-clinical, it is important to mention that when interviewing the nurses attending the patient, they would remark that the mother would often appear distressed at the bedside when visiting the child and vocalized feelings of guilt about potentially infecting her child on multiple occasions. On patient H's 6th day of life, the maternal FTA-Abs repeat assay sent out to Quest diagnostics was interpreted as negative, and the department of public health was consulted again. The department of public health advised the providers to complete the course of penicillin as per CDC guidelines. When the provider contacted the mother about the new negative results, she informed them that her husband, with whom she was sexually active, also had a negative FTA-Abs serology study. Patient H's mother expressed a great deal of confusion regarding these results. The clinicians and the department of public health were hesitant to give any definitive answer to patient H's mother concerning how she should interpret the results; instead, focusing on advising her about the need to complete her course of treatment to ensure eradication of any potential infection.

Patient H completed the 10-day IV Penicillin G and was discharged to follow up with an outpatient pediatrician. Mother to Baby H was encouraged to follow up with her PCP or OB for postpartum care and discuss these results in an outpatient setting for further testing. Although discussion of false-positive testing with the mother was planned, she was Spanish speaking, and the times she would visit were sporadic due to issues with arranging transportation. When clinicians wanted to discuss this with her, she could not stay for that discussion due to her need to leave and meet the person who was waiting to transport her home. Due to the delay in arranging professional Spanish translation, a more extensive conference with mom could not be performed. It is uncertain of her level of awareness regarding the potential false-positive result and its implications for future pregnancies.

“Due to the delay in arranging professional Spanish translation, a more extensive conference with mom could not be performed. It is uncertain of her level of awareness regarding the potential false-positive result and its implications for future pregnancies.”

Retrospective analysis

Regarding this case, it is essential to discuss the testing and the interventions of this case specifically. The first major topic to bring up is the lapse of prenatal care on the mother's part. Due to this lapse of care, treatment was initiated far too late for even a term baby, as she should have been screened much earlier. Her medical chart mentions that her follow-up with obstetrics was sparse, but it is important to note that insurance was likely not a contribu-

tor to poor follow-up, given the fact that all pregnant women qualify for state-supplied medical insurance in this region of the United States. However, a lack of transportation is a significant barrier to care in the US medical system and is responsible for approximately 50% of patient no-shows for appointments(10).

Given that the patient's mother would arrive at unpredictable times and explicitly state that she needed someone else to transport her, it's reasonable to suggest that transportation was likely a factor in failing to meet prenatal guidelines. For this reason, a policy-based solution on behalf of the state insurance organization should be considered. If the system could have lowered the obstacles the patient's mother faced by providing her free transportation, this could have prevented the need to admit patient H altogether. This solution could be more cost-effective for the state insurance organization while also less stressful for the family. This potential solution would need to be further investigated with a cost-benefit analysis by state insurance, but this is something for which to advocate.

“The test used to confirm was an additional FTA-ABS, sent out to a more skilled laboratory to confirm the diagnosis. Instead, the clinicians should have ordered the more accurate test: the TP-PA, which is more sensitive and specific than FTA Abs and is the current recommended confirmatory test per the CDC (8).”

The second feature of this case concerns Patient H's mother's potential false-positive serologic findings. The CDC's data shows the current rate of false-positive findings for FTA Abs immunoassay is 0.26-0.1%, and the false-positive rate of RPR is approximately 3% when screening the general population (8) (11). It is important to note that autoimmune disease can potentially elevate the incidence of false-positive values in both studies, and this patient H's mother is a Hispanic female within a 15- 40-year-old age range, which are all high-risk categories for Lupus (11). Lupus can also cause spontaneous fetal demise in pregnancy (6). However, the patient was not a good historian, and this could not be thoroughly evaluated before delivery, which makes the possibility of Lupus decreasing the positive predictive value of both studies a reasonable explanation. Although the odds of a false positive in both tests are quite low, it is still reasonable and more likely than a false negative serology study in patient H's mother, especially since no evidence of transmission was seen in her husband, with whom she was sexually active. There was an aspect of testing that could have been improved in this case: the sent-out confirmatory test. The test used to confirm was an additional FTA-ABS, sent out to a more skilled laboratory to confirm the diagnosis. Instead, the clinicians should have ordered the more accurate test: the TP-PA, which is more sensitive and specific than FTA Abs and is the current recommended confirmatory test per the CDC (8).

Another area to discuss is clinical decision-making. It is important

to note that before the 6th day when the negative confirmatory test was known, the treating physicians only knew the patient's mother had a positive treponemal and non-treponemal test without appropriate prenatal antibiotic therapy and a history of a past pregnancy ending in fetal demise. This knowledge alone warranted the diagnosis of probable syphilis and treatment as per current CDC guidelines (1). Appropriate care was provided to the neonate promptly. Regarding the decision not to obtain a lumbar puncture, guidelines suggest that this was an appropriate clinical decision. Given the normal neurological exam, initiation of appropriate treatment, and negative serology findings, the lumbar puncture would not have provided any potential benefit. The CDC guidance allows providers to decide against lumbar puncture based on clinical findings and suspicions (1). One might entertain the possibility that X-ray findings of the femoral metaphyseal lucency supported the need for a lumbar puncture. However, studies have shown these X-ray findings are sensitive for congenital syphilitic infection but non-specific and can be a normal anatomical variation seen in the general population (4). This finding is only used to support the clinical decision to initiate treatment, but it is not diagnostic of congenital infection. Even in light of the long bone X-results, withholding lumbar puncture was still clinically appropriate given current guidelines and what is known in the current literature.

The last area of care to discuss is the absence of patient education on discharge about false-positive tests. Communication should be improved, as it could provide patient benefit without any additional cost to the hospital or patient. One important consideration is the stability of a home situation before discharge (1,7). Patients place much faith in the validity of medical testing, and failing to educate the patient about false-positive findings could generate marital animosity and reduce the stability of the nuclear family, which can be attributed to worse neonatal outcomes (11). For this reason, all healthcare sites that test and treat sexually transmitted diseases should consider having a standardized protocol to best educate their patients about false-positive results, to reduce familial tensions and stress prior to discharge. Providing this information could give peace of mind to the entire family while potentially preventing the risk of spousal abuse, divorce, and parental feelings of guilt regarding their child. A system of care should take the responsibility to educate their patients about potential false-positive results, rather than leave it up to the patient's family to figure out which test results should be trusted.

“For this reason, all healthcare sites that test and treat sexually transmitted diseases should consider having a standardized protocol to best educate their patients about false-positive results, to reduce familial tensions and stress prior to discharge. Providing this information could give peace of mind to the entire family while potentially preventing the risk of spousal abuse, divorce, and parental feelings of guilt regarding their child.”

Discussion

In the modern era of medicine, approximately 70% of all clinical decisions are made through diagnostic testing (2). This practice is seemingly at odds with one of the oldest paradigms taught in medicine: “the test result should confirm what you already know after a thorough history and physical.” In this case, many factors stand in opposition to this paradigm, including the fact that this test is a test looking for diseases that clinicians do not suspect, which reduces the positive and negative predictive value. Additionally, the disease being tested is stigmatized in our monogamous society, as it would typically be acquired through extramarital intercourse, creating additional obstacles to taking an accurate medical history. One Web MD survey conducted in 2004 found that 17% of patients will exclude details of their sexual history from their physician when asked (2). In essence, screening for sexually transmitted infections in the general population subverts many aspects of the traditional paradigms surrounding clinical testing, and clinicians should be prepared to think about these test results with greater skepticism. Physicians must remain educated about false positives and false negatives rates within common screening laboratory studies and be ready to question if these are representative of the truth. Admittedly, with congenital syphilis, there is no time to wait for a confirmatory test before therapy, as untreated syphilis can cause widespread irreversible damage in neonates whose immune system is still developing (1). No matter how accurate or expedient the repeat study is, there would likely be no change in the current course of treatment given current CDC guidelines. The intervention of admission and administration of penicillin is relatively harmless, but the harm instead comes from the strife and stigmatization surrounding diagnosis. Therefore, we as medical professionals should give value to those repeat serology findings by calling initial syphilis into doubt in cases such as these to provide reassurance towards the family unit, reduce suspicions of spousal infidelity, ultimately achieve a reduction in neonatal early life instability. These quality improvement suggestions could be a long-lasting solution to improve neonatal quality of life.

Conclusions of this case

- 1) Insurance companies and other healthcare organizations should consider proactively arranging adequate transportation to an obstetrician for prenatal care if an actively pregnant patient has difficulty obtaining personal transportation. This could potentially improve follow-up rates for prenatal care and may reduce the need to use hospital services for conditions that can be addressed without urgency in the outpatient setting.
- 2) Providers should order the more sensitive and specific TP-PA assay over TP Abs for confirmational serology of syphilis as per CDC guidelines, whenever patient's insurance can cover it.
- 3) Hospitals should create a standardized resource that educates patients on the potential of false-positive and false-negative results before screening patients for sexually transmitted infections and give that resource to the patients equitably. This resource should be implemented to reduce stress and tension in the family, providing more holistic care to a neonatal patient focusing on the family unit.

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Child Passenger Safety: Investigation into American Academy of Pediatrics Recommendations, Laws, Regulations, and Safety Testing and How They Compare to California Regulations

Candace LeFlame, D.O., Anh Rebhan, D.O., M.S.

In the United States, motor vehicle accidents are the leading cause of death among children ages four years and older(1). Fortunately, parents, caregivers, and physicians can make a lifesaving difference by advocating for the correct use of child safety seats (CSS). The proper use of child safety seats can reduce the risk of injury by 71-82% in children involved in a motor vehicle collision(1). Unfortunately, an estimated 46% of car seats and booster seats are misused, decreasing their effectiveness and protection of child passengers (2). A look at San Bernardino and Riverside Counties in California shows the age-adjusted rate of death by car accident per 100,000 people has been consistently higher than the national average(3). Therefore, it is imperative to learn the local CSS laws and discuss child passenger safety with our patients and their families to ensure proper placement and utilization.

Newborn Period:

The American Academy of Pediatrics (AAP) released a policy statement that guides child passenger safety with five best practice recommendations for child restraint systems for children from birth through adolescence (Table 2). For the newborn period, the AAP recommends "All Infants and Toddlers Should Ride in a Rear-Facing CSS Until They Are 2 Years of Age or Until They Reach the Highest Weight or Height Allowed by the Manufacturer of Their CSS" (4). California law follows this AAP Best Practice Recommendation with Vehicle Code Section 27360, stating, "Children under two years of age shall ride in a rear-facing car seat unless the child weighs 40 or more pounds OR is 40 or more inches tall. The child shall be secured in a manner that complies with the height and weight limits specified by the manufacturer of the car seat" (3). Rear-facing car seats are important in this age group because their spines are developing, and their heads are disproportionately large for their bodies. Therefore, in a forward-facing car seat, a newborn's head is likely to be propelled forward, and their spinal cords stretched, possibly resulting in serious injury. Whereas, in a rear-facing car seat, a baby's head, neck, spine, and upper body are cradled by the back of the child safety seat



Figure 1. Forward-facing carseats may propel a newborn's head forward resulting in serious injury as opposed to rear-facing carseats where the head and neck are cradled during a motor vehicle accident. <https://rearfacingtoddlers.com/pages/why-rear-facing-is-safer>

(figure 1) (5-7).

"Using car seats can save lives if used correctly. However, many caregivers are only met with frustration and confusion when it comes to installing car seats. Most car seats follow a similar set of instructions; therefore, when counseling parents, it is crucial to advise they follow the steps below (unless instructed otherwise by their car seat manual) (Table 2) (6-9)."

Using car seats can save lives if used correctly. However, many caregivers are only met with frustration and confusion when it comes to installing car seats. Most car seats follow a similar set of instructions; therefore, when counseling parents, it is crucial to advise they follow the steps below (unless instructed otherwise by their car seat manual) (Table 2) (6-9).

Steps to Install Rear-Facing Car Seat

1. Make sure the seat has the correct angle by using the car seat angle indicator. Many rear-facing car seats also have an adjustable base to help set the angle.
2. Next, strap the seat into the car. There are two different methods to fix the car seat in place - the Lower Anchors and Tethers for Children (LATCH) and the seat belt system. Both methods are safe.
 - a. The LATCH system was developed to make it easier to install child safety seats without using seat belts correctly. They are in most vehicles made after September 1, 2002. Caregivers can check their vehicle's owner manual to see if the LATCH system is available in their car. Most vehicles have fabric tags or small plastic buttons on the automobile's seat to indicate where to find the lower anchors. When installing a car seat with the LATCH system, attach each hook onto its own rigid lower anchor.
 - b. Seat belt system: When installing with a seat belt, pull the seat belt and thread it through the belt path of the car seat. Make sure the seat belt does not have any twists and buckle the seat belt.
3. Tighten and adjust the car seat's straps so that the seat does not move more than one inch in any direction. Press down on the car seat and pull the LATCH or seat belt to tighten further. This will secure the car seat and establish a tight fit.

Placing a child correctly into a car seat is just as important as correctly installing a car seat. Follow the steps below to ensure the infant or toddler is properly secured (figure 2) (1,5-9).



Figure 2: Appropriate placement of infant in rear-facing car seat placement

1. The harness straps should be threaded through the slots at or directly below the baby's shoulders.
2. The harness should be a 5-point restraint system and buckled at the armpit level.
3. The straps should be tightened so that the harness lies in a straight line with no slack. Advise parents that they should not be able to pinch a fold at the shoulders.
4. The child's head should be positioned at least 1 inch below the top of the car seat.

“Children should stay in a rear-facing car seat as long as possible because every transition to a new type of car seat decreases the level of protection provided to the child (4). Parents should not move their children to forward-facing car seats until at least two years of age or until they reach the maximum height and weight limit of their rear-facing car seat (4,7-9).”

Children should stay in a rear-facing car seat as long as possible because every transition to a new type of car seat decreases the level of protection provided to the child (4). Parents should not move their children to forward-facing car seats until at least two years of age or until they reach the maximum height and weight limit of their rear-facing car seat (4,7-9). The AAP best practice

recommendation may differ from local state or government requirements, so please check what the local law allows.



Figure 3. Illustration of incorrect booster seatbelt positioning vs. correct booster seatbelt positioning. https://www.cdc.gov/transportationsafety/child_passenger_safety/resources.html

Infant Car Seat Challenge

An infant car seat challenge is a period of observation before discharge to monitor for bradycardia, apnea, and desaturations while the infant sits in a car safety seat (10). Most recent AAP guidelines from 2009 recommend a period of observation for 90-120 minutes or the duration of the car ride home, whichever is longer for all infants born <37 weeks GA (10). The AAP has provided no specific recommendations for testing infants with complex medical issues. Therefore, it is left up to each health institution to decide which neonates should undergo a car seat challenge (10). Besides premature infants, one of the most tested groups is the low birth weight (LBW <2.5kg) neonates. Almost half of the NICUs surveyed by the AAP had LBW as an inclusion criterion, regardless of birth GA (10). Loma Linda University Children's Hospital car seat challenge criteria include Gestational age <37weeks, birth weight less than 2g, or a compromised airway.

“Besides premature infants, one of the most tested groups is the low birth weight (LBW <2.5kg) neonates. Almost half of the NICUs surveyed by the AAP had LBW as an inclusion criterion, regardless of birth GA (10)”

Toddler Period:

For the toddler period, AAP's additional best practice recommendation states that “All children 2 Years or older, or those young-



Convertible
safety seat

Combination
child seat

Belt-positioning
booster seat

Built-in child
seat

Travel Vest

Figure 4: Different types of forward-facing car seats.

er than two years who have outgrown the rear-facing weight or height limit for their CSS, should use a forward-facing CSS with a harness for as long as possible, up to the highest weight or height allowed by the manufacturer of their CSS” (4.) California law also follows this AAP recommendation. “Children over two years of age or children under two years of age and weighs 40 pounds or more or is 40 inches or more may ride forward-facing. The child shall be secured in a manner that complies with the height and weight limits specified by the manufacturer of the car seat” (3). Installing rear and forward-facing CSS are remarkably similar, with only a few minor differences. Advise parents to adjust the angle so that the child sits more upright in the vehicle (7-9). If using the seat belt method, make sure the belt runs through the forward-facing belt path. If using the lower anchors, the child must not exceed 65 pounds (7-9). Parents and caregivers will also need to optimize the safety of forward-facing car seats by attaching the seat’s top tether strap to the correct anchor point in the vehicle (7-9).

There are many different types of forward-facing car seats (figure 4). The combination child seat/belt-positioning booster seat is a booster seat with an internal harness that can be used until the child weighs about 40-65lbs (1,7-8). The parent can then remove the harness and convert the seat into a belt-positioning booster seat that utilizes the vehicle’s lap and shoulder belt. Travel vests are another type of forward-facing car seat. They can be worn by children between 20-168 lbs (7-8). They are especially useful when a car has lap-only seat belts or for children whose weight exceeds what is allowed by most child safety seats. Some vehicles even have forward-facing child safety seats integrated into their rear seats (7-8). Advise parents to check their vehicle’s owner manual to see what their vehicle has installed.

What to Buy

Parents are often overloaded with car seat choices and ask their pediatrician for recommendations for car restraint systems. The best child safety seat is the one that suits their family needs, one that is easy to use, fits in their vehicle(s), and is compatible with their vehicle’s seat belt or LATCH system. Advise parents to make sure their car seat meets national standards. This information is

often found on a sticker on the side of their car seat. The label should say, “This child restraint system conforms to all applicable U.S. federal motor vehicle safety standards” (7-9). Furthermore, caregivers should be informed that most car seats will need to be replaced if they have been in a motor vehicle accident. For parents buying a used car seat, providers should recommend caregivers inquire about the following: history of the car seat (any MVA), car seat recalls, and the car seats expiration date. Inform parents they can visit the National Highway Traffic Safety Administration for recall information (1,7-9).

Young Children Ages 4-8

The AAP recommends “All children whose weight or height is above the forward-facing limit for their CSS should use a belt-positioning booster seat until the vehicle lap and shoulder seat belt fits properly, typically when they have reached 4ft 9inches in height and are between 8 and 12y of age” (4). No California law addresses when to transition to a booster seat. However, California law does address that, at a minimum, any child younger than eight years old must use a seat belt (3). A booster seat is used in this age group to raise the child, so the vehicle’s lap and shoulder belt is appropriately positioned across the child’s hips and chest away from their neck and abdomen (fig 4) (1,7-8). When a child reaches the highest weight and height limit allowed for their forward-facing car seat with a harness, they should then use a belt-positioning booster seat until the vehicle lap and shoulder belt fits them properly (1,7-8). This is typically around a height of 4 feet 9 inches and 8-12 years of age. A belt-positioning booster seat should go in the back seat of a caregiver’s vehicle and always with the vehicle’s lap and shoulder belt. For proper seat belt positioning, the lap belt should lay across the child’s upper thighs, below the hip bones (1,7-8). The shoulder belt should cross the center of the child’s chest and shoulder and not cut across the neck or face. Many boosters come with belt guides or plastic clips to help the belt stay on the shoulder to make the shoulder belt fit better (1,7-8). If this is not available, parents can use the shoulder belt height adjusters built into their vehicles. Furthermore, it is important to remind caregivers never to put the shoulder belt behind a child’s back or under their arms. Healthcare providers can utilize



Figure 5: Once children are old enough parents can try this Five-step seat belt test to assess their child's readiness for a seat belt without a booster seat

the rhyme: "Under the arm, seat belts cause harm. Behind the back, safety will lack" (8).

Older Children

When a child reaches the appropriate age and height to use the vehicle seat belt alone, the AAP recommends, "They should always use lap and shoulder seat belts for optimal protection" (4). They also advise, "All children <13 years of age should be restrained in the rear seats of vehicles for optimal protection" (4). In contrast, California law states that children who are eight years of age OR who have reached 4'9" in height may be secured by a booster seat, but at a minimum, must be secured by a safety belt (3). Therefore, parents can test their child's readiness for a seat belt when they reach 4 feet 9 inches and are between 8-12 years of age. Parents and caregivers can accomplish this by doing a 5-step seat belt test as seen below (Fig 5) (1,7-8).

5-Step Belt Test for Older Children

1. The lower back is against the vehicle seat. If the child needs to sit forward to allow their legs to go over the edge of the seat, it can cause the seat belt to be on their abdomen instead of their upper thighs. It can also create slack which can allow a child to be thrust forward during an accident.
2. Children need to be tall enough so that their knees bend comfortably at the edge of the seat.
3. The lap belt stays on the upper thighs across the hip bones. This step is critical because improper seat belt use poses a higher risk of intra-abdominal injury in MVC. A seat belt position on the upper thighs allows the belt to be placed on rigid body parts, protecting abdominal and internal organs.
4. The shoulder belt crosses between the neck and shoulder. This positioning is important because a shoulder belt that sits off the shoulder can fall off during an accident, reducing its protection.
5. A child can follow all the rules for the length of the car ride.

Children who move excessively or cannot tolerate proper seat belt placement are not ready for the seat belt only without a booster seat. In this case, they will be safer in a 5-point harness car seat or travel vest.

If a child can follow all the steps mentioned above, s/he may be ready to transition to seat belt-only from the booster seat. The AAP recommends that any child under age 13 remain seated in the rear seat (4). If there is only a front row in the car, then many vehicle owner's manuals instruct caregivers how to deactivate the safety airbag in the passenger seat. Research has shown that airbags can cause more serious injury and even death to a rear-facing infant passenger vs. injury to an adult (11).

Special Considerations

A population of children with special health needs also must be protected with a CSS when riding in a vehicle. Special health needs can include airway obstruction, muscle tone abnormalities, gastrointestinal issues, casts, challenging behavior, or wheelchair transportation. Although most children may safely ride in a traditional car seat, there are special considerations and circumstances where that may not be the safest option. The AAP has written a supplemental policy statement that further details how to transport this special population (6).

Parents/Caregivers Still Need Help?

If caregivers have children with special requirements or are still confused about child passenger safety, there are many community resources available. Advise caregivers to find a Child Passenger Safety Technician in their area through the National Child Passenger Safety Certification Program. They will provide in-person step-by-step instructions on how to safely and correctly install any child passenger restraint system (12). Many local fire stations also provide this service.

"Proper child passenger safety is imperative because child safety seats can reduce the risk of death by as much as 71% (1). Unfortunately, motor vehicle collision is still the leading cause of death in children four years and older (1). Even more unsettling, a recent study showed more than half of car seats are not used or installed correctly, and 1 in 3 occupants ages 0-12 who were killed in MVC was unrestrained at the time of the accident (1)."

Summary

Proper child passenger safety is imperative because child safety seats can reduce the risk of death by as much as 71% (1). Unfortunately, motor vehicle collision is still the leading cause of death in children four years and older (1). Even more unsettling, a recent

Best practice recommendation for child safety restraint system	Recommendation	Typical age/weight/height criteria
Infant-only or convertible CSS used rear-facing	All infants and toddlers should ride in a rear-facing CSS as long as possible until they reach the highest weight or height allowed by their CSS manufacturer.	Newborn - 2 years of age
Convertible or combination CSS used forward-facing	All children who have outgrown the rear-facing weight or height limit for their CSS should use a forward-facing CSS with a harness for as long as possible, up to the highest weight or height allowed by their CSS manufacturer.	2 - 8 years of age
Belt-positioning booster seat	All children whose weight or height is above the forward-facing limit for their CSS should use a belt-positioning booster seat until the vehicle lap and shoulder seat belt fits properly.	Height: 4 ft 9 inches Age: 8 - 12 years
Lap and shoulder vehicle seat belt	When children are old enough and large enough to use the vehicle seat belt alone, they should always use lap and shoulder seat belts for optimal protection All children <13 years should be restrained in the rear seats of vehicles for optimal protection	Age: > 13 years

Table 1: Summary of Best Practice Recommendations by the American Academy of Pediatrics

study showed more than half of car seats are not used or installed correctly, and 1 in 3 occupants ages 0-12 who were killed in MVC was unrestrained at the time of the accident (1). Therefore, continued education and guidance surrounding child passenger safety are essential. The American Academy of Pediatrics has provided their best practice recommendations to assist healthcare and caregivers on correct child passenger safety (1,4,7-10). AAP best practice recommendations are as follows: rear-facing car safety seats as long as possible, forward-facing car safety seats from the time they outgrow rear-facing seats for most children through at least four years of age, belt-positioning booster seats from the time they outgrow forward-facing seats for most children through at least eight years of age, lap and shoulder seat belts for all who have outgrown booster seats, and all children younger than 13 years to ride in the rear seats of vehicles (Table 1) (4). A common mistake made among parents is transitioning their children to the next phase of the child passenger restraint system too early (1,4,7-10). However, caregivers should be encouraged to delay these transitions as each transition is associated with decreased

protection. The American Academy of Pediatrics urges all pediatricians to know and promote these recommendations as part of child passenger safety anticipatory guidance at every health supervision visit.

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Briefly Legal: Was Baby's Brain Damage Caused by Mismanagement of Preeclampsia?

Maureen E. Sims, M.D., Barry Schifrin, M.D.

A 700-g, 27 1/7 weeks' gestation female infant is delivered by cesarean delivery to a 28-year-old, gravida 1, para 0 morbidly obese woman. To determine if the woman had gestational diabetes, her obstetrician ordered a glucose tolerance test, but because the woman vomited the gluco^{la}, the evaluation for diabetes was not performed. **The plaintiff obstetrician was critical of the treating obstetrician for not making a greater effort to resolve the patient's glucose tolerance, including HbA1c and serial urine glucose testing. He stated it was standard to obtain a measure of glucose tolerance, and that could be done in several ways-beyond which he was required to tell the patient its importance, especially because of the patient's morbid obesity. The obstetrician retained by the defense explained that it was not standard to repeat the glucose tolerance testing or to order an HbA1c automatically. He further pointed out that it was the patient's fault that the test was not repeated.**

"To determine if the woman had gestational diabetes, her obstetrician ordered a glucose tolerance test, but because the woman vomited the gluco^{la}, the evaluation for diabetes was not performed."

Ten days prior to delivery, the woman called her obstetrician because she was experiencing severe right upper quadrant/epigastric pain. **The woman stated on her deposition that her obstetrician told her to try to calm down and that it was her choice to go to the Emergency Department (ED) or not. The plaintiff expert pointed out that this approach was negligent, given the risk of HELLP syndrome (Hemolysis, elevated liver enzymes, low platelets). Because the pain was severe, she went to the ED. She rated her pain in the ED 8/10. Her blood pressure (BP) was 146/87 mm Hg, and her complete blood count (CBC) was normal except for a platelet count of 145/uL. Her urinalysis demonstrated +3 proteinuria. The documentation in the ED did not include anything regarding vision changes, hyperreflexia, headaches, or edema. An ultrasound was done to rule out gallstones. The plaintiff obstetrician pointed out that her elevated blood pressure, abdominal pain, and proteinuria should have concerned the ED physicians about preeclampsia, especially that leading to HELLP syndrome, which may present without very high blood pressures and even normal blood pressures. He also pointed out that a fetal ultrasound should have been performed to assess fetal growth and amniotic fluid level. He further pointed out that the ED physician should have sought an obstetrical consult**

and have ordered a fetal heart rate tracing. He considered that the failure to consult an obstetrician entering the ED was a gross deviation from the standard of care in a pregnant patient entering the ED.

The abdominal ultrasound did not show gallstones. **Plaintiff expert pointed out that even had it had, preeclampsia would not have been excluded.** The ED physician diagnosed gastritis and told the woman to avoid fat in her food and eat small volumes of food. He then discharged her home without an obstetrical consult. **The plaintiff obstetrician explained that right upper quadrant or epigastric pain was probably due to periportal and focal parenchymal necrosis, hepatic cell edema, Glisson's capsule distension, or a combination represented a potentially catastrophic situation. He also pointed out that the ED at that hospital had a policy that said pregnant patients over 20 weeks' gestation with findings consistent with, but not necessarily diagnostic of, preeclampsia must be transferred to Labor and Delivery.**

"He also pointed out that the ED at that hospital had a policy that said pregnant patients over 20 weeks' gestation with findings consistent with, but not necessarily diagnostic of, preeclampsia must be transferred to Labor and Delivery."

Further, the plaintiff obstetrician pointed out that the diagnosis of preeclampsia, as recommended by ACOG, required a 2nd reading at least 4 hours later. However, he added that if the signs and symptoms are compelling enough, the diagnosis of preeclampsia must be made on a presumptive basis. The hospital policy stated that if a diagnosis of preeclampsia were made, then some or all of the following steps should be taken, depending on the obstetrician's evaluation: hospitalization, administration of at least 24 hours of intravenous magnesium sulfate and steroids, seizure prevention, serial platelet counts and liver function tests, close fetal surveillance, including frequent fetal heart monitoring and biophysical profiles, assessment of placenta sufficiency, management of maternal hypertension and potential non-emergent delivery depending on the evaluation. **Plaintiff expert pointed out that, at a minimum, the patient should not have been discharged as it represented a significant violation of their own policies and procedures.**

Five days after the ED visit, the woman was evaluated by her obstetrician. She stated in her deposition that she shared with him the paperwork from the ED. She shared that her abdominal pain continued after the visit and was currently present despite dietary changes. She had gained 18 pounds in the past four weeks. The treating obstetrician did not comment if the weight gain was due

to excessive fluid retention. One blood pressure was performed in the obstetrician's office, and it was 126/64 mm Hg. **The plaintiff obstetrician pointed out that the obstetrician needed to be concerned about preeclampsia and should have rechecked her urine and obtained multiple blood pressures 10 minutes apart. According to the mother, the treating obstetrician purportedly told the patient that there was nothing to worry about. The plaintiff obstetrician strongly disagreed with this assessment.**

“Five days after this visit with her obstetrician, the patient sustained a grand mal seizure at home. Her partner heard a thump in the middle of the night, which awakened him. He observed that she had fallen off the bed and was having a seizure. Since the father of the baby was asleep, the duration of the seizure was not clear.”

Five days after this visit with her obstetrician, the patient sustained a grand mal seizure at home. Her partner heard a thump in the middle of the night, which awakened him. He observed that she had fallen off the bed and was having a seizure. Since the father of the baby was asleep, the duration of the seizure was not clear. He called the paramedics. Upon examination by the paramedics, the patient was postictal and had a BP of 178/144 mm Hg. She was 27 1/7 weeks gestation. **The plaintiff experts pointed out that this situation could have been avoided if the standard of care had been met in evaluating the patient for preeclampsia. The plaintiff experts stated that eclamptic seizures were dangerous to both the woman and fetus. He noted that affected women might develop long-lasting cognitive issues. The literature on eclamptic seizures showed that during the seizures, the fetus sustains profound fetal bradycardia that may last up to 20 minutes as a measure of the severity of potentially injurious fetal hypoxia. In addition to acute events, studies on women with eclampsia have found increased white matter lesions demonstrated by magnetic imaging resonance (MRI) with lasting psychological and cognitive effects.**

The patient was then treated with midazolam by the paramedics. She arrived at an ED 35 minutes afterward and was given magnesium sulfate. The fetal heart rate was 208 beats per minute. The woman had a computerized brain tomography (CT) scan that showed brain swelling in the parietal-occipital region but no acute bleed. Over the next 2 hours, the baseline fetal heart rate decreased to 160 bpm. Most of the fetal heart rate tracing was not interpretable except for a 3 minute period that showed moderate variability. The mother's labs were notable for elevated liver function tests and a low platelet count; she was diagnosed with HELLP syndrome. Three hours after arriving in the ED, the baby was delivered by cesarean section. Immediately after delivery, the mother sustained another grand mal seizure followed by a cardiac arrest while the surgery was still underway. After being

revived in the operating room, she was sent to the intensive care unit. After weeks of a stormy course in the intensive care unit, the mother eventually recovered except for the complication of bilateral retinal detachment.

The neonatal resuscitation team was present at the delivery and provided positive pressure ventilation for 15 seconds. The neonate had Apgar scores of 7¹ and 9⁵. She was appropriate for gestational age. Her weight was 700 grams, her head circumference was 23 cm, and her length was 31 cm. She had a normal physical examination, consistent with a gestational age of 27 1/7 weeks. The arterial cord gas had a pH of 7.18, a pCO₂ of 60 mm Hg, and a base excess of -7.5, and the venous cord gas had a pH of 7.15, a pCO₂ 59, and a base excess of -9.7. **Much discussion ensued among the experts about the cord gases. The defense said that the maternal seizure had no impact on the fetus because the cord gases were normal. The defense pointed out that the base deficits were inconsistent with a hypoxic-ischemic insult because the base excess was -7.5 and -9.7. The plaintiff expert pointed out that the seizure was 3 hours earlier than delivery and that no challenges, such as uterine contractions, were ongoing. The seizure was then, the cord gases long after recovery were now.**

Further, the plaintiffs stated that the difference in the cord pHs was too narrow (0.03), pointing out that the average difference between the cord venous and arterial pH is normally 0.07. Thus a difference <0.04 indicates that the gases were likely from the same vessel or the laboratory made a mistake. The plaintiff added that the venous cord deficit was worse than the arterial gas, which is physiologically not possible, another point in favor of the lack of validity of the cord gases. The plaintiff also noted that the cord gases should have been normal (7.35-7.45) because there was no period of labor or ongoing stress after the seizure, which with all reasonableness was accompanied by a significant amount of uterine activity, now dissipated. The plaintiff stated that the cord gases quoted in the literature refer to vaginal deliveries after labor and do not refer to infants born by cesarean section without a period of labor well after an obvious hypoxic-ischemic event. He noted that the pH was too low, the pCO₂ too high, and the base excess too low for a cesarean-sectioned neonate born without a period of labor.

The defense quoted the American College of Obstetrics and Gynecology (ACOG) “essential criteria” from the 2003 Manual, Neonatal Encephalopathy and Cerebral Palsy that must be met to define an acute intrapartum event sufficient to cause cerebral palsy. These “essential criteria” were: 1) evidence of metabolic acidosis in fetal umbilical cord arterial blood obtained at delivery (pH <7 and base deficit ≥ 12 mmol/L) 2. Early-onset of severe or moderate neonatal encephalopathy in infants born at 34 or more weeks of gestation 3. Cerebral palsy of the spastic quadriplegic or dyskinetic type 4. Exclusion of other identifiable etiologies, such as trauma, coagulation disorders, infectious conditions, or genetic disorders. The plaintiff experts pointed out that the “essential criteria” being quoted were not based on scientific literature but rather an attempt to protect obstetricians. He pointed out that specific evidence showed that the “essential criteria” of the 2003 ACOG Monograph was to impede a parents’ understanding of the event(s) leading to their child developing a brain injury. The most obvious distortion of the scientific literature is

on view in the section requiring a pH of ≤ 7.0 as one of the “essential criteria.” The literature quoted in the Monograph does not support this position. The plaintiff experts also pointed out that the criteria for hypothermic intervention for babies born after an acute intrapartum hypoxic event severe enough to cause cerebral palsy were very different. Thus, the “essential criteria” do not pass scientific muster, a fact underscored by the fact that it was successfully defeated in legal challenges as not holding scientific credibility and therefore not allowed to be presented in a court of law. (1-3)

Ultimately the plaintiff expert pointed out the “essential criteria” in the 2003 edition were not included in the follow-up ACOG Monograph (Neonatal Encephalopathy and Neurologic Outcome) published in 2014. Additionally, these “essential criteria” that the defense quoted were criteria developed to assess term and near-term infants, not preterm neonates. The defense argued that the Apgar scores showed that the neonate did not suffer a hypoxic-ischemic insult. The plaintiff pointed out that the insult, the maternal seizure, occurred hours before the delivery, and the fetus had recovered from a cardiovascular standpoint, although neurologically injured. Furthermore, Apgar scores are not a valid measure of intrapartum hypoxic-ischemic insult.

The child’s CBC revealed a white blood cell (WBC) of 5.5 u/L, a hematocrit of 38.4%, and a platelet count of 87 u/L. The neonate had several low blood glucose values that were timely treated with boluses of glucose. A bolus of normal saline was given immediately after birth. The first blood gas was drawn between 1.5 hours after birth and had a base excess of -6.6. The first lactate level was drawn at 4 hours, and it was 5 mm, and it remained elevated for the next 24 hours -- **incurred during the maternal seizure, caused an elevation in lactic acid, and it gradually entered the circulation and then gradually dissipated through the circulation.** The neonate was briefly intubated for respiratory distress syndrome (RDS) and received surfactant. After several weeks of total parenteral nutrition, she eventually fed successfully. She developed cholestatic jaundice, apnea of prematurity, and a medically treated patent ductus arteriosus. She had several courses of antibiotics, but sepsis evaluations were negative. Her liver function tests and creatinine levels were all normal. **The defense argued that these normal results ruled out a prior hypoxic-ischemic insult. The plaintiff expert disagreed and maintained that with an acute insult, lactic acid is more likely to be normal and inconsistently and unpredictably elevated even with a subacute or chronic insult.** The neonate’s brain ultrasound was negative; magnetic resonance imaging (MRI) was not performed during the admission.

The neonate was discharged at 75 days. On follow-up, she developed hypotonic cerebral palsy and severe developmental delays. MRIs were performed at 2 and 4 years of age. **The plaintiff neuroradiologist read the MRIs as a combination of PVL types 2 (non-cystic with gliotic scarring), and 3 (diffuse with decreased myelination with associated injury of the axons) and mild ventriculomegaly. The plaintiff experts contended that the MRIs were consistent with a hypoxic and or ischemic event. However, because imaging was not done until after the neonatal period, the timing of the injury was not possible. The defense radiologist interpreted the MRIs as being normal.** At age 5, the treating neurologist thought that the child had severe developmental delays and hypotonic cerebral

palsy. **The neurologist retained by the defense maintained that the child did not have cerebral palsy but was autistic. The plaintiff neurologist pointed out that neither he nor the treating neurologist thought she showed any evidence of autism.**

“The plaintiff experts contended that the MRIs were consistent with a hypoxic and or ischemic event. However, because imaging was not done until after the neonatal period, the timing of the injury was not possible. The defense radiologist interpreted the MRIs as being normal.”

