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Health and Wellness, Sleep Part 3: How to Improve Your Sleep

Hun-Seng Chao, MD

We healthcare workers work hard to care for our patients, but we sometimes forget to care for ourselves. In this series, I will discuss health and wellness, two things most of us never really learned much about in medical school, including nutrition, ways to prevent disease, and how vitally important our lifestyle is to our health. It will occasionally be relevant to our patients but is mainly directed toward healthcare workers. I am not an expert in this topic, but I will share with you what I have learned over the past few decades since med school from multiple research-backed sources, including functional medicine, functional nutrition, integrative medicine, and others, as well as allopathic medicine. Of course, this is not intended to be medical advice or to diagnose or treat any illness or condition.

In the previous articles, we discussed the deteriorating effect of aging on sleep, the subsequent risk of cognitive decline, and the importance of adequate sleep in maintaining hormonal balance to support metabolic health.

We should get 7–9 hours of quality sleep every night (1). However, as health professionals with shift work and/or long, irregular hours with ensuing sleep deprivation, it is difficult for most of us to optimize our sleep habits, and therefore, we are at higher risk for obesity and metabolic syndrome with insulin resistance, diabetes, and cardiovascular disease (2).

"We should get 7–9 hours of quality sleep every night. However, as health professionals with shift work and/ or long, irregular hours with ensuing sleep deprivation, it is difficult for most of us to optimize our sleep habits, and therefore, we are at higher risk for obesity and metabolic syndrome with insulin resistance, diabetes, and cardiovascular disease."

However, it may be helpful to optimize sleep habits as much as possible the rest of the time. Below are ways that sleep experts recommend to improve "sleep hygiene" and/or circadian rhythm disorders.

1. Keep a regular schedule for waking, sleeping, and meals as much as possible.

As mentioned in previous articles, keeping your circadian rhythm regular by waking, exercising, sleeping, and having meals at approximately the same time every day, including weekends, helps the biological rhythms throughout the different systems in your body stay in sync with each other—like all the parts of a symphony playing harmoniously together. When there is circadian disruption, as in shift work, lack of good quantity or quality of sleep, or jet lag (including social jet lag [see below]), then the body suffers from circadian misalignment, which, if chronic, can lead to metabolic (insulin resistance, type 2 diabetes, obesity), cardiovascular (heart disease, stroke), immunologic (inflammation), and psychologic (depression) disorders as well as cancer and cognitive decline (2–5), as discussed in the previous articles.

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Social jet lag is defined as the circadian misalignment due to the discrepancy between activity/sleep schedules on work/school days and free days (usually more in sync with one's chronotype [see below]). This misalignment tends to be pervasive throughout most people's entire study/work career since most of us cannot set our own work or school hours. About 70% experience at least one hour of social jet lag (per day), and up to 50% have two hours or more, usually associated with sleep deficit (6–8) and its attendant health problems.

"Social jet lag is defined as the circadian misalignment due to the discrepancy between activity/sleep schedules on work/school days and free days (usually more in sync with one's chronotype."

In multiple studies, sleep deficit is associated with increased allcause mortality (9). Most researchers have found that sleeping 7–8 hours was associated with the lowest mortality and that those with ≤ 6 or ≥ 9 hours had significantly increased mortality. A Swedish study looking at over 38,000 individuals found that in the group under 65 years of age, sleeping ≤ 5 hrs on weekdays and weekends was associated with a 65% increase in mortality compared to those sleeping 6–7 hrs a day. Of note, those who



slept \leq 5 hrs on weekdays but longer on weekends (i.e., those with catch-up sleep) did not have increased mortality (10). However, as mentioned previously, sleep deprivation is associated with many metabolic diseases, so it is still best to get >5 hrs of sleep consistently. Exercise has been shown to alleviate this effect on mortality (11), which might be secondary to the anti-inflammatory effect of exercise.

"A Swedish study looking at over 38,000 individuals found that in the group under 65 years of age, sleeping ≤5 hrs on weekdays and weekends was associated with a 65% increase in mortality compared to those sleeping 6–7 hrs a day. Of note, those who slept ≤5 hrs on weekdays but longer on weekends (i.e., those with catch-up sleep) did not have increased mortality."