The obstetricians, neonatologists, and neurologists whom the plaintiff’s attorney retained were questioned about the cause of the child’s adverse outcome. **The plaintiff experts maintained that the adverse outcome was secondary to the hypoxic-ischemic event incurred during the maternal seizure. The blood was preferentially transferred to her vital organs (heart, brain, and adrenals) at the expense of other organs and tissues, including the uterus and placenta. The mother’s brain showed cerebral edema, and her retinas were detached, underscoring the profound insult during the seizure. The fetal tachycardia underscored the stress that occurred during the seizure, an improbable development for anything other than recovery from a very severe hypoxic-ischemic insult. The defense opined that the neonate’s adverse outcome was secondary to her prematurity and an “unknown genetic predisposition for developmental disorders and autism.” The plaintiff experts strongly disagreed and called the defense’s explanation of events “concocted” They pointed out that none of the treating physicians, those who directly cared for the child and who were unfettered by the need to protect the physician, opined or diagnosed a genetic issue or autism. Several metabolic and genetic tests, including microarray analysis, were performed after the lawsuit because the defense offered a metabolic or genetic basis as a probability. Further, they pointed out that all tests were normal. The defense further opined that around 80% of neonates born at this gestation were developmentally abnormal on follow-up examinations. The plaintiff disagreed and pointed out that unless anomalies, asphyxia, intrauterine growth restriction, multiple gestations, infection, or a defined problem after birth were involved, most 27 week infants did fine.**

The plaintiff experts pointed out that by not diagnosing preeclampsia, not only was the fetus compromised during the mother’s seizures, but the mother needlessly suffered and developed long-term vision problems. They maintained that all adverse consequences would have been prevented by the timely diagnosis and management of even uncertain preeclampsia. Intervention may have never been necessary, and “rescue” was likely never to be necessary. The plaintiff experts pointed out that the fetus was deprived of antenatal steroids and magnesium sulfate by failing to diagnose

preeclampsia in a timely manner. Such timely and effective care would have avoided the need to rescue—delivery of the baby by emergency cesarean section at 27 1/7 weeks gestation. A course of antenatal steroids would have reduced the probability of RDS, PDA, and PVL; a 24-hour course of magnesium sulfate would have decreased the risk of cerebral palsy by 50%. Moreover, had preeclampsia been diagnosed, probably a significant prolongation of the pregnancy would have occurred. Also, had diabetes been diagnosed, it would have pointed to the need for close surveillance of blood pressures early on in the pregnancy because 30-40% of women with gestational diabetes develop preeclampsia.

The obstetrician and the ED hospital and staff were sued because of the failure to appreciate and implement therapy for the mother's preeclampsia. The jury ruled in favor of the defense.

“The obstetrician and the ED hospital and staff were sued because of the failure to appreciate and implement therapy for the mother’s preeclampsia. The jury ruled in favor of the defense.”

Discussion

General

Hypertensive disorders are the most common complications of pregnancy, with an incidence of about 10% of pregnancies worldwide. The incidence of preeclampsia has increased by 25% in the United States during the past two decades. Preeclampsia is a leading cause of maternal and perinatal morbidity and mortality. This disorder causes a significant increase in maternal, fetal, and neonatal mortality and morbidity. Hypertensive disorders of pregnancy are major contributors to prematurity. While prevention of hypertensive disorders of pregnancy has been an elusive target, early detection and treatment with safe and effective pharmacologic therapies effectively optimize the outcome for the pregnant woman and fetus.

The increased incidence of preeclampsia in the United States is likely related to the higher prevalence of predisposing disorders such as hypertension, diabetes, and obesity, the delay in child-bearing, and the use of assisted reproductive technologies with their associated increase in multifetal gestation. The global impact of preeclampsia is profound, with short- and long-term effects on both the mother and infant. Maternal pre-existing conditions for preeclampsia include nulliparity, multifetal gestations, preeclampsia in a previous pregnancy, chronic hypertension, pregestational diabetes, gestational diabetes, thrombophilia, systemic lupus erythematosus, prepregnancy body mass index greater than 30, antiphospholipid antibody syndrome, maternal age 35 years or older, kidney disease, assisted reproductive technology, and obstructive sleep apnea. Three to 7% of preeclamptic women have gestational diabetes. Preeclampsia affects multiple organ systems and may manifest with a wide variety of symptoms. The cause is unknown.

Classification

Preeclampsia is a disorder of pregnancy-associated with new-onset hypertension, which occurs most often after 20 weeks of gestation and frequently near term. Although often accompanied by new-onset proteinuria, hypertension and other signs or symptoms of preeclampsia may present in some women in the absence of proteinuria.

Gestational hypertension is defined as systolic BP of 140 mm Hg or more or a diastolic BP of 90 mm Hg or more, or both, on two occasions at least four hours apart after 20 weeks of gestation in a woman with a previously normal BP.

Eclampsia is the convulsive manifestation of the hypertensive disorders of pregnancy.

Chronic hypertension is hypertension that predates pregnancy.

HELLP syndrome is an acronym for the presentation of hemolysis, elevated liver enzymes, and low platelet count that may develop in a severe form of preeclampsia.

Management

The cornerstones of management of a pregnant woman with preeclampsia are delivery or close antenatal observation, seizure prophylaxis with magnesium, and control of hypertension. Delivery always benefits the pregnant woman and not the fetus, except when severe uteroplacental insufficiency or intrauterine growth restriction (IUGR) are present. The timing of delivery is determined by the severity of the disease and gestational age. Patients with mild preeclampsia may be observed and delivered, preferably vaginally, between 37-40 weeks' gestation. Of note, the 2019 ACOG Practice Bulletin 202 recommends expectant management of preeclamptic women unless they demonstrate “severe features,” which the woman in this case report did not have. Thus, national guidelines would support the patient having been followed expectantly). However, severe preeclampsia mandates delivery at any gestational age. Prolongation of antenatal days may be considered to allow a course of antenatal corticosteroids to help with pulmonary maturity, reduction in severe intracranial hemorrhage, cystic periventricular leukomalacia, and a course of magnesium sulfate for neuroprotection.

“The cornerstones of management of a pregnant woman with preeclampsia are delivery or close antenatal observation, seizure prophylaxis with magnesium, and control of hypertension. Delivery always benefits the pregnant woman and not the fetus, except when severe uteroplacental insufficiency or intrauterine growth restriction (IUGR) are present.”

Consequences of eclamptic seizures

One of the severe complications of preeclampsia is maternal seizures during pregnancy. Prolonged generalized tonic-clonic seizure activity during pregnancy has been shown to

cause maternal acidosis, hypoxia, and brain trauma, including hemorrhage. Abruptio placenta is common after a prolonged seizure, occurring in 20–50% of affected women. Convulsive seizures are also dangerous for the fetus as the fetal heart rate slows during and for up to 20 minutes after a maternal convulsion, suggestive of fetal hypoxia. In addition to acute events, recent studies have found that women with a previous diagnosis of eclampsia have increased white matter lesions and lasting psychological and cognitive effects. Thus, maternal convulsions can acutely cause trauma to both the pregnant woman and the fetus and have long-lasting negative consequences.

Fetal consequences

Because of the accompanying impairment of uteroplacental blood flow, complications include fetal growth restriction, oligohydramnios, placental abruption, and non-reassuring fetal status.

“The long-term impact on children exposed to preeclampsia with respect to growth, development, and health status is not established. Some authors suggest that exposure to a stressful intrauterine environment could accelerate organ maturation and improve the outcome of preterm infants, while others have not observed this.”

Short-term effects on the neonate

Neonates exposed to preeclampsia have an increased risk of respiratory morbidity, especially in preterm and late preterm infants. The pulmonary risks include RDS, need for respiratory assistance, and bronchopulmonary dysplasia. Additionally, feeding difficulties are more common for those infants born to mothers with preeclampsia. Magnesium sulfate, administered antenatally for prophylaxis of maternal seizures and neonatal neuroprotection, may cause decreased neonatal intestinal motility, necessitating a slower-than-normal introduction of enteral feedings. It is unclear if necrotizing enterocolitis is more common or not.

Hematologic abnormalities are often found in infants born to mothers with preeclampsia. Transient neutropenia and thrombocytopenia are often found, particularly in small for gestational age infants. Neutropenia may occur in up to 50% of infants born to mothers with preeclampsia. The severity is directly related to the severity of preeclampsia. A proposed mechanism for neutropenia is decreased neutrophil production secondary to a placental inhibitor factor. Neutropenia mainly affects the smaller and younger neonates. Thrombocytopenia occurs mainly in IUGR neonates, and it is generally found in the first 72 hours and resolves by ten days. The data on the mechanism of thrombocytopenia point to decreased platelet production from fetal hypoxia, microangiopathic sequestration, and destruction in the placental thrombi. Increased numbers of nucleated red blood cells and polycythemia have been found depending on the level

of chronic fetal hypoxia. Maternally administered magnesium may cause respiratory depression at birth. Severe intraventricular hemorrhage and periventricular leukomalacia are less common in premature infants born to preeclamptic mothers than mothers without preeclampsia.

Long-term impact

The long-term impact on children exposed to preeclampsia with respect to growth, development, and health status is not established. Some authors suggest that exposure to a stressful intrauterine environment could accelerate organ maturation and improve the outcome of preterm infants, while others have not observed this. Follow-up studies for growth, development, and health status are needed to understand the potential repercussions of hypertension in pregnancy.

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CORONAVIRUS

COVID-19

RELIABLE RESOURCES:

- **CDC:** 2019 Novel Coronavirus
- **The Lancet:** COVID-19 and pregnancy
- **MotherToBaby:** Coronaviruses
- **WHO:** Emerging respiratory viruses

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SHARED DECISION-MAKING PROTECTS MOTHERS + INFANTS

DURING COVID-19

KEEPING MOTHERS + INFANTS TOGETHER

Means balancing
the risks of...

- **HORIZONTAL INFECTION**
- **SEPARATION AND TRAUMA**



EVIDENCE

We encourage families and clinicians to remain diligent in learning **up-to-date evidence**.

PARTNERSHIP

What is the best
for this unique dyad?

SHARED DECISION-MAKING

- S**EEK PARTICIPATION
- H**ELP EXPLORE OPTIONS
- A**SSESS PREFERENCES
- R**EACH A DECISION
- E**VALUATE THE DECISION



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Both parents and providers
are confronting significant...

- **FEAR**
- **GRIEF**
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LONGITUDINAL DATA

We need to understand more about outcomes for mothers
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Gravens By Design: Standards, Competencies and Best Practices for Infant and Family Developmental Care in Intensive Care: The Time Has Come

Joy Browne, Ph.D., PCNS, IMH-E(IV)

“As evidence mounts to ensure the quality of care for hospitalized infants, and as families become more central to their baby’s caregiving, the time has come for assuring that such data are identified, examined, and standards set for family integration into all aspects of care.”

As evidence mounts to ensure the quality of care for hospitalized infants, and as families become more central to their baby’s caregiving, the time has come for assuring that such data are identified, examined, and standards set for family integration into all aspects of care. Neurodevelopmental and family-centered care now have a scientific base, practical application, and, most importantly, humane caregiving approaches that provide a basis for the development and implementation of neuroprotective standards to intensive care.

Excellence in neonatal care has produced remarkable outcomes in both mortality and morbidity, but optimal neurodevelopmental and social and emotional outcomes for the most vulnerable babies remain elusive. We have learned from basic and developmental science that early nurturing and caregiving impact neurophysiologic and epigenetic outcomes; however, these important findings are only beginning to be fully understood by medical professionals and applied to fragile newborns.

Recent advances in neuroprotection and developmental caregiving have provided significant opportunities to enhance early brain development and subsequent neurodevelopmental outcomes, yet applying those findings in intensive care is inconsistent and spotty at best. Without recognizing the available evidence, application to clinical care, and integration into all aspects of medical and nursing policies and procedures, the potential benefits will be lost. Global recognition of the need for guidelines and standards for developmental care has resulted in the publication of the European Foundation for the Care of Newborn Infants (EFCNI) Standards of Care for Newborn Health (<https://www.efcni.org/health-topics/in-hospital/developmental-care/>) and the Canadian Guidelines for Developmental Care

(<https://extranet.ahsnet.ca/teams/policydocuments/1/clp-neonatology-devcare-development-care-hcs-203-01.pdf>). Until recently, the United States has not established standards or guidelines for developmental, family-centered care. Instead, various

disciplines and organizations have developed their own expectations and competencies for intensive care developmental care and family-centered care practices (for example, from NIDCAP, OT, PT, Speech and Parent groups).

“In recognizing the need for evidence-based standards, competencies, and practice guidelines for infant and family-centered developmental care, an interprofessional group including representatives from all intensive care practice leading organizations and parents came together in 2015 to begin to determine if evidence for a variety of aspects of developmental care, neuroprotection, and family-centered care warranted identification, development, and publication of standards of care.”

In recognizing the need for evidence-based standards, competencies, and practice guidelines for infant and family-centered developmental care, an interprofessional group including representatives from all intensive care practice leading organizations and parents came together in 2015 to begin to determine if evidence for a variety of aspects of developmental care, neuroprotection, and family-centered care warranted identification, development, and publication of standards of care. After review of over 1000 publications, classification of quality of studies, and review by national and international professionals, the Standards, Competencies and Best Practice Guidelines for Infant and Family-Centered Developmental Care (IFCDC) process and articulation were published (1) and made readily available on the web (<https://nicudesign.nd.edu/nicu-care-standards/>).

Development of the Standards was based on the scientific principles that 1. Baby is an active participant and the primary focus of caregiving, 2. Family as integral and inseparable from the baby, 3. Neuroprotection of the developing brain; 4. Environmental impact, 5. Infant mental health; and 6. Individualized care. These principles can be demonstrated in intensive care only with appreciation for the change process and application to the system in which it is integrated.

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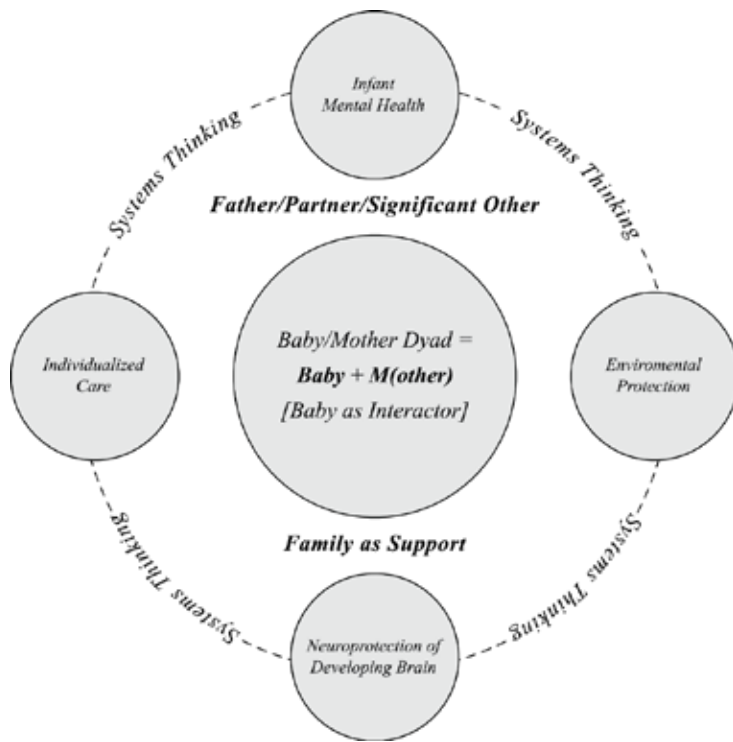


Figure 1 Used with permission

“The evidence is now beyond hearsay and is based on stringent scientific review, so it cannot be relegated to an ‘add-on practice when the situation is right.’”

The panel additionally identified six content areas that exemplified the aforementioned principles and for which IFCDC is well represented in the literature. The six areas that have ample evidence for the development of standards and competencies for practice include

- Systems Thinking;
- Positioning and Touch;
- Sleep and Arousal;
- Skin-to-Skin Contact with Intimate Family Members;
- Reducing and Managing Pain and Stress in Newborns and Families; and
- Feeding, Eating, and Nutrition Delivery.

IFCDC Standards in each content area include measurable com-

petencies, appropriate references, and instruments by which an intensive care professional, administrator, or manager can assess current practice. Additionally, it includes reflective opportunities for improvement of practices, including policy change toward integration into all aspects of intensive caregiving.

The evidence is now beyond hearsay and is based on stringent scientific review, so it cannot be relegated to an “add-on practice when the situation is right.”

The panel of professionals agrees that the time has come to become serious about the opportunities that IFCDC affords for optimizing the outcomes of babies and families who experience intensive care at birth, so they not only will survive but thrive. The evidence is based on stringent scientific review, so it cannot be considered “nice but not essential” or an “add-on practice when the situation is right.” The IFCDC standards and competencies are readily accessible and should raise a call to action for intensive care professionals, managers, quality assurance administrators, and families alike. More information and resources can be found at the website: (<https://nicudesign.nd.edu/nicu-care-standards/>).

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COVID-19

STOP THE SPREAD AT HOME

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

HYGIENE TIPS

- MOUTH**
 - Wear a face mask or face shield.
 - If in car, wear mask & put windows down.
 - NO cloth face masks for children younger than 2yrs.
 - Avoid kissing.
- EYES**
 - Wear protective eye gear (glasses)
- HANDS**
 - ALWAYS wash your hands down.
- CLOTHING**
 - Wear a jacket when dealing with infected.
 - DO NOT share clothing, sheets, or pillows.

BATHROOM

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

PROTECT

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

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

SELF ISOLATION

- Sick should be separate from household.
- Room with window preferred.
- Aerate room 3x day.
- Create a room divider with sheet.
- Keep water and sanitation liquids near room.
- Don't cuddle with pets.
- Use SEPARATE utensils.
- Clean utensils separately.
- If sick avoid the kitchen.

KITCHEN

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



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COVID-19

DETENER LA PROPAGACION EN CASA

Qué hacer cuando usted o un ser querido está infectado.

CONSEJOS DE HIGIENE

- BOCA**
 - Use una mascarilla o careta.
 - Si está en el automóvil, use una máscara y baje las ventanas.
 - NO mascarillas de tela para niños menores de 2 años.
 - Evitar besos.
- OJOS**
 - Use equipo de protección para los ojos (lentes)
- MANOS**
 - SIEMPRE lávate las manos
- ROPA**
 - Use una chaqueta cuando se trata de infectados.
 - NO comparta ropa, sábanas o almohadas.

BAÑO

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

PROTEGER

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

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

ASLAMIENTO

- Los enfermos deben estar separados del hogar.
- Habitación con ventana preferida
- Alinea la habitación 3x al día
- Crear un separador de ambientes con sábanas.
- Mantener agua y líquidos de saneamiento cerca
- Mantenga una bolsa de basura en la habitación.
- Use utensilios SEPARADOS.
- Limpie los utensilios por separado.
- Si está enfermo, evite la cocina.

COCINA

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



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Ways to Manage Covid 19 @ Home

Household

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

Sick

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

Stop the Spread at HOME Miora



Maneras de manejar COVID-19 en casa

Hogar

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

Enfermo

- Aíslase permaneciendo en una habitación separada con baño separado. No vayas a espacios compartidos
- Si no se puede aislarse crea un separador de ambiente con una sábana.
- Ventile la habitación con aire fresco por lo menos 3 veces al día.
- Mantenga agua y productos de saneamiento en la habitación.
- Mantenga una bolsa de basura en la habitación.
- Proteja a las mascotas, no las abra.
- Notifique a todos los contactos de los últimos 10 días.
- No espere! Si se siente peor llame a su médico.

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WEAR A MASK

PROTECT PARENTS + BABIES

COVID-19

When we all wear masks...

We protect parents and babies.



Project Sweet Peas + National Perinatal Association

USA UNA MASCARILLA

PROTEGER A LOS PADRES Y BEBÉS

COVID-19

Cuando todos usamos mascarillas ...

Protegemos a los padres y los bebés.



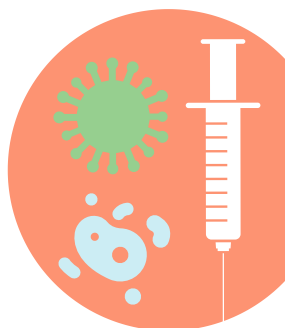
Project Sweet Peas + National Perinatal Association

PROTECT YOUR FAMILY FROM RESPIRATORY VIRUSES

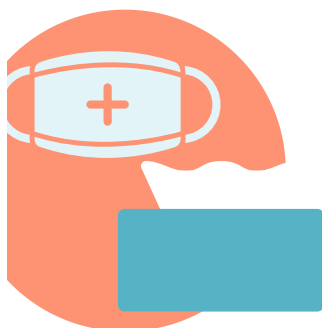
flu coronavirus
pertussis RSV



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



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



COVER COUGHS AND SNEEZES. Sneeze and cough into your elbow.



USE A HAND SANITIZER THAT IS 60%+ ALCOHOL.



STAY AWAY FROM SICK PEOPLE Stay at home to protect vulnerable babies and children. Avoid crowds when out.



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

KEEPING MOTHERS + INFANTS TOGETHER

Means balancing...



EVIDENCE

We encourage families and clinicians to remain diligent in learning **up-to-date evidence**.

PARTNERSHIP

SHARED DECISION-MAKING

What is the best for this unique dyad?

- S**EEK PARTICIPATION
- H**ELP EXPLORE OPTIONS
- A**SSESS PREFERENCES
- R**EACH A DECISION
- E**VALUATE THE DECISION



TRAUMA-INFORMED

Both parents and providers are confronting significant...

- **FEAR**
- **GRIEF**
- **UNCERTAINTY**

LONGITUDINAL DATA

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

- **MENTAL HEALTH**
- **POSTPARTUM CARE DELIVERY**



NEW DATA EMERGE DAILY.

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

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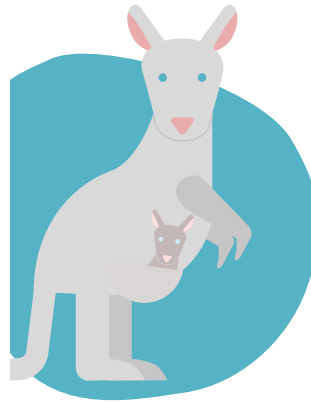
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SUPPORTING KANGAROO CARE

SKIN-TO-SKIN CARE DURING COVID-19



GET INFORMED ABOUT THE RISKS + BENEFITS

work with your medical team to create a plan

GET CLEAN

WASH YOUR HANDS, ARMS, and CHEST

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



PUT ON FRESH CLOTHES

change into a clean gown or shirt.

IF COVID-19 + WEAR A MASK

and ask others to hold your baby when you can't be there



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

In Loving Memory

August 9, 1996 - April 3, 2010



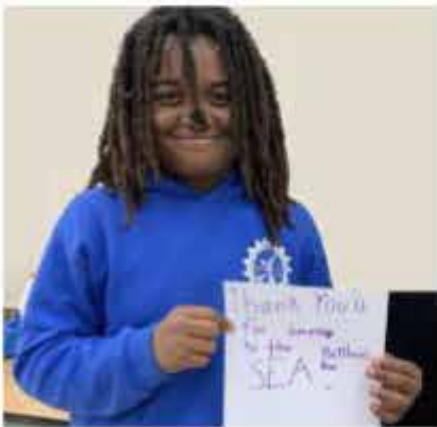
Each year, the Emily Shane Foundation SEA(Successful Educational Achievement) Program provides academic and mentoring support to over 100 disadvantaged middle school students who risk failure and have no other recourse. We have served over 700 children across Los Angeles since our inception in the spring of 2012. Due to the COVID-19 outbreak, our work is in jeopardy, and the need for our work is greatly increased. The media has highlighted the dire impact online learning has caused for the very population we serve; those less fortunate. **We need your help now more than ever to ensure another child is not left behind.**

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Machine Learning Workflow – Part 1

John B. C. Tan, PhD, Fu-Sheng Chou, MD, PhD

Starting this month, we would like to go through the entire workflow for developing a machine learning model and highlight some of the available techniques for each step. The goal is to introduce terminology and provide a general idea about the workflow rather than in-depth technical details. We hope you find this article helpful if you are thinking about developing one or two prediction tools for your practice. We are also open to collaboration to help you get your first predictive modeling project started.

“This month, we would like to take a deeper dive into discussing two major types of classical machine learning and introducing several “non-linear” algorithms to the readers.”

Overview

Figure 1 depicts the general process for machine learning model development. Data collection and processing are key to successful modeling and will be discussed in this article. In predictive

modeling, data is typically split into training and testing datasets. While the training dataset is used for model development and fine-tuning, the testing dataset should not be touched. The testing dataset is used to validate the model externally. Ideally, in the context of healthcare predictive modeling, the training data set should be collected retrospectively, and the test data set should be collected prospectively. However, this assumes that the prospective test cohort will follow the same standardized and stringent clinical management standards as the retrospective training dataset. More frequently, the retrospective dataset is split into the training and the testing datasets. There will be more discussion about ways to construct the training and testing datasets in a later article.

Data preparation

Define the question and determine the prediction goal

In the practice of neonatology, we deal with uncertainty about the future constantly. Now that the mortality rate of neonates has decreased, the current focus of neonatal research has shifted from “how can we get these babies to survive?” to “how can we give these babies a good quality of life?” While this goal may seem too ambitious at first glance, we can utilize the latest machine learning algorithms and predictive modeling practices to contribute significantly to the answer to this question. In general, the goal of predictive modeling is to use the hidden patterns in current or past data to predict the outcome. “Hidden,” in this instance, refers

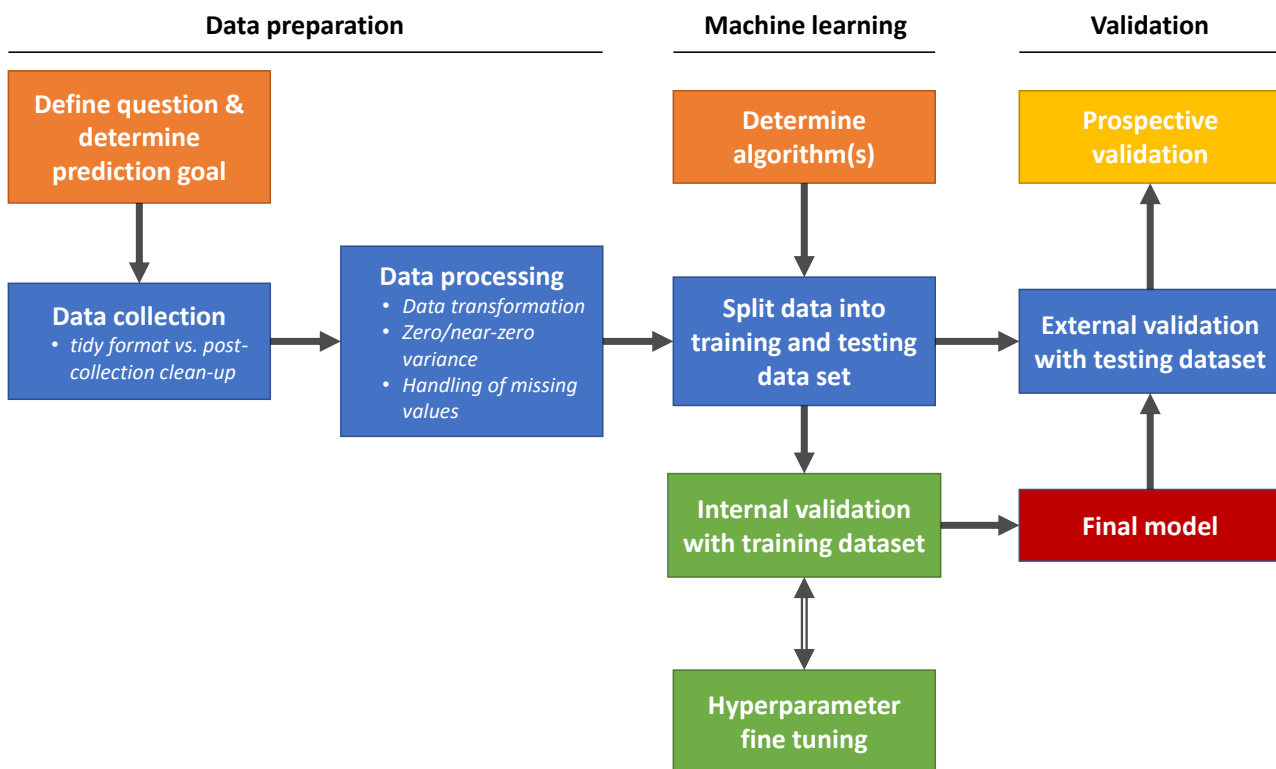


Figure 1: The general process for machine learning model development.

to the fact that there are a lot of quantifiable patterns in biology that are unrecognizable to the human eye; therefore, we must rely on machines to recognize these patterns for us. While traditional hypothesis generation and testing may not always be necessary for a predictive modeling project, as such projects are exploratory by nature, it is imperative to identify the clinical question and the prediction goal. Key aspects to consider are (1) cohort size and (2) clinically relevant variables.

Cohort size is critical to successful modeling. Machine learning algorithms require a large amount of data to sort out the patterns. The orders of magnitude for the amount of data required depend on the type of machine learning algorithm. Classic machine learning relies on data points in the range of at least hundreds, while deep learning requires data points in the range of thousands. Furthermore, there may not be enough data within a single center to successfully create a prediction model depending on the prediction goal. Therefore, it is essential to determine whether data from a single center will suffice or if a multi-center collaboration is required.

“Classic machine learning relies on data points in the range of at least hundreds, while deep learning requires data points in the range of thousands. Furthermore, there may not be enough data within a single center to successfully create a prediction model depending on the prediction goal.”

Using clinically relevant variables is also key to a successful predictive modeling project. We are trained to use an existing staging/grading system to “quantify” disease severity in clinical practice. The classification system usually has a prognostic association but is not “predictive.” For example, a recent report using data from Vermont Oxford Network showed that Grade 3 bronchopulmonary dysplasia is associated with a significantly higher likelihood of having a tracheostomy (18.3% vs. 1.0% in all infants) and longer hospital stay (median discharge at 49 weeks postmenstrual age vs. 39 weeks in all infants) (1). However, there is no guarantee that using this existing classification system is the best way to capture the hidden patterns within our data. Depending on the project’s goal, the variables chosen for your predictive model should be intentional and discussed thoroughly. Notably, in machine learning jargon, “variables” are known as “predictors” or “features.”

Data collection

Once the question has been defined, and a prediction goal is set, the next step is to collect data. We highly recommend collecting only raw data instead of processed or interpreted data. For example, collect data on PDA size in millimeters, not as small/moderate/large. Raw, untransformed, and humanly uninterpreted data with higher resolution will maximize the predictability. Plus, we can also recode the data elements into lower resolution as needed during data processing. It is also essential to use the tidy format in data collection: (a) each variable must have its own column; (b) each observation must have its own row; (c) each value must have

its own cell (2). These rules seem straightforward, but it takes considerable effort when designing the data collection sheet to abide by them. One approach, which we have taken successfully, is to work with database experts in the medical informatics department to directly extract data from the database server that stores all the data for the electronic health records (EHR). While there is a slight learning curve when it comes to communicating with the database architect and learning about database systems, it does help tremendously to get the mindset of what tidy data means right after being familiar with the database system because all structured EHR data are stored in a tidy format. Notably, it is still tricky to extract free-text data from the EHR. Sometimes it is much easier to go into the charts and do a manual chart review. Ideally, data are collected in a tidy format. But if not, the subsequent data clean-up steps should be taken to restructure the data into a tidy format for more straightforward analysis.

Which specific data to collect and what format the data should be in is a very complex topic and can severely alter your predictive model outcomes. While it may not be desirable and is impossible to collect data on all variables, we do agree that we must bear an adventurous mind and be bold about what data to collect. To start, we may search the literature for risk and protective factors that have been reported to be associated with the outcome we would like to predict. These well-established risk factors can serve as “positive controls.” For example, gestational age would be a good “positive control” when predicting respiratory outcome due to its strong correlation. Clinical observation is also important. We would suggest including those variables that may have a correlation with the outcome based on anecdotal experience. One may also include factors that may seem irrelevant to serve as “negative controls,” although true independence between a feature and the desired outcome measure may not be detected by human perception. Collinearity is not a huge concern because there are techniques (regularization or non-linear algorithms as examples) to address it (3,4). For decision tree-based models, highly correlative variables should have similar importance scores (4). In such cases, the physiological relationship between the two variables in question can be further confirmed. Nonetheless, during the initial planning stages of the study, it is imperative to discuss which variables are to be collected and in which format. Deciding on these aspects of data collection midway through the study rather than the start of the study can lead to bias and overfitting.

Data processing

Data processing may include transforming data, eliminating zero- or near-zero-variance features, and dealing with missing values. Transforming data is particularly useful when using specific algorithms such as linear regression or Gaussian naïve Bayes, which require continuous variables to have a normal distribution. Exponential and power transformations (Box-Cox or Yeo-Johnson) are common techniques. Additionally, techniques such as centering around the mean and feature scaling may be performed to normalize or standardize the dataset. For example, if you have a variable with a range of 0 to 10 and another variable with a range from 0 to 1000, centering and scaling the data will strengthen your prediction model because it increases the comparability of the variables.

It is important to assess zero- or near-zero-variance in the features and eliminate these variables before training a model. Simply, when a variable has a high percentage of zero data, it is very likely that only observations with zero values will be selected when randomly selecting observations to construct the training dataset.

In this case, the variable becomes useless because all observations have the same value, which is zero. These predictors should be removed during data processing steps.

“The major concern regarding missing values is whether the final model developed is skewed by the missing values and/or how the missing values are handled. Handling missing values by itself is a huge area of research and should be discussed with the machine learning engineer or the data scientist early on during project development.”

Missing values

Missing values are common in healthcare data and can be a headache in machine learning. While some algorithms, such as regularized linear regression and generalized additive modeling, can tolerate missing values, most algorithms require complete data. There are three major types of missing values: (a) missing completely at random (MCAR), (b) missing at random (MAR), and (c) missing not at random (MNAR) (5). The mechanism of missingness in MCAR is independent of the collected or the missing data. In MAR, the mechanism of missingness is dependent on the collected data, whereas, in MNAR, the mechanism of missingness is dependent on the missing data. It is not easy to distinguish among different types of MCAR, MAR, and MNAR. The major concern regarding missing values is whether the final model developed is skewed by the missing values and/or how the missing values are handled. Handling missing values by itself is a huge area of research and should be discussed with the machine learning engineer or the data scientist early on during project development.

One way to deal with missing values is to eliminate the rows that contain missing values, but by doing this, the total observation number will decrease and may also cause bias in the final model. Generally speaking, if the missing data only comprise no more than 5% of the total observations, those incomplete observations can be ignored, an approach called complete case analysis (only analyzing complete data). On the other hand, if the percentage of the observations with missing values is significant, effort should be spent on understanding the missingness mechanism and whether another round of chart review or selecting additional surrogate features is feasible.

Alternatively, imputation of missing values may be performed. There are three “easy” methods to impute missing values: (a) add a constant value (using the last observed value or the worst value observed for the subject, for example); (b) use the corresponding value for the predictor from a random observation; (c) use the mean, median, or mode value from the variable. These methods can collectively be considered as single imputations. Single imputation has its own caveat, including underestimation of the variability

Figure 3. Visual depiction of a decision tree.

ity and potentially creating bias. In contrast, multiple imputations, which are based on developing additional predictive models to predict the missing values, can be performed to impute the missing values. Multiple imputations are out of the scope of the article, so they will not be discussed here. Regardless of which method to choose, the same method must be used during the model validation process. Different methods can be tried to process the data for training. The best method may then be determined based on model performance, which we will discuss in Part 2 next month.

“Regardless of which method to choose, the same method must be used during the model validation process. Different methods can be tried to process the data for training.”

Summary

Data preparation takes up most of the time during model development. Most data scientists would agree that they spend at least 80% of their time on data processing, emphasizing the importance of crafting well-processed data before training should occur. We hope you enjoy reading this article. We will discuss model training and validation next month.

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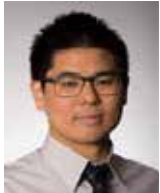
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3. An archive search will be available for journals older than 2012.
4. A new section called news and views will enable the submission of commentary on publications from other journals or news sources. We anticipate that this will be available as soon as the site completes the beta phase
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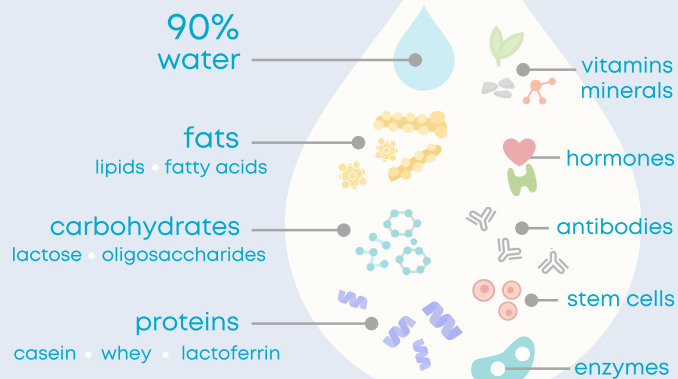
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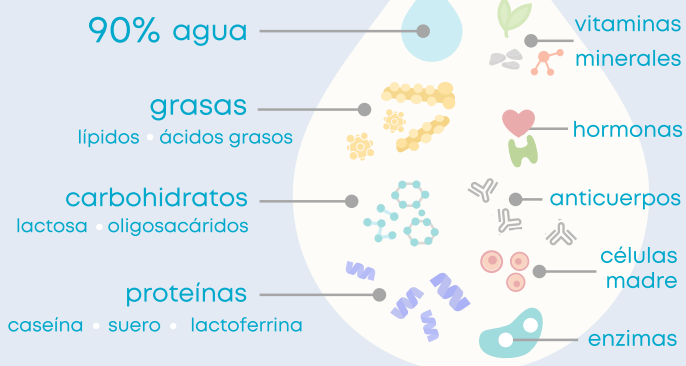


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The Village Son



A Life's Journey

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

Houchang D. Modanlou

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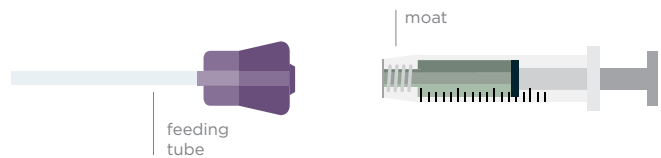
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New tubes, new problems?

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

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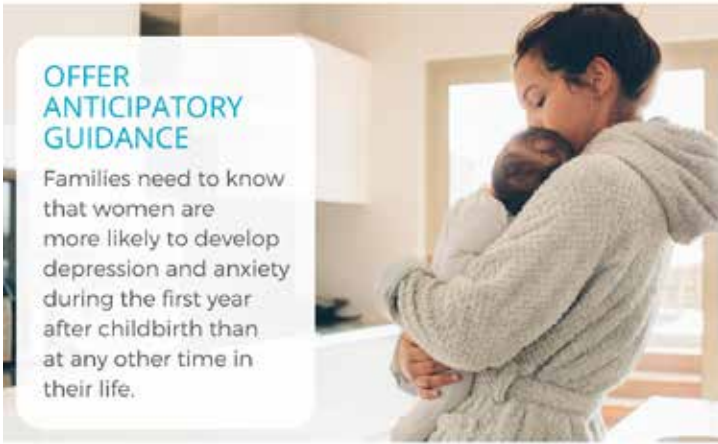
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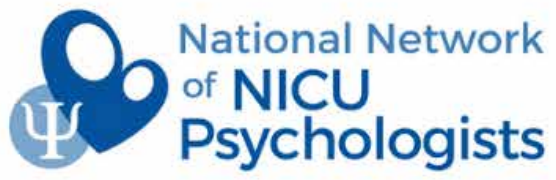
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Barb Himes, IBCLC, CD

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It is August, when we mark both World Breastfeeding Week from August 1-7 and Black Breastfeeding Week from August 25 – 31, annual initiatives that focus on the lifesaving benefits of breastfeeding.

The [World Alliance for Breastfeeding Action](#) (WABA), the global network that organizes World Breastfeeding Week, sees breastfeeding as a public health issue requiring support from health systems, workplaces, and communities, and this perspective is shared by the organizers of Black Breastfeeding Week, including [The Black Mothers' Breastfeeding Association](#).



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

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The American Academy of Pediatrics (AAP) recommends breastfeeding as the exclusive source of nutrition for the infant's first six months of life, then complemented by other food sources and continued for one year or longer, as desired. The resulting health benefits include nutrition, a level of protection against common childhood infections, and a reduced risk of Sudden Infant Death Syndrome (SIDS) (1), as well as the infant physical stabilization and maternal-infant bonding effects of skin-to-skin contact.

"First Candle has long supported breastfeeding, with the proviso that the infant should only be taken into the mother's bed to feed and comfort, and when it is time for maternal or infant sleep, the baby should be placed back in his or her own sleep space. This space should follow AAP guidelines for infant-safe sleep: room share but not bed-share; a firm sleep surface; no loose bedding or objects; and a prone sleeping position."

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Breastfeeding and Public Health Ramifications

The public health imperatives of breastfeeding become obvious when examining racial disparities in breastfeeding and infant mortality. According to the Centers for Disease Control and Pre-

vention (CDC), fewer Black infants (73.7%) are ever breastfed compared with Asian (90%), White (86.7%), and Hispanic infants (84.1%). (2)

This must be looked at as a contributing factor to the fact that infant mortality in the United States is 10.8 per 1,000 live births for Blacks and 4.6 for Whites. (3) Black infants are disproportionately born “too small, too sick or too soon,” as maternal and infant health advocate [Kimberly Seals Allers](#) notes, and research confirms, (4) they need the immunizing and nutritional benefits of breast milk. This means Black families must have access to health care, and there should be diversity among lactation health care providers.

Breastfeeding and the New Family

These are the macro concerns we face, but in our work and discussions with health care providers, we have also anecdotally heard of the everyday concerns of new parents, which, if not shared and discussed, can prompt decisions to end breastfeeding before the optimal time. Offering support to families can include reassurances about interpreting infant behaviors in the early days after birth. Providers may find it helpful to discuss with expectant and new families:

- Joining a local breastfeeding support group before the baby is born for educational preparation and a sense of community.
- That after the birth, the baby will go to the breast first and may feed for a long period, up to 45 minutes or so.
- The baby should then return to the breast every two to three hours, the timing of which may be driven by feeding cues: lip-smacking, fist-chewing, or moving around. The last cue is crying, but feeding should begin before that stage to reduce stress for both mother and child.
- In general, Day One will be a sleeping day for the infant; Day Two may be a generally fussy day not necessarily due to hunger, and Day Three will be a heavy feeding day.
- Mothers may later notice heavier feeding at certain intervals due to growth spurts. Common growth spurts are the first few days; a week to 10 days; three weeks; three months; six weeks; six and nine months. During this time, infants may become fussy and clingy, with some disruption in sleep habits.

There are also several benefits to breastfeeding mothers themselves:

- Breastfeeding promotes a faster and easier recovery from childbirth. The release of the “feel-good” endorphin oxytocin during breastfeeding acts to return the uterus to its normal size and may reduce postpartum bleeding.
- Breastfeeding also triggers the release of prolactin, which promotes milk production as well as maternal feelings of relaxation and wellbeing, contributing to the bonding experience.
- Studies have also shown that women who have breastfed are at lower risk for breast and ovarian cancer later in life. (5)

Providers can also help ensure that fathers are proactively included in preparation discussions and a hands-on post-natal role, supporting the mother and establishing a direct tactile and voice relationship through skin-to-skin contact and talking to the infant.

Partners can also help the mother have a proper diet, hydration, rest, get her comfortable, and bring the baby to her for breastfeeding.

Regarding COVID-19 and breastfeeding, the CDC continues to update its guidelines, including continued support for breastfeeding for its nutritional and immunizing benefits. (6) These include:

- Those who do not have suspected or confirmed COVID-19 and have not been in close contact with someone who has or have been vaccinated need no special precautions when breastfeeding or expressing milk.
- A breastfeeding individual not fully vaccinated should protect themselves and the infant when either of them has suspected or confirmed COVID-19. This could include isolation, quarantine, masking, and sanitation practices.
- Any healthy caregiver, preferably fully vaccinated and not at increased risk for severe illness from COVID-19, may feed expressed breast milk. If not vaccinated and co-habiting and in contact with the breastfeeding person, they should wear a mask during feeding during the lactating parent’s time of isolation and their quarantine thereafter.

“Breastfeeding continues to be an opportunity to provide infants with important nutritional and health benefits and is a critical component of their post-natal development. It also begins the bonding and nurturing relationship between the infants and parents and can be an enriching beginning for the family.”

Breastfeeding continues to be an opportunity to provide infants with important nutritional and health benefits and is a critical component of their post-natal development. It also begins the bonding and nurturing relationship between the infants and parents and can be an enriching beginning for the family.

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Disclosure: The author is an International Board Certified Lacta-

tion Consultant, Certified Doula, and the Director of Education and Bereavement Services of First Candle, Inc., a Connecticut-based not for profit 501(c)3 corporation.

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www.firstcandle.org

About First Candle

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

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Providing Psychosocial Support to NICU Parents

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Neonatologist Opportunity

Davenport, Iowa

Looking to make a change? We have the total package...

The Department of Pediatrics at the University of Illinois College of Medicine and OSF Healthcare are partnering with Genesis Medical Center-Davenport and currently seeking a board certified Neonatologist. Genesis Medical Center-Davenport is a Level II nursery with roughly 1,700 deliveries/year. An excellent benefits package is available including vacations, sick time, malpractice coverage, CME, health and life insurance and retirement plan.

Genesis Medical Center-Davenport is a licensed 502 bed facility, which offers a wide range of inpatient and outpatient medical

services. Specifically, the NICU is a 20 bed unit, which consists of ten private rooms and three open bays. The NICU functions as a Level II intensive care nursery. The NICU is equipped to stabilize and manage neonates with acute and chronic illness. It is equipped with emergency and resuscitative equipment including:

- Cardiac and apnea monitors with capabilities for trending/monitoring pulse oximetry
- Non-invasive and invasive blood pressure monitoring
- Oxygen therapy (ventilators, CPAP, bag/mask, high flow nasal cannula, RAM cannula and nasal cannula)
- Warmer units
- Isolettes
- Neonatal instruments for insertion of UAC/UVC lines, PICC lines and chest tubes

The Quad Cities (made up of 5 cities, including Davenport Iowa), representing roughly 400,000 people, is the largest metropolitan area on the Mississippi River between Minneapolis and St. Louis. It is three hours west of Chicago and two and a half hours east of Des Moines, Iowa. The area has recently been ranked as a “best place to live” and is known for safe neighborhoods, short commute times and a reasonable cost of living. The community is fortunate to have excellent schools (in the Quad Cities and surrounding areas), the Niabi Zoo, museums, fine arts, a local festival scene, minor league baseball and hockey, and many seasonal outdoor activities. The John Deere Classic, PGA Tour event, and the Bix 7 road race bring in people from all over the world every summer. The Quad Cities International airport located in Moline, IL connects our community to almost a dozen other cities in the US.

Please contact or send CV to:

Stacey E. Morin, OSF HealthCare Physician Recruitment

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The National Urea Cycle Disorders Foundation



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 PEDNOTES

Neonatal Nurse Practitioner Opportunity

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Reporting to the Medical Director of the Neonatal Intensive Care Unit, and according to professional nursing standards of care, performs a variety of advanced nursing diagnostic and therapeutic procedures for the high risk neonates in the critical care setting at Genesis Healthcare—Davenport (Davenport, IA). Demonstrates the knowledge and skills necessary to provide patient care that is appropriate to the ages of the patients served.

Genesis Medical Center-Davenport is a licensed 502 bed facility, which offers a wide range of inpatient and outpatient medical services. Specifically, the NICU is a 20 bed unit, which consists of ten private rooms and three open bays. The NICU functions as a Level II intensive care nursery. The NICU is equipped to stabilize and manage neonates with acute and chronic illness. It is equipped with emergency and resuscitative equipment

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Burnout, Exhaustion, and ... It Is Not Just COVID

Kelly Welton, RRT-NPS

“Whether access to log on to the computer, the blood gas machine, or access to a patient’s chart so I could document or Pyxis, this was taking time away from patient care every time I had to sit on hold while IT was experiencing higher-than-normal-call-volume.”

I’d been waiting for the Email for days.... And there it was: The subject line, “IT would like your feedback on your recent interaction with tech support.” My chance to be heard! There better not be any character limits on this one! My IT guy was a dream. [He] had me back in the system in no time. It’s just that..... every other day I came to work, I had to call IT to sort out some new befuddlement with my access. Whether access to log on to the computer, the blood gas machine, or access to a patient’s chart so I could document or Pyxis, this was taking time away from patient care every time I had to sit on hold while IT was experiencing higher-than-normal-call-volume. In the comments section, I wrote:

“Once, just once, I would like to come to work, log in to my computer, and get on with my day. As it is, I spend my first one to 2 hours each shift on the phone with someone to get me logged in. I find this an insane waste of time”.

I sent a copy to administration with a gentle explainer that I am still expected to perform patient care whether on hold with or interacting with IT those first 2 hours.

CoVid has done a number on all of us in healthcare, no matter what our specialty. But the insidious increase in time stolen by our computers in the name of patient care has been going on for years. And we are not equipped to fight it. Or are we? As bedside patient care clinicians, can we fight back or otherwise revolt against this system and put things back the way they ought to be: Patients come first, with thorough documentation of only pertinent information. What is the correct protocol for the rebellion?

For example, if I make a ventilator change, I should also know what other parameters need to be accounted for as a professional. If I change the PIP, I should also document returned tidal volume, any change in O₂ saturations or ETCO₂, and chest rise or breath sounds. The system often requires that I document the entire ventilator check and allows a very dangerous practice of copying and pasting the last entry. Can we band together and let Clinical Informatics know this is not working for us? Several ar-

ticles have shown that even ‘mature’ EHR’s require that we spend approximately 1.5-time units documenting for every 1.0 time unit in actual patient care. But no one is factoring this into our workloads. (1, 2)

I read accounts by my fellow CoVid RT’s in adult capacities of crazy workloads, constant codes being called, non-stop intubations, and HFNC and BiPap setups. When do they chart all of this? Did someone perhaps ingeniously develop a minimum documentation protocol for when things get crazy? Think 24-week triplets, and you are the only MD or RT on the unit. Or, a baby crumps requiring an oscillator, which needs to be found, set up, calibrated, and vents moved around. Then we must titrate to optimal settings and wait 20 min to draw the ABG. If I get called to a crash C-section in the middle of this, that will surely take priority over finishing documenting every change we made on the “crumping” baby.

Patient care always comes first, but staying late every shift to complete documentation on every last detail of every baby in the unit does not allow us the time off we need to reset and regroup.

“I am reminded of my last hospital, where a critical result on a CBG required 65 (yes, that is sixty-five) clicks of the mouse to enter a result per The Joint Commission (TJC) and College of American Pathologist (CAP) standards.”

I am reminded of my last hospital, where a critical result on a CBG required 65 (yes, that is sixty-five) clicks of the mouse to enter a result per The Joint Commission (TJC) and College of American Pathologist (CAP) standards. I could have run to the MD and showed him the slip of paper and run back ten times by the time I met the requirement -- Not to mention the delay in care. This delay was not TJC or CAP’s fault; this situation occurred because the modern ABG machine could not make a way to interface with our old, pieced-together, and patched-up EHR.

How can we get back to patient care truly being our focus? Can we talk IT into giving us a SOAP button for those days when we need to focus on what the baby is doing or not doing and lose extraneous charting parameters that, although they may be related, are not affected by the changes we made?

Many healthcare personnel left the field in the Spring when the pandemic calmed down, understandably so. Nevertheless, the undercurrent of a different pandemic – the need for more information and to cover us and our health systems in case of lawsuits – presents a different level of exhaustion and burnout. Instead of just allowing MDs, RNs, and RTs to leave in droves, why not start

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a conversation about building a better (more straightforward) system. We built it; we can un-build it. Moreover, we MUST convince administration, IT, and insurance carriers that clicking boxes is not patient care.

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Disclosures: The author is President of the Academy of Neonatal Care, A Delaware 501 C (3) not for profit corporation.

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and TCOM'S -
Neonatal
Assessment - NICU
Ventilator Settings -
HFNC in NICU -
Surfactants -
Infection Control-
Hands-on workshop

SESSION 2

Neonatal Pneumonia
and Sepsis - Oscillator
basics - Neonatal
Chest X-Rays - HFNC
vs. CPAP - Apneas and
Bradycardias -
Intraventricular
Hemorrhage -
Neonatal Respiratory
Distress Syndrome-
Non-Invasive
Ventilation - Prove
yourself as a NICU
Newbie -and Hands
on workshop

SESSION 3

Ventilator
waveforms - ECMO
- iNO update - Jet
ventilators -
Infection Control
in the NICU -
Psych-social
aspect of NICU
Care - Transports
- and Hands-on
Workshop
-And MORE!

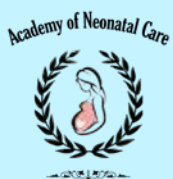
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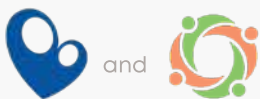
Provide culturally-informed and respectful care.

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



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

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National Perinatal Association
NICU Parent Network

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

TOP 10

RECOMMENDATIONS FOR THE PSYCHOSOCIAL SUPPORT OF NICU PARENTS



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

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

1 PROMOTE PARTICIPATION

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



2 LEAD IN DEVELOPMENTAL CARE

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



3 FACILITATE PEER SUPPORT

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



4 ADDRESS MENTAL HEALTH

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



5 SCREEN EARLY AND OFTEN

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



6 OFFER PALLIATIVE & BEREAVEMENT CARE

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

7 PLAN FOR THE TRANSITION HOME

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



8 FOLLOW UP

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

9 SUPPORT NICU CARE GIVERS

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



10 HELP US HEAL

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

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



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



Keep prenatal **APPOINTMENTS.**



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

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Protecting Access for Premature Infants through Age Two

SUPPORTING KANGAROO CARE

SKIN-TO-SKIN CARE DURING COVID-19



GET INFORMED ABOUT THE **RISKS + BENEFITS**

work with your medical team to create a plan

GET CLEAN
WASH YOUR HANDS, ARMS, and CHEST

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



PUT ON **FRESH CLOTHES**

change into a clean gown or shirt.



IF COVID-19 + **WEAR A MASK**

and ask others to hold your baby when you can't be there



National Perinatal Association

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

NPN
NICU PARENT NETWORK

TAKE THE NECESSARY STEPS TO ELIMINATE INEQUITIES



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Keeping Your Baby Safe

during the COVID-19 pandemic

How to protect your little one from germs and viruses

Even though there are some things we don't know about COVID-19 yet, there are many more things that we do know. We know that there are proven protective measures that we can take to stay healthy.

Here's what you can do...

Wash Your Hands

- This is the single, most important thing you can do to stop the spread of viruses.
- Use soap.
- Wash for more than 20 seconds.
- Use alcohol-based sanitizers.



Limit Contact with Others

- Stay home when you can.
- Stay 6 feet apart when out.
- Wear a face mask when out.
- Change your clothes when you get home.
- Tell others what you're doing to stay safe.



Provide Protective Immunity

- Hold baby skin-to-skin.
- Give them your breast milk.
- Stay current with your family's immunizations.



Take Care of Yourself

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



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

WARNING

Never Put a Mask on Your Baby

- Because babies have smaller airways, a mask makes it hard for them to breathe.
- Masks pose a risk of strangulation and suffocation.
- A baby can't remove their mask if they're suffocating.



If you are positive for COVID-19

- Wash with soap and water and put on fresh clothes before holding or feeding your baby.
- Wear a mask to help stop the virus from spreading.
- Watch out for symptoms like fever, confusion, or trouble breathing.
- Ask for help caring for your baby and yourself while you recover.



We can help protect each other.

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Raising Global Awareness of RSV

Global awareness about respiratory syncytial virus (RSV) is lacking. RSV is a relatively unknown virus that causes respiratory tract infections. It is currently the second leading cause of death – after malaria – during infancy in low- and middle-income countries.

The RSV Research Group from professor Louis Bont, pediatric infectious disease specialist in the University Medical Centre Utrecht, the Netherlands, has recently launched an RSV Mortality Awareness Campaign during the 5th RSV Vaccines for the World Conference in Accra, Ghana.

They have produced a personal video entitled “*Why we should all know about RSV*” about Simone van Wyck, a mother who lost her son due to RSV. The video is available at www.rsvgold.com/awareness and can also be watched using the QR code on this page. Please share the video with your colleagues, family, and friends to help raise awareness about this global health problem.



The Survey says RSV



What you need to know about RSV

RSV stands for **Respiratory Syncytial Virus**

RSV is a **Really Serious Virus**

WHEN IS RSV SEASON?

Typically RSV season runs from November - March. But it can begin as early as July in Florida and end as late as April in the West.

Protect babies and families this RSV season
Educate. Advocate. Integrate.

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Consult the CDC's RSV Census Regional Trends to learn more www.cdc.gov/rsv/census/regional-trends-surveillance.html

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5 THINGS YOU CAN DO TO CELEBRATE NICU AWARENESS



- 1 Educate Yourself**
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High-Frequency Oscillatory Ventilation (HFOV) New Patients, New Strategies -- Same Physics

Rob Graham, R.R.T./N.R.C.P.

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

“As the limits of viability are pushed ever lower, our patients have become ever smaller. What all too often has not changed are the HFOV parameters chosen.”

While HFOV has been a recognized mode of ventilation in the NICU for 40 years, its application on different patients with different pathologies demands different settings. As the limits of viability are pushed ever lower, our patients have become ever smaller. What all too often has not changed are the HFOV parameters chosen.

For years it has been assumed that smaller patients require higher frequencies (and there are indeed situations where higher frequencies are desirable). There are also situations where this is not the case, and lower frequencies are the more appropriate. Confounding the clinician's selection of frequency are differences between machines, the availability of volume-targeted HFOV, airway resistance (R_{aw}), pulmonary compliance (CI), achieving proper lung volume (via mean airway pressure (MAP) to ensure an “open lung” approach to ventilation, and surfactant.

Corner frequency (f_c) has been identified as the best and appropriate frequency at which to ventilate, while some believe resonant frequency (ω) is the most appropriate. f_c is the frequency at which energy passed through the system (airways) decreases instead of passing through. ω , conversely, is the frequency at which response to any given amplitude is greatest (and can even be amplified)(1). The most common example of ω is a glass shattering when a vocalist hits a specific note at sufficient volume. (“Gallop Gertie,” otherwise known as the original Tacoma Narrows Bridge, was initially thought to have collapsed due to sustained

wind matching the bridge's ω ; however, it was an aerodynamic phenomenon known as “flutter” that caused the collapse. More on that later). From an efficiency standpoint, ω gives the most bang for the buck, but, just as the shattering glass, ω has the potential to damage the lung. In the neonatal lung, f_c is usually lower than ω . (1)

While HFOV is generally considered a gentler, lung-protective mode of ventilation, it is hardly foolproof. The most glaring example is the infamous “HIFI” study of the early 1980s terminated early due to bad outcomes, particularly severe brain bleeds, while offering no statistical pulmonary benefit. (2) While the results of this study did not support HFOV, it was not futile; we learned from it the dangers of not ventilating with an adequately recruited lung, now known as the “open lung” approach.

“While HFOV is generally considered a gentler, lung-protective mode of ventilation, it is hardly foolproof. The most glaring example is the infamous “HIFI” study of the early 1980s terminated early due to bad outcomes, particularly severe brain bleeds, while offering no statistical pulmonary benefit. (2)”

Underinflation is not the only practice that can lead to undesirable results. The behaviour of the oscillatory waveform itself can also create damage regardless of proper recruitment. During HFOV, gas is pushed into and pulled out of the airways at high frequency and velocity. While we associate shear stress with the lung's relatively large expansion and deflation during conventional ventilation, we assume the small, sub-dead space volumes of HFOV prevent or significantly limit shear stress. This can be true, but high-velocity gas flow creates turbulent flow, which, in turn, causes eddies to form. The more turbulent flow created, the more eddies form. This non-laminar flow is advantageous from the standpoint of gas mixing enhancing ventilation (and indeed is essential for HFO to work); however, localized pressure differences produced by eddies create shear forces that can distort the surface of the airway cell structure and potentially cause damage. Because the gas flow is rapidly changing, these shear forces are potentiated,

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particularly in proximal airways(1). This concept is very similar to aeroelastic flutter. “Flutter is a dynamic instability of an elastic structure in a fluid flow, caused by positive feedback between the body’s deflection and the force exerted by the fluid flow. In a linear system, “flutter point” is the point at which the structure is undergoing simple harmonic motion—zero net damping—and so any further decrease in net damping will result in a self-oscillation and eventual failure. «Net damping» can be understood as the sum of the structure’s natural positive damping and the negative damping of the aerodynamic force. Flutter can be classified into two types: *hard flutter*, in which the net damping decreases very suddenly, very close to the flutter point; and *soft flutter*, in which the net damping decreases gradually” .(3) Damping increases as the gas travels further down the airways thus the potential for this phenomenon is greater in proximal airways. (Damping refers to the reduction, restriction, or prevention of oscillations within or upon that system. Damping in physical systems is a result of a process that dissipates the energy stored within the oscillation. In an overdamped system, the system returns (exponentially decays) to equilibrium without oscillating. (1)

“Oscillatory waveform pressure also behaves differently with varying compliance and resistance. High resistance dampens the waveform and attenuates pressure, whereas low resistance produces less damping and less pressure attenuation.”

Oscillatory waveform pressure also behaves differently with varying compliance and resistance. High resistance dampens the waveform and attenuates pressure, whereas low resistance produces less damping and less pressure attenuation. Longer time constants characteristic of high resistance call for lower frequency, resulting in greater pressure transmission, although higher amplitude may still be necessitated. Conversely, low resistance allows for higher frequency. Again, associated lower pressure transmission with higher frequency may be offset by higher pressure transmission due to low resistance. It is important to note that Ra/w increases as flow increases. In order to maintain a given Vt as frequency increases, amplitude must also increase, which, in turn, results in increased flow.

The opposite holds for compliance. Higher oscillatory pressures are transmitted to areas of low compliance (in addition to higher pressure required to ventilate effectively), whereas in areas of high compliance, pressure is rapidly attenuated, although effective ventilation requires a lower pressure. In the presence of low compliance, such as during recruitment, higher frequencies are favourable for two reasons. Firstly, lower compliance results in shorter time constants, and, secondly, the higher pressure transmitted to the distal airways and alveoli may be beneficial in aiding recruitment. A caveat here is that while higher pressure transmission is equal to the critical opening pressure of the lung aids recruitment, pressures above that level may cause barotrauma. As with low resistance, increased pressure attenuation with higher

frequencies may mitigate distal barotrauma.

When considering compliance, one must consider the lungs and the system; oscillatory volume is lost to circuit compliance, and an appropriate low compliance circuit and humidifier should be used. As the water level in the humidifier decreases, system compliance increases. Using an auto-filling humidifier eliminates this problem.

In real life, compliance and resistance do not exist in separate worlds, and lungs and airways rarely are homogeneous in compliance and resistance. Patients may have high airway resistance and high or normal lung compliance or low airway resistance and low compliance. We know that compliance varies between segments of the lung and that airway resistance increases further down the tracheobronchial as diameter decreases. Where resistance and compliance are low lower frequency should be used, whereas where compliance is low, but resistance is normal higher frequency is preferred. What about high resistance coupled with high compliance? Here lower frequency is preferred due to long time constants in both the lung and the airways. Regardless of lung compliance, pressure transmission to the carina is high in the face of high resistance relative to normal/low resistance and must be considered as this may create large airway damage.

“Regardless of lung compliance, pressure transmission to the carina is high in the face of high resistance relative to normal/low resistance and must be considered as this may create large airway damage.”

Mean Airway Pressure (MAP)

Perhaps the most inappropriately used parameter in HFOV is MAP. MAP is required to both maintain conducting airway patency and maintain lung volume above functional residual capacity. If MAP is too low, airways may collapse, particularly during the expiratory phase of HFOV, leading to gas trapping. Insufficient MAP results in lower lung compliance and will require higher amplitude to ventilate, which, in turn, potentiates barotrauma. Over time atelectasis may progress to total lung collapse, respiratory and ventilatory failure. Sequelae of lung collapse are increased pulmonary vascular resistance (PVR) and atelectotrauma. The former impedes blood flow and decreases blood pressure, while the latter triggers an inflammatory cascade. If MAP is too high, the result is also a decrease in compliance and increased PVR. In either scenario, FiO_2 will be increased relative to that of a lung maintained in a proper state of inflation. Regular readers of this column will know I believe that the best FiO_2 is the lowest possible, which, it turns out, coincides with optimal compliance resulting from a proper MAP. With HFOV, MAP is the primary regulator of FiO_2 .

Because the latest ventilators combine CV and HFOV in a single machine, it is possible to superimpose CV breaths on HFOV and a manual inspiration feature that provides a CV breath on demand. The pressure of the CV breaths is independently adjustable. As the lung develops, MAP may not be sufficient to recruit them; it is, therefore, logical to aid their recruitment with an occasional CV or

manual inspiration. Care must be taken here since the open lung approach to HFOV (and HFJV) maintain lung volume above normal FRC and closer to volumes that may precipitate volutrauma. It is my practice to set CV/manual breath pressures at 5 cmH₂O above MAP. This strategy reduces the chance of both volutrauma and barotrauma, and if this setting does not evoke sufficient response, pressure can be increased stepwise until the desired effect is achieved. When superimposing CV breaths on HFOV (HFOV/CMV) CV rate should be set at a minimum. If more CV breaths are required, it probably indicates higher MAP is needed.

“This strategy reduces the chance of both volutrauma and barotrauma, and if this setting does not evoke sufficient response, pressure can be increased stepwise until the desired effect is achieved. When superimposing CV breaths on HFOV (HFOV/CMV) CV rate should be set at a minimum. If more CV breaths are required, it probably indicates higher MAP is needed.”

MAP, I:E Ratio, Frequency and Endotracheal Tube (ETT) Size

Intrapulmonary pressure (IP) is not readily directly measurable. It is the pressure transmitted to the lung by MAP and is the pressure that directly affects PVR and venous return. IP is affected by both the I:E ratio, frequency, and ETT diameter. At an I:E ratio of 1:1, IP is closest to set MAP. Increasing I:E ratio results in a decrease in IP. The increasing frequency and decreasing ETT size also reduce IP, and this is accelerated as either frequency is increased or ETT tube size is decreased. While IP is greatest at an I:E of 1:1, since more pressure is transmitted, the risk of barotrauma is increased. Airway lumen is also decreased in the expiratory phase, which increases time constants hence the risk of gas trapping (at least theoretically), especially as frequency is increased. The deeper trough may exacerbate this in the expiratory phase compared to I:E of 1:2. In practice, I submit that if I:E ratio of 1:1 is required, then another mode of ventilation (particularly HFJV) should be considered.

Frequency, Amplitude and Tidal Volume (Vt)

Vt is the primary determinant of ventilation in HFOV. Unlike conventional ventilation (CV), in which CO₂ removal is determined equally by rate and peak inspiratory pressure, in HFOV, this is relative to rate (frequency) multiplied by the square of Vt as represented by DCO₂, the coefficient of ventilation ($DCO_2 = f \times Vt^2$). Increasing amplitude directly increases Vt and hence CO₂ clearance. Clinicians must be aware that as the amplitude increases, so does the depth of the expiratory trough. Although we do not think about PEEP when using HFOV, it is the pressure at the lowest point on the oscillatory waveform. Airway instability, gas trapping, and atelectasis may result if the trough is too low. This instability must be compensated for by increasing MAP. In clinical practice,

it is very difficult to determine when this is happening until after the fact since we cannot directly measure distal airway pressure. Increased FiO₂ may be the first warning of trouble ahead.

The fixed I:E ratio in HFOV also has implications for Vt. As the frequency is increased, the absolute inspiratory time decreases, as does expiratory time. Since there is less time to deliver volume, Vt will decrease as frequency increases; decreasing frequency has the opposite effect. This relationship must be kept in mind when using first-generation machines such as the Sensormedics 3100A or 3rd generation machines without volume targeting. Time constants lengthen as compliance improves, and frequency should be decreased to reflect this, but the resulting increase in Vt increases ventilation unless amplitude is simultaneously decreased to prevent overventilation.

Ra/w and Gestational Age (GA)

HFOV recommendations are often based on infant weight. However, one study found that GA more than birthweight(4) accurately predicted cricoid ring diameter. Airway diameter increases linearly from 22 weeks GA until eight months post-natal age(5). Since Ra/w is primarily determined by airway radius, it, therefore, increases exponentially with declining GA. This ratio has implications for time constants and choice of frequency.

This is where I have concerns regarding higher frequencies. While tiny babies should be ventilated with small Vt (whether CV or HFOV is used), this may require higher frequencies with 1st generation machines or without volume-targeted ventilation. This strategy may result in gas trapping and, in my opinion, may be one reason evidence to support the superiority of HFOV over CV has traditionally been inconclusive or lacking. Physics dictates that at some point, Ra/w overtakes lung compliance as the major determinant of time constants and choice of frequency whether using HFOV or HFJV.

“Ventilating the tiniest of babies is a delicate dance at the best of times, while the recency at which we have been offering resuscitation to infants <24 weeks GA severely limits evidence upon which to base our ventilation strategies.”

Ventilating the tiniest of babies is a delicate dance at the best of times, while the recency at which we have been offering resuscitation to infants <24 weeks GA severely limits evidence upon which to base our ventilation strategies. To me, the precautionary principle dictates assuming gas trapping exists to a degree (whether globally or regionally) in all micro-premies and ventilating accordingly. Perhaps the nature of HFJV makes it the preferred mode for these babies; indeed, Iowa's outcomes lead credence to this submission. I leave it to clinician-researchers such as Dr. Jane Pillow (whom I have referenced extensively in this column) to provide incontrovertible evidence to guide us.

Volume-targeted HFOV (HFO/VG)

Outside the U.S., HFO/VG has been available on 3rd generation

ventilators for over ten years, and there are now several machines from which to choose. While each machine has its own characteristics, the basic principle is the same; Vt is monitored breath-to-breath, and amplitude is adjusted to maintain an average set Vt.

The ability to control Vt independent of frequency allows clinicians to adjust frequency to match pathology and time constants more closely without worrying about Vt increasing or decreasing. Since the square of Vt times frequency determines DCO₂, small increases in Vt result in much more CO₂ clearance than increasing frequency. In practice, this may result in maintaining adequate ventilation at a lower frequency with less amplitude. In theory, this should reduce gas trapping (should it be present) and may be beneficial for tiny babies.

Like HFOV without using VG, MAP, frequency, and amplitude are set according to patient needs. While frequency is fixed, the amplitude is automatically adjusted to maintain Vt and set amplitude functions as a maximum limit. Should Vt not be reached at this limit, the machine will alarm. Clinicians are cautioned to avoid a “set it and forget it” approach to HFO/VG, and I strongly recommend setting amplitude at 5 cmH₂O above the average used by the machine. Allowing the machine too much latitude will fail to alert the clinician if compliance decreases or if suctioning is required. It is important to note that whether using HFOV or HFO/VG, even a small buildup of secretions in the ETT greatly reduces ventilation. The person suctioning may report removing scant or no secretions; however, if amplitude required to achieve set Vt decreases after suctioning, the need to have done so is self-evident.

As with VG in CV, Vt in HFO/VG is set according to weight and is adjustable in 0.1 ml increments. While volumes of 1-2 ml/kg are usually adequate, more may be required. Vt is measured proximately and how much of it is actually delivered to the lung is not directly measurable at the bedside, but it stands to reason as Vt increases, the lung protectiveness of HFOV is decreased. My personal practice is to limit Vt to 2.5 ml/kg, although I have used 3 ml/kg briefly as required, provided amplitude is not too high. (Please note my patients are primarily micro-prems). If high Vt is consistently needed after optimizing frequency and MAP, I will switch to HFJV.

“As with any device, Vt delivered by the machine is subject to a margin of error. Nevertheless, using HFO/VG will adjust to changing compliance and Ra/w to provide relatively consistent volumes. This physiology is particularly advantageous during lung recruitment and after surfactant administration, as it prevents inadvertent overventilation as compliance improves.”

As with any device, Vt delivered by the machine is subject to a margin of error. Nevertheless, using HFO/VG will adjust to chang-

ing compliance and Ra/w to provide relatively consistent volumes. This physiology is particularly advantageous during lung recruitment and after surfactant administration, as it prevents inadvertent overventilation as compliance improves. A bench study compared the Sensormedics 3100A, SLE 5000, Drager Babylog VN500, Leoni 8000 +, and the Fabian. (The latter three machines are equipped to provide HFO/VG). Tests were conducted using 5, 10, and 15 Hz.

All 3 HFO/VG capable machines were able to maintain a Vt of 1 ml at 15 Hz under varying test conditions but could not maintain a Vt of 4 ml at the same frequency. The testing was done with a humidifier in line, but it was dry and unheated. I suspect the added compliance of the empty humidifier likely had a greater effect at higher volumes as these machines have limited power available, considerably less than the Sensormedics 3100A and the SLE 5000. At lower frequencies, delivered Vt was higher than indicated at the 1 ml setting(6), and clinicians should be aware of this when ventilating tiny babies. With larger babies, it may be necessary to decrease the frequency with or without VG to achieve adequate Vt.

The HFO/VG adjunct on the Drager Babylog VN500 has had FDA approval pending for quite some time. American clinicians accustomed to using the Sensormedics 3100A must be aware of differences between it and the VN500 once the latter is available. Most notable is that the VN500 (and the other 3 HFO/VG capable machines tested) delivered lower Vt than the 3100A at the same settings, and delivered Vt also varied between the 4(6). In practice, the response should dictate settings, and clinicians should not expect identical performance with different machines.

Hard evidence supporting HFO/VG over standard HFOV is lacking; however, it should, at least in theory, be beneficial, particularly in tiny babies. It is vitally important to understand how the mode works and the difference between the two modes to utilize HFO/VG to its best advantage.

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A Call to Action & Open Invitation

Cody Miller Pyke, JD, LLM, MSBe

The National Perinatal Association (NPA) is an interdisciplinary organization that strives to be a leading voice for perinatal care in the United States. Our diverse membership is comprised of healthcare providers, parents & caregivers, educators, and service providers, all driven by their desire to give voice to and support babies and families at risk across the country.

Members of the NPA write a regular peer-reviewed column in *Neonatology Today*.



“In an oversimplified way, equality in health care can be understood as applying the same standard of care to all patients regardless of their demographics. However, true health equity seeks to improve the health of disproportionately affected minority groups to the same level as the majority.”

“Equity” and “Justice” are not ordinarily the first two words that come to mind when one thinks about the practice of perinatology. However, during the global SARS-CoV-2 (COVID-19) pandemic—wherein African Americans, Native Americans, and LatinX people face disproportionately greater mortality, morbidity, and financial harm than Whites (1)—these two words are at the forefront of public consciousness in the United States. “Equity” should not be misunderstood as “equality.” The latter term speaks to providing equal (i.e., “identical”) support to diverse individuals, *regardless* of their different levels of need. The former instead seeks to provide whatever amount of support is necessary to each community in order for all communities to have their needs met. In an oversimplified way, equality in health care can be understood as applying the same standard of care to all patients regardless of their demographics. However, true health *equity* seeks to improve the health of disproportionately affected minority groups to the same level as the majority.