Many try to "make up" their weeknight sleep deficits on weekends. Does this work? Well, maybe (as in the Akerstedt study above) but maybe not. Studies have found that catch-up sleep (if >2 hrs on weekends with <6 hrs sleep during weekdays)(12) may alleviate the detrimental effect of sleep deprivation on the cardiovascular system. Some studies show that catch-up sleep may alleviate the risk of metabolic syndrome found in sleep deprivation (13–16). However, other researchers have not shown the same benefit on metabolism (17) or performance (18). In another study, researchers looked at all-cause mortality and incidence of cardiovascular disease with catch-up sleep in over 70,000 subjects over 8 years. They found <u>no</u> difference between those who had no catch-up sleep may not provide protective benefits against mortality or cardiovascular disease.

"In another study, researchers looked at all-cause mortality and incidence of cardiovascular disease with catch-up sleep in over 70,000 subjects over 8 years. They found <u>no</u> difference between those who had no catch-up sleep and those who did have catch-up sleep, i.e., catch-up sleep may not provide protective benefits against mortality or cardiovascular disease."

A person's chronotype is a person's preferred sleep and wake schedule, which is mostly genetically determined but may be influenced by environmental factors (light, time zone, season, geographical location) and lifestyle (diet, exercise, drug use, work). You can be a "morning person," "a night owl," or somewhere in between. Chronotype can also change with age. Young children tend to be early risers (much to the dismay of their parents) and sleepers, but teens like to sleep in and go to bed late, and adults are usually in between but can be either. You can find out your chronotype by taking the Morningness Eveningness Questionnaire (https://cet.org/wp-content/uploads/2019/12/MEQ-SA-2019.pdf) or the Munich Chronotype Questionnaire (https://www.ornge. ca/Media/Ornge/Documents/Campaign%20Documents/ACAT/ Munich-ChronoType-Questionnaire-(1).pdf), but the MEQ is easier to score. It is best to have a daily routine in sync with your chronotype and circadian rhythm for optimal health.

"A study taken from the Korean Community Health Survey of >225,000 adults looked at waking time (and inferred morningness and eveningness) and found that while sleeping 7–9 hrs (without considering sleep quality) was associated with the least cognitive decline, there was a difference in sleep duration and cognitive decline between those who wake early (morningness, 4–6:30 AM), late (eveningness, 8:30– 11:30 AM), intermediate (6:30–8:30 AM), or none (0–4 AM)."

Some studies have looked at cognitive decline and morningness and eveningness. While the lowest risk for cognitive decline was sleeping 7-8 hrs overall, and the official sleep recommendation from the National Sleep Foundation is 7-8 hrs for older adults (≥65 yrs) and 7–9 hrs for young adults and adults (24–64 yrs) (1), most studies have not looked at the effect of chronotype and sleep duration on cognitive decline. A study taken from the Korean Community Health Survey of >225,000 adults (20) looked at waking time (and inferred morningness and eveningness) and found that while sleeping 7-9 hrs (without considering sleep quality) was associated with the least cognitive decline, there was a difference in sleep duration and cognitive decline between those who wake early (morningness, 4-6:30 AM), late (eveningness, 8:30-11:30 AM), intermediate (6:30-8:30 AM), or none (0-4 AM). As expected, poor sleep quality was found more common in those with memory loss (69.8%) than in the no memory loss group (48.0%, p<0.001) but varied with morningness (OR 2.14%), intermediate (OR 2.21%), and eveningness (OR 2.69%). Interestingly, when sleep quality was considered, the sleep hours with the lowest incidence of memory loss was 5-6 hrs in the overall group; however, this varied by morningness/eveningness. Compared to sleeping the recommended 7-8 hrs, the morningness group showed lower memory loss with sleep <5 hrs (0.92 OR), 5-6 hrs (OR 0.85), and 6-7 hrs (OR 0.88). In the intermediate group, sleeping 6-7 hrs was associated with the lowest incidence of memory loss (OR 0.92) compared to sleeping 7-8 hrs and with shorter or longer hrs with higher risk (OR 1.2 for <5 hrs; OR 1.17 in 8-9 hrs; and OR 1.48 in >9hrs). In the eveningness group, the risk of memory loss was lowest in the 7-8 hrs group with insignificantly higher risk in the <5 hr, 6–7 hr, and 8–9 hrs and marginally significantly increased in the 5-6 hrs group. Overall, interestingly and usually not relevant to medical personnel, the risk of developing cognitive decline in those who sleep longer hours (in this study, >9 hrs) was significantly elevated (OR 1.38, p<0.001), as several other studies have similarly found but with varying definition of long hours (>8–10 hrs) (21–26). What seems to be consistent is that sleep duration has a U-shaped relation to cognitive decline and overall mortality—too little (usually <5 hrs) or too much (≥8–9 hrs) is bad for the brain and the body.