“Early studies of the impacts of the COVID-19 pandemic on maternal and infant health have revealed troubling realities.”

Issues of equity and justice in maternal and infant health are not novel, (2) and, in fact, go back to (and arguably persist from) the practice of chattel slavery in the United States. (3) Early studies of the impacts of the COVID-19 pandemic on maternal and infant health have revealed troubling realities. A scoping review published in *Reproductive Health* of 97 peer-reviewed publications on the pandemic’s effects on perinatal health found, *inter alia*, evidence of significantly reduced access to antenatal and postnatal health services, increased mental health illness among pregnant people and new gestational parents who recently delivered, widely variable and inconsistent guidance on pregnancy

and breastfeeding during the pandemic, increased incidence of C-sections likely attributable to more aggressive management of pregnancy, increased domestic violence, and disproportionate rates of loss of employment. (4)

The COVID-19 pandemic has undoubtedly put maternal and infant health under a critical lens. So when I had the privilege of being named one of the co-chairs for the National Perinatal Association (NPA) annual conference for 2021—along with my colleague, Dr. Tiffany Willis—we knew immediately what the theme of this conference must be: Perinatal Care at the Intersection of Health Equity and Social Justice. NPA believes that *everyone* has the right to high-quality, respectful perinatal care. We also acknowledge the unfortunate reality that in the United States, the health care community has failed to deliver equitable care to people of diverse socioeconomic backgrounds. As an organization, our core goals are to educate professionals and communities, advocate for patients and families, and integrate best practices across perinatal care by fostering interdisciplinary collaboration. In accordance with these core goals, NPA’s 2021 conference will bring together a diverse body of speakers to educate, advocate, and integrate on behalf of the diverse bodies and communities we serve as perinatal health professionals. The 2021 Conference will be held over three days, from December 1 to December 3, 2021, in Aurora, Colorado, U.S.A. The conference will be a time to critically examine and discuss not only the nuances of clinical care for pregnant patients and neonates but also our own biases and the health infrastructures that lead to disparate outcomes. It will be a time to commit (or, for many, recommit) to a call to action—that perinatology as a field ensures every pregnancy, every baby, and every parent receives trauma-informed, family-centered, and equitable care.



Amidst the pandemic, it can be tempting to maintain the status quo to avoid adding additional strains to an already stressful and uncertain time. However, while COVID-19 is new, the issues of inequity and injustice in maternal and infant health are not. We cannot afford to wait for the pandemic to subside or, worse, wait for another pandemic to motivate us into action. Therefore, Dr. Willis and I invite you to attend the National Perinatal Association's 2021 Annual Conference. Both in-person and remote options are available at this time, and we are closely monitoring Centers for Disease Control and local health authority guidelines regarding best practices to ensure safety for attendees and presenters. We encourage academic poster submissions by professionals, trainees, and students alike and look forward to seeing you—even if on a computer screen—very soon.

“Therefore, Dr. Willis and I invite you to attend the National Perinatal Association’s 2021 Annual Conference. Both in-person and remote options are available at this time, and we are closely monitoring Centers for Disease Control and local health authority guidelines regarding best practices to ensure safety for attendees and presenters.”

Respectfully,

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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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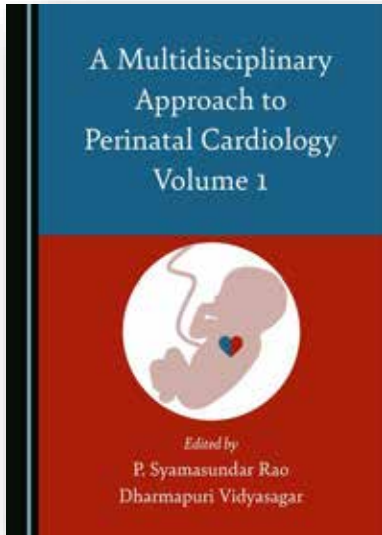


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Book Description

Recent developments in diagnostic and therapeutic aspects of cardiac and neonatal issues have advanced the care of the newborn. To achieve excellence in cardiac care, however, close interaction and collaboration of the pediatric cardiologists with neonatologists, pediatricians, general/family practitioners (who care for children), anesthesiologists, cardiac surgeons, pediatric cardiac intensivists, and other subspecialty pediatricians is mandatory. This book provides the reader with up-to-date evidence-based information in three major areas of neonatology and prenatal and neonatal cardiology. First, it provides an overview of advances in the disciplines of neonatology, prenatal and neonatal cardiology, and neonatal cardiac surgery in making early diagnosis and offering treatment options. Secondly, it presents a multidisciplinary approach to managing infants with congenital heart defects. Finally, it provides evidence-based therapeutic approaches to successfully treat the fetus and the newborn with important neonatal issues and congenital cardiac lesions. This first volume specifically explores issues related to perinatal circulation, the fetus, ethics, changes in oxygen saturations at birth, and pulse oximetry screening, diagnosis, and management.

About the Editors

Dr P. Syamasundar Rao, MD, DCH, FAAP, FACC, FSCAI, is Professor of Pediatrics and Medicine and Emeritus Chief of Pediatric Cardiology at the University of Texas-Houston Medical School. He received his medical degree from Andhra Medical College, India, and subsequently received post-graduate training both in India and the USA before joining the faculty at the Medical College of Georgia, USA, in 1972. He has also served as Chairman of Pediatrics at King Faisal Specialist Hospital and Research Center, Saudi Arabia, and Professor and Director of the Division of Pediatric Cardiology at the University of Wisconsin and St. Louis University, USA. He has authored 400 papers, 16 books and 150 book chapters, and is a recipient of numerous honors and awards.

Dr Dharmapuri Vidyasagar, MD, MSc, FAAP, FCCM, PhD (Hon), is currently Professor Emeritus in Pediatrics at the University of Illinois, Chicago, where he served as Professor of Pediatrics for four decades. He is a graduate of Osmania Medical College, India. He has published over 250 papers and authored several books with a focus on prematurity, neonatal pulmonary diseases and neonatal ventilation. His goal is to reduce neonatal mortality in the USA and around the world, and he has received multiple awards and honors including the Ellis Island Award.

A Multidisciplinary Approach to Perinatal Cardiology Volume 1 is available now in Hardback from the Cambridge Scholars [website](#), where you can also access a free [30-page sample](#).



Online L&D Staff Education Program

Caring for Pregnant Patients & Their Families: Providing Psychosocial Support During Pregnancy, Labor and Delivery

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Continuing education credits provided by



About the Program

- **WHO SHOULD TAKE THE PROGRAM?** This program is designed for both office and hospital staff in all disciplines that interact with pregnant patients and their families. A key focus is recognizing risk factors for perinatal mood and anxiety disorders, and mitigating their impact through provision of trauma-informed care.
- **WHY TAKE THE PROGRAM?** Families will benefit when staff have improved skills, through enhanced parental resilience and better mental health, and improved parent-baby bonding leading to better developmental outcomes for babies. Benefits to staff include improved skills in communicating with patients; improved teamwork, engagement and staff morale; reduced burnout, and reduced staff turnover.
- **HOW DOES THE PROGRAM ACHIEVE ITS GOALS?** Program content is representative of best practices, engaging and story-driven, resource-rich, and developed by a unique interprofessional collaboration of obstetric and neonatal professionals and patients. The program presents practical tips and an abundance of clinical information that together provide solutions to the emotional needs of expectant and new parents.
- **HOW WAS THE PROGRAM DEVELOPED?** This program was developed through collaboration among three organizations: a multidisciplinary group of professionals from the National Perinatal Association and Patient + Family Care, and parents from the NICU Parent Network. The six courses represent the different stages of pregnancy (antepartum, intrapartum, postpartum), as well as perinatal mood and anxiety disorders, communication techniques, and staff support.

Program Objectives

- Describe principles of trauma-informed care as standards underlying all communication during provision of maternity care in both inpatient and outpatient settings.
- Identify risk factors, signs, and symptoms of perinatal mood and anxiety disorders; describe treatment options.
- Define ways to support pregnant patients with high-risk conditions during the antepartum period.
- Describe obstetric violence, including ways that providers may contribute to a patient's experience of maternity care as being traumatic; equally describe ways providers can mitigate obstetric trauma.
- Describe the importance of providing psychosocial support to women and their families in times of pregnancy loss and fetal and infant death.
- Define the Fourth Trimester, and identify the key areas for providing psychosocial support to women during the postpartum period.
- Identify signs and symptoms of burnout as well as their ill effects, and describe both individual and systemic methods for reducing burnout in maternity care staff.

Continuing education credits will be provided for physicians, clinic and bedside nurses, social workers, psychologists, and licensed marriage and family therapists. CEUs will be provided by Perinatal Advisory Council: Leadership, Advocacy, and Consultation.

PROGRAM CONTENT



COMMUNICATION SKILLS CEUs offered: 1

Learn principles of trauma-informed care, use of universal precautions, how to support LGBTQ patients, obtaining informed consent, engaging in joint decision-making, delivering bad news, dealing with challenging patients.

Faculty: Amina White, MD, MA, Clinical Associate Professor, Department of OB/Gyn, University of North Carolina, Chapel Hill, NC; Sue Hall, MD, MSW, FAAP, St. John's Regional Medical Center, Oxnard, CA; Karen Saxer, CNM, MSN, University of North Carolina Maternal-Fetal Medicine, UNC Women's Hospital, Chapel Hill, NC; Tracy Pella, Co-Founder & President, Connected Forever, Tecumseh, NE.



PERINATAL MOOD AND ANXIETY DISORDERS CEUs offered: 1

Identify risk factors for and differential diagnosis of PMADs (perinatal mood and anxiety disorders), particularly perinatal depression and/or anxiety and posttraumatic stress syndrome. Learn the adverse effects of maternal depression on infant and child development, and the importance of screening for and treating PMADs.

Faculty: Linda Baker, PsyD, psychologist at Unstuck Therapy, LLC, Denver, CO; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Angela Davids, Founder of Keep 'Em Cookin', Baltimore, MD; Brittany Boet, Founder of Bryce's NICU Project, San Antonio, TX.



PROVIDING ANTEPARTUM SUPPORT CEUs offered: 1

Identify psychosocial challenges facing high risk OB patients, and define how to provide support for them, whether they are inpatient or outpatient. Recognize when palliative care is a reasonable option to present to pregnant patients and their families.

Faculty: Amina White, MD, MA, Clinical Associate Professor, Department of OB/Gyn, University of North Carolina, Chapel Hill, NC; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Angela Davids, Founder of Keep 'Em Cookin', Baltimore, MD; Erin Thatcher, BA, Founder and Executive Director of The PPRM Foundation, Denver, CO.



PROVIDING INTRAPARTUM SUPPORT CEUs offered: 1

Describe how to manage patient expectations for labor and delivery including pain management; identify examples of obstetric violence, including identification of provider factors that may increase patients' experience of trauma; learn how to mitigate patients' trauma, and how to provide support during the process of labor and delivery.

Faculty: Sara Detlefs, MD, Fellow in Maternal-Fetal Medicine, Baylor College of Medicine, Houston, TX; Jerry Ballas, MD, MPH, Associate Clinical Professor, UCSD Health System, Maternal-Fetal Medicine, Department of Obstetrics, Gynecology and Reproductive Sciences, University of California at San Diego, San Diego, CA; MaryLou Martin, MSN, RNC-NIC, CKC, Women's and Children's Services Nurse Educator, McLeod Regional Medical Center, McLeod, SC; Claire Hartman, RN, IBCLC, Labor & Delivery, University of North Carolina Hospital, Chapel Hill, NC; Crystal Duffy, Author of Twin To Twin (from High Risk Pregnancy to Happy Family), and NICU Parent Advisor, Houston, TX; Erin Thatcher, Founder and Executive Director of The PPRM Foundation, Denver, CO.



PROVIDING POSTPARTUM SUPPORT CEUs offered: 1

Define the 4th Trimester and the importance of follow-up especially for high risk and minority patients, learn to recognize risk factors for traumatic birth experience and how to discuss patients' experiences postpartum; describe the application of trauma-informed care during this period, including support for patients who are breastfeeding and those whose babies don't get to go home with them.

Faculty: Amanda Brown, CNM, University of North Carolina Hospital, Chapel Hill, NC; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Crystal Duffy, Author of Twin To Twin (from High Risk Pregnancy to Happy Family), and NICU Parent Advisor, Houston, TX.



SUPPORTING STAFF AS THEY SUPPORT FAMILIES CEUs offered: 1

Define burnout and compassion fatigue; identify the risks of secondary traumatic stress syndrome to obstetric staff; describe adverse impacts of bullying among staff; identify the importance of both work-life balance and staff support.

Faculty: Cheryl Milford, EdS, Consulting NICU and Developmental Psychologist, Director of Development, National Perinatal Association, Huntington Beach, CA; Sue Hall, MD, MSW, FAAP, neonatologist at St. John's Regional Medical Center, Oxnard, CA; Erin Thatcher, BA, Founder and Executive Director, The PPRM Foundation, Denver, CO

Cost

- RNs: \$10/CEU; \$60 for the full program
- Physicians, licensed clinical social workers (LCSWs), licensed marriage and family therapists (LMFTs): \$35/CEU; \$210 for the full program
- Although PACLAC cannot award CEs for certified nurse midwives, they can submit certificates to their own professional organization to request credit. \$35/CEU; \$210 for the full program

Contact help@myperinatalnetwork.org to learn more.

Faculty

Linda Baker, PsyD

Psychologist at Unstuck Therapy, LLC, Denver, CO.

Jerasimos (Jerry) Ballas, MD, MPH

Associate Clinical Professor, UCSD Health System, Maternal-Fetal Medicine, Department of Obstetrics, Gynecology and Reproductive Sciences, University of California at San Diego, San Diego, CA.

Amanda Brown, CNM, MSN, MPH

University of North Carolina-Chapel Hill Hospitals, Chapel Hill, NC.

Sara Detlefs, MD

Fellow in Maternal-Fetal Medicine, Baylor College of Medicine, Houston, TX.

Sue L. Hall, MD, MSW, FAAP

Neonatologist, Ventura, CA.

Claire Hartman, RN, IBCLC

Labor & Delivery, University of North Carolina Hospital, Chapel Hill, NC.

MaryLou Martin, MSN, RNC-NIC, CKC

Women's and Children's Services Nurse Educator, McLeod Regional Medical Center, McLeod, SC.

Cheryl Milford, EdS.

Former NICU and Developmental psychologist, in memoriam.

Karen Saxer, CNM, MSN

University of North Carolina Maternal-Fetal Medicine, UNC Women's Hospital, Chapel Hill, NC.

Amina White, MD, MA

Clinical Associate Professor, Department of Obstetrics and Gynecology, University of North Carolina, Chapel Hill, NC.

Parent/Patient Contributors:**Brittany Boet**

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

Angela Davids

Founder, Keep 'Em Cookin', Baltimore, MD.

Crystal Duffy

Author of Twin To Twin (from High Risk Pregnancy to Happy Family), and NICU Parent Advisor, Houston, TX.

Tracy Pella, MA

Co-Founder and President, Connected Forever, Tecumseh, NE.

Erin Thatcher, BA

Founder and Executive Director, The PPROM Foundation, Denver, CO.

CANCELLATIONS AND REFUNDS

For Individual Subscribers:

- If you elect to take only one course, there will be no cancellations or refunds after you have started the course.
- If you elect to take more than one course and pay in advance, there will be no cancellations or refunds after payment has been made unless a written request is sent to help@myperinatalnetwork.com and individually approved.

For Institutional Subscribers:

- After we are in possession of a signed contract by an authorized agent of the hospital and the program fees have been paid, a 50% refund of the amount paid will be given if we are in receipt of a written request to cancel at least 14 (fourteen) days prior to the scheduled start date for your hospital's online program.
- Refunds will not be given for staff members who neglect to start the program. Also, no refunds for those who start the program, but do not complete all 6 courses within the time frame allotted.

For Physicians: This activity has been planned and implemented in accordance with the Institute for Medical Quality and the California Medical Association's CME Accreditation Standards (IMQ/CMA) through the Joint Provisership of the Perinatal Advisory Council: Leadership, Advocacy and Consultation (PAC/LAC) and the National Perinatal Association. PAC/LAC is accredited by the Institute for Medical Quality/California Medical Association (IMQ/CMA) to provide continuing education for physicians. PAC/LAC takes responsibility for the content, quality and scientific integrity of this CME activity. PAC/LAC designates this activity for a maximum of 6 *AMA PRA Category 1 Credit(s)™*. Physicians should only claim credit commensurate with the extent of their participation in the activity. This credit may also be applied to the *CMA Certification in Continuing Medical Education*.

For Nurses: The Perinatal Advisory Council: Leadership, Advocacy and Consultation (PAC/LAC) is an approved provider by the California Board of Registered Nursing Provider CEP 5862. When taken as a whole, this program is approved for 7 contact hours of continuing education credit.

For CAMFT: Perinatal Advisory Council: Leadership, Advocacy, and Consultation (PAC/LAC) is approved by the California Association of Marriage and Family Therapists to sponsor continuing education for LMFTs and LCSWs. CE Provider #128542. PAC/LAC maintains responsibility for the program and its content. Program meets the qualifications for 6 hours of continuing education credit for LMFTs and LCSWs as required by the California Board of Behavioral Sciences. You can reach us at help@myperinatalnetwork.org.

Follow us online at [@MyNICUNetwork](https://www.instagram.com/MyNICUNetwork)

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



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TAKE THE NECESSARY STEPS TO
ELIMINATE INEQUITIES

- Make **health equity** and **implicit bias** training mandatory.
- Prioritize health + racial equity as a goal.
- Communicate with parents using **plain language**.
- Partner with **Black parents** to deliver bias free care.
- Hire, retain, or partner with **Black Premie family support groups + professionals** to fill diversity gaps.
- Make **digital + virtual resources** available.
- Encourage **reading to Premie babies** while bedside.



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

Take precautions & LIMIT INTERACTIONS.

6 FT

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

Keep prenatal **APPOINTMENTS.**

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

LEARN MORE ▶

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

NATIONAL PERINATAL ASSOCIATION

Update: **CORONAVIRUS COVID-19**



According to the CDC
Breast milk provides protection against many illnesses.

KEEP GIVING YOUR BABY YOUR MILK even if you're sick.

THERE ARE RARE EXCEPTIONS. ASK YOUR HEALTHCARE TEAM.



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SHARED DECISION-MAKING PROTECTS MOTHERS + INFANTS

DURING COVID-19

KEEPING MOTHERS + INFANTS TOGETHER

Means balancing
the risks of...

- **HORIZONTAL INFECTION**
- **SEPARATION AND TRAUMA**



EVIDENCE

We encourage families and clinicians to remain diligent in learning **up-to-date evidence**.

PARTNERSHIP

What is the best
for this unique dyad?

SHARED DECISION-MAKING

- S**EEK PARTICIPATION
- H**ELP EXPLORE OPTIONS
- A**SSESS PREFERENCES
- R**EACH A DECISION
- E**VALUATE THE DECISION



TRAUMA-INFORMED

Both parents and providers
are confronting significant...

- **FEAR**
- **GRIEF**
- **UNCERTAINTY**

LONGITUDINAL DATA

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

- **MENTAL HEALTH**
- **POSTPARTUM CARE DELIVERY**



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

Partnering for patient-centered care
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National
Association of
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Nurses



Coping with COVID-19



A viral pandemic

A racial pandemic within a viral pandemic



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- Helping Children and Families Cope
- Bonding with Your Baby
- Caregivers Need Care Too



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Putting a Stop to Surprise Medical Bills for New Parents

Michelle Winokur, DrPH, and the AfPA Governmental Affairs Team, Alliance for Patient Access (AfPA)

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.



“New parents experience a lot of surprises – their baby’s hair color or eye shape, perhaps even the gender. Many parents can also add unexpected medical bills to that list.”

New parents experience a lot of surprises – their baby’s hair color or eye shape, perhaps even the gender. Many parents can also add unexpected medical bills to that list.

According to a recently published study, as many as one in five deliveries could lead to a surprise medical bill. (1) These unexpected bills result from the care provided by an “out-of-network clinician or ancillary service provider.” Examples include laboratory, radiology, and anesthesiologist services, durable medical equipment, and ambulance transportation.

The study reports that the average surprise bill is \$750, with one-third of families unexpectedly on the hook for more than \$2,000. Charges relate to the delivery, newborn hospitalization, or both.

Surprise Billing Ban

Now, the Biden administration is poised to put a stop to surprise billing.

Last month, the Health and Human Services, Labor, and Treasury departments released an interim final rule that bans the practice effective July 1, 2022. (2) The rule puts into effect the law Congress passed on surprise billing in December 2020.

First and foremost, the rule prohibits what is known as “balance billing.”

When patients are seen by providers or at facilities outside their health plan’s network, the insurance company usually pays a portion of the bill, then leaves the balance to the patient. This is where the term “balance billing” originated.

The practice has also become known as “surprise billing” since patients do not expect to receive the bill. In many cases, patients are unaware that an out-of-network provider provided their care. Furthermore, the expense can be much higher than the co-pay or co-insurance a patient would expect to pay for in-network service.

The federal rule also limits certain out-of-network charges and specifies that all emergency services, including air ambulance services, must be treated as in-network. The change applies to patients whose insurance is sponsored by their employer or was purchased through the individual market.

“The federal rule also limits certain out-of-network charges and specifies that all emergency services, including air ambulance services, must be treated as in-network. The change applies to patients whose insurance is sponsored by their employer or was purchased through the individual market.”

Deviating from the Anticipated Plan of Care

Patients often find themselves with unexpected bills when medical services are rendered outside of their anticipated plan of care. At one of the first prenatal appointments, most expectant moms are provided with a summary of medical services that they and their baby will receive through a routine delivery and postpartum stay at the hospital. The patient’s financial responsibility and share of the cost paid by insurance for each item are also listed.

If a medical complication causes the expectant mom to be rushed to an emergency room, for example, it is possible that the ambulance she rode in, the hospital she was taken to, and the emergency room physician who treated her were all out of network.

It would be impractical for the patient to confirm the network status

of each entity before they helped her. Regardless, she will likely end up with a surprise bill, even though she has insurance.

As Health and Human Services Secretary Xavier Becerra said, “Health insurance should offer patients peace of mind that they won’t be saddled with unexpected costs.” (3) And if there is anything new parents do not need, it is unexpected expenses.

“As Health and Human Services Secretary Xavier Becerra said, “Health insurance should offer patients peace of mind that they won’t be saddled with unexpected costs.” (3) And if there is anything new parents do not need, it is unexpected expenses.”

References:

- <https://www.fiercehealthcare.com/hospitals/nearly-1-5-deliveries-could-lead-to-a-surprise-medical-bill-study-findthethes>
- <https://www.fiercehealthcare.com/payer/biden-admin-releases-first-interim-final-rule-to-ban-surprise-medical-bills-sets>
- <https://www.hhs.gov/about/news/2021/07/01/hhs-announces-rule-to-protect-consumers-from-surprise-medical-bills.html>

Disclosures: Michelle Winokur, DrPH, is the Policy Communications Director for the Alliance for Patient Access.

NT

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Still a Premie?




Some preemies are born months early, at extremely low birthweights. They fight for each breath and face nearly insurmountable health obstacles.

But that’s not every preemie’s story.


Born between 34 and 36 weeks’ gestation?

STILL A PREMIE

Just like preemies born much earlier, these “late preterm” infants can face:

And their parents, like all parents of preemies, are at **risk for postpartum depression and PTSD.**




Born preterm at a “normal” weight?

STILL A PREMIE

Though these babies look healthy, they can still have complications and require NICU care.

But because some health plans determine coverage based on a preemie’s weight, **families of babies that weigh more may face access barriers and unmanageable medical bills.**

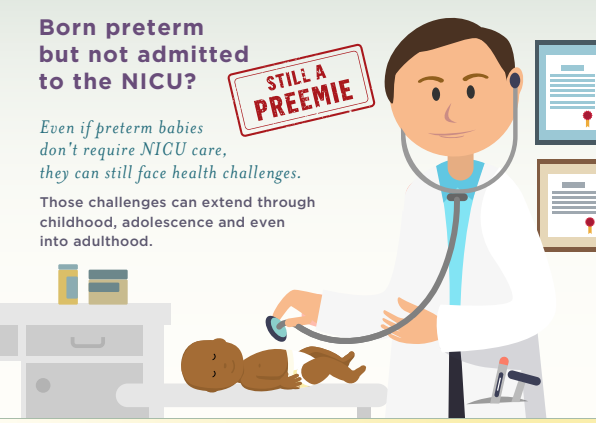


Born preterm but not admitted to the NICU?




STILL A PREMIE

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




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




Some Premies

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

All Premies

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



NCJIH National Coalition for Infant Health
Protecting Access for Premature Infants through Age Two
www.infanthealth.org



DID YOU KNOW?
 Postpartum
 depression
 affects
10%
 of fathers

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Keeping Your Baby Safe

during the COVID-19 pandemic

How to protect your little one from germs and viruses

Even though there are some things we don't know about COVID-19 yet, there are many more things that we do know. We know that there are proven protective measures that we can take to stay healthy.

Here's what you can do...

Wash Your Hands

- This is the single, most important thing you can do to stop the spread of viruses.
- Use soap.
- Wash for more than 20 seconds.
- Use alcohol-based sanitizers.



Limit Contact with Others

- Stay home when you can.
- Stay 6 feet apart when out.
- Wear a face mask when out.
- Change your clothes when you get home.
- Tell others what you're doing to stay safe.



Provide Protective Immunity

- Hold baby skin-to-skin.
- Give them your breast milk.
- Stay current with your family's immunizations.



Take Care of Yourself

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



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



WARNING

Never Put a Mask on Your Baby

- Because babies have smaller airways, a mask makes it hard for them to breathe.
- Masks pose a risk of strangulation and suffocation.
- A baby can't remove their mask if they're suffocating.



If you are positive for COVID-19

- Wash with soap and water and put on fresh clothes before holding or feeding your baby.
- Wear a mask to help stop the virus from spreading.
- Watch out for symptoms like fever, confusion, or trouble breathing.
- Ask for help caring for your baby and yourself while you recover.



We can help protect each other.

[Learn more](#)

www.nationalperinatal.org/COVID-19



The Gap Baby: An RSV Story



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



The National Coalition for Infant Health advocates for:

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

www.infanthealth.org

I CAN Digitally Involved (I CANDI): Supporting Involvement of Children in Research

Amy Ohmer



“With the end of summer quickly approaching, we have been busy at work with the week-long International Children’s Advisory Network, Inc. (iCAN) Virtual 2021 Summit, held in July.”

With the end of summer quickly approaching, we have been busy at work with the week-long International Children’s Advisory Network, Inc. (iCAN) Virtual 2021 Summit, held in July. If you missed this year’s sessions, we invite you to watch the exciting learning sessions at <https://www.icanresearch.org/2021-summit>. Additionally, iCAN is happy to announce the unveiling of the next learning module for kids, families, and the community shared through the newly announced video and educational series of Pediatric Clinical Research Trials at <https://www.icanresearch.org/ican-curriculum>. iCAN continues to help support the pediatric voice by sending youth members to share their experiences at the FDA and through collaborative partnerships with MRCT, PFMD, and AIMed. All recordings may be found of our youth member sessions sharing support of medical device wear, insight to health conditions, and more on <https://www.icanresearch.org/videos>.

Coming up this fall, iCAN’s Director, Amy Ohmer, will partner once again with Theresa Shalaby, Senior Regulatory Services Manager, Functional Plain Language Summaries, Synchrogenix, a Certara Company, to share in support for how to involve young people throughout the lay summary review. Certara, the global leader in biosimulation, will host the inaugural New Horizons in Pediatric Drug Development Symposium on October 28-29, 2021. The two-day virtual symposium is being held to bring together thought leaders and innovators in pediatric drug development to share new developments in the field and collaborate on new ideas to advance pediatric drug development into a new era.

See us at the American Academy of Pediatrics (AAP) NCE from October 8th - 12th, 2021, in Philadelphia, Pennsylvania. iCAN will be in Booth #563, conveniently located near the refreshments area. We hope to see everyone there as we will be sharing a new youth-led research project and our partner, Hope for Henry.

As a reminder, if any interested kids are not involved in an iCAN chapter but would like to participate, iCAN offers a Virtual Chapter to accommodate any child, anywhere in the world. There is no

“The two-day virtual symposium is being held to bring together thought leaders and innovators in pediatric drug development to share new developments in the field and collaborate on new ideas to advance pediatric drug development into a new era.”

cost to create a chapter or for a child to participate, as iCAN is supported through sponsoring partnerships. Starting a chapter is free and easy, as iCAN helps each group get started and up and running. If you would like to sponsor a child, a chapter, or our summit, please contact us by email at info@icanresearch.org or visit www.icanresearch.org

In 2022, for the second week of July, iCAN and their KIDS France Chapter will be hosting the 8th Annual iCAN Summit, June 11th - June 15th, 2022. iCAN will offer an interactive series of in-person sessions at the University of Lyon, France, to support learnings through the pediatric patient perspective and industry learnings on innovation, science, and pediatric research. Children from ages 8-18 will meet with stakeholders to share their knowledge and expertise as kids, many of whom live with rare, complicated, and

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OPIOIDS and NAS

When reporting on mothers, babies, and substance use

LANGUAGE MATTERS



I am not an addict.

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



I was exposed to opioids.

While I was in the womb my mother and I shared a blood supply. I was exposed to the medications and substances she used. I may have become physiologically dependent on some of those substances.



NAS is a temporary and treatable condition.

There are evidence-based pharmacological and non-pharmacological treatments for Neonatal Abstinence Syndrome.



My mother may have a SUD.

She might be receiving Medication-Assisted Treatment (MAT). My NAS may be a side effect of her appropriate medical care. It is not evidence of abuse or mistreatment.



My potential is limitless.

I am so much more than my NAS diagnosis. My drug exposure will not determine my long-term outcomes. But how you treat me will. When you invest in my family's health and wellbeing by supporting Medicaid and Early Childhood Education you can expect that I will do as well as any of my peers!

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



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Really Serious Virus

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Coughing that gets worse and worse



Breathing that causes their ribcage to "cave-in"

Rapid breathing and wheezing



Bluish skin, lips, or fingertips

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

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If your baby isn't breathing call 911.



Thick yellow, green, or grey mucus



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

Fever that is higher than 101° Fahrenheit



which is especially dangerous for babies younger than 3 months

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flu

coronavirus

pertussis

RSV



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USE AN ALCOHOL-BASED HAND SANITIZER.



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High-Reliability Organizing (HRO), Decision Making, the OODA Loop, and COVID-19

Daved van Stralen, MD, FAAP, Thomas A. Mercer, RAdm, USN

Abstract:

Organizations do not make decisions; people do. The entropy of any system moves toward disorder of its elements and the corruption of information as it is transmitted. This flux creates uncertainty. As we gain additional information, we find that the property of monotonicity from classical logic and scientific reasoning does not allow us to change our conclusions. We must engage with these situations without a developed plan or even without a plan. Reciprocal decision-making describes how we act, observe the response to our action, and how that response guides our next action. Decision-making with reciprocal feedback keeps the operator close to events, generates information, identifies relevance, and gives meaning to information. This is an active method for generating information, creating structure, and identifying the boundaries of performance. John Boyd's OODA loop is a cycle for rapid, real-time interactive hypothesis development and testing. This is not decision-making independent of others or the organization. The Orient function of Boyd's OODA loop integrates the individual, situation, and organization through culture.

“Organizations do not make decisions; people do. People do not make errors; the decision does not fit the situation. Failure is not an option; failure is the option that drives engagement.”

Introduction

Organizations do not make decisions; people do. People do not make errors; the decision does not fit the situation. Failure is not an option; failure is the option that drives engagement.

Operational interpretations of these terms have become washed out for management, planning, and conceptual tractability. Decision, error, and failure have shifted from the concreteness and the continuation necessary for actual-world operations to the abstractions and concepts favored by academicians and spectators. “The advantage of confining attention to a definite group of abstractions is that you confine your thoughts to clear-cut definite things, with clear-cut definite relations,” Alfred North Whitehead (1). Once defined, the definition becomes the object.

The privileged role that abstractions, concepts, and cognition have in the organization tacitly corrupts processing information. Operators continuously develop information from threats, and information fluctuates within the changing environment. “Clear-cut

definite things, with clear-cut definite relations” do not help make decisions during uncertainty, ambiguity, and threat. Problems arise when our knowledge does not fit our definitions or the situation. We can engage while learning by doing or retreat, identify best practices, and find appropriate rules.

“Science does not press analysis too far beyond the surface of reality into the detailed specifics of life, remaining instead in the world of probabilities, common denominators, concepts, models, and abstractions (2, 3).”

Science does not press analysis too far beyond the surface of reality into the detailed specifics of life, remaining instead in the world of probabilities, common denominators, concepts, models, and abstractions (2, 3). “Thought deals thus solely with surfaces. It can name the thickness of reality, but it cannot fathom it, and its insufficiency here is essential and permanent, not temporary,” William James (4). Abstract generalities are not expert systems (3-5). Real-life problems are specific and concrete, to be dealt with on their own terms with commonsense problem solving, action, and interaction, experiencing the problem directly in the realm of expertise (3, 4, 6, 7). “Thinking begins first with suggestive but defective plans and images, that are slowly (if ever) refined and replaced by better ones,” Marvin Minsky (8).

HROs developed from operations that rapidly “refined and replaced better ones.” These are rapidly changing and evolving regions that exist or develop between the rules (protocols, algorithms), when rules (policies) do not apply, or when rules conflict or compete (9). This is where HRO operates. Describing operations for this region means that HRO does not function in opposition to any program. The HRO approach neatly, quietly fits within the organization.

We must not forget that the language of HRO, reliability, and safety is built from interactive decisions and engaged sensemaking. The *function* of decision-making and sensemaking is to maneuver through changing events while bringing those events to resolution. Error is a product of decision-making under uncertainty (10). Failure is to quit too soon.

Decision-making with reciprocal feedback keeps the operator close to events, generates information, identifies relevance, and gives meaning. The experience of reciprocal feedback forms the sense of agency that staff need to engage uncertainty. Communicating by reciprocal feedback, that is, using statements of “action-

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response,” drives a more lucid and objective flow of information in a confusing situation. This form of decision and communication relies on authority migration that allows individuals to make decisions then act on those decisions.

At this point, leaders, executives, administrators, and managers will turn to abstractions, the clarity of defined concepts, and the certitude of cognitive processes. Possibly it is a leap of faith, but reciprocal decision-making to reduce complexity is the hidden foundation of responsiveness and generates communication that forms safety, reliability, and resilience. Without it, HRO becomes another abstract cognitive program that makes sense to central leaders, is measurable and straightforward to teach but comes with diminished functional value.

Decision-making for high reliability is an active method for generating information, creating structure, and identifying the boundaries of performance. The literature on decision-making and error distracts us from the nature of local, individual decision-making in uncertainty, even for mundane, routine activities. The literature misses that, even for routines, we must select a rule or algorithm early on from imperfect and ambiguous information. The fact that many of these situations self-resolve or respond to almost any action can mislead us about the effectiveness of our program. From the most to the least experienced, we must at times choose between conflicting or competing rules or engage in situations that lie between the rules. People will choose appropriate but different rules, or they will make their best decisions between established rules.

“The operator in the flux of a trajectory learns the salience of subtle and nuanced signals, identifies information’s relevance and gives meaning to changing information. Experience teaches us to change the level of salience, work with partial or contingent relevance, and shift the meaning of information as events evolve. To the spectator at a fixed point outside of events, these appear as weak signals, irrelevant information, fat-tailed distributions, or random, independent outliers.”

The operator in the flux of a trajectory learns the salience of subtle and nuanced signals, identifies information’s relevance and gives meaning to changing information. Experience teaches us to change the level of salience, work with partial or contingent relevance, and shift the meaning of information as events evolve. To the spectator at a fixed point outside of events, these appear as weak signals, irrelevant information, fat-tailed distributions, or random, independent outliers. (In the fat-tailed distribution, the probability of an event in a sigma farther from the mean is greater than the same sigma in the normal distribution. That is, the risk of an event becomes increasingly significant.) To the operator buffeted by events, these same signals represent possible covert, compensated early failures.

Our interactions with failure make visible the early heralds of that

failure. Visibility facilitates earlier engagement of subsequent incidents. To respond earlier, however, is to respond to ambiguous signals. While much is made of “weak” signals, these are more likely early, subtle, nuanced, and even punctuated signals in an emergency. The salience, meaning, and relevance of these signals are lost to outsiders.

This article will describe straightforward methods for decision making in the VUCA-2T environment (Volatility, Uncertainty, Complexity, Ambiguity-Threat, and Time Compression, see Table 1) (11), modified from the U.S. Army concept VUCA (12, 13) and the anthropological concept of liminality (14). Such situations do not often readily translate into rules, protocols, algorithms, or purely cognitive processes (10, 15, 16). Inquiry is active and operational, generating information, supporting information flow, and supporting authority migration (9, 16, 17).

Volatility	A rapid, abrupt change in events
Uncertainty	Lack of precise knowledge, need for more information, unavailability of the necessary information
Complexity	A large number of interconnected, changing parts
Ambiguity	Multiple interpretations, causes, or outcomes
Threat	Impaired cognition and decision-making
Time Compression	Limitation acquiring information, deciding or acting before consequential changes

Table 1. VUCA-2T (11)

Decisions are how we engage real-life problems in the VUCA-2T environment or during ordinary and mundane operations. What is expected by the veteran is novel to the beginner, yet the decision processes for refining and replacing plans are the same. Decisions must be timely; we must form mental concepts for the situation and change these concepts as the situation changes. “The concepts can then be used as decision models for improving our capacity for independent action...How do we generate or create the mental concepts to support this decision-making activity?” John Boyd (18). Reciprocal decision-making to reduce complexity is a method facile to the beginner and elegant for the veteran.

The Embedded Problem

At first, observation is all we have. Our engagement of a situation starts with our first look when we let our looking teach us. With experience, we gain the “art of describing in darkness and through the fog” (5). The inclusion of uncertainty widens our operational environment making available a fuller spectrum of analysis and the pursuit of weak but salient signals (19).

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Uncertainty as an advantage appears counterintuitive. When we encounter a new situation, it seems advantageous to select a similar frame (8) or draw upon a rule or maxim (20, 21). Our choices

bring expectations, adding difficulties if the frame does not accurately match the situation. An organization or industry may institutionalize competency over proficiency because generalizable principles can be taught to a high-turnover, novice workforce (21). Consequently, the most likely person to encounter an emerging problem or new situation may be a relative novice who will think from rules.

“The entropy of any system moves toward disorder of its elements and the corruption of information as it is transmitted (22). This flux creates uncertainty.”

The entropy of any system moves toward disorder of its elements and the corruption of information as it is transmitted (22). This flux creates uncertainty. Our observations will shape the concepts we formulate and shape our observations and inquiries (18). Accepting uncertainty and incompleteness of our concepts reduces surprises (8). Boyd posited that “according to Gödel, we can not—in general—determine the consistency, hence the character or nature, of an abstract system within itself.” To rely solely on established concepts is to operate within the system. Boyd described the need to use analysis to differentiate elements while using synthesis with outside information to integrate a solution outside the system (18).

The organization with a ‘rule-error’ focus may force the expert to accept concepts and follow the rules. The expert will then perform poorly, at a lower level than the novice (20, 21, 23-25). We also risk surprises when we must use the ‘best-fit frame (8). Dynamic conjunctions of facts have different relations than we can predict or expect. Events may abruptly change trajectory. Our actions cause punctuated responses. When we have fewer expectations, we create fewer surprises, lowering the barrier to earlier engagement.

Organizations seeking to increase reliability and decrease error look to cognitive processes and classical problem-solving. These methods utilize deductive analysis, scientific logic, and critical thinking. Unintentionally, this supports certainty, disregards ambiguity, and supports deterministic, linear problem solving, more like puzzle-solving where knowable information fits together to produce the right answer (19, 26).

The limits of logic and science

“Thought deals thus solely with surfaces. It can name the thickness of reality, but it cannot fathom it, and its insufficiency here is essential and permanent, not temporary,” William James (4). Classical logic and scientific reasoning fail the operator faced with an unfamiliar situation (27).

Classical logic and scientific reasoning do not allow additional information to invalidate conclusions, the property of monotonicity (8, 28). Enforcement of classical logic and monotonicity explains why we may consider a person who changes their stance as “flip-flopping” or “waffling” rather than someone who revises beliefs from new or updated information. The principle of consistency in classical logic does not allow contradictions (29, 30). “Logical reasoning is not flexible enough to serve as a basis for thinking... The consistency that logic absolutely demands is not otherwise usually available – *and probably not even desirable!*—because consistent systems are likely to be too ‘weak,’” Marvin Minsky (8).

Scientific theories preserve order by putting a name to some observed object, subsuming the observation within a known object (2), and organizing findings into logical, compartmentalized categories of knowledge (6, 31). “When we conceptualize, we cut out and fix, and exclude everything but what we have fixed. A concept means a *that-and-no-other*,” William James (4).

In the typical situation, the operator must find an analogy between what is explored and known (2), does not know what facts are relevant, and revises knowledge even as the operator uses that knowledge (31). A gap begins to form “between the apparent reality and one methodically ascertained; between phenomena in their concreteness and particularity and facts stripped of all that is tangible and individual so that they may be fitted into some all-embracing regularity,” Siegfried Frederick Nadel (2).

James described “thought” as solely dealing with surfaces. Nadel (2) describes how science does “not press their analysis very far beyond the ‘apparent’ reality and into an order of things where waves of probability undulating into nothingness offer the ultimate common denominators... The human sciences are concerned with the phenomenal surface of reality; if they discarded it immediately, they would destroy their subject matter.”

Action without a plan

It was common to engage in a situation without a developed plan. Less typical was to engage without any plan. One author (DvS) discussed this with members of a special group in SOCOM (Special Operations Command) that to engage without a plan was to accept that “failure is an option.” Plans can lead to adherence and disregard of anomalies and failures in operations.

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The “phenomenal surface of reality” is our first observation, all that we have. “The only way in which to apprehend reality’s thickness is either to experience it directly by being a part of reality one’s self or to evoke it in imagination by sympathetically divining someone else’s inner life,” William James (4). Our engagement of a situation starts with our first look, it is our “looking” that teaches us. Only action by interaction can change or remake objects.

The “primary purpose of problem-solving is to understand the problem space better,” Marvin Minsky (8). The belief that knowable information enhances decision-making contributes to collecting more information and increases confidence but with little change in accuracy (26). Rather than a puzzle solved by identifiable, knowable information, we can approach the problem as a mystery where generated information generates new decisions

(19). Loop decision-making is practical, providing answers to what works rather than why or how the answer came about. Common-sense decision-making deals with every concrete situation on its own terms (6). “Thinking begins first with suggestive but defective plans and images, that are slowly (if ever) refined and replaced by better ones,” Marvin Minsky (8).

“[I]ntelligence is incarnate in overt action, using things as a means to affect other things. Thought, reason, intelligence, whatever word we choose to use, is existentially an adjective (or better an adverb), not a noun. It is the disposition of activity, a quality of that conduct which foresees consequences of existing events, and which uses what is foreseen as a plan and method of administering affairs,” John Dewey (32). When we foresee the consequences of our situation, consequences of acting and not acting, then those consequences form our plan, and they direct our decisions.

“When we foresee the consequences of our situation, consequences of acting and not acting, then those consequences form our plan, and they direct our decisions.”

Complexity

Complexity at a distance seems to have sufficient organization for spectators to discuss forms, structures, and causes. Complexity up close gives the operator few options for engagement. Ensuring safety through distance from the threat seems more reliable than safety through engaged operations. Well-thought-out decisions have greater effectiveness than hasty actions. Maybe this is because “a story always sounds clear enough at a distance, but the nearer you get to the scene of events, the vaguer it becomes” George Orwell, *Shooting an Elephant* (33). These are the paradoxes and contradictions of the VUCA-2T environment.

Complexity and chaos appear identical to the operator. Uncertainty generates information (22). Ambiguous information drives investigation (34). Actions create equipoise (35). The only certainty is learning by doing. With a far more limited spatial and time horizon than the spectator, the operator can only experience relations and movements. The complexity comes from a large number of elements in linear relations. Chaos develops from a few elements with nonlinear relations but at a high rate of change (36).

The operator enters the VUCA-2T situation by reducing linear relations and slowing the rate of change. The reduction of complexity makes the problem’s structure visible. The slower rate of change decreases the constant presentation of randomness. Friction and failure to respond create negative space around the threat, generating a better understanding of demands (5). This approach favors engagement over assessment. Approaching an emergency, a Los Angeles City firefighter said, “I don’t know what’s happening, but I know what to do.”

From the normative stance outside the flow of events, uncertainty, complexity, chaos, and randomness are independent threats. They are the operating environment from the pragmatic stance within the trajectory and experiencing the flux of events. Common sense differentiates these approaches (7): “The motions of a round-about [British, merry-go-round] are only puzzling until we lift the trapdoor and discover a well-known engine driving the thing. Common sense always urges us to look for such trapdoors,” Nadel (2). The reciprocal decision-making of common sense is

how we lift trapdoors.

The surface of reality, what we observe and can more readily measure, is the trapdoor concealing the mechanism of the problem. It particularly confounds the novice and new residents in the ICU. Numerous active critical care problems can make the initial presentation of a patient difficult. The author (DvS) would list all information on a whiteboard, no matter how insignificant. The first items mentioned were always fluids, electrolytes, and nutrition (“FEN”), active tasks for all patients in the hospital, therefore, most available to the resident’s mind. We routinely developed four columns of seven to ten items. We crossed out information duplicated because of separate means to measure the same thing. We grouped the remaining information by physiological system or treatment modality, producing four to five groupings. We identified what could kill the patient, what would prevent the transfer to the hospital ward, and routine problems from this list. We generally found only two problems were deadly. Changing from a complex situation to a few deadly problems allowed the residents to focus on the one or two life-threatening problems and feel assured the routine problems would continue to be addressed.

This approach came about from an early resuscitation in the NICU during the author’s internship. The author, as a former paramedic, was deciding whether to intubate the infant. The senior resident rushed in and immediately called for a flashlight. Intrigued, as neonatology was new to the author, he watched as the senior resident transilluminated the scrotum and loudly diagnosed hydrocoele. When the Neonatologist arrived, the author was working on the connection between the scrotum, hydrocoele, lack of chest wall movement, and how to fix it. We proceeded with intubation. This central problem, repeated throughout the author’s experience in healthcare, was how people would first address the problem they knew.

Working with concepts is to focus on the surface of the problem rather than its thickness. The individual is then separated from the problem. Decisions will emanate from decontextualized thought and the inability to perceive subtle or nuanced early heralds. In the HRO, thought, described by Dewey (32) as an adverb, modifies decision making, enabling us, as described by William James, to directly experience and apprehend reality’s thickness (4).

We experience complexity and chaos during VUCA-2T. Concepts inform but do not define the thought that modifies decision-making. To solve the problem, we must better understand the problem space (8) and feel the texture of events. We become part of the problem and the texture of the environment. That is how you solve the problem – we make decisions to change the texture. We change texture from within.

Approaching a situation

At our first look, without expectations or surprises, all problems appear to be complex and chaotic. Duncan Dieterly (37) described the three elements of a problem: the situation, intervention, and objective. Knowing all three makes the problem trivial, efficiently dealt with using rules and protocols. Because the situation defines the problem (Dieterly’s “defined problem”), we can select the appropriate decision tree, algorithm, or clinical pathway when we know the initial situation. This computation now describes much of healthcare’s efforts for safety, error management, and reliability.

The more intractable problem is the uncertain or unknown situation, classified by Dieterly as the intuitive or undefined problem. It is the basis of this paper.

We approach these situations by developing a concrete objective. Dieterly’s work, elaborated by George Orr (38), describes con-

ditions with multiple situations, interventions, and objectives. At first, this may appear confusing, but by correlating these conditions with your experience, you readily elaborate decision-making for complex, chaos-driven situations.

Information collection. We urge caution when collecting information to justify a decision. The team may follow their focus, disregarding or discounting any disconfirming information. Lack of support from the organization or leadership creates a sense of never having sufficient information to act. A more readily addressed problem is the difficulty in documenting indications to support a decision.

Multiple situations. The novice may see one situation: everyone in turmoil. Through observation, modeling, and experience, events begin to settle, and multiple situations are identified. The Neonatologist will identify more subtle situations, such as failure to respond to treatment, an unexpected finding, or some anomaly. Distinguishing such situations facilitates assigning appropriate team members, providing greater clarity and purpose for authority migration.

Multiple interventions. We commonly teach novices a single intervention. Rotating with different Attendings, medical students and residents learn different treatments. Rather than a point of value judgment toward those who teach, the student can benefit from this. The RCPs at a subacute facility refused to participate in rounds with the author (DvS). The respiratory manager inquired and received the complaint that they answered the author's question, then the next week, that answer was incorrect. The following week was the same experience; now, both answers were incorrect. The manager explained that the author did not want them to think there is only one answer. He wanted them to have 3-4 ways to treat any problem because their patient will be dying one day, and their regular treatment would not work. Knowing multiple ways to treat became a matter of pride when the RCPs would teach students.

“ He wanted them to have 3-4 ways to treat any problem because their patient will be dying one day, and their regular treatment would not work. Knowing multiple ways to treat became a matter of pride when the RCPs would teach students.”

Multiple objectives. Physiologically we address cardiac output, respiratory function, neurologic function, and nutrition. However, during an emergency, we also monitor stress-fear-threat effects in our staff to ensure optimal performance. If parents are present, we make visible our physical efforts to save their baby. We have the objectives and interventions to increase success, but we add the necessary objectives and interventions to reduce failure. Less experienced participants often miss this as they focus on approaching success. Finally, and quite delicately, we have the objective close to our heart for the parents. Should their baby die, the parents feel that everything was done for their baby and that the staff know they love their baby. All parents want us to know how much they love their baby.

Decompose objectives. George Pólya described a problem-solving heuristic of varying the problem by decomposing and recombining its elements or use of analogy (39), methods also found in

practical common sense problem solving (7). When we cannot always reach our objective, we can rapidly decompose the objective to 'sub-objectives.' For example, Airway and Breathing are decomposed objectives to achieve respiratory function.

Not reaching an objective can initiate stress-fear-threat responses and further degrade decision performance. If staff cannot identify a solution, they may become frustrated. With repeated occurrences, staff become susceptible to learned helplessness or loss of agency.

The Neonatologist can decompose objectives at multiple points, from teaching and planning through active resuscitation when situational problems become evident. When decomposed during training, the student can amalgamate steps in a way that makes sense to them. A dance instructor learned this from the author (DvS). Rather than the standard to guide how to amalgamate dance steps, the instructor told the student to decide how to amalgamate steps. Specialized training in rope work for special groups in SOCOM (Special Operations Command) now uses this approach, significantly increasing learning.

Decomposed objectives facilitate authority migration. The Neonatologist can decompose larger objectives to a set that various operators can achieve within their capabilities and scope of practice. This capability also forms the basis of the Incident Command System used by the fire service (40, 41) and is now a part of hospital disaster response.

“Decomposed objectives facilitate authority migration. The Neonatologist can decompose larger objectives to a set that various operators can achieve within their capabilities and scope of practice. This capability also forms the basis of the Incident Command System used by the fire service (40, 41) and is now a part of hospital disaster response.”

Uncertainty. Here, we discuss uncertainty in the information itself. Uncertainty is embodied in the presentation. Heisenberg's Uncertainty Principle arises from the "complementarity principle" that describes how the measurement of one property requires measurements from the other complementary property. For example, a particle's position requires the value of the momentum, and the particle's momentum requires the value of the position. This property is inherent to wave-like systems such as those with linear-time variance. There is a spread in time and frequency; you cannot have substantial limitations in both or know both simultaneously. We can encounter these relationships during an active resuscitation, such as collecting information (frequency) that takes time. In an active event during a VUCA-2T incident, the situation has changed in the time to collect information for precision.

Reciprocal decision making

Reciprocal decision-making describes how we act, observe the response to our action, and how that response guides our next action. We learn what works through action. Decisions linked to action are probes to learn structure, redirect trajectory, create

structure, and engage the threat. This decision is not trial-by-error or random action but focused on the objective and observed situation. It is also not simple feedback, a component of decision trees or algorithms.

You identify reality by the way it responds to you. While abstractions do not respond to your actions, many people do respond to abstractions. This context differentiates reflective thought from thinking by acting and motor cognition. Acting gives constant feedback for updating and revision of beliefs.

“It is dangerous during an emergency to think that people from different socio-economic statuses make their decisions differently. More likely, their decisions are influenced by stress and fear and are more alike than is recognized (42). Inexperienced or untrained people are equally likely to make decisions for the good of others.”

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Accuracy versus Precision. “Ready, fire, aim!” Army artillery cannot use precision when their target is not ideally placed. Instead, they use ‘bracketing’ to increase their accuracy by firing, taking a measure, re-aiming, and firing again. Their rounds hit increasingly closer to the target. We achieve accuracy through feedback with the environment, changing our actions as we observe how close we are to our objective. Precision initially may seem more desirable, but it is an internal measure independent of the environment yet will be affected by it. Repeated actions will not reliably reach the target. In precision, we hit the same point repeatedly, even if we miss our target. Accuracy allows us to change with the situation, coming closer to the target each time.

Feedback. We have immediate, short, long, delayed, and indirect feedback loops. We select actions from past experiences to gain exploitation by making new choices for exploration and through observation for growth or safety. Environmental responses must be observable and salient if they are to reinforce behavior and lead to learning. This response is HRO trial-and-error learning. In this way, the environment acts upon the individual and organization described by Bob Bea, Professor Emeritus, Civil Engineering, University of California, Berkeley (43), as *interactive, real-time risk assessment and management*.

Short feedback loops are more specific to our actions and more readily accepted, rightly or wrongly, as causative. For example, instrumental anger or intimidation to gain control of staff has a short feedback loop used for that effect in movies. The long and indirect feedback is disastrous and may be hidden, such as in high staff attrition.

The time compression inherent to the flux of rapid, dynamic events confounds the real-time use of prolonged or indirect feedback loops. To obtain short feedback loops, we must closely approach the environment, even entwining with the environment. Entering

the situation shortens feedback loops, thus improving accuracy.

Negative and positive feedback. Feedback maintains homeostasis for stable operations within a VUCA-2T environment, supports safety, generates self-organization WHILE simultaneously bringing resolution to the event. Negative feedback corrects deviations from our desired state, and positive feedback supports our strength and resilience. To an outside observer, this method of homeostasis may appear to be one of constant or repeated error rather than continuous assurance of effectiveness and safety.

A control system maintains *homeostasis* by monitoring distance from a set point. *Negative feedback* is a deviation from the desired set point that can be offset by corrective action. Negative feedback marks our boundaries for safe operations.

“ Negative feedback correction may be classified as an error, but it is a mark of safety, resilience, and adaptability. As we operate in this unstable environment, we will also test the boundaries between our performance capabilities and the limits for safety and harm.”

Negative feedback correction may be classified as an error, but it is a mark of safety, resilience, and adaptability. As we operate in this unstable environment, we will also test the boundaries between our performance capabilities and the limits for safety and harm. These boundary checks can sometimes only be performed in real-world situations in real-time. Failures are helpful in these situations because they mark our performance *boundaries*. The outsider, not appreciating the exigencies of the situation, may have a different, negative interpretation of this level of operation.

Self-organization. Amplification of positive feedback causes growth and pattern formation, which is calibrated by the stabilizing effects of negative feedback for safe boundaries.

Improvisation. Negative feedback increases the safety of improvisation and, through recalibration, reduces the effect of noise (Weick, personal communication).

Outliers. Outliers in statistics are a tiny population of random, independent values. Outliers in probability are very rare outcomes. The events we work with emerge from routine operations, even if our routine is an extreme cardio-respiratory failure. Events may grow from the routine, creating a power distribution where large events are rare, or from stochastic probability distributions; that is, the event follows a probability distribution, but the distribution changes.

In a series of short feedback loops, people develop sensemaking and create more easily transmitted information. Communicating information as action-response carries information. Describing what the person believes is happening or stating what they believe should be done carries less meaningful information.

The OODA Loop

Loop decision-making, like common sense problem solving, is practical and drives interaction. It provides answers to what works

rather than why or how the answer came about.

“Our [dangerous] work has termed this *interactive-real-time assessment and management of risks*. This approach was completely overlooked until the early 1990s. We were taught that there was only *proactive* (before operations) and *reactive* (after) - and that was it. And we thought we could capture all of the risks with the proactive approaches - and then provide adequate defenses if ‘justified’ - but we were missing some really major risks that were fundamentally unpredictable and unknowable.”

Bob Bea, 8/30/2005, personal communication

In 1968, John Boyd presented his concept of the OODA loop (Figure 1) during the Vietnam War for fighter pilots to outmaneuver their opponents (44). After studying air-to-air combat in the Korean conflict, he developed this approach to better understand why American pilots in Korea flying the F-86, a plane inferior to the MiG-15, had better kill ratios than American pilots in the Vietnam War planes superior to the MiG. He found the difference to be that the American pilots in Korea had better ability to see out of the cockpit and switch from one activity much more quickly to another. We use the OODA loop in healthcare to outmaneuver a rapidly changing disease state (45).

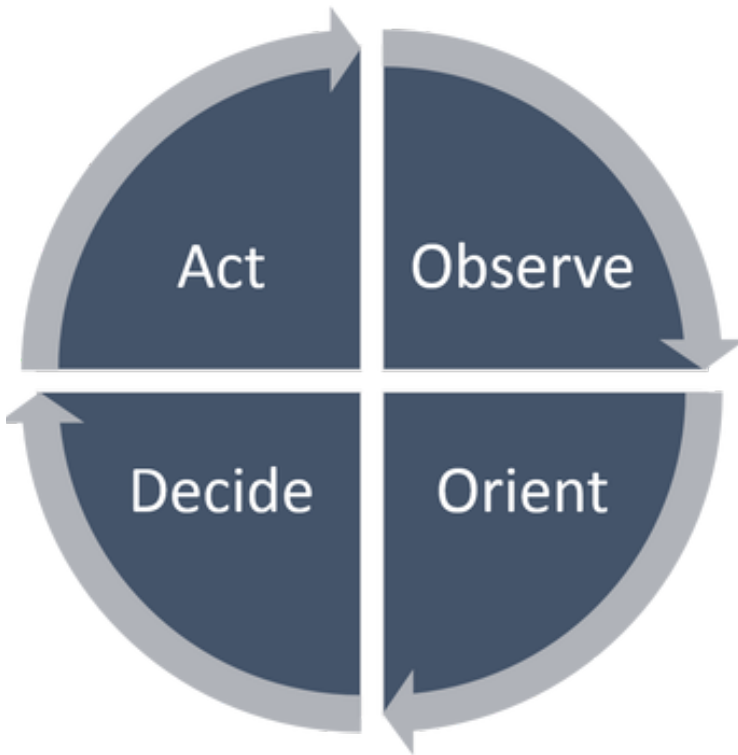


Figure 1. Boyd's OODA loop
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The OODA loop is a cycle for rapid, real-time interactive hypothesis development and testing. To create the loop, the person **Ob**serves, **O**rients, **D**ecides, and **A**cts then loops back to observe the effect of the action. The action creates the loop for a continuous cycle and gives the OODA loop its power and agility.

There need not be a consistent starting element. Weick observed that “one can start this sequence anywhere and move either in a clockwise or counterclockwise direction” (personal communication). Weick has described Boyd's OODA loop (in either sense-

making or enactment) by starting at A, the “act” phase (personal communication). Acting is the first step in engagement and is the active part of Weick's sensemaking; acting is also the initiator of Weick's enactment. Acting can create both visible and correctable failure through looping. The latter is critical in HRO to oppose failure from *not* acting, which is invisible, not detectable, and not correctable.

We think by acting (35); that is, we make sense of the situation by acting and gaining positive and negative information, and we enact change in the environment by acting (46).

Observe. An *attention* function for discrepancies, disruptions, and outliers does not require a complete analysis of the situation. The observe function also notices the responses to our just-completed action and whether we received the results we expected. The system can improve, in which case we may continue; the system may deteriorate, in which case our actions generate new information about its structure, or the system may not change. This last option is dangerous because we might have the wrong dosage, drug, or diagnosis.

“The observe function also notices the responses to our just-completed action and whether we received the results we expected. The system can improve, in which case we may continue; the system may deteriorate, in which case our actions generate new information about its structure, or the system may not change.”

Orient. “Shapes the way we interact with the environment...The way we *observe*, the way we *decide*, the way we *act*.” “Seen as a *result*, represents images, views, or impressions of the world shaped by *genetic heritage, cultural tradition, previous experiences, and unfolding circumstances*,” John Boyd (44). Also, updated information; and analysis and synthesis from feedback, guidance, and control. In this function, we synthesize new information and build support for our decisions. (Some consider this an orientation to the circumstances, but the orientation function is much richer.) This emphasis on orientation makes conflict into a learning contest to better maintain awareness of the world; one can create opportunities to act; orientation of group members (47).

Decide. Generate a hypothesis. The circumstances operate in the affective domain of emotion, values, attitudes, and personal evaluation. Create new repertoires (47).

Act. Initiates the *loop action*, which acts as a control mechanism operating on the environment while changing people's perceptions of the environment. Using the loop action is a method to explore the situation while exploiting any path of least resistance. When we encounter friction as part of the feedback, we can observe whether we should pursue another path with less friction or identify the friction point as something significant that should remain in focus (38). The use of positive feedback through the loop action directs focus and actions toward paths of success. In contrast, negative feedback marks practical and safety boundaries that can act as a safety function.

Loop. We calibrate our mental model with actuality and responsiveness of the environment. Encountering resistance or friction, we rapidly resolve whether to change our approach or seek resources. This resolution is not through speed or shortcuts but by increasing our tempo. Boyd described the methods and benefits of a faster tempo: the ability to transition more rapidly than events change, develop more repertoires of action, free and open communication, interactive support, increased information sources to select from, and generation of new ideas that can be rapidly tested (48).

Table 2. OODA Loop functions

Function	Description
Observe	Observe the situation Match prediction to response
Orient	Process and synthesis of observations Actual world function Culture, experience, physiology
Decide	Develop hypothesis; decide the action
Act	Test hypothesis interface between operator and environment
Loop	Effect of action

Connecticut Paramedics

Two paramedics arrived on the scene to find a woman in her late sixties lying face down in the street. They saw she was nonresponsive and pale. Her skin felt damp, and her oxygen saturation was in the low eighties, with a slow, weak heartbeat in the forties. On the EKG, they identified a regular electrical pattern except for premature ventricular contractions. The first thought was that she had had a cardiac event, so they considered cardiac protocols. The two paramedics were unsure which protocol to use, but each paramedic had 15 years of experience and could see that she was dying. They began to feel helpless to stop her death.

“The two paramedics were unsure which protocol to use, but each paramedic had 15 years of experience and could see that she was dying. They began to feel helpless to stop her death.”

While accomplishing this evaluation, they made a rapid visual respiratory exam and observed very shallow breathing; they identified lower airway obstruction from the prolonged expiratory phase. This indicated treatment with a bronchodilator drug, something they would not have considered without the rapid five-point visual respiratory exam (49). However, they were not sure if they should treat what could be a second disease, if the bronchodilator would work, or if the bronchodilator might stimulate the heart and cause the extra beats to fibrillate, creating cardiac arrest.

They decided to administer the drug and observe the response, which is something they would not have considered without the use of Boyd’s OODA loop decision-making. After the bronchodilator treatment, the woman’s chest expansion increased, the expi-

ratory phase shortened, her oxygen saturation increased above 90 percent without supplemental oxygen, and she became alert. Most critically, her heart rate increased, and the premature ventricular contractions resolved. This woman’s life was saved by treatment the paramedics had learned four months earlier.

Steep Authority Gradients

Whether intentional or assumed, healthcare has steep authority gradients. This gradient may not pose a significant problem for routine situations, but it leads to poor dynamics in time-compressed states or information that disconfirms the physician’s beliefs. Bedside caregivers will commonly resolve this discrepancy by “adjusting” information to be congruent with the physician’s views, withholding information that disconfirms the physician’s beliefs, or withstanding personal attacks on their abilities.

The OODA loop can be used for communication as action and response. Presenting *only* observation (the *observe* function) relies on credibility. Presenting *only* the decision (the *decide* function) is also problematic when we view decision-making as a process of weighing subjective observations, objective data, indications, and contraindications. Instead, by modifying the approach used by fire departments, the caregiver will describe the action taken (act function) and the response observed (looping to a new *observe* function). This loop brings focus to the disease process and interventions rather than personal biases and credibility.

“Instead, by modifying the approach used by fire departments, the caregiver will describe the action taken (act function) and the response observed (looping to a new observe function). This loop brings focus to the disease process and interventions rather than personal biases and credibility.”

The decision frame

Faced with a situation having an uncertain, possibly harmful, outcome, we may hesitate to act. A decision frame can bring focus to the consequences of acting or not acting. To create the frame, ask what happens if you act too soon or too late. Then ask what consequences are likely to happen if your intervention is too little or too much.

The licensed vocational nurse (LVN) wanted fluids through the gastrostomy tube to treat thick pulmonary secretions. We had two discussions, one for treating the secretions and one regarding the fluid. “What would happen if we didn’t treat the secretions, or if we treated them and didn’t need to? And what would happen if we gave too much or not enough fluid?”

She answered that treating the secretions too early would thin secretions and increase the urine output. Waiting to treat the secretions could lead to the formation of thick mucus plugs, an obstructed airway, and cardiac arrest. For the amount, giving too much would increase the urine output, while giving insufficient amounts would delay response and increase the threat of thick secretions, which could lead to cardiac arrest. She realized that, within her decision frame, her decisions would lead to more urine or death. The LVN became vigilant for secretions and better un-

derstood what we were treating, how we treated it, and why we make the decisions we do.

“We can reverse the administration of too much fluid with a diuretic. This problem arises when we titrate fluids for dehydration or blood volume and, though we can calculate ideal weight and expected blood volume, we still do not know precisely how much fluid would benefit our patient.”

Is the decision reversible? Often, we find the novice decision-maker worrying over an action that can readily be reversed. For example, we can reverse the effect of a diuretic with the administration of fluid. We can reverse the administration of too much fluid with a diuretic. This problem arises when we titrate fluids for dehydration or blood volume and, though we can calculate ideal weight and expected blood volume, we still do not know precisely how much fluid would benefit our patient.

Another critical factor in the decision frame is the outcome, whether good, bad or no change. If it is good, then we continue doing it. We do not express it as a poor decision if it is bad but as new and vital information. A harmful or unwanted result identifies the boundary of our envelope for operational purposes and helps us identify structure within what initially appears to be an unstructured situation.

The most dangerous outcome is “no change.” In the medical field, we may have the wrong dose, wrong drug, or wrong diagnosis. “No change” increases our uncertainty and supports more vigorous attempts to characterize the structure of our problem.

The most critical decision is the decision “not to act.” This “non-acting” can signal to others that no action is necessary or that the problem is not severe. Observation, the key to “not acting,” may be passed over. The leader must reiterate that “the decision not to act is a decision.”

“In the medical field, we may have the wrong dose, wrong drug, or wrong diagnosis. “No change” increases our uncertainty and supports more vigorous attempts to characterize the structure of our problem.”

Conclusion

The central issue for the HRO is the embedded problem -- where the entropy of the system moves toward the disorder of its elements and information is corrupted by its transmission. Individuals find themselves in situations where they must act without a plan, working from rapidly identified objectives. Decomposing dif-

icult to reach objectives while simultaneously working on multiple objectives is made possible by reciprocal decision making. The decision changes the environment, which then changes the next decision.

This is not making decisions independent of others or the organization. The Orient function of Boyd's OODA loop integrates the individual, situation, and organization through culture.

Dynamic, complex problems are specific and concrete that we deal with on their terms, not ours. We interact to learn what works while simultaneously ensuring safety. We achieve this, not through plans or rules but reciprocal feedback. We create our expertise through our own experience and from watching others.

We gain that experience through interaction with the problem, the situation, and the environment (50). Perhaps it is the function of decision-making and sensemaking to allow us to maneuver through these changing events.

Decision making with reciprocal feedback has multiple functions:

- the operator works close to, even within, events,
- uncovering information and generating Shannon Information,
- identify the relevance of information, give meaning, and reduce ambiguity,
- contributes to the sense of agency needed to engage uncertainty,
- communication through “action-response,” and
- drive the lucid and objective flow of information in a confusing situation.

Decision-making for high reliability is an active method for generating information, creating structure, and identifying the boundaries of performance.

“Decision-making for high reliability is an active method for generating information, creating structure, and identifying the boundaries of performance.”

“Operators are maintained in [complex technological] systems because they are flexible, can learn and do adapt to the peculiarities of the system, and thus they are expected to plug the holes in the designer's imagination,” Jens Rasmussen (51).

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18% Only 18% know "a lot" about RSV

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Survey Says: RSV

RESPIRATORY SYNCYTIAL VIRUS, or RSV, is a dangerous virus that can lead to:

-  **Hospitalization**
 -  **Lifelong health complications**
 -  **Death**
- for infants and young children.

ACCORDING TO A NATIONAL SURVEY,
Specialty Health Care Providers say:

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

But Parents are Unprepared.

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

RSV EDUCATION & AWARENESS CAN HELP

After parents learned more about RSV, they were:

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



NCJIH National Coalition for Infant Health

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

OPIOIDS and NAS

When reporting on mothers, babies, and substance use

LANGUAGE MATTERS



I am not an addict.

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



I was exposed to opioids.

While I was in the womb my mother and I shared a blood supply. I was exposed to the medications and substances she used. I may have become physiologically dependent on some of those substances.



NAS is a temporary and treatable condition.

There are evidence-based pharmacological and non-pharmacological treatments for Neonatal Abstinence Syndrome.



My mother may have a SUD.

She might be receiving Medication-Assisted Treatment (MAT). My NAS may be a side effect of her appropriate medical care. It is not evidence of abuse or mistreatment.

My potential is limitless.

I am so much more than my NAS diagnosis. My drug exposure will not determine my long-term outcomes. But how you treat me will. When you invest in my family's health and wellbeing by supporting Medicaid and Early Childhood Education you can expect that I will do as well as any of my peers!



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





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The CE activity explains safe infant sleep recommendations from the American Academy of Pediatrics and is approved by the Maryland Nurses Association, an accredited approver of the American Nurses Credentialing Center's Commission on Accreditation.



Eunice Kennedy Shriver National Institute
of Child Health and Human Development



Compiled and Reviewed by David Vasconcellos, MSIII

AAP urges post-COVID-19 follow-up to monitor for residual symptoms

August 02, 2021

Editor's note: For the latest news on COVID-19, visit <http://bit.ly/AAPNewsCOVID19>.

New AAP interim guidance on post-COVID-19 [conditions](#) in children and adolescents recommends all patients who test positive for SARS-CoV-2 infection have at least one follow-up conversation or visit with their pediatrician to discuss residual symptoms, explore new symptoms and guide their return to activities.

More than 4 million U.S. children have tested positive for SARS-CoV-2. Although acute illness may be less severe in children and adolescents than adults, severity does not predict subsequent or ongoing symptoms. According to the guidance, "COVID-19 can lead to many secondary conditions, which can range from sub-acute to severe. Long-term effects from SARS-CoV-2 infection may be significant, regardless of the initial disease severity."

Post-COVID-19 check

During the visit, pediatricians should work with families to identify any continuing symptoms of COVID-19, which may include respiratory symptoms, cardiac symptoms, fatigue or cognitive fogging. Pediatricians and families also should determine if the child or adolescent might require additional academic supports such as a gradual return to school and cognitive activities based on tolerance and offer guidance on rest periods and other accommodations. Some children and adolescents may require the support of pediatric subspecialists, and patients with previously underlying medical or behavioral conditions may require additional support.

Pediatricians should discuss COVID-19 vaccination for all eligible individuals, which can occur immediately after the recommended quarantine period unless the patient received monoclonal antibody therapy.

A telehealth visit may be sufficient for patients who were asymptomatic or had mild disease severity and have no residual symptoms.

Common post-COVID-19 conditions

The guidance outlines ongoing or residual symptoms known to occur in children after infection and explains next steps.

- **Respiratory symptoms** like chest pain, cough and exercise-induced dyspnea can last for three months or longer. The guidance addresses when to follow up with chest imaging, pulmonary function testing or cardiopulmonary exercise testing.
- **Cardiac involvement** may be part of the initial disease presentation, a sequela of disease or occur after vaccination. Myocarditis can develop after COVID-19 infection or, less frequently, after receipt of the mRNA vaccine. Common presenting symptoms can include chest pain and shortness of breath, arrhythmias and fatigue. Severe cases can lead to heart failure, myocardial infarction, stroke or sudden cardiac arrest. Pediatric cardiologists may be a helpful resource in supporting patients with myocarditis.
- **Anosmia and ageusia** can affect nutritional status, mood and quality of life. For persistent anosmia, the AAP recommends further evaluation, nutrition optimization, olfactory testing and potentially olfactory training.
- **Neurodevelopmental** and age-specific evaluation can assess for delays/changes in cognitive, language, academic, motor or mood/behavior domains. Pediatricians should watch for subtle neurodevelopmental sequelae, especially in younger children.
- **Cognitive fogging or fatigue** may manifest as inattentiveness, slower reading or processing, or less endurance on cognitive tasks. Persistent cognitive complaints may warrant a neuropsychological evaluation.
- **Physical fatigue/poor endurance** typically improves over time, assuming cardiac and respiratory functions are clinically normal.
- **Headache** is common but mostly related to factors such

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as changes in routine and sleep, medication overuse, social isolation and poor hydration. Evaluation for red flag characteristics is recommended.

- **Mental health/behavioral health** sequelae are very common and likely multifactorial. Pediatricians can refer to the AAP interim guidance on emotional and behavioral health [needs](#).

The AAP guidance emphasizes a conservative approach that includes minimal diagnostic evaluation, optimizing function in those patients with continued symptoms and working toward achievable goals during the first four to 12 weeks after illness to avoid potential harm from excessive testing. Pediatricians should consider other differential diagnoses and pursue additional investigation as clinically appropriate.

If concerns persist past 12 weeks, the AAP recommends additional testing or referral to a multidisciplinary post-COVID-19 clinic for consultation.

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New AAP main number: 630-626-6000

NT

American Academy of Pediatrics, Section on Advancement in Therapeutics and Technology

Released: Thursday 12/13/2018 12:32 PM, updated Saturday 3/16/2019 08:38, Sunday 11/17/2019 and Friday 11/20/2020

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

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

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

NT

CDC says delta variant easily transmissible, recommends universal masking in school

July 27, 2021

Editor's note: For the latest news on COVID-19, visit <http://bit.ly/AAPNewsCOVID19>.

Everyone in schools and those living in areas with substantial or high COVID-19 disease transmission should wear a mask in public indoor settings regardless of their vaccination status, according to [new guidance](#) from the Centers for Disease Control and Prevention (CDC).

The updated public health recommendations are based on new information on the delta variant from several states and other countries showing that on rare occasions, fully vaccinated individuals infected with the variant may spread the virus to others, according to CDC Director Rochelle Walensky, M.D.

"This new science is worrisome and unfortunately warrants an update to our recommendations," she said.

The updated recommendations align with [AAP school guidance](#): both groups support keeping children safe and physically present in school and urge masking, vaccination and other layers of protection to prevent transmission.