"What seems to be consistent is that sleep duration has a U-shaped relation to cognitive decline and overall mortality—too little (usually <5 hrs) or too much (≥8–9 hrs) is bad for the brain and the body."

2. Expose yourself to bright light in the morning. Go for a 20–30-minute walk outdoors every morning soon after waking up, or use light therapy to set ("entrain") your circadian rhythm.

Light and darkness are the primary "zeitgebers," meaning "time givers" in German. Light in the morning leads to the suprachiasmatic nucleus (SCN), activating the adrenocortical system to start the day and stopping melatonin release. Hominids evolved for the first few million years, waking at sunrise, performing most activities during daylight, and sleeping soon after the onset of darkness with the release of melatonin. After fire was discovered, our ancestors could stay awake a bit longer after sunset, although, for practical reasons (like having to feed the fire every so often), this did not significantly impact the timing of sleep-wake patterns (27). It was not until candles and then oil- and gas-burning lamps were invented and utilized that humans developed later and later bedtimes, beginning to alter circadian rhythms. Now, after the invention of electric lighting and exposure to pervasive artificial light at night, our SCN is fooled into thinking that it is still daytime and stops melatonin's release, delaying the onset of sleep and desynchronizing our circadian rhythm.

"The brighter the light, the stronger the response of the SCN (28) and the inhibition of melatonin release (29), which is why exposure to daylight early in the day is much better than indoor light."

The brighter the light, the stronger the response of the SCN (28) and the inhibition of melatonin release (29), which is why exposure to daylight early in the day is much better than indoor light (30). I was amazed at the extent of the difference between even what I thought was very bright indoor light and natural sunlight (Figure 1). In bright, indoor, artificial light, we get a few hundred lux (lumens/m²) at best—usually lower—while, even on a cloudy day, we are exposed to over several hundred lumens and, of course, much more in full daylight but not the direct sun (10,000–25,000 lux) and even more in direct sun (32,000–100,000 lux).

Figure 1. Intensity of light under different conditions (Wiki)(https://en.wikipedia.org/wiki/Lux)

Illuminance (lux)	Surfaces illuminated by	
0.0001	Moonless, overcast night sky (starlight)	
0.05–0.3	Full moon on a clear night	
20–50	Public areas with dark surroundings (street- lighting)	
50	Family living room lights	
80	Office building hallway/toilet lighting	
100	Very dark, overcast day	
320–500	Office lighting	
400	Sunrise or sunset on a clear day	
1000	Overcast day; typical TV studio lighting	
10,000–25,000	Full daylight (not direct sun)	
32,000– 100,000	Direct sunlight	

Another reason outdoor light is better than indoor light is that sunlight provides a full spectrum of intense light, including bluegreen light (I 450–460 nm), which is best for activating the SCN (28).

"If exposure to sunlight is not available, some people may use light therapy to help entrain their circadian rhythm. Light therapy involves exposure to light boxes, which produce bright light similar to sunlight."

If exposure to sunlight is not available, some people may use light therapy to help entrain their circadian rhythm. Light therapy involves exposure to light boxes, which produce bright light similar to sunlight. There are light visors and light glasses available as well. These devices may be used in the morning to shift wake and sleep times earlier, improve irregular sleep-wake disorder, or help with jet lag when traveling eastward. They can also be used later in the day to shift wake and sleep times back, for shift workers (31), or to help with jet lag when traveling westward (32, 33). Sometimes, red light (I 600–650 nm) can be used later in the day to simulate sunset, which may enhance sleep and melatonin release (34) but may be too stimulating and have adverse effects on some people (35). People with eye pathology or light sensitivity or on certain medications that cause photosensitivity should use caution and speak with their physician before trying these devices.