Universal masking in school

The CDC recommends indoor masking for all teachers, staff, students and visitors to schools, regardless of vaccination status.

About 7.1 million children between ages 12 and 17 are fully vaccinated, representing 39% of 16- to 17-year-olds and 27% of 12- to 15-year-olds, according to an [AAP analysis](#) of CDC data.

Federal health officials hope more kids are vaccinated by the start of the school year.

Universal masking will help protect those who are not able to be vaccinated, such as children under 12, as well as those who are vaccinated but immunocompromised and not fully protected, Dr. Walensky said. "The vast majority of transmission, the vast majority of severe disease, hospitalization and death is almost exclusively happening among unvaccinated people," she said. "We still largely are in a pandemic of the unvaccinated."

Delta is different

CDC officials say the authorized mRNA vaccines provide good protection against variants of concern, including the delta strain.

"We continue to estimate that the risk of a breakthrough infection with symptoms upon exposure to the delta variant is reduced by sevenfold; the reduction is 20-fold for hospitalizations and deaths," Dr. Walensky said.

Fully vaccinated individuals in areas with low transmission may choose to wear a mask to protect household members who are unvaccinated, immunocompromised or at increased risk for severe disease.

The CDC recommends the following for fully vaccinated individuals:

- Get tested if you have symptoms of COVID-19.
- Test three to five days following a known exposure to someone with suspected or confirmed COVID-19 and wear a mask in public indoor settings for 14 days after exposure or until receipt of a negative test result.
- Isolate if you have had a positive COVID-19 test in the prior 10 days or symptoms of COVID-19.
- Wear a mask, keep 6 feet away

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from people outside your household and avoid crowds and poorly ventilated indoors spaces regardless of vaccination status if immunocompromised.

The recommendations apply to non-health care settings. Pediatricians and other health care personnel should refer to the [CDC's recommendations on infection prevention and control for health care settings](#).

Health Alert Network recommendations

The CDC also issued a [health advisory](#) urging public health practitioners and clinicians to increase COVID-19 vaccination coverage. Recommendations for health care practitioners include:

- Clinical providers who are not fully vaccinated should get vaccinated as soon as possible.
- Increase patient outreach efforts to encourage, recommend and offer COVID-19 vaccination.
- Remind patients that vaccination is recommended for all people ages 12 years and older, even those with prior SARS-CoV-2 infection.
- Follow trusted sources carefully for any new recommendations and changes in vaccine guidance.
- Support efforts to ensure people receiving a first dose of a COVID-19 mRNA vaccine (i.e., Pfizer-BioNTech or Moderna) return for their second dose.
- Communicate with unvaccinated staff, patients and other individuals to increase confidence in vaccination, <https://bit.ly/2UTlqwn>.
- Recommend that fully vaccinated immunocompromised patients practice [prevention measures](#) for unvaccinated people.

Resources

- CDC Guidance for Implementing COVID-19 Prevention Strategies



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in the Context of Varying Community Transmission Levels and Vaccination Coverage, <https://bit.ly/3x6Xdsn>

- COVID Data Tracker, <http://bit.ly/cdccoovidatatracker>

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NT

Take steps to improve care of newborns and reduce medical liability risks

July 30, 2021

Newborn care represents a significant malpractice risk for pediatricians, hospitalists and neonatologists.

Nearly 50% of pediatric malpractice cases involve patients under 1 month (Jena AB, et al. *Pediatrics*. 2013;131:1148-1154). The top 10 most prevalent presenting medical conditions in closed pediatric malpractice claims include neurologically impaired infant, newborn respiratory problems and premature infant (Physician Insurers Association of America. *Risk Management Review*. Rockville, Md. 2013).





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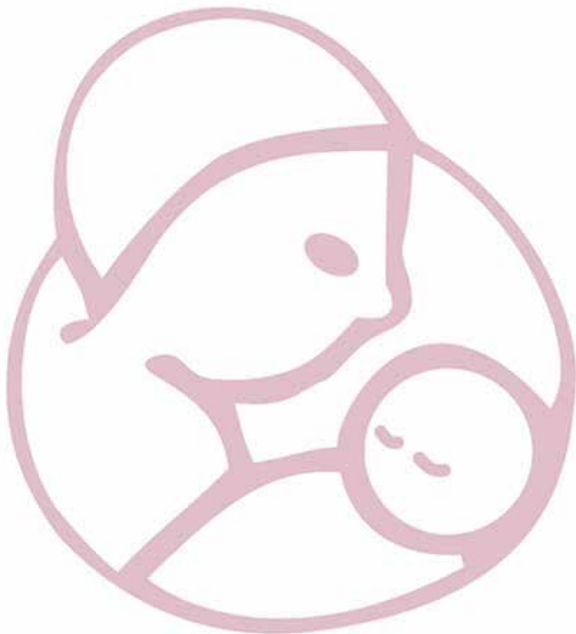
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Medical liability claims in pediatrics often are described as low frequency and high severity, meaning they don't happen as often as those in other specialties, but when they do, the indemnity payments are significantly higher. Factors that often contribute to the severity of pediatric malpractice payouts are 1) high parental expectations for a healthy newborn, 2) early hospital discharge for newborns, 3) payments calculated to cover care for the rest of a child's life and 4) sympathy among jurors for disabled children.

Following are some common allegations of negligence in newborn care and suggestions to improve patient safety and outcomes and reduce the risk of litigation.

Resuscitation

Delay in attendance and/or inadequate personnel at a delivery can contribute to a poor outcome. Pediatricians should be made aware of potential high-risk deliveries and have a reliable system to communicate with the delivery room and newborn nursery staff.

Nationally, up to 10% of low-risk deliveries will require significant resuscitation (positive pressure ventilation) at birth. Therefore, every birth should be attended by at least one individual skilled in newborn resuscitation whose only responsibility is the newborn.

Ventilation of a newborn's lungs is the single most important and effective action during neonatal resuscitation. The majority of depressed newborns will respond to properly performed bag and mask ventilation, which allows stabilization while waiting for assistance from an anesthesiologist or on-call neonatologist.

Chest compressions should be initiated if the newborn's heart rate remains less than 60 beats per minute after at least 30 seconds of effective positive pressure ventilation; however, very few newborns will require chest compressions once effective ventilation has been established.

If intubation is required, the inability to intubate may result in a preventable, devastating outcome. With less exposure to the neonatal intensive care unit in residency training, the opportunity and skill to intubate is greatly reduced.

If intubation is not feasible secondary to congenital or traumatic airway compromise, a laryngeal mask is an alternative to a face mask or endotracheal tube.

If an adequate airway is established and the newborn continues to deteriorate, it would be prudent to consider etiologies such as a plugged endotracheal tube, more pressure to open up stiff lungs, right mainstem intubation and transillumination to rule out a pneumothorax.

When administering epinephrine, the dose (1:10,000/0.1 mg/mL) is dependent on the route of administration: 1 mL/kg down the endotracheal tube and 0.2 mL/kg IV. The umbilical vein is the recommended route of vascular access for a newborn in the delivery room. If there are signs of shock or a history of acute blood loss, the umbilical vein provides relatively easy access when volume expansion is required.

Cooling an asphyxiated newborn

Some negligence claims allege that if passive cooling/whole body cooling had been provided to an asphyxiated newborn within a six-hour window, a normal outcome would have occurred.

The criteria to initiate cooling can be complex and subjective. Perinatal depression with a sentinel event warrants a high index of suspicion for hypoxic ischemic encephalopathy. Delivery room physicians should be familiar with local criteria for initiating passive cooling and the six-hour window for total body cooling.

A newborn blood gas in the first hour of life can provide valuable information. A cord arterial pH <7.00 and/or base deficit <-12 should prompt immediate consultation with a tertiary center.

It is critical to document the newborn's

neurological exam, including level of consciousness, activity, posture, tone, reflexes and pupillary reaction to light.

Issues in immediate post-care period

Among the issues that can arise in the immediate post care of a newborn are hypoglycemia, sepsis and seizures.

There is a lack of consensus on the definition of hypoglycemia in newborns, whether there are risks associated with transient hypoglycemia and the ideal threshold for intervention. Physiologically, newborns' glucose normally drops in the first hour of life. Therefore, careful documentation of the presence or absence of signs and symptoms of hypoglycemia can help in a malpractice case.

When an experienced nurse feels the newborn is not acting right, an immediate evaluation should be considered to assess for subtle conditions such as sepsis or seizures. Diagnostic tests, however, cannot replace good clinical judgment, which should be documented.

Kernicterus

Kernicterus is the only pediatric disease listed as a "never event" by the National Quality Forum (NQF). Approximately 60% of newborns develop jaundice, and levels often peak after early discharge. Careful follow-up is critical. Newborns should be examined within 48 hours of discharge, and follow-up bilirubin values for neonates should not be delayed on weekends or holidays.

Despite the NQF designation, not all cases of kernicterus are preventable. However, clear communication with parents and between providers will improve recognition of hyperbilirubinemia.

Key takeaways

- Pediatricians who are on call for newborn emergencies and attend deliveries should maintain their technical and cognitive skills through the Neonatal Resuscitation Program (see resources).



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- Make sure your notes are objective, timely and accurate. Avoid inappropriate superlative modifiers such as severe, profound, prolonged or urgent.
- Physicians attending deliveries in nontertiary centers should be familiar with perinatal center agreements/state criteria to transfer a newborn to a higher level of care and contact the facility early.
- Regardless of the circumstances, always be a competent, caring, concerned and compassionate clinician. Not only is it good medical care, it will minimize professional liability.

The information in this article addresses specific conditions often found in medical malpractice claims. For comprehensive guidance on newborn resuscitation and newborn care, see resources.

Dr. Muraskas is a member of the AAP Committee on Medical Liability and Risk Management.

Resources

- 📖 [“Textbook of Neonatal Resuscitation,” 8th Edition](#)
- 📖 [The Neonatal Resuscitation \(NRP\) eBook Collection](#)
- 📖 [“Guidelines for Perinatal Care,” 8th Edition](#)
- 📖 [Additional Pediatricians and the Law columns](#)

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NT

More than 1.5 million children lost a primary or secondary caregiver due to the COVID-19 pandemic

Tuesday, July 20, 2021

Addressing the impact of caregiver deaths critical for pediatric mental health, authors note.

More than 1.5 million children around the world are estimated to have lost at least one parent, custodial grandparent, or grandparent who lived with them due to death related to COVID-19 during the first 14 months of the pandemic, according to a study published today in *The Lancet*. The study highlights orphanhood as an urgent and overlooked consequence of the pandemic and emphasizes that providing evidence-based psychosocial and economic support to children who

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have lost a caregiver must be a key part of responding to the pandemic.

The analysis used mortality and fertility data to model rates of COVID-19-associated orphanhood (death of one or both parents) and deaths of custodial and co-residing grandparents (ages 60-84) from March 1, 2020 to April 30, 2021, across 21 countries. This study was funded in part by the National Institute on Drug Abuse (NIDA), part of the National Institutes of Health.

In the paper, "COVID-19-associated deaths" referred to the combination of deaths caused directly by COVID-19 and those caused indirectly by other associated causes, such as lockdowns, restrictions on gatherings and movement, decreased access or acceptability of health care and of treatment for chronic diseases.

Traumatic experiences, such as the loss of a parent or caregiver, are associated with increases in substance use, mental health conditions, and other behavioral and chronic health conditions. NIDA supports research aimed at understanding the impact of trauma on young people, preventing substance use after experiencing hardship, and treating substance use in populations that experience trauma.

"Studies like this play a crucial role in illuminating the COVID-19 pandemic's long-lasting consequences for families and the future mental health and wellbeing of children across the globe," said NIDA Director Nora D. Volkow, M.D. "Though the trauma a child experiences after the loss of a parent or caregiver can be devastating, there are evidence-based interventions that can prevent further adverse consequences, such as substance use, and we must ensure that children have access to these interventions."

To estimate pandemic-associated orphanhood and caregiver deaths, the study used excess mortality and COVID-19 mortality data for 21 countries that accounted for 77% of global COVID-19 deaths during 2020 and early 2021. These include Argentina, Brazil, Colombia, England and Wales, France, Germany, India, Iran, Italy, Kenya,

Malawi, Mexico, Nigeria, Peru, Philippines, Poland, Russian Federation, South Africa, Spain, United States, and Zimbabwe.

The authors estimate that 1,134,000 children lost a parent or custodial grandparent due to COVID-19-associated death. Of these, 1,042,000 children were orphaned of a mother, father, or both – most lost one, not both parents. Overall, 1,562,000 children are estimated to have experienced the death of at least one parent or a custodial or other co-residing grandparent (or other older relative).

The countries with the highest numbers of children who lost primary caregivers (parents or custodial grandparents) included South Africa, Peru, United States, India, Brazil, and Mexico. The countries with rates of COVID-19-associated deaths among primary caregivers (>1/1000 children) included Peru, South Africa, Mexico, Brazil, Colombia, Iran, United States, Argentina, and Russia.

The study found that for every country, COVID-19 associated deaths were greater in men than women, particularly in middle- and older-ages. Overall, there were up to five times more children who lost a father than who lost a mother.

"We know from our research that loss of a parent or caregiver can upend children's lives and potentially affect their development if they are not in a stable home setting. If we take into consideration variants of concern or possible severity of illness among youth, we must not forget that the pandemic continues to pose a threat to parents and caregivers – and their children," said [Chuck A. Nelson, III, Ph.D.](#), study author, Boston Children's Hospital.

While research on the science of substance use and addiction remains the primary focus of NIDA's work, NIDA is supporting COVID-19 research, and has issued over \$15 million in funding for COVID-19-related projects since the start of the pandemic that could leverage current infrastructure, projects, or scientific knowledge and resources.

About the National Institute on Drug Abuse (NIDA): NIDA is a component of the National Institutes of Health, U.S. Department of Health and Human Services. NIDA supports most of the world's research on the health aspects of drug use and addiction. The Institute carries out a large variety of programs to inform policy, improve practice, and advance addiction science. For more information about NIDA and its programs, visit <https://www.nida.nih.gov>.

About the National Institutes of Health (NIH): NIH, the nation's medical research agency, includes 27 Institutes and Centers and is a component of the U.S. Department of Health and Human Services. NIH is the primary federal agency conducting and supporting basic, clinical, and translational medical research, and is investigating the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

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S Hillis, et al. [Global Minimum Estimates of Children Affected by COVID-19-associated Orphanhood and Death of Caregivers\(link is external\)](#). *The Lancet*. DOI: 10.1016/S0140-6736(21)01253-8 (2021).

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New Moms Latched On to Remote Breastfeeding Help. Will Demand Wane as Pandemic Fades?

August 03, 2021

Madison Cano knew she wanted to breastfeed her son, Theo. But breastfeeding was painful for her. The skin on her breasts was chafed and blistered last July when she returned home from the hospital. And Theo sometimes screamed during feedings.

Cano, 30, realized she needed help to get the [short- and long-term health benefits](#) of breastfeeding for moms and babies. [New studies](#) also have shown that covid-vaccinated mothers pass protective antibodies on to their newborns. However, Cano lives in Montrose in western Colorado, 60 miles away from her lactation counselor, Ali Reynolds, in Grand Junction — and it was during the thick of the pandemic.

She messaged Reynolds on Facebook and took photos and recorded videos of herself breastfeeding so Reynolds could offer advice and encouragement from afar. It worked. She no longer had pain. Cano is still breastfeeding Theo, who just turned 1.

“I don’t think I would have understood what was happening and been able to work through it without that resource,” said Cano.

Support for breastfeeding was upended last year, when it no longer seemed safe to take a baby class at the hospital or invite a nurse into one’s home. Hospitals, lactation counselors and support groups turned to virtual platforms like Zoom or phone calls. That made lactation support accessible to struggling families during the pandemic, said Danielle Harmon, executive director of the [United States Lactation Consultant Association](#).

Today, although lactation specialists have more options to safely meet in person with families after their covid-19 vaccinations, many are choosing to continue virtual classes, keeping alive the online communities they created and relying on the technology that worked for many families. Virtual options especially help those in remote areas or those with limited transportation access, breastfeeding experts say.

Right before the pandemic, for example, Sandrine Druon typically had one or two moms attend in-person meetings she held for [La Leche League of Longmont](#) at the First Evangelical Lutheran Church or at a Ziggie’s Coffee shop. But because they could no longer meet in person, last June she launched two monthly virtual meetings. Now, an online meeting will typically include nine or 10 moms. She started an online Spanish-speaking meeting in May and parents joined from their homes in several states and even from other countries. She hopes eventually to have a mix of online and in-person meetings.

The virtual switch hasn’t worked for everyone. Harmon said the logistics of video support remain difficult, along with privacy concerns on platforms that could be hacked. Other lactation experts noted Black and Hispanic mothers are sometimes still left behind. So lactation specialists are trying to learn from the pandemic on what worked — and what didn’t — to reach all kinds of new parents.

Before the pandemic, 84% of U.S. mothers breastfed at least initially, according to [2019 data](#) from the Centers for Disease Control and Prevention, while Colorado had a 93% rate.

The pandemic hasn’t seemed to change the picture, said Stacy Miller, Colorado’s breastfeeding coordinator for the Special Supplemental Nutrition Program for Women, Infants and Children, shorthanded as WIC. Citing state birth certificate data, Miller said preliminary breastfeeding rates among families discharged from Colorado hospitals remained similar in the first quarter of 2021 to rates from 2020 or 2019.

Throughout the pandemic, lactation specialists have tried to offer convenient options for parents. St. Joseph Hospital in Denver launched virtual breastfeeding support groups that still occur today, in addition to breastfeeding help during families’ hospital stays, said Katie Halverstadt, the hospital’s clinical nurse manager of lactation and family education.

Last year in [North Carolina](#), experts adapted an in-person prenatal breastfeeding program to an interactive video platform in English and Spanish. A separate effort [on New York’s Long Island](#) successfully converted in-person breastfeeding support to phone and video calls in 2020.

To help support parents in Grand Junction, Colorado, Reynolds expanded her private practice, [Valley Lactation](#), by offering virtual appointments while continuing to see some clients in their homes. That hybrid model continues today, although Reynolds said the demand for virtual or phone appointments has decreased lately as the

country reopens.

Paying out-of-pocket for appointments is a hurdle her clients face, said Reynolds, but she encourages them to submit claims for telehealth or in-person visits to their health insurance companies for reimbursement. Early in the pandemic, [telehealth rules were relaxed](#) to encourage more telephone and virtual appointments — many of which have been covered by insurance.


But insurance coverage for lactation support will likely continue to be an issue independent of whether pandemic telehealth rules expire, USLCA’s Harmon said. While the Affordable Care Act mandates that insurance companies cover lactation support and supplies, such as breast pumps, Harmon said reimbursement is often spotty. Mirroring Medicaid, insurance providers often cover services only from licensed providers, she said, but just four states — Georgia, New Mexico, Oregon and Rhode Island — license lactation consultants.

Experts such as [Jennifer Schindler-Ruwisch](#), an assistant professor at Fairfield University in Connecticut, found the pandemic may have exacerbated breastfeeding barriers for those without access to online technology or translation services, among other things. She published one of [the first studies](#) in the U.S. to examine covid’s effect on lactation services by collecting experiences from lactation support providers in Connecticut, including many working in WIC programs. For income-eligible WIC families, all breastfeeding classes, peer groups and one-on-one consultations are free.

Birdie Johnson, a doula who provides breastfeeding and other postpartum support to Black families as part of [Sacred Seeds Black Doula Collective of Colorado](#), said virtual support groups during the pandemic also did not meet her clients’ needs for connection and interaction. Social media built communities online, particularly by normalizing breastfeeding struggles among Black parents, she said, but obstacles remained.

“Covid brought our community together and at the same time destroyed it,” Johnson said.

Black parents in the U.S. already had lower rates of breastfeeding than Asian or white parents, according to [2017 CDC data](#), and both Black and Hispanic parents have had lower rates of exclusively breastfeeding their babies at 6 months, which is what the American Academy of Pediatrics recommends. Socioeconomics and lack of workplace support have been found to contribute to the gap. Research also has found Black mothers are more likely than white moms to be [introduced to infant formula at hospitals](#).



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A scarcity of Black health care providers in lactation, women's health and pediatrics is a continuing concern, Johnson said. In Colorado last year, the [Colorado Breastfeeding Coalition](#), the [Center for African American Health](#), [Elephant Circle](#) and [Families Forward](#) Resource Center held three training sessions for people of color to become lactation specialists, said Halverstadt, who chairs the coalition.

"You are more confident and more at ease with someone who knows your language, your culture and who is part of the community," said Brenda Rodriguez, a dietitian and certified lactation consultant for [Jefferson County Public Health](#), which reaches roughly 400 breastfeeding families each month through its WIC programs.

Angelica Pereda, a maternal and child health registered nurse, is part of that training program. Pereda, who is Hispanic and bilingual, gave birth to son Ahmias in April 2020 and struggled with breastfeeding because he could not latch on to her breasts. A lactation consultant could not come into her home during the pandemic, and she was skeptical of virtual consultations because of privacy concerns. So she pumped her breast milk and bottle-fed it to her son.

Her experience gave her newfound empathy for families, and she wants to help other Spanish-speaking parents find solutions — whether in person or virtually.

"There is just not enough breastfeeding support in general, but especially when that support is in a different language," said Pereda.

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NT

Shifting respiratory care strategies for preterm infants could lead to improved health outcomes

July 7 2021

A decade's worth of data shows that neonatologists are shifting the type of respiratory support they utilize for preterm infants, a move that could lead to improved health outcomes.

Using two large national datasets that included more than 1 million preterm infants, researchers in a new Vanderbilt-led study found that from 2008 to 2018 there was a greater than 10% decrease in the use of mechanical ventilation for this patient population. Concurrently, there was a similar increase in the use of non-invasive respiratory support, such as continuous positive airway pressure (CPAP), for these infants.

The study, "Changes in Use of Respiratory Support for Preterm Infants in the U.S.," published July 6 in *JAMA Pediatrics*.

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been able to keep a lot of babies off mechanical ventilation and potentially spare them of lung injury and injuries to other organ systems as well."

Dupree Hatch, MD, MPH, Senior Study Author and Assistant Professor of Pediatrics, Division of Neonatology at Monroe Carell Jr. Children's Hospital at Vanderbilt

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during the COVID-19 pandemic

How to protect your little one from germs and viruses

Even though there are some things we don't know about COVID-19 yet, there are many more things that we do know. We know that there are proven protective measures that we can take to stay healthy.

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- Use soap.
- Wash for more than 20 seconds.
- Use alcohol-based sanitizers.



Limit Contact with Others

- Stay home when you can.
- Stay 6 feet apart when out.
- Wear a face mask when out.
- Change your clothes when you get home.
- Tell others what you're doing to stay safe.



Provide Protective Immunity

- Hold baby skin-to-skin.
- Give them your breast milk.
- Stay current with your family's immunizations.



Take Care of Yourself

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



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

WARNING

Never Put a Mask on Your Baby

- Because babies have smaller airways, a mask makes it hard for them to breathe.
- Masks pose a risk of strangulation and suffocation.
- A baby can't remove their mask if they're suffocating.



If you are positive for COVID-19

- Wash with soap and water and put on fresh clothes before holding or feeding your baby.
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For preterm infants, mechanical ventilation can have adverse pulmonary and neurodevelopmental outcomes. To reduce these risks, neonatologists over the past two decades have been exploring and researching non-invasive respiratory support options like CPAP therapy for these infants. Much of the shift in mechanical ventilation seen in the study coincided with a large study released in 2010 that showed mechanical ventilation was not superior to non-invasive ventilation, and in fact may involve more risks.

“In multiple studies mechanical ventilation has been associated with adverse outcomes. There are several studies that show for every week you stay on a ventilator as a preterm baby, your odds of having adverse neurodevelopmental outcomes go up,” Hatch said.

“Since large studies were published in 2008, 2010 and 2011 showing the effectiveness of non-invasive respiratory support, we thought that respiratory support patterns in preterm infants had likely changed, but no one had really quantified that, or looked if it was widespread across the entire country or if it was just in pockets.”

Related Stories

- [Children exposed to second-hand marijuana smoke may experience viral respiratory infections](#)
- [How antibody production in the lungs can determine severe respiratory infections](#)
- [Study suggests potential role for probiotics in preventing respiratory infections](#)

Hatch and colleagues examined two large national datasets, confirming the changes in practices. They looked at data collected over an 11-year period on the type of respiratory support used for infants born between 22 weeks’ and 34 weeks’ gestation.

In one of the study datasets that included admissions to over 350 NICUs in the U.S., they found that mechanical ventilation utilization in preterm infants decreased from 29.4% in 2008 to 18.5% in 2018. Nationally, the study authors wrote, the changes were associated with about 30,000 fewer infants receiving mechanical ventilation during the study period. As the number of infants on mechanical ventilation went down, the duration of time that ventilated babies spent on mechanical ventilators also went down.

Also, in their findings, researchers discovered that the total number of days on non-invasive respiratory support went up across all gestational ages from 13.8 days to 15.4 days. Hatch said more research is needed to understand the implications of spending more time on non-invasive respiratory support therapies.

“We need to figure out if the increase in duration of respiratory support is a good thing, and what does that do to NICU length of stay and overall resource utilization for preterm infants in the U.S. It raises more questions,” he said.

Additionally, they saw an increase in the number of extremely preterm infants, 22 to 24 weeks’ gestation, being placed on mechanical ventilation as there has been increased intervention and im-

proved survival for this age group. Hatch notes that the respiratory support strategies for this particular population of infants needs more examination.

“The field of neonatology has worked really hard to examine our practices and get better. I am proud of how quickly some of the landmark respiratory care studies have penetrated our clinical care,” said Hatch. “Care in the NICU is becoming less invasive and gentler because it is the right thing to do for babies’ long-term outcomes.”

Journal reference:

Dupree Hatch III, L., *et al.* (2021) Changes in Use of Respiratory Support for Preterm Infants in the US, 2008-2018. *JAMA Pediatrics*. doi.org/10.1001/jamapediatrics.2021.1921.

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The Genetics Corner: A Mother and Child with Cleft Lip and Palate Have an Atypical 1p36 Deletion that Disrupts KIF1B, a Cause of Autosomal Dominant Charcot-Marie-Tooth Disease, Type 2A1

Subhadra Ramanathan, MSc MS, Robin Dawn Clark, MD

Case History:

An eight-week-old male infant with prenatally diagnosed bilateral cleft lip and palate was initially evaluated by the genetics team during a Craniofacial Team clinic appointment. His mother reported that prenatal care was intermittent, and the pregnancy was stressful due to emotional conflict with her partner. The baby was delivered by NSVD at term to a 42-year-old G2P1→2 woman at a local community hospital. The baby was in the NICU for 12 days for feeding issues related to the oral cleft. BW was 2454 g (Z score -2.01), discharge weight was 2531 g. By eight weeks of age, he failed to thrive, and his weight was low at 2060 g (Z score -4.58). He had a poor suck, and there was concern that the formula had not been mixed appropriately at home. After his cleft lip and palate repair at eight months, his growth improved. His last recorded weight at 12 months was 9.48 kg (Z score -0.27).

“By eight weeks of age, he failed to thrive, and his weight was low at 2060 g (Z score -4.58). He had a poor suck, and there was concern that the formula had not been mixed appropriately at home. After his cleft lip and palate repair at eight months, his growth improved.”

At eight weeks, he was developing appropriately. He smiled socially, laughed, and vocalized responsively. He regarded a face. He reached out for and mouthed objects. He moved all extremities symmetrically with good muscle tone and muscle mass.

The family history was significant for cleft lip in his mother, who had a repaired unilateral cleft lip and palate, right exotropia, and learning disabilities, although she was in regular classes. She did not graduate from high school. On examination, she had bilateral pes cavus and extensive, thick calluses on the plantar surfaces of both feet, suggesting a sensory neuropathy. The mother reported that her sister has a possible diagnosis of hereditary sensory and motor neuropathy (Charcot-Marie-Tooth disease or CMT). She had another sister who died at age 2 of heart problems.

“The mother reported that her sister has a possible diagnosis of hereditary sensory and motor neuropathy (Charcot-Marie-Tooth disease or CMT). She had another sister who died at age 2 of heart problems.”

Chromosome microarray analysis was ordered at this visit and revealed a 2.8 megabase interstitial deletion on chr1p36, subsequently confirmed to be maternally inherited: arr[hg19] 1p36.22p36.21(10,388,064-13,182,587)x1. The infant and his mother have an atypical interstitial 1p36 deletion that interrupts *KIF1B*, a gene associated with autosomal dominant Charcot-Marie-Tooth

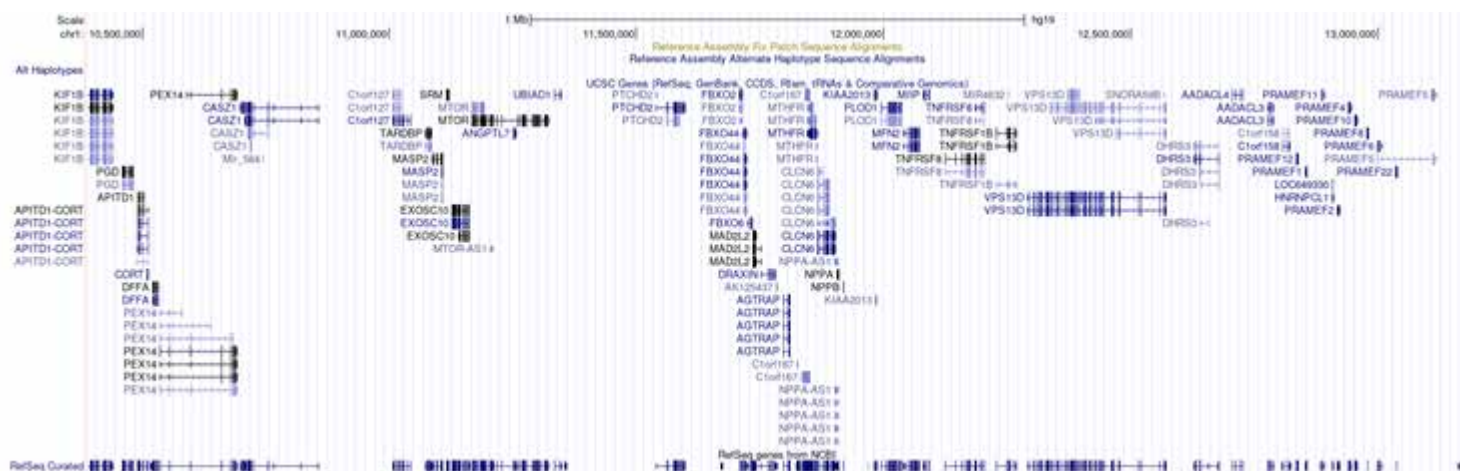


Figure 1: The genomic coordinates from the microarray report were used to identify the genes involved in this familial interstitial 1p36 deletion. The genomic coordinates were inputted in the UCSC genome browser (<https://genome.ucsc.edu>), which shows that the distal breakpoint interrupts *KIF1B* (far left), a gene associated with autosomal dominant Charcot-Marie-Tooth disease (CMT).

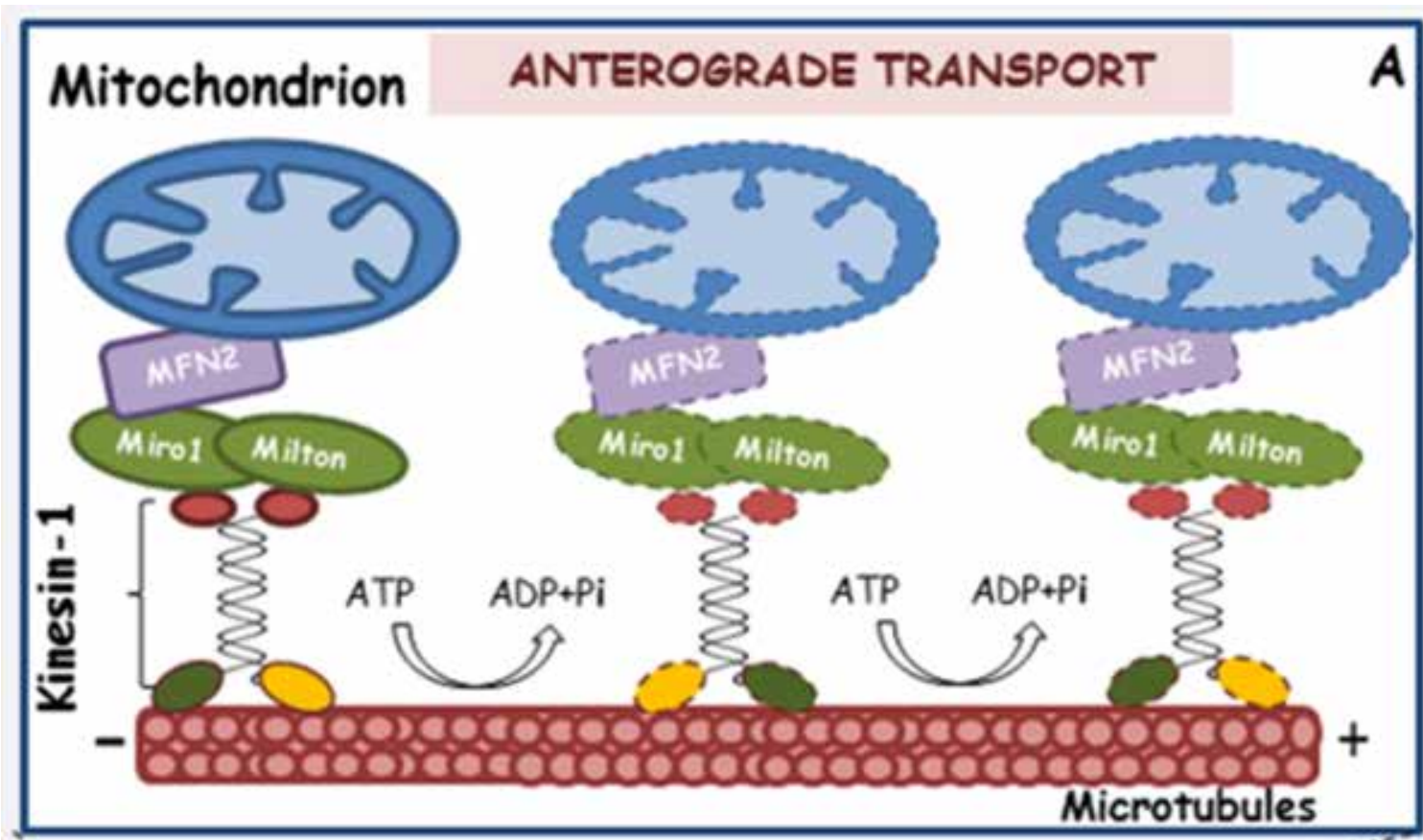


Figure 2: *KIF1B* encodes the kinesin-1 protein, a key component of a “molecular motor” that transports mitochondria in the peripheral nerve axon. This illustration shows how mitochondria are normally “walked” up the axon by coordinating the alternative binding and releasing of the two kinesin heads, keeping one head bound to the microtubular pathway at all times. Most kinesins move toward the plus end of the microtubular pathway. (Adapted from Pareyson, et al. 2015.) (2)

disease, type 2A1 (Figure 1). The mother underwent gene sequencing and deletion/duplication analysis for *KIF1B* (Invitae) that confirmed a large deletion in one homologue. She has been referred for a neurological assessment at a neuromuscular disease clinic.

Assessment:

The 1p36 deletion syndrome (OMIM 607872) occurs in 1 in 5000 newborns and is one of the most commonly reported chromosome deletion syndromes. Most are pure terminal deletions, and a smaller number are caused by interstitial deletions of varying size and position (10-29%). Mosaicism and unbalanced translocations have been reported less commonly. There is wide clinical variability in chromosome 1p36 deletion syndrome, as the deletions vary in size, up to 30 Mb of DNA. There is no single common breakpoint.

The classic 1p36 deletion syndrome can be recognized by characteristic facial features: straight eyebrows, deep-set eyes, a wide nasal bridge with a pointed chin, and posteriorly-rotated, low-set,

abnormal ears. Affected individuals have late-closing anterior fontanel, microcephaly, microbrachycephaly, and, often, seizures (44%-58%). Brain anomalies, orofacial clefting, congenital heart defects, cardiomyopathy, usually left ventricular noncompaction type, renal anomalies, and sensorineural hearing impairment are common. The region on 1p36 that is responsible for cleft lip and palate has not been delineated. The areas on 1p36 that are responsible for dysmorphic features and intellectual disability have been narrowed to 2 critical regions. (1)

Our patient’s 2.8 Mb deletion is smaller and more proximal than the more typical and generally larger classic, terminal 1p36 microdeletions. This may help define and narrow the critical region associated with oral clefting in this syndrome. It is not clear at this time whether the maternal aunt who has CMT also has the familial chromosome 1p36 deletion, but she does not have an oral cleft. Our patient and his mother do not have hypotonia or dysmorphic facial features described in the classic 1p36 deletion syndrome. Our patient has bilateral cleft lip and palate and hypertelorism but none of the other classic facial features. His echocardiogram



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Figure 3: Bilateral cleft lip and palate, hypertelorism and infraorbital creases in the child and repaired unilateral cleft lip in his mother.

was normal. He had failure to thrive but has been gaining weight steadily since his surgical repair.

Charcot-Marie-Tooth disease (CMT) is divided into type 1, the demyelinating form, characterized by a slow motor nerve conduction velocity (NCV) (less than 38 m/s), and type 2, the axonal form, with a normal or slightly reduced NCV.

The energy requirements of peripheral nerve axons depend on the proper function and distribution of mitochondria. Abnormal mitochondrial transport along the axonal microtubular system can present as peripheral neuropathy and Charcot-Marie-Tooth disease. *KIF1B* (OMIM 605995, hg19 chr1:10,270,764-10,441,661) encodes a kinesin family motor protein, kinesin-1, that acts as the main anterograde motor in axons and binds mitochondria through adaptor proteins (Figure 2). Heterozygous pathogenic variants in *KIF1B* cause Charcot-Marie Tooth Disease axonal type 2A1, CMT2A1 (OMIM 118210).