3. Avoid blue light (from cool LEDs, digital devices, and TVs) in the evening, especially within two hours of bedtime.

Blue light, the strongest zeitgeber for the SCN and circadian rhythm, prepares the body for optimal performance and alertness by activating the adrenocortical system. It is the most potent suppressant of melatonin as well. Any exposure to blue light in the evening will activate the SCN to decrease and delay melatonin production and may disrupt the circadian rhythm.

6

Figure 2 shows the spectrum of different sources of light. Sunlight provides the broadest and most intense range of light. Also, note that the now ubiquitous cool LED lights provide significant blue light. Often used in offices and hospitals, fluorescent lighting provides a limited spectrum, including blue light, though not as intense as found from cool white LEDs. Incandescent lighting provides a similar visible spectrum as sunlight, though not as intense, and halogen lights also have very little blue light. However, both incandescent and halogen lights are not energyefficient. They are, therefore, no longer being manufactured in the US. Thus, when spending time indoors with artificial lighting, we are constantly exposed to blue light, which can disrupt the circadian rhythm if exposure occurs at the wrong time of day, i.e., in the evening, for most of us.

"Any exposure to blue light in the evening will activate the SCN to decrease and delay melatonin production and may disrupt the circadian rhythm."

Figure 2. The spectrum of different light sources

(https://cs184.eecs.berkeley.edu/sp20/lecture/11-20/radiometryand-photometry)



If you read before bedtime, it is better to use a lamp with a bulb of around 2700 Kelvin, which is considered "warm white." (Figure 3.)

Figure 3. The color temperature of lightbulbs.

(https://www.prolampsales.com/pages/color-temperature?srsltid=AfmBO oo4MJmiSq2KI_Cihm9e9Ge0v2PFZ83xK5Tgf8h374P3ZOa2XpM-)



The degrees Kelvin of a bulb does not measure the relative heat a bulb gives off. A 2700K bulb and a 5000K bulb can have the same or similar heat. (Likewise, a 2700K incandescent bulb will be much hotter than an equivalent wattage 2700K LED bulb.) A light bulb that produces light perceived as yellowish white will have

a color temperature of around 2700K. As the color temperature increases, the color of the light appears less yellow and more white. 2700–2800K is considered "Warm Light." 3500–4000K is "Neutral Bright Light." A slightly bluer, "cooler" effect uses 4000K. Many office buildings use 4000–4100K fluorescent bulbs. When the color temperature is 5000K or higher, the light appears bluish-white and simulates "Daylight." The color temperature of daylight varies but is usually in the 5000–7000K range. At noon, the light temperature is 5600K, but sunlight color temperature can vary widely based on time of day and weather conditions.

"Do <u>not</u> use e-readers before bedtime! The use of e-readers has been found to decrease and delay melatonin production, prolong the time to fall asleep, delay the amount and timing of REM sleep, and reduce alertness the following morning."

Do <u>not</u> use e-readers before bedtime! The use of e-readers has been found to decrease and delay melatonin production, prolong the time to fall asleep, delay the amount and timing of REM sleep, and reduce alertness the following morning (36). While most researchers have shown that blue light may be the cause of sleep delay, in a recent podcast, Dr. Matthew Walker, a world-renowned expert on sleep research, author of the highly regarded book, <u>Why We Sleep</u>, and host of the podcast, "The Matt Walker Podcast," said the culprit may not be blue light itself but that it is emitted from devices that stimulate our brain when we need to start relaxing (37), like e-readers, computers, and TVs.

Besides getting off electronics, replete with blue light and stimulating for the brain, in the evening, a few hours before bedtime, you can also use "blue blocker glasses" (38), turn on the night mode of some devices, and some TVs, and dim the lights (and maybe replace with softer lighting because even a small amount of blue light exposure will affect the SCN). Keep your bedroom dark at night (or during the day if you work the late shift), using blackout curtains to keep the light out if needed. Use eye masks if the bedroom cannot be kept dark. Keep the overhead lights out overnight--use soft light or motion-activated nightlights if you have to get up in the middle of the night. Do not be tempted to look at your phone in the middle of the night (unless it is an emergency and you are on call) since blue light from the device can stimulate the SCN and suppress melatonin, sabotaging the rest of the night's sleep.

4. Do not eat within two hours of going to bed.

As mentioned in our previous article, food is also a zeitgeber, with the composition of nutrients and timing of food intake affecting the peripheral clocks (39) rather than the central clock (40, 41). Late night or delayed mealtimes lead to misalignment of peripheral clocks (42, 43) within tissues (and indeed within all cells) and with other peripheral clocks. Circadian misalignment, seen in shift work, sleep deprivation, and jet lag, can lead to insulin resistance and inflammation (44). Body temperature increases during digestion ("postprandial thermogenesis"), which is not optimal when trying to go to bed when you want the body temperature to go down for better sleep.

Glucose disposal exhibits diurnal variation and is both insulindependent (following meals) and insulin-independent (with activity/exercise) (45, 46). Remember that the circadian peak for insulin action is in the afternoon, so eating carbohydrates late in the evening (and therefore causing circadian misalignment) leads to higher blood glucose levels overnight (47) and eventually insulin resistance and Type 2 diabetes if this becomes a chronic habit (48–50). In addition, exogenous melatonin (with pharmacologic doses usually much higher than physiologic levels), a common supplement in the US, also worsens glucose tolerance (51).

"Late night or delayed mealtimes lead to misalignment of peripheral clocks within tissues (and indeed within all cells) and with other peripheral clocks. Circadian misalignment, seen in shift work, sleep deprivation, and jet lag, can lead to insulin resistance and inflammation."

Lipid metabolism also displays time-of-day-dependent rhythms, which are affected by behaviors like the sleep-wake and feedingfasting cycles (41). As shown in mice, lipid digestion/absorption in the intestinal tract is clock-dependent (52, 53), and circadian alignment is essential for maintaining the integrity of intestinal epithelial barrier function (41, 54). (We will discuss the importance of the microbiome and leaky gut in a future article.) Not surprisingly, lipid turnover and fatty acid b-oxidation, which decrease the level of fatty acids in the blood, are also diurnally regulated (41). Fatty acid metabolism decreases after late meals, leading to increased fatty acid levels in the blood overnight, which may promote human obesity (48, 49) and cardiometabolic syndrome in mice (55).

"Fatty acid metabolism decreases after late meals, leading to increased fatty acid levels in the blood overnight, which may promote human obesity and cardiometabolic syndrome in mice."

Late meals also can lead to decreased quality of sleep (56). In men, late meals with fat intake were associated with decreased sleep efficiency (% of time asleep while in bed) and REM sleep with longer sleep latency (time to fall asleep), REM sleep latency, N2 sleep (stage 2 of non-REM sleep), and WASO (Wake After Sleep Onset). "In women, there were positive associations between sleep latency and caloric, protein, carbohydrate, and fat nocturnal intake; N2 sleep and caloric, carbohydrate, and fat nocturnal intake; and WASO and caloric and fat nocturnal intake. In women, negative associations were found between sleep efficiency and caloric, carbohydrate, and fat nocturnal intake; and REM sleep and nocturnal fat intake" (56). The bottom line is not to eat late meals, especially fatty meals, right before bedtime, especially if you are a woman.

4. Keep a regular bedtime wind-down routine.

We cannot just go to bed after something stimulating and expect to fall asleep immediately. As Matt Walker said in a podcast interview, "We all fail to recognize that sleep is not like a light switch...Sleep

is much more like landing a plane. It takes time to come down onto the sort of terra firma of good sleep at night." He compared most of our expectations and practices to be "like driving into your garage... at still 60 miles an hour and then slamming the brakes on. You think it is gonna be a good outcome." (37) We need consistent wind-down routines, like dimming the lights, taking a warm bath or shower (which causes vasodilation and subsequent cooling of the body in preparation for sleep), meditation, practicing deep breathing, reading (but not with bright overhead lights), listening to calming music or sleep stories (like we have for our children but more adult and relaxing stories), or some other relaxing practice for you.