Although the loss of the *KIF1B* gene or *haploinsufficiency* alone does not cause CMT2A1 and CMT has not been previously described in the 1p36 deletion syndrome phenotype, (3) we postulate that in this case, disruption of *KIF1B* produces an abnormal gene product that interrupts normal axonal transport of mitochondria and causes CMT2A1. The mother has suggestive clinical findings of CMT; she has not yet undergone formal neurologic assessment and confirmatory diagnosis. If the diagnosis of CMT2A1 is confirmed in her, we anticipate that our patient will also exhibit signs of Charcot-Marie-Tooth disease, type 2A1, with time.

Practical Applications:

1. Carefully examine the parents of infants with congenital anomalies and take a detailed family history. In this case, the family history of an aunt with CMT leads us to examine the mother more thoroughly.
2. Use chromosome microarray as a first-line diagnostic test. Suspect a microdeletion or microduplication when intellectual disability, learning problems, delayed development, or congenital anomalies are seen in the parent of an affected child.
3. Recognize that 1p36 microdeletion syndrome is a relatively common and variable microdeletion syndrome, including cleft lip and palate.
4. Input genomic coordinates at <https://genome.ucsc.edu> to identify genes in the chromosome segment of interest and pay attention to genes at the breakpoints that the deletion or duplication may disrupt.

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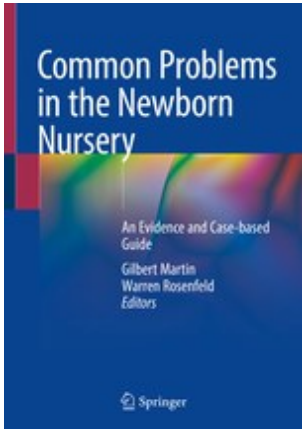
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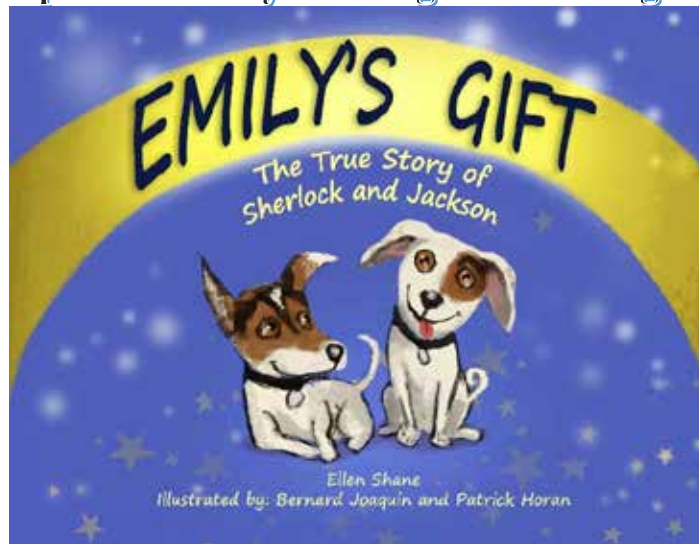
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False Alarms Signal Urgency of Infant-Specific Devices

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.

I am a neonatologist by training, a “neo-gadgetologist” by passion. I love testing out device prototypes and integrating new technologies at the hospital where I practice. I get excited by their potential to improve care for the infants we treat.

But when it comes to medical innovation, I am acutely aware that not all patients are the same. The premature babies I care for are not just tiny adults. We cannot just give them a smaller dose of an adult medication or use a smaller version of an adult device and expect the same outcome.

Take a pulse oximeter, for example. Most people know it as the “ET light” that goes on the end of your finger. The sensor measures the oxygen saturation in a patient’s blood.

The pulse oximeter was first developed in the early 1970s. Its widespread use helped reduce fatalities. Oxygen saturation monitoring became another vital sign – along with temperature, blood pressure, pulse rate, and respiratory rate. The device saved thousands of – mostly adult – lives. (1)

As recently as the early 1990s, however, the devices were unreliable when used on children, especially tiny babies. Monitoring in situations where there was high motion and low perfusion – reduced blood flow to the fingers and toes – was not an easy task. The device was designed to work in mostly optimal conditions on

adult patients.(2)

The frequent alarming and inability to rely on these devices led to some babies inadvertently receiving too much oxygen. Excess oxygen can cause retinopathy of prematurity, the condition that robbed singer-songwriter Stevie Wonder of his sight shortly after birth in 1950.

“These newborns needed someone to adapt the technology for their use. That work was already underway, but getting this technology to those most in need was yet another challenge.”

In the NICU, the machines constantly alerted us about inaccurate low oxygen saturation or an inability to read a saturation at all. Frustrated by the false alarms, a colleague walked around one day and unplugged all the machines. While we eventually plugged them all back in, his bold move caught my attention. These newborns needed someone to adapt the technology for their use. That work was already underway, but getting this technology to those most in need was yet another challenge.

I share this story as a reminder of the vital role of ongoing innovation.

Dr. Takuo Aoyagi’s initial pulse oximeter saved tens of thousands of lives. I am thankful he – and subsequent innovators – did not stop with the first iteration of this device, or we’d still have morbidity and mortality from conditions that are now preventable, especially among premature babies.(2, 3)

In addition to infant pulse oximetry, the newborns I treat rely on various medical technologies every day. Some are standalone machines; others are devices carefully, surgically implanted in even the tiniest babies. All allow me to practice more patient-centered care. They also pique my interest in what is around the corner.

Propelling the next generation of medical devices from concept to reality requires financial support and political capital. It requires a willingness from patients to participate in clinical trials and from providers, like me, to be early adopters. This broad show of support is necessary to advance the practice of medicine – and save lives. We must challenge each horizon daily and look to what the dawn of each new technology brings.(4)

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clinical practice decrease the incidence of severe retinopathy of prematurity in very low birth weight infants? *Pediatrics*. 2003;111(2):339-45. Epub 2003/02/04. doi: 10.1542/peds.111.2.339. PubMed PMID: 12563061.

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Disclosure: the author is a neonatologist in Loma Linda, California, and the medical director for the National Coalition for Infant Health.

NT



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National Coalition for Infant Health Values (SANE)

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

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

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

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

Which Infants are More Vulnerable to Respiratory Syncytial Virus?

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

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

*Source: Respirator Syncytial Virus and African Americans

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



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



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The Premie Parent's SURVIVAL GUIDE to the NICU

By

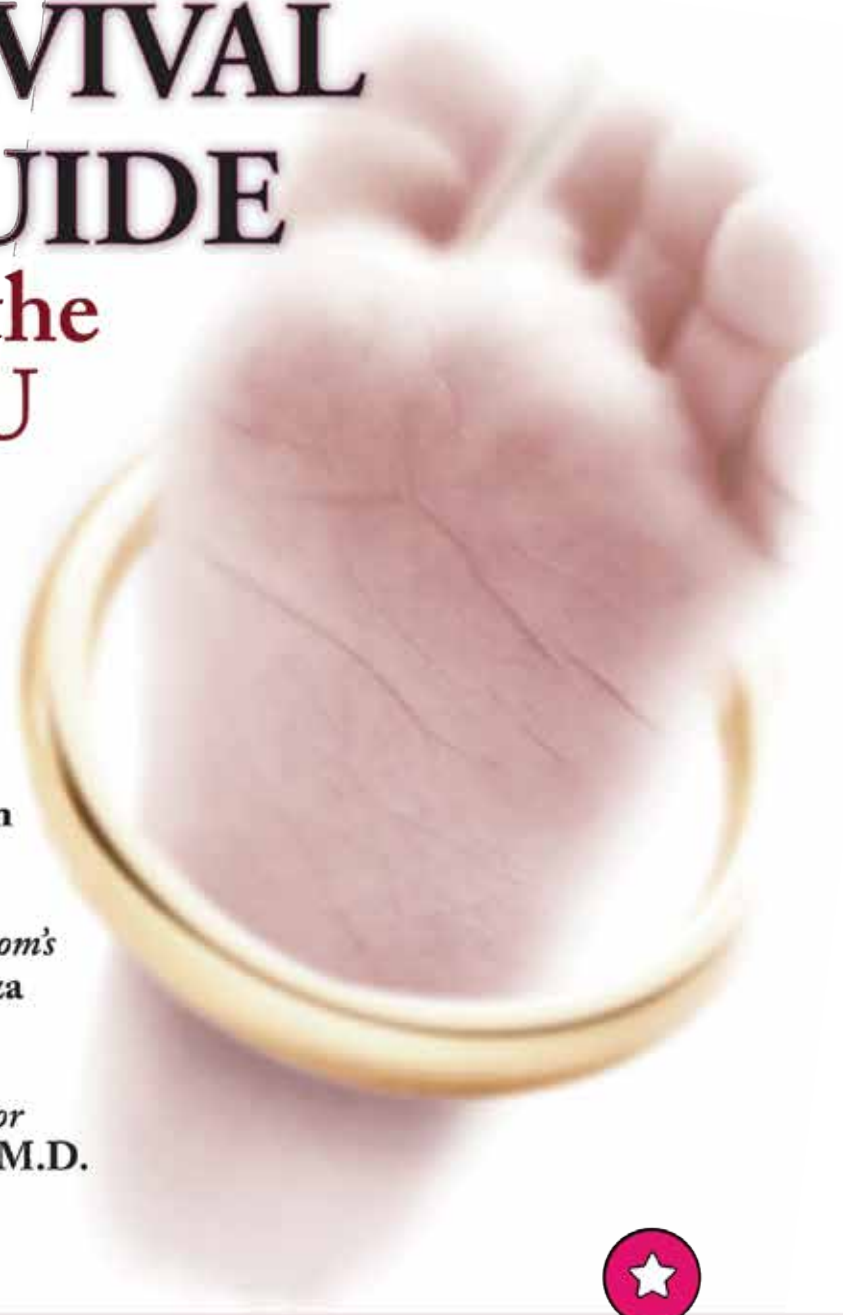
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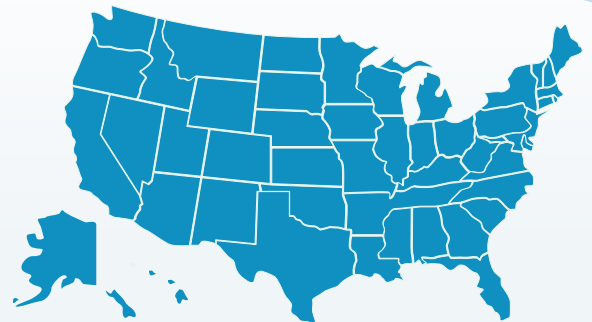
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National Statistics

Respiratory Syncytial Virus



About Respiratory Syncytial Virus

Respiratory syncytial virus, or RSV, is a contagious seasonal respiratory virus that can cause bronchiolitis and pneumonia. It is also the leading cause of hospitalization in babies less than one year old.¹ RSV can be deadly for premature infants and at-risk infants with congenital heart disease or chronic lung disease.

Preventive treatment called palivizumab can protect infants from RSV, but national claims data shows certain babies aren't getting access to this FDA-indicated therapy.

National Health Plan Coverage & Access

A national data supplier provided palivizumab claims for Medicaid and commercial health plans across the nation from January 2019 through December 2019.



"Gap" Babies

Commercial Plans Denied

40%

Medicaid: **25%**

Health plans deny 40% of palivizumab prescriptions for premature infants born between 29 and 36 weeks gestation.



"In-Guidance" Babies

Commercial Plans Denied

25%

Medicaid: **14%**

One in every four prescriptions is denied for infants who should qualify for coverage under standard insurance policies.

This includes severely premature infants born before 29 weeks gestation, babies born before 32 weeks gestation who have chronic lung disease, and babies born with congenital heart disease.

National Perinatal Association PERINATAL SUBSTANCE USE

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barriers that
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accessing care.
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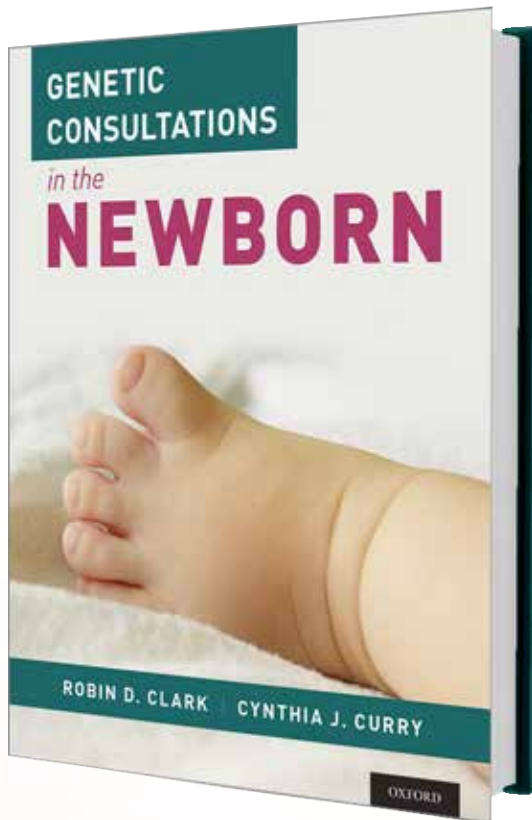


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RSV AWARENESS:

A National Poll of Parents & Health Care Providers

Respiratory syncytial virus, or RSV, is far from the common cold. It can lead to hospitalization, lifelong health complications or even death for infants and young children. **In fact, it is the leading cause of hospitalization in children younger than one.**

Yet a national poll of parents and specialty health care providers reveals a startling divide in attitudes toward the virus. While both groups acknowledge RSV as a significant concern, the two populations vary widely in their reported ability to meet RSV's threat head-on. Health care providers vigilantly

monitor for the virus, which they report seeing regularly in their practices. Parents, however, feel unequipped to protect their young children.

Meanwhile, specialty health care providers overwhelmingly report that health plan rules and insurance denials block vulnerable infants' access to preventive RSV treatment. Such barriers can put unprepared parents at a double disadvantage. The survey does suggest, however, that education can embolden parents to seek more information about RSV and take steps to protect their children.

KEY FINDINGS

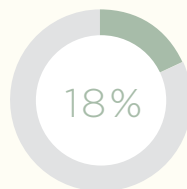
Preparedness

Parents of children age four and under report that understanding of RSV is lacking. That leaves them less than fully prepared to prevent their young children from catching the virus.

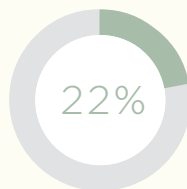
Specialty health care providers reiterated these concerns; 70% agreed that parents of their patients have a low awareness of RSV. Meanwhile, specialty health care providers themselves actively monitor for RSV. They reported that:

PARENTS

Only 18% said parents know “a lot” about RSV, reflecting an awareness level that’s roughly half that of the flu

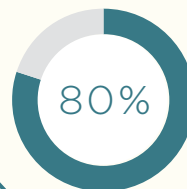


Only 22% of parents consider themselves “very well prepared” to prevent RSV.

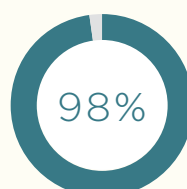


SPECIALTY HEALTH CARE PROVIDERS

They treat RSV as a priority, “often” or “always” evaluating their patients (80% doctors; 78% nurses)



During RSV season, they are especially vigilant about monitoring patients for symptoms or risk factors for RSV (98%).



Clinical Pearl: Inhaled Budesonide with Surfactant Decreases BPD Rates Without Affecting Neurodevelopmental Outcomes

Melanie Wielicka, MD, PhD, Joseph R Hageman, MD

“Since Bronchopulmonary Dysplasia (BPD) was first described over 50 years ago, we have made significant progress in understanding its pathophysiology, risk factors, prevention, and management.”

Since Bronchopulmonary Dysplasia (BPD) was first described over 50 years ago, we have made significant progress in understanding its pathophysiology, risk factors, prevention, and management. Nevertheless, BPD remains one of the most common and devastating chronic medical conditions faced by premature infants, with incidence rates ranging between 15-35% among infants born before 32 weeks gestation (1).

Recently, the use of budesonide with surfactant has been shown to decrease BPD rates and severity (2). It has been suggested that surfactant administration facilitates the delivery of other medications, including budesonide (3). However, budesonide has been detected at high levels in plasma within 15 minutes of intratracheal administration in preterm sheep, with levels gradually decreasing but still detectable by 24 hours after administration (4). Studies on human infants have also shown that inhaled budesonide is absorbed into the circulation, with an estimated elimination half-life of 4 hours. (3) Given that steroid use in premature infants has a well-known association with adverse neurodevelopmental outcomes, it is crucial to evaluate the long-term, systemic effects of inhaled corticosteroids in this group of patients. Outcome data was evaluated in a recent observational study by Anderson et al. (5).

The authors analyzed data from the neonatal intensive care unit at the Saint Louis University and SSM Health Cardinal Glennon Children’s Hospital after a clinical practice change in 2016, administering intratracheal budesonide combined with pulmonary surfactant in all infants born at birth weight at or below 1,250g who failed an initial CPAP trial within the first 24 hours of postnatal life or were intubated in the delivery room. The authors compared the infants who received the combination of surfactant and budesonide between 2016-2018 to a historical cohort of infants who received surfactant alone between 2013-2016, looking into data of 470 infants. There was statistically less severe type 2 and 3 BPD in the surfactant and budesonide group ($p < 0.03$ and $p < 0.02$, respectively) (5). The patients were monitored in the outpatient setting and evaluated with the Peabody Developmental Motor Scales II at 4-6 months corrected age and Bayley Scales of Infant and Toddler development III at 18-22 months corrected age. The comparison of results revealed no significant differences between the

two groups. Additionally, the number of hospitalizations and emergency room visits were similar, with less use of nebulized albuterol in patients who received surfactant and budesonide.

What is worth noting, both BPD and the use of postnatal steroids carry the risk of adverse neurological outcomes (6). Therefore, one could argue that using corticosteroids in patients with more severe RDS appears to have a more reasonable risk-to-benefit ratio. The authors cite data by Yeh et al., who demonstrated a significant decrease in BPD rates from 50% to 29% using budesonide and surfactant, and did not show significant differences in neurodevelopmental outcomes when comparing to infants treated with surfactant alone (3). The data presented by Anderson et al. provide additional value as the cohort of infants included in their study had less severe RDS, potentially advocating for inhaled corticosteroids with surfactant in premature infants regardless of RDS severity.

“Combined with the available studies on the impact of budesonide/surfactant therapy on rates of BPD, we will hopefully be able to implement this promising treatment as a standard of care across the country, pending larger clinical trial results.”

More data is still needed to help develop specific guidelines regarding this mode of therapy, and, as the authors point out, large, randomized trials are underway (7,8). However, the data presented by Anderson et al. are certainly very encouraging from a safety perspective. Combined with the available studies on the impact of budesonide/surfactant therapy on rates of BPD, we will hopefully be able to implement this promising treatment as a standard of care across the country, pending larger clinical trial results.

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- Preventing Chronic Lung Disease in Extremely Preterm Infants Using Surfactant + Steroid (PLUSS) (ACTRB12617000322)

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NT

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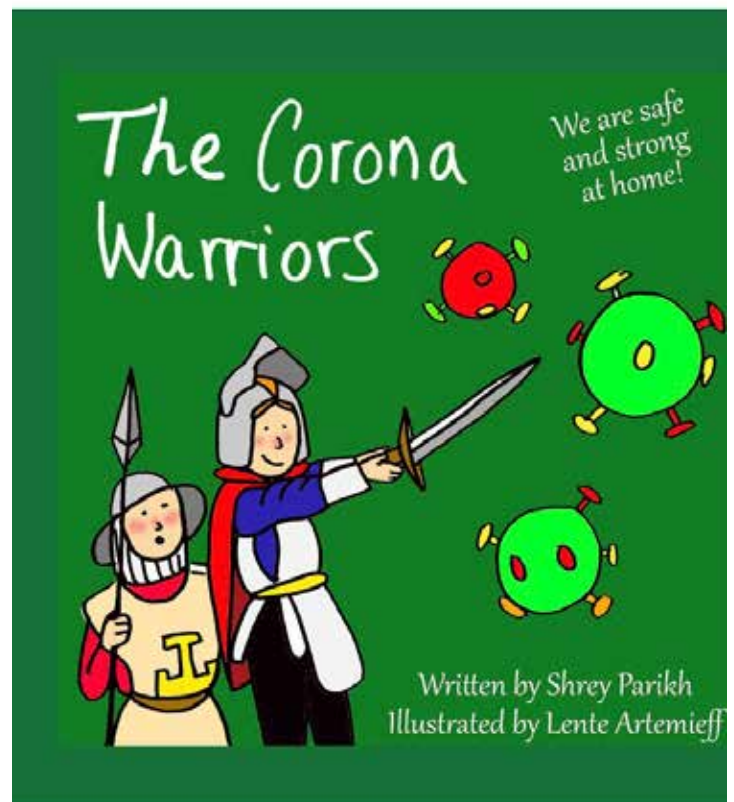
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OPIOIDS and NAS

When reporting on mothers, babies, and substance use

LANGUAGE MATTERS



I am not an addict.

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



I was exposed to opioids.

While I was in the womb my mother and I shared a blood supply. I was exposed to the medications and substances she used. I may have become physiologically dependent on some of those substances.



NAS is a temporary and treatable condition.

There are evidence-based pharmacological and non-pharmacological treatments for Neonatal Abstinence Syndrome.



My mother may have a SUD.

She might be receiving Medication-Assisted Treatment (MAT). My NAS may be a side effect of her appropriate medical care. It is not evidence of abuse or mistreatment.

My potential is limitless.

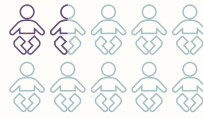
I am so much more than my NAS diagnosis. My drug exposure will not determine my long-term outcomes. But how you treat me will. When you invest in my family's health and wellbeing by supporting Medicaid and Early Childhood Education you can expect that I will do as well as any of my peers!



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



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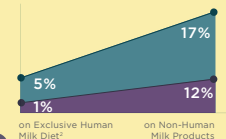


MICRO PREMIES are at risk for Necrotizing Enterocolitis (NEC), which:

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- Threatens infants' lives

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Why Is An Exclusive Human Milk Diet Important?

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When a micro preemie can access an EXCLUSIVE HUMAN MILK DIET:



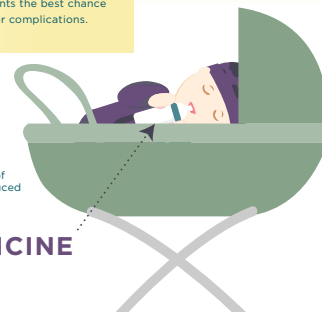
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Feeding intolerance decreases*



Chances of NEC are reduced by **77%***



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* Hair AB, et al. "Beyond Necrotizing Enterocolitis Prevention: Improving Outcomes with an Exclusive Human Milk-Based Diet." *Breastfeeding Medicine* 2015; 10:108-116. DOI: 10.1089/bfm.2015.0104
 † Abrams SA, et al. "Greater Mortality and Morbidity in Extremely Premature Infants Fed a Diet Containing Cow Milk Protein Products." *Breastfeeding Medicine* July/August 2014; 9(6): 281-285
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Defining the Lines: Coding for the Neonatal Delivery and Admission

Kate Peterson Stanley, MD, FAAP

“As a race, the initial care of a premature newborn infant begins with the delivery and ends with the admission. In between, multiple procedures may be performed to stabilize the infant. Coding for these procedures depends on where the delivery ends and the admission begins.”

While watching the Tokyo Olympic Track and Field events this past month, I couldn't help but think about the well-defined beginning and end of each race. Glory or defeat is defined by the runner's performance between the start and finish line. For any given race, the outcome changes depending on what occurs between those two lines. As a race, the initial care of a premature newborn infant begins with the delivery and ends with the admission. In between, multiple procedures may be performed to stabilize the infant. Coding for these procedures depends on where the delivery ends and the admission begins. When procedures are required to support acute inadequate ventilation or cardiac output during delivery room resuscitation, they are coded separately from the delivery room care. In contrast, when procedures are part of ongoing care post-resuscitation, they are bundled with the neonatal critical/intensive care admission codes as a “package” and are not coded separately. Examples include intubation for surfactant administration or umbilical line placement for vital sign monitoring and medication administration. In the past, many providers determined the difference between these two events by location. Procedures performed in the corner of the mother's room to stabilize the infant directly after birth were part of the “delivery room resuscitation.” Afterward, the infant was placed in an incubator and wheeled to a bed space in the NICU. Additional procedures were included in the “admission.” With the development of Golden Hour protocols and high-tech delivery room resuscitation bays, the lines defining the end of the delivery and the beginning of the NICU admission may be gray. But, despite a change in where we deliver care, the “lines” of CPT coding rules remain the same.

Scenario:

A neonatologist at a regional neonatal center is called to the ER for an emergency delivery of a 29-week premature infant. The mother is en route to the hospital by ambulance after going into labor while at the shopping mall. The infant is delivered before you arrive. The ER physician provides the initial steps of newborn resuscitation (NRP) at a warmer in the trauma room. When you arrive at the warmer 3 minutes after delivery, you assess the infant, provide PPV, intubate the baby due to persistent respiratory failure and continue to follow NRP guidelines. The infant responds to these resuscitative measures. Apgars are 2/6/8. Birthweight is 1100 grams. You speak with the mother and continue to care

for the infant while the NICU prepares a bed, and the ER team attends to another emergency. CXR shows RDS. While waiting, you give surfactant, stabilize the infant on a ventilator, place a UVC and begin starter TPN. When the bed is ready, the infant is transferred to the NICU for further care. The total time you spent in the ER was 65 minutes.

The correct CPT codes for the neonatologist are:

- A. 99465 Delivery room resuscitation
- B. 99464 Delivery room attendance
- C. 99468 Admission of a critically ill newborn, < 29 days
- D. 99291 Evaluation and management of a critically ill patient, first 30-74 minutes
- E. 31500 Intubation
- F. 36510 Catheterization of umbilical vein (UVC)
- G. 94610 Surfactant



Answer: A, C, E

- A. **99465:** This CPT code is the correct code for the “work” provided at the newborn's birth resuscitation: providing NRP including PPV and/or chest compressions to establish ventilation and/or cardiac output, visually inspecting the infant, assigning Apgars, and updating the parents. Although the ER physician was the first provider at the resuscitation, the neonatologist provided the majority of the work, so it is appropriate for the neonatologist to bill for the encounter. This code may only be used for resuscitation provided at the time of birth, regardless of birth location.

- B. **99464:** This CPT code should be used when resuscitation of the newborn does not require PPV or other measures such as CPR. It includes providing the initial stabilization steps of NRP (drying, stimulation, suctioning), providing blow-by oxygen, CPAP without PPV, visual inspection of the infant, Apgar assignment, and discussion with the parents. Like 99465, it may only be used at the time of birth, regardless of birth location.
- C. **99468:** This is the correct CPT code for the inpatient admission of a critically ill newborn < 29 days of age. It is an age-based, global, per diem, bundled code. The infant meets the criteria for critical care secondary to respiratory failure requiring ventilator management. Critical care may be provided in any location such that the patient has an illness or injury that acutely impacts one or more vital organ systems where there is a high probability of imminent or life-threatening deterioration in the patient's condition. The care provided must involve high complexity decision-making to assess, manipulate and support vital system function to treat vital organ system failure and/or prevent further life-threatening deterioration. In this specific situation, the modifier 25 is appended to the admission code to signify a significant, separately identifiable E/M by the same physician on the same day as another service (the delivery room intubation).
- D. **99291:** This code is used when providing critical care to patients older than 6 years of age, co-managing a critically ill patient in a consultative role or when providing critical care services to a patient transferred to a separate institution on the same day. In the scenario above, the ER physician could have used this code if he/she had assisted the neonatologist with stabilizing the infant after the delivery resuscitation for a minimum of 30 minutes.
- E. **31500:** The neonatologist may code for the intubation performed during the delivery resuscitation because it is a distinct, separate procedure and was required to support inadequate ventilation immediately following birth. It is not included or "bundled" as part of the resuscitation code. If the neonatologist performed the intubation after the delivery room resuscitation, it is considered part of the admission. The neonatologist would not code for the procedure because it is bundled into the global newborn admission code.
- F. **36510:** Since the UVC was placed to provide nutritional support as part of the NICU admission, the neonatologist would not code for it. An umbilical line (venous or arterial) is a bundled procedure when using the global newborn admission code 99468. If a UVC was required during the delivery room resuscitation for management of acute inadequate cardiac output, the neonatologist may code for the procedure. If more than one procedure is required during the resuscitation, modifier 59 "Distinct Procedural Service" is added to the additional procedures.
- G. **94610:** Similar to UVC placement, the neonatologist may not code for surfactant administration because it is bundled with the admission code 99468. On rare occasions, the surfactant is administered as part of newborn resuscitation in acute inadequate ventilation and/or cardiac output. The provision of surfactant immediately following resuscitation as part of a delivery room protocol is considered part of the admission process and is therefore bundled into the global

newborn admission code. If the provider is coding for hourly critical care services as a consultant or when transferring the infant to another service or institution for ongoing care, surfactant administration, UVC and intubation may be coded in addition to hourly critical care since they are not bundled procedures when providing this service.

The correct ICD-10 codes are:

- Z38.00 Single liveborn infant delivered vaginally
- P07.14 Other low birth weight newborn, 1000-1249 grams
- P07.32 Preterm newborn, gestational age 29 weeks
- P22.0 Respiratory distress syndrome of the newborn

The Finish Line:

Defining when newborn resuscitation ends and the NICU admission begins is not always easy because each newborn runs a different race. When the lines are gray, I consider this coding pearl: Any procedure required to establish ventilation and cardiac output during newborn resuscitation to obtain an Apgar > 7 is considered delivery room care and is not included in the admission. With this in mind, I can see the finish line and complete the race.

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TOP 10

RECOMMENDATIONS FOR THE PSYCHOSOCIAL SUPPORT OF NICU PARENTS



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

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

1 PROMOTE PARTICIPATION

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



2 LEAD IN DEVELOPMENTAL CARE

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



3 FACILITATE PEER SUPPORT

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



4 ADDRESS MENTAL HEALTH

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



5 SCREEN EARLY AND OFTEN

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



6 OFFER PALLIATIVE & BEREAVEMENT CARE

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

7 PLAN FOR THE TRANSITION HOME

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



8 FOLLOW UP

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

9 SUPPORT NICU CARE GIVERS

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



10 HELP US HEAL

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

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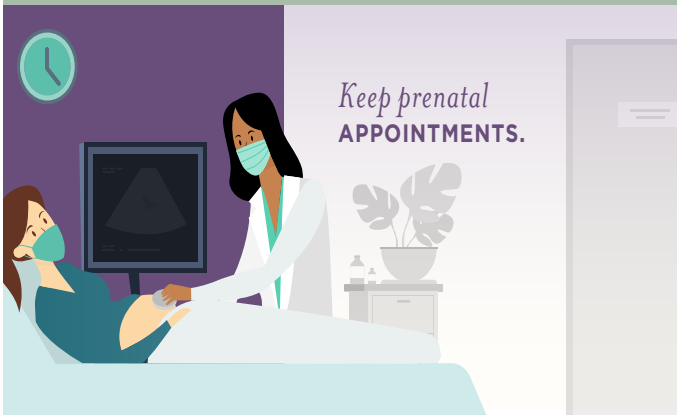
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A 30-DAY SUPPLY
OF YOUR MEDICATIONS.



Keep prenatal
APPOINTMENTS.



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

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

SUPPORTING KANGAROO CARE

SKIN-TO-SKIN CARE DURING
COVID-19



GET INFORMED
ABOUT THE
RISKS + BENEFITS

work with your medical
team to create a plan

GET CLEAN
WASH YOUR HANDS,
ARMS, and CHEST

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



PUT ON
FRESH CLOTHES

change into a clean
gown or shirt.



IF COVID-19 +
WEAR A MASK

and ask others to
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From the National Perinatal Information Center: Raising the Bar: Elevating Breastmilk Utilization Rates for ALL Babies

Elizabeth Rochin, PhD, RN, NE-BC

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

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



“Each August, hospitals, organizations, and communities rally to recognize National and World Breastfeeding Awareness Month. Despite these annual calls to action, breastfeeding and breastmilk utilization rates in the NICU continue to reveal significant racial and ethnic disparities, particularly among very low birthweight infants (VLBW, < 1500 grams).”

Each August, hospitals, organizations, and communities rally to recognize National and World Breastfeeding Awareness Month. Despite these annual calls to action, breastfeeding and breastmilk utilization rates in the NICU continue to reveal significant racial and ethnic disparities, particularly among very low birthweight infants (VLBW, < 1500 grams). In the US, Black women deliver VLBW babies 2.6 times more often than white women (1) while less likely to initiate mother’s own milk (MOM) during hospital-

ization and at discharge. The American Academy of Pediatrics (2012) recommends MOM exclusively for the first six months of life, particularly for VLBW infants. (2)

“In 2017, the Centers for Disease Control and Prevention published data that described the use of Mother’s Own Milk (MOM) was lower in hospitals located in areas with higher percentages of Black residents(3).”

Racial and Ethnic Disparities Among Breastmilk Initiation and Utilization

In 2017, the Centers for Disease Control and Prevention published data that described the use of Mother’s Own Milk (MOM) was lower in hospitals located in areas with higher percentages of Black residents(3). Over the next four years, multiple publications from various locations throughout the US would describe the same phenomena:

1. Parker and colleagues (2019) described a Massachusetts study that found MOM initiation was similar across racial groups, but infants in the non-Hispanic Black and Hispanic mothers stopped receiving MOM earlier in the hospitalization than non-Hispanic white mothers. (4)
2. Ellis and colleagues (2020) described a convenience sample of 1,160 babies in which Black babies were less likely to be discharged to home on MOM ($p < 0.001$) than any other racial or ethnic group(5)
3. Patel and colleagues (2019) found similar findings in a separate setting. 98% of VLBW babies initiated MOM provision; however, significantly fewer ($p < 0.001$) VLBW Black babies were providing MOM at discharge. Black women had a lower pumping frequency ($p < 0.001$) than other racial or ethnic groups. (1)
4. Brignoni-Pérez and colleagues (2020) conducted a study on the use of Kangaroo Care (KC) and its impact on breastfeeding in the NICU and found less utilization (total, frequency, duration) in low socioeconomic status patients ($p < 0.001$) as well those speaking language(s) other than English ($p < 0.001$). (6)
5. Hendricks-Muñoz and colleagues (2013) detailed a study re-

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garding attitudes of KC between mothers and nurses. Non-white mothers (61%) were not made aware of KC versus 39% of white mothers ($p < 0.001$). Within this same study, non-white and foreign-born nurses were 2.8 and 3.1 times more likely to encourage KC. (7)

These findings detail pervasive and systemic issues related to assuring access to equitable care and equitable opportunities for initiation and sustainable breastmilk feedings among minority and ethnic populations. Units and organizations must provide time and resources for honest, thoughtful, and crucial conversations about current practices, including care and outcome disparities. Enlisting parent and community advisors on the needs of mothers, infants, and communities being served is essential, if not already a standard within core policy and procedure development. Utilizing Race and Ethnicity Dashboards to understand key metrics driving quality improvement strategies is but one layer of a dynamic and iterative process.

Race and Ethnicity Dashboards

One strategy detailed by Howell & Zeitlin (2018) is the use of race and ethnicity dashboards for perinatal care that can provide an instructive and illustrative frame to outcomes by race and ethnicity. The National Perinatal Information Center (NPIC) has utilized this

approach for both maternal and neonatal outcomes. Rochin and colleagues (2021) described the development and utilization of a race and ethnicity dashboard and how it can be incorporated into a quality improvement schema(8). The ability to identify, monitor, and mitigate disparate outcomes cannot be overstated and must be implemented in a culturally sensitive and thoughtful approach. Understanding the importance of equity of care and outcomes must be established and accepted at every level of an organization to be fully effective and sustainable.

These types of data and visualization can be a valuable adjunct to the work required to assure equitable and respectful care for all patients and newborns. Understandably, *normalization of deviance* can invade equitable care just as it can invade processes and procedures such as normalizing postpartum hemorrhage rates, cesarean section rates, newborn readmission rates, and other outcome measures that can drift. Careful review and acknowledgment of such variations in outcome can be crucially important to care standardization and process improvement.