"He [Matt Walker] compared most of our expectations and practices to be 'like driving into your garage... at still 60 miles an hour and then slamming the brakes on. You think it is gonna be a good outcome.""

5. Get regular physical exercise.

Physical exercise has consistently been shown to help improve sleep-whether low intensity (a casual walk, stretching, beginner's yoga or taichi, bike riding or using an elliptical at a leisurely pace), moderate (brisk walking or walking uphill, a strenuous yoga session, weight training, jogging, cycling, or swimming), or high intensity (circuit training, vigorous weight training, sprinting, or taking laps in the pool)(57). Moderate-intensity exercise improved insomnia in older adults, gaining 75 minutes more sleep (58)! A single bout of moderate-intensity exercise increased time in that all-important Slow-Wave Sleep (SWS), boosting the number of slow waves produced at night (59), helping to clear b-amyloid and tau proteins from brain cells to prevent Alzheimer's. A National Sleep Foundation survey found that exercisers of all intensity levels reported better quality sleep than non-exercisers although the total number of hours remained about the same (60). Not unexpectedly, the high-intensity exercisers reported the best sleep. High-intensity exercise requires and uses up the most ATP and, therefore, produces the most adenosine, contributing to sleep pressure (as discussed in the first article of this series).

"Moderate-intensity exercise improved insomnia in older adults, gaining 75 minutes more sleep! A single bout of moderate-intensity exercise increased time in that all-important Slow-Wave Sleep (SWS), boosting the number of slow waves produced at night, helping to clear β -amyloid and tau proteins from brain cells to prevent Alzheimer's."

Muscles also have a circadian rhythm and are strongest and most powerful in the late afternoon and evening (5–8 PM) compared

with early morning (61–63), with the most records broken, fastest serves, and similar accomplishments in evening competitions. These high-intensity or resistance exercises (like tennis, tennis, swimming, and distance racing) require fast twitch muscles, which are fatigable, exhaust glycogen stores faster, and are more subject to circadian rhythms. An athlete's natural circadian preference also plays a role in performance and accounts for up to 26% of the diurnal variation in performance (64), i.e., whether it is aligned with the timing of the competition (night owl in morning event or evening event).

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On the other hand, endurance exercise (such as long-distance running and cycling) requires more slow twitch muscles, is not as influenced by circadian rhythms, and shows little variation between morning and night but is very dependent on good quality sleep (65). The depletion of glycogen stores in muscles causes fatigue and is replenished during sleep. If sleep is inadequate, the athlete still feels fatigued the following day and performs poorly (65, 66).

However, more relevant for us medical professionals—who are usually non-competitive non-athletes—is to exercise earlier in the day and <u>not within two hours before bedtime</u> since the body will be revved up instead of relaxed for bedtime. Besides the cardiovascular and sleep-promoting benefits of exercise, it also lowers inflammation in the body by inhibiting proinflammatory cytokines (67, 68), which will improve all those conditions throughout the body caused by chronic inflammation—cardiovascular disease, metabolic syndrome and insulin resistance, arthritis, dementia, depression, and many others. In a future article, we will discuss exercise as one of the pillars of health.

"However, more relevant for us medical professionals—who are usually noncompetitive non-athletes—is to exercise earlier in the day and <u>not within two</u> <u>hours before bedtime</u> since the body will be revved up instead of relaxed for bedtime."

6. Limit caffeine, alcohol, nicotine, and certain medications before bedtime.

In our first article of this series, we discussed **caffeine** and its effect of blocking adenosine receptors, which temporarily mask the feeling of sleepiness. In contrast, adenosine accumulates, eventually leading to increased sleep pressure (or "the caffeine")

crash") when the caffeine is metabolized. Also, as mentioned previously, aging decreases the metabolism of caffeine, so older people are more sensitive to its effect for a more extended period. Thus, we should stop caffeine early in the day to prevent sleeping problems caused by caffeine.

Alcohol is a sedative-hypnotic and initially can promote sleepiness and sleep latency and increase Slow-Wave Sleep (69) for the first few nights, but then tolerance develops, requiring more alcohol to have the same effect (70). Also, it sabotages REM sleep (69), leading to poorer quality sleep overall. So, enjoy those cocktails (if you must) between 5–7 PM but no later for better sleep quality.

Nicotine, in all its various forms, is a stimulant with increased wakefulness, alertness, and focus. Not surprisingly, its use is associated with insomnia symptoms, such as increased sleep onset latency, sleep fragmentation, decreased REM sleep, decreased Slow-Wave Sleep, and increased daytime sleepiness (71). Smoking is deleterious for your health, so it is best to avoid nicotine unless using nicotine patches for withdrawal from smoking, during which it may help with sleep (72).

Several medications and supplements can interfere with a good night's sleep. Alpha-blockers for high blood pressure or prostate problems can sabotage REM sleep. Beta-blockers, used to treat high BP, cardiac dysrhythmias, or chest pain, can lower melatonin levels. ACE inhibitors and angiotensin II-receptor blockers can cause side effects, like muscle cramps or coughing, that are not conducive to sleep. Antidepressants, like SSRIs, may cause insomnia. Corticosteroids, used as an anti-inflammatory agent for many conditions, can be too energizing. Statins, optimally taken at night since most cholesterol synthesis occurs overnight, can cause muscle pain, making it difficult to sleep. Cholinesterase inhibitors, used for dementia, may cause sleeplessness and bad dreams. Stimulants, used for ADHD and narcolepsy obviously can sabotage sleep. Theophylline for asthma can also cause sleep problems. Non-drowsy antihistamines, decongestants, and cough suppressants may cause anxiety and jitteriness, also leading to sleep problems. Some supplements, such as glucosamine and chondroitin, can also cause insomnia. For some of these, you may be able to find alternative medications or a different dose or timing of administration of the medication/supplement or make lifestyle changes that would obviate the need for a particular drug (73).

"Alcohol is a sedative-hypnotic and initially can promote sleepiness and sleep latency and increase Slow-Wave Sleep for the first few nights, but then tolerance develops, requiring more alcohol to have the same effect. Also, it sabotages REM sleep, leading to poorer quality sleep overall."

7. Avoid late afternoon naps (after 3 PM or less than 8 hrs before bedtime), though shift workers may want to take one just before starting their shift.

Late morning–early afternoon naps have been shown to improve alertness and boost memory and performance (57, 74). Researchers have looked at different lengths of naps and their

respective effects. A complete sleep cycle lasts around 90 minutes, so the first 30 minutes is mostly stage 2, and the next 60 minutes is SWS and REM. A 20–30-minute nap can boost energy levels and alertness. A 60-minute nap includes SWS, which is important for memory and executive functioning, and a 90-minute nap includes REM sleep, thereby increasing creativity and integrating memories (57). However, longer naps may decrease adenosine buildup and, therefore, decrease sleep pressure and cause more difficulty falling asleep if taken too close to bedtime, which is why the suggestion of napping is greater than 8 hrs before expected bedtime.

However, napping throughout the day is a sign that you are not getting enough sleep at night—common in the post-call day, of course—but if you are experiencing this frequently when you are not post-call, then you may not be getting adequate sleep for other reasons, like possibly sleep apnea, and you may need to consult with your doctor and/or a sleep expert.

"Late morning–early afternoon naps have been shown to improve alertness and boost memory and performance "

8. What about medications to help sleep?

The most well-known is melatonin, a natural hormone produced by the pineal gland that helps set your circadian rhythm and get to sleep. It is generally safe, but start with the lowest dose (about 1 mg) and titrate up as needed around an hour before your expected bedtime (57). Contraindications include but are not limited to bleeding disorders, anti-seizure medications, birth control medications, anti-hypertensive medications, diabetes medications, immunosuppressants, and depression (75). Discuss this with your doctor if you are on any of these kinds of medications or pregnant or lactating and, especially, if you are using this in the long term. Sometimes, other behavioral measures (like those above) may be as effective and safer.

"There are many classes of sleeping pills (benzodiazepines, barbiturates, antidepressants, and Z-drugs [like zolpidem, better known as Ambien®]), but, in addition to the possibility of side effects and developing dependency and tolerance, the primary concern with all of these is their effect on memory the day following administration with a higher risk of dementia sometimes associated with their use."