Think about your own breastmilk feeding and MOM rates. What would your breastmilk feeding rates look like if placed on this type of dashboard? At initiation? At discharge? During hospitalization, how does the mother's milk supply continue through the NICU journey? Are there disparities that exist, and do you measure? Do

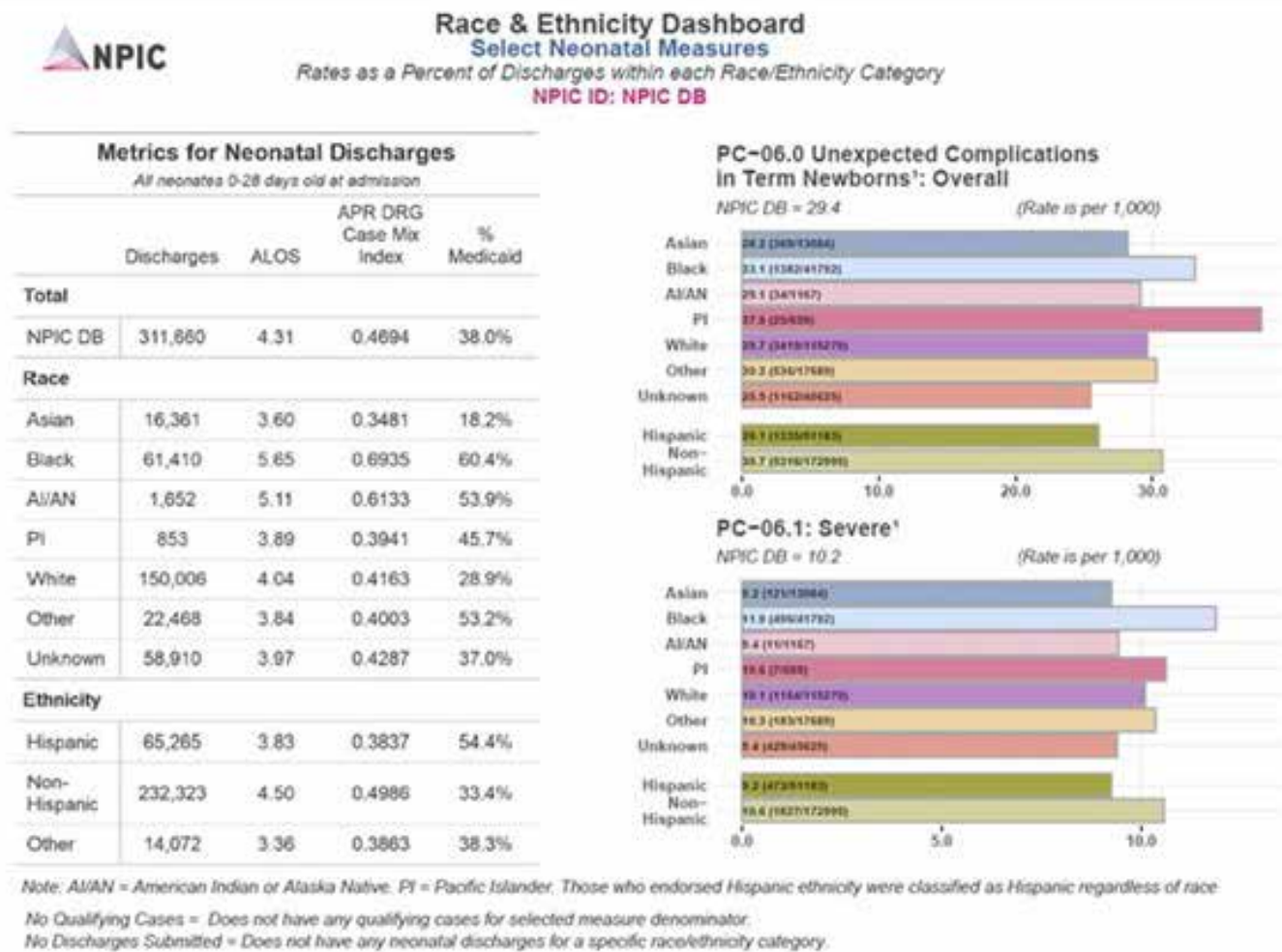


Figure 1. NPIC Race and Ethnicity Dashboard, Select Neonatal Measures, Perinatal Center Database 01/01/2020 – 12/31/2020 (n = 311,650)

you measure KC initiation and utilization rates and variations by race and ethnicity? Utilizing your own electronic medical record and incorporating key facets of care to improve is but one way of measuring and valuing the need to highlight and mitigate racial and ethnic disparities of initiating and sustaining breastmilk feeding during the entirety of NICU care.

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Health Equity Column: Leading with Health and Racial Equity in the NICU: A Neonatologist Perspective

Jenné Johns, MPH, Dalia M. Feltman MD, MA, FAAP



What is your definition of health equity?

In the neonatal and perinatal kind of patient world, not everyone is coming from the same baseline level of health. We know that Black Moms have much higher rates of some of the morbidities that come with being pregnant and that they also have increased rates of dying in the first year after delivery or around delivery. Clearly, there's something going

on with baseline health and maybe help at that intersection when they're actually delivering. Maybe there's more that needs to be done as far as listening to Moms and symptoms.

"We know that Black Moms have much higher rates of some of the morbidities that come with being pregnant and that they also have increased rates of dying in the first year after delivery or around delivery. Clearly, there's something going on with baseline health and maybe help at that intersection when they're actually delivering."

However, they're also coming in, sometimes not as healthy. Because of that, other factors, and the wearing down on health from structural racism and other social determinants of health, it makes it really hard to hope for an equally good outcome for their babies because obviously, the baby's health depends on Mom's health. We know Black Moms are more likely to deliver prematurely, and within those premature newborns, the group I study, extremely premature newborns, are also more likely to be born to Black vs. White Moms.

For me, health equity means trying to get everybody, parents, mostly Moms, because their health is mostly in this. However, Dads' mental health is important as well. Moms and babies [are] coming out with equally good levels of health, and knowing that for the people that aren't coming in with that same higher baseline that they're probably going to need some extra attention.

There's an image of health equity that shows nicely that it doesn't mean equal. For example, you don't give everybody a walker. Everybody does not need a walker to walk. Some people just need a brace; some people need a wheelchair; some people need a cane to get to that same level of health, which would be ambulating and getting around in their daily lives. Thus, it has to be customized for each family.

Our families come from different levels of privilege. There are

families that know how to advocate for themselves really well, and they get heard almost immediately. There are also the families that sometimes aren't even able to be there physically, maybe because mom is still really sick, or mom is at home taking care of other kids or doesn't have the transportation. Maybe mom's there, but she really can't effectively communicate. Although we have translators, it's just not the same as when you can just kind of chit-chat and talk with a mom if they don't speak English.

What are your organizational priorities for addressing health and racial equity in perinatal and neonatal care?

I'll explain a little bit about what we've done so far since last June. Well, last year was a very difficult summer in Chicago. That was the time the police that killed George Floyd were arrested

, and there were a lot of protests as well as backward protests. There were obviously protests against police, and there were also protests against the fact that this guy wasn't really killed. Rather, the police were doing their job, and it became such a bombshell and an explosive issue. For some reason, that was an alarm clock. A wake-up call just went off and said, "**You know, racism is really alive and well, and we have to do something about it. Enough is enough.**"

That Sunday, I reached out to some friends that write with me for bioethics and opinion pieces and things like that. I asked if anybody wanted to write with me, and one of them did. We wrote something for the Bioethics Net blog. We brainstormed a title such as "The Time is Now." Basically, it was just a wake-up call to say, "I have to start working against racism as that is the only way we're going to get rid of it; it has to be figured out at every level."

" We formed our Diversity and Health Equity committee and recruited people from our unit so anybody could join. The whole idea was for everybody to be able to be involved, such as our secretaries, respiratory therapists, nurses, or doctors."

In the ICU, which is what we call our NICU, I got together with one of our nurse managers, one of our nurses. We formed our Diversity and Health Equity committee and recruited people from our unit so anybody could join. The whole idea was for everybody to be able to be involved, such as our secretaries, respiratory therapists, nurses, or doctors. My goal was for this to be a space where

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we could get together and talk about this issue because, unfortunately, racism seeps into so many different aspects of people's lives.

Certainly, I'm not in the police force, and what started this whole thing isn't where I would be really doing any work. However, in my brain, at least everyone in their little part of the world could do something. I thought it could be helpful. I'm really happy about our committee. We have worked together. We have two goals. Our first goal is to increase an appreciation and celebration of diversity among our staff and families. The other goal is to work for identifying and making health equity a reality for our family specifically.

“We have two goals. Our first goal is to increase an appreciation and celebration of diversity among our staff and families. The other goal is to work for identifying and making health equity a reality for our family specifically.”

What's been really awesome is that my co-chair and I have had some interesting ideas, but some of them have gone to the way-side because some of our other members have come up with amazing things, things that we hadn't thought of. We've been able to do a lot of interesting things. We have a bulletin board now in our break room so that we can track when we reach our first mission of education and celebrating diversity. We change it out every month. During Black History Month, the nurse takes care of that bulletin board focused on literacy efforts.

One nurse found a local literacy organization that helps bring books that have people of color as characters in the books or celebrate people, historical figures, or celebrity people who have made a difference to help kids be inspired when they read their books. We raised \$1,000.00 for them. Then, we also put in for a grant from one of our auxiliary boards that have a small grant program. We raised funds, and we were accepted. We are going to be building a library for our parents so that Moms and Dads can check out books and read to their babies to help get Moms and Dads get engaged.

Unfortunately, a lot of times, the Moms and Dads can't do a whole lot if they visit their baby, especially if they're pretty sick, if they're on a lot, or if they're on a breathing machine or I.V.s. They have just a lot of connections, and they need to be in that warm incubator. It's hard to interact with their babies at that point, and they want to be there, and they want to visit. However, they kind of just end up having to sit next to the baby and sometimes just look at the monitor and watch the numbers because, of course, we're always looking at a screen.

We also wanted to provide at least a diverse, nice content library for parents to be able to pull out some books and read to their families. I know Jenné and I have talked about the importance of reading, and she even wrote something about the book that she wrote for her son and that other preemie families can use, which was a lab for preemies. It's called Once Upon Preemie. That's some of the stuff we've done. The other thing is that we have shared opportunities like webinars, interesting research papers that we've come across, and articles for our members to be able to learn more about other equity efforts.

One of those was the Once Upon a Preemie webinar that was

“live” and offered last year. That's how I came to learn about the Once Upon a Premium Academy. We were fortunate enough to participate. I wasn't able to watch all of the webinars, but two of them that I watched were excellent. When the CME emails came out, I just emailed Ms. Johns and said, “Thank you for this opportunity. It was excellent.” She and I met. She reached out to me to see if I wanted to talk about this, and then it was clear. I told her a little bit about the stuff that we were doing already, and she asked if I could talk maybe about that in the Academy.

It just does a very nice turn of events that I was able to join the faculty. I shared with her that one of the talks that we had seen by one of the Moms, Shanté Nixon, had kind of inspired those of us who had seen it to start working on some other ways to really empower parents to speak up because the people that know how to speak up do it just fine. They usually get what they need. However, it's the Moms that maybe don't feel like they can speak up, or they want to speak up, but they don't exactly know how in this weird setting because most people are not medical. This is a very different environment for anyone to be in. We made a document that gave some hints about how to speak up.

It was Pride Month in June. On our bulletin board, we had some articles and some nice things from the corporate diversity committee. Diversity efforts had been set up on how to speak respectfully and appropriately; for example, people who may prefer certain pronouns. What we did is customize it to our NICU families. We talked about transgender parents having babies, lactation support, and things like that.

“Diversity efforts had been set up on how to speak respectfully and appropriately; for example, people who may prefer certain pronouns. What we did is customize it to our NICU families.”

That's what we're trying to do. We're trying to make it take that general idea of equity and diversity and bring it home to our everyday work lives, which is in our unit, and that is where the issue resides. Basically, my priority is empowering Moms so that they can partner best, and we can partner with them in a meaningful way to care for their babies. We have to know what questions to ask and listen only to Mom's answers. That might not just mean listening to the Moms that are always there and talking to us. It might mean figuring out ways of better communicating with the Moms that, as I said before, have some barriers to engaging, communicating, and interacting, including looking at our own biases. We can figure out we can get implicit bias training. However, once you even know you have a bias, you still have to know how to deal with it and how to interact with Moms. I keep saying Moms, but I really want to get Dad involved, too. I do mean Dads when they're available as well. However, the Moms are a little bit higher priority just because their health is often intertwined with the babies to their physical health. Then another way to really help meaningfully engage is to have a diverse medical team. So that's something else that we just brought in, a speaker who is a first-generation college student.

She talked about the website that she and some other first-generation college students (and are now first-generation medical students). They have made a website for helping people who are looking into medical school. She gave us some statistics that I was not aware of, including there was a large proportion of medical students who already have a parent that's a physician. There's a lot of familiarity for some people that give them privilege and

makes it a lot smoother process and probably perpetuates the fact that we don't have a diverse workforce and that we do need fresh voices who don't come from a family where everybody has been a doctor. Thus, those are my priorities.

It's unfortunate that it took very unfortunate circumstances to make me realize, "Oh, that's the wake-up call," but hopefully, good things will come out of a bad situation. COVID was just this horrible illustration of the fact that, yes, health equity is not present. There are total inequities that need to be addressed. Maybe for those who have been studying it since college, they know about it. However, I think for other people, it was like, what the heck? Then there are other people that don't believe it, and that's very infuriating. In fact, Black Lives Matter makes people upset, and that makes me upset.

"COVID was just this horrible illustration of the fact that, yes, health equity is not present. There are total inequities that need to be addressed. Maybe for those who have been studying it since college, they know about it. However, I think for other people, it was like, what the heck? Then there are other people that don't believe it, and that's very infuriating."

What personal and professional experiences led you to focus on health equity in perinatal and neonatal care?

Personally, my family is transracial. I have two internationally adopted children, my husband is white, and my children are Asian and Latino. That said, we've always talked about racism. I've been very cognizant of the way life might be different if I were not white. I've been a little bit more sensitive to issues from that standpoint. I thought, okay, we're going to deal with this as a family. That's one level, and then another level is at work in the unit. What can we do?

Professionally, I'm a bioethicist. So, writing to bioethicists is one part of my life, and then another part of my life is my research. In my research, I am already looking at families' experiences. Because of the nature of our preemies, a lot of them are Black and Brown babies. For this reason, I could kind of focus on that a little bit in a different little lens, but I felt like that was already being taken care of.

My bioethics research is mostly about how families make decisions for when they're facing the prospect of delivering an extremely early newborn. That has led me into a deeper appreciation for what families are going through, the decisions they are making, and really the expertise that they bring that doctors don't bring to the decision-making.

The idea of shared decision-making is that the doctor's kind of

lens is supposed to help families figure out the best options for their family and how they see the best interest for their baby. They tell us what we should do; that's easier said than done. I'm researching different kinds of tools and ways to actually make those conversations effectively happen instead of the usual model where factors just come in, lay out a bunch of information, and then say, "Well, what would you like?" I think that's really hard for families who were never even expecting to be in the hospital and thinking about delivering at such an early age. More recently, I've kind of used that family experience and the idea of amplifying voices. When we look at families in the NICU, there are a lot of the voices that really need help being amplified or listened to in an effective way.

What is your call to action for the industry as we seek to eliminate health and racial inequities in perinatal and neonatal care?

I am heartened by the efforts of different departments like O.B., social work, and at the corporate level to try to address racism and health equity from different aspects. Many efforts right now to improve equity are grassroots and voluntary, done on borrowed bandwidth. I see that with our nurses and doctors in our Diversity and Health Equity committee. Time is money—financial support for time to allow work in this area is important. Corporate efforts are necessary but should include supporting work at the level of the medical team/patient, for example, in the NICU.

In neonatology, we have a unique relationship that needs attention at the unit level; we need to partner with parents to help the babies, who are officially our patients. However, a healthy baby needs a healthy Mom, Dad, and siblings. We need their expertise as the babies' families, and they require our medical expertise. By networking with others engaged in similar efforts at their units, we can learn from and support each other.

Disclosure: The authors have no disclosures.

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READ

NPA's
statement:

BLACK LIVES MATTER



About the Author: Dalia M. Feltman MD, MA, FAAP



Attending Neonatologist and Clinical Assistant Professor

Attending Neonatologist, Evanston Hospital NorthShore University HealthSystem and

Clinical Assistant Professor, University of Chicago Pritzker School of Medicine

Dr. Dalia M. Feltman is a board-certified neonatologist at NorthShore University HealthSystem Evanston Hospital north of Chicago. She co-founded their NICU's Diversity and Health Equity Committee which works to encourage a culture of mutual respect and to address health

disparities for NICU patients and families. Her fluency in Spanish allows her to appreciate the needs of parents who do not speak English. As a Clinical Assistant Professor at the University of Chicago Pritzker School of Medicine, her teaching sessions focus on communicating effectively and compassionately with families. Dr. Feltman earned her M.A. in Bioethics and Health Policy from Loyola University Chicago's Neiswanger Institute. Using this ethical "lens," Dr. Feltman publishes bioethics research including book chapters and numerous peer-reviewed journal articles and has presented at national academic conferences. Dr. Feltman leads a collaborative study group of researchers from over 15 U.S. training centers called Investigating Neonatal Decisions for Extremely Early Deliveries (INDEED) which studies socioeconomic and medical maternal factors and delivery hospital characteristics with respect to resuscitation decisions for the earliest premature newborns to identify disparities and improve care. Dr. Feltman is a Fellow of the American Academy of Pediatrics, active in their Sections on: Bioethics; Hospice and Palliative Medicine; and Minority Health, Equity and Inclusion.

About the Author: Jenné Johns, MPH:



President, Once Upon A Premie www.onceuponapremie.com

Founder, Once Upon A Premie Academy www.onceuponapremieacademy.com

Jenné Johns, MPH is President of Once Upon A Premie, Founder of Once Upon A Premie Academy, mother of a micropreemie, author, speaker, advocate, and national senior health equity leader. Once Upon A Premie is a non-profit organization with a two-part mission: 1.) to donate Once Upon A Premie books to NICU families in under resourced communities, and 2.) lead virtual health and racial ethnic training programs and solutions to the neonatal and perinatal community through the Once Upon A Premie Academy. Jenné provides speaking, strategic planning and consultation services for fortune 500 companies focused on preemie parent needs from a cultural lens and reading as a tool for growth, development, and bonding. Jenné is also a national senior health equity thought leader and has led solutions-oriented health equity and quality improvement portfolios for the nations' largest health insurance and managed care companies.

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COVID-19



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ABOUT THE
RISKS + BENEFITS

work with your medical
team to create a plan

GET CLEAN
WASH YOUR HANDS,
ARMS, and CHEST

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



PUT ON
FRESH CLOTHES

change into a clean
gown or shirt.

IF COVID-19 +
WEAR A MASK

and ask others to
hold your baby when
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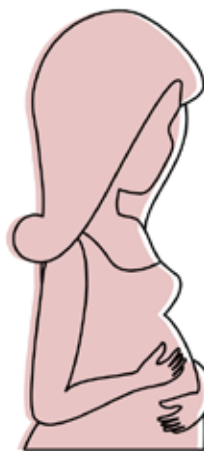
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COVID-19**



According to data
published in The Lancet

Pregnancy
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**VERTICAL
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Time is precious, just like your patients.





Why Pregnant and Nursing Women Need Clear Guidance on THE NET BENEFITS OF EATING FISH

2 to 3 servings per week of properly cooked fish can provide health benefits for pregnant women and babies alike:



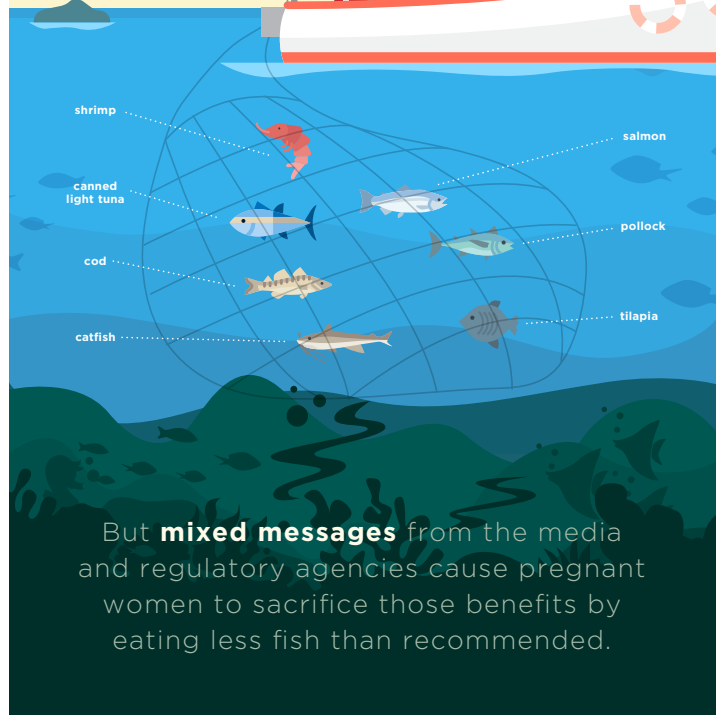
Iron



Omega 3 fatty acids



Earlier Milestones for Babies



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



Did you know that PMAD related suicides account for

20%

of Postpartum Maternal Deaths?

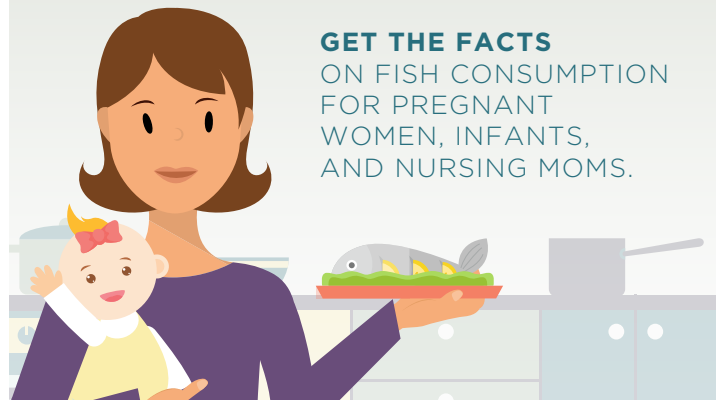
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Letters to the Editor

Where Are We with RSV and COVID-19?

“Covid 19 and RSV are both surging this summer in certain parts of the country in the pediatric age groups. A friend said that they are now giving Synagis to eligible neonatal patients at their hospital since RSV has appeared in their area.”

Dear Dr. Goldstein:

Covid 19 and RSV are both surging this summer in certain parts of the country in the pediatric age groups. A friend said that they are now giving Synagis to eligible neonatal patients at their hospital since RSV has appeared in their area.

What should we do nationally: should we wait for a surge of RSV in our own areas before starting Synagis in neonates being discharged, or should we start Synagis now nationwide so that patients who have gone home already when the RSV cases increase will be protected?

Best regards,

Gail L. Levine, M.D.

glevine18@gmail.com

"Kindness builds the world" Psalms 89:3

"We do the right thing because it's the right thing, not because of what we get out of it." Kyra Sedgwick

'Tis the gift to be simple, 'tis the gift to be free,

'Tis the gift to come down where we ought to be,

And when we find ourselves in the place just right,

'Twill be in the valley of love and delight.

When true simplicity is gained,

To bow and to bend we shan't be ashamed.

To turn, turn will be our delight,

Till by turning, turning we come 'round right.

Shaker song, 1848, Joseph Brackett

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Dear Dr. Levine,

We have seen a dramatic shift in the usual pattern of winter pathogens due to proactive masking. Although COVID-19 was not definitively controlled by masking, the introduction of effective immunizations resulted in a broad reduction in masking policies. As a secondary effect, winter pathogens, including RSV, communicated mainly by droplet formation, could once again spread widely. Although earlier models, based on the reduction of RSV immune protection, suggested that 2022-2023 would be a significantly worse year for RSV and Influenza, these predictions were based on a single-year disruption in normal contagion patterns. (1-3) With a resurgence of COVID-19 secondary to the appearance of the Delta variant, masking policies are once again being enforced. The effect of this new vigilance on RSV rates cannot be estimated. (4, 5)

“Although earlier models, based on the reduction of RSV immune protection, suggested that 2022-2023 would be a significantly worse year for RSV and Influenza, these predictions were based on a single-year disruption in normal contagion patterns. With a resurgence of COVID-19 secondary to the appearance of the Delta variant, masking policies are once again being enforced. The effect of this new vigilance on RSV rates cannot be estimated.”

However, there are currently broad upticks in the RSV positive rate across the Southeast United States. (6) Other areas, including Southern California, are seeing positivity rates approach that normally herald the winter season. In specific, certain demographics are approaching 10% (personal communication). Our pattern currently mirrors that usually experienced in the Southern hemisphere.

Regardless of the epidemiology, our most at-risk babies remain at risk. The American Academy of Pediatrics recently released guidance on RSV prophylaxis addressing the shift of seasonality.(6) It would appear reasonable to consider initiation of prophylaxis in patients with an FDA indication as positivity rates rise past 2-3% in a given geographical area rather than waiting for Fall-Winter season. (7-9)

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Sincerely,

Mitchell Goldstein, MD

Editor in Chief

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

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Erratum (Neonatology Today July 2021)

Neonatology Today is not aware of any erratum affecting the July, 2021 edition.

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

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TAKE THE NECESSARY STEPS TO ELIMINATE INEQUITIES

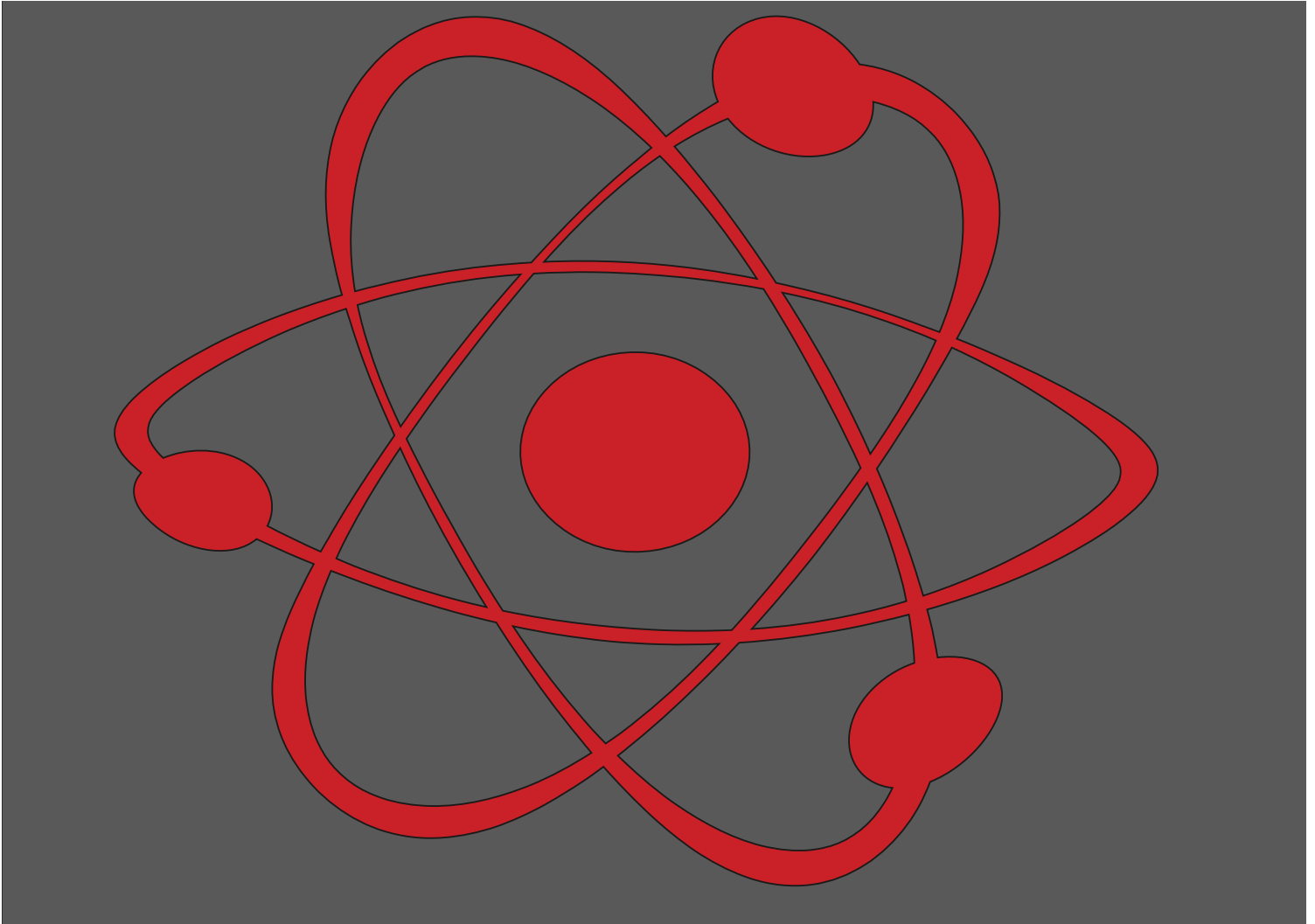


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Will your **PRETERM INFANT** need **EARLY INTERVENTION** services?

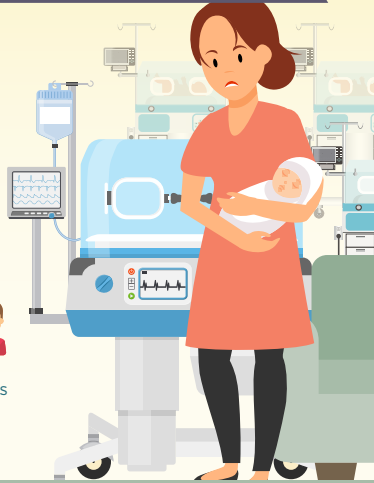
Preterm infants are:

2x more likely to have developmental delays

5x more likely to have learning challenges



1 in 3 preterm infants will require support services at school



Early intervention can help preterm infants:



Enhance language and communication skills



Build more effective learning techniques



Process social and emotional situations



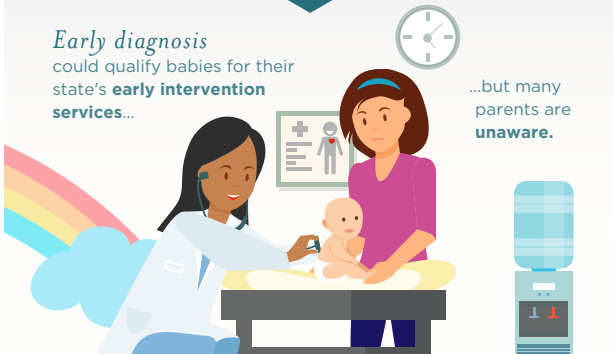
Address physical challenges



Prevent mild difficulties from developing into major problems

Early diagnosis could qualify babies for their state's **early intervention services**...

...but many parents are **unaware**.



NICU staff, nurses, pediatricians and social workers should talk with NICU families about the challenges their baby may face.

Awareness, referral & timely enrollment in early intervention programs can help **infants thrive** and grow.



NCFIH National Coalition for Infant Health
Protecting Access for Premature Infants through Age Two
www.infanthealth.org

Visit CDC.gov to find contact information for your state's early intervention program.

Las nuevas mamás necesitan acceso a la detección y tratamiento para **LA DEPRESIÓN POSTPARTO**



1 DE CADA 7 MADRES AFRONTA LA DEPRESIÓN POSTPARTO, experimentando



Sin embargo, sólo el **15%** recibe tratamiento!

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

El sueño, la alimentación y el comportamiento del bebé a medida que crece?



La salud de la madre
La capacidad para cuidar de un bebé y sus hermanos

PARA AYUDAR A LAS MADRES A ENFRENTAR LA DEPRESIÓN POSTPARTO



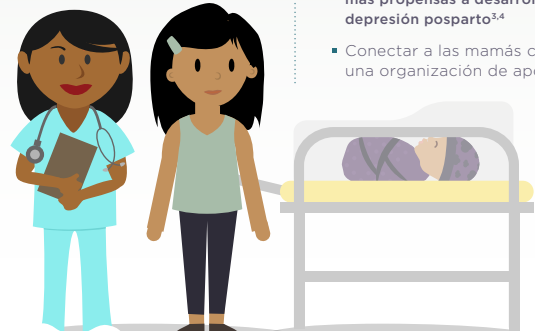
LOS ENCARGADOS DE FORMULAR POLÍTICAS PUEDEN:

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



LOS HOSPITALES PUEDEN:

- Capacitar a los profesionales de la salud para proporcionar apoyo psicosocial a las familias... **Especialmente aquellas con bebés prematuros, que son 40% más propensas a desarrollar depresión postparto**^{3,4}
- Conectar a las mamás con una organización de apoyo



NCFIH National Coalition for Infant Health
Protecting Access for Premature Infants through Age Two
www.infanthealth.org

¹ American Psychological Association. Accessed on: <http://www.apa.org/women/resources/reports/postpartum-depression.aspx>
² National Institute of Mental Health. Accessed on: <http://www.nimh.nih.gov/health/publications/postpartum-depression-facts/index.shtml>
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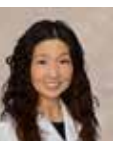
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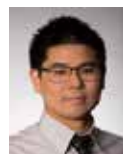
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PROTECT YOUR FAMILY FROM RESPIRATORY VIRUSES

flu

coronavirus

pertussis

RSV



SOAP

WASH YOUR HANDS
often with soap and
warm water.

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



**COVER COUGHS
AND SNEEZES.**
Sneeze and cough
into your elbow.

**USE AN
ALCOHOL-BASED
HAND SANITIZER.**



**STAY AWAY
FROM SICK PEOPLE**
Avoid crowds.
Protect vulnerable
babies and children.

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Neonatology and the Arts

This section focuses on artistic work which is by those with an interest in Neonatology and Perinatology. The topics may be varied, but preference will be given to those works that focus on topics that are related to the fields of Neonatology, Pediatrics, and Perinatology. Contributions may include drawings, paintings, sketches, and other digital renderings. Photographs and video shorts may also be submitted. In order for the work to be considered, you must have the consent of any person whose photograph appears in the submission.

Works that have been published in another format are eligible for consideration as long as the contributor either owns the copyright or has secured copyright release prior to submission.

Logos and trademarks will usually not qualify for publication.

This month we continue to feature artistic works created by our readers on one page as well as photographs of birds on another. This month's original artwork of a Sunflower in Bloom is provided by Paula Whiteman, MD. Our bird of the month is "The Blue Jay" rendered by is Barbara Strobel-Dellger on a Quilt. (blldellger@gmail.com), the aunt of Katie Strobel, MD (KMStrobel@mednet.ucla.edu) a Neonatal-Perinatal Medicine Fellow PGY-6 at UCLA.



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Manuscript Submission: Instructions to Authors

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

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

3. There is no charge for submission, publication (regardless of number of graphics and charts), use of color, or length. Published content will be freely available after publication. There is no charge for your manuscript to be published. NT does maintain a copyright of your published manuscript.

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

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

6. An abstract may be submitted.

7. The main text of the article should be written in formal style using correct English. The length may be up to 10,000 words. Abbreviations which are commonplace in neonatology or in the lay literature may be used.

8. References should be included in standard "NLM" format (APA 7th may also be used). Bibliography Software should be used to facilitate formatting and to ensure that the correct formatting and abbreviations are used for references.

9. Figures should be submitted separately as individual separate electronic files. Numbered figure captions should be included in the main file after the references. Captions should be brief.

10. Only manuscripts that have not been published previously will be considered for publication except under special circumstances. Prior publication must be disclosed on submission. Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.

11. NT recommends reading Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals from ICMJE prior to submission if there is any question regarding the appropriateness of a manuscript. NT follows Principles of Transparency and Best Practice in Scholarly Publishing (a joint statement by COPE, DOAJ, WAME, and OASPA). Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.

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

Please submit your manuscript to: LomaLindaPublishingCompany@gmail.com



NICU BABY'S Bill of Rights

1- THE RIGHT TO ADVOCACY

My parents know me well. They are my voice and my best advocates. They need to be knowledgeable about my progress, medical records, and prognosis, so they celebrate my achievements and support me when things get challenging.

2- THE RIGHT TO MY PARENTS' CARE

In order to meet my unique needs, my parents need to learn about my developmental needs. Be patient with them and teach them well. Make sure hospital policies and protocols, including visiting hours and rounding, are as inclusive as possible.

3- THE RIGHT TO BOND WITH MY FAMILY

Bonding is crucial for my sleep and neuroprotection. Encourage my parents to practice skin-to-skin contact as soon as and as often as possible and to read, sing, and talk to me each time they visit.

4- THE RIGHT TO NEUROPROTECTIVE CARE

Protect me from things that startle, stress, or overwhelm me and my brain. Support things that calm me. Ensure I get as much sleep as possible. My brain is developing for the first time and faster than it ever will again. The way I am cared for today will help my brain when I grow up. Connect me with my parents for the best opportunities to help my brain develop.

5- THE RIGHT TO BE NOURISHED

Encourage my parents to feed me at the breast or by bottle, whichever way works for us both. Also, let my parents know that donor milk may be an option for me.

6- THE RIGHT TO PERSONHOOD

Address me by my name when possible, communicate with me before touching me, and if I or one of my siblings pass away while in the NICU, continue referring to us as multiples (twin/triplets/quads, and more). It is important to acknowledge our lives.

7- THE RIGHT TO CONFIDENT AND COMPETENT CARE GIVING

The NICU may be a traumatic place for my parents. Ensure that they receive tender loving care, information, education, and as many resources as possible to help educate them about my unique needs, development, diagnoses, and more.

8- THE RIGHT TO FAMILY-CENTERED CARE

Help me feel that I am a part of my own family. Teach my parents, grandparents, and siblings how to read my cues, how to care for me, and how to meet my needs. Encourage them to participate in or perform my daily care activities, such as bathing and diaper changes.

9- THE RIGHT TO HEALTHY AND SUPPORTED PARENTS

My parents may be experiencing a range of new and challenging emotions. Be patient, listen to them, and lend your support. Share information with my parents about resources such as peer-to-peer support programs, support groups, and counseling, which can help reduce PMAD, PPD, PTSD, anxiety and depression, and more.

10- THE RIGHT TO INCLUSION AND BELONGING

Celebrate my family's diversity and mine; including our religion, race, and culture. Ensure that my parents, grandparents, and siblings feel accepted and welcomed in the NICU, and respected and valued in all forms of engagement and communication.

Presented by:



NICU Parent Network

NICU PARENT NETWORK

Visit nicuparentnetwork.org to identify national, state, and local NICU family support programs.

* The information provided on the NICU Baby's Bill of Rights does not, and is not intended to, constitute legal or medical advice. Always consult with your NICU care team for all matters concerning the care of your baby.

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Infant Health

Policy Summit

THURSDAY, SEPTEMBER 2

11:30AM TO 2:30PM ET

TOPICS INCLUDE:

- The value of safety and innovation for neonates
- Respiratory syncytial virus and compounding disparities
- Newborns and rare diseases
- The long-term effects of separating mothers and babies during COVID-19
- Nutrition and the safety of a growing human donor milk market
- Perspectives from the Asian, Black, Hispanic and LGBTQ communities



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