There are many classes of sleeping pills (benzodiazepines, barbiturates, antidepressants, and Z-drugs [like zolpidem, better known as Ambien®]), but, in addition to the possibility of side effects and developing dependency and tolerance, the primary

concern with all of these is their effect on memory the day following administration with a higher risk of dementia sometimes associated with their use (76–78). The mechanism for this has not been elucidated yet. However, earlier this month, Hauglund showed in mice that zolpidem significantly decreases the flow of the glymphatic system during deep sleep (79), which is needed to clear b-amyloid and tau from our brains to prevent cognitive decline. On the other hand, zolpidem has been found to increase stage 3 sleep (80) and memory in some people by increasing sleep spindles (81). While decreasing the sleep latency period (so you get to sleep faster), these drugs have been shown to alter sleep architecture negatively (82–85), so drug-induced sleep may often be inadequate. It is probably best to avoid any of these sleeping medications as a long-term solution to insomnia, given the risk of cognitive decline.

Conclusion:

Getting adequate quantity and quality of sleep are crucial to the body's healthy functioning—a considerable challenge for medical professionals with long working hours and/or shift work, which cause circadian dysrhythmia and may lead to serious, long-term metabolic problems. Using some of the methods above (as much as possible) may help offset some of the deleterious effects of sleep deprivation or disruption.

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Figure 10. Levels of TSH and T4 with Sleep Deprivation (modified from Van Cauter [40])

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The Evolution of Practice: Reflections on a Career

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.

"Nobody says "I wish I'd spent more time at work" on their deathbed." It is an axiom familiar to most people. While this may be true, I can confidently say I have not regretted a minute I have spent at work. My job has been one of the greatest blessings in my life.

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I officially retired on February 28th, 2024, after working full-time for 34 years in the NICU at Toronto's Women's College Hospital (WCH, which has been relocated to the Bayview Campus of Sunnybrook Health Sciences Centre). After recovering from a reverse shoulder replacement, I returned to work at one-half fulltime hour equivalency. With respiratory therapist staffing levels at a critical (and chronic) low level, those hours quickly increased, so I have been working nearly full-time for the past year. I was ready to collect my pension; however, giving up the sense of purpose and fulfillment working in the NICU that has been and continues to give me was not on the table. It still is not.

My good fortune began in the late fall of 1988 when I was assigned to the NICU at WCH for my neonatal rotation. The model of care I observed there was unlike any I would see in any clinical rotation in my training. I have described the clinical team at Sunnybrook in a prior column (Professional Autonomy Within a Multi-professional Team "Why Have a Dog and Bark Too": <u>Neonatology Today</u> Oct 2019), and while growing pains are to be expected in any team aspiring to transition to a trans-professional model of care, our team has continued to develop within the model of care envisioned by, and born of the efforts of the late Dr. Andrew Shennan.

My base site for clinical training was at Toronto General Hospital (now University Health Network, Toronto General Hospital). TGH, as it is known locally, has a history of firsts. It was the first publicly funded hospital in the world; it performed the first successful single-lung transplant, the first successful double-lung transplant, the first external pacemaker in open-heart resuscitation, and treated the world's first patient with insulin (1). It is one of the largest research and teaching institutions in Canada (The Toronto Institute of Medical Technology (TIMT), now "The Michener Institute," where I received my didactic training, is now also part of UHN). Newsweek ranks it the number one hospital in Canada and the number 3 hospital globally.

TGH hired me upon graduation, but after working there for six months, I realized I would not change the world (at least not at TGH!). I walked the short block up Elizabeth Street to WCH and never looked back.

"I arrived at WCH's NICU as a freshfaced graduate (and much younger!), full of excitement and wonder. Moreover, I was scared to death! My fear was tempered by a feeling that, in this environment, I could truly make a difference. Being a student was much different than being a staff RT responsible for ventilating our tiny patients."

I arrived at WCH's NICU as a fresh-faced graduate (and much younger!), full of excitement and wonder. Moreover, I was scared to death! My fear was tempered by a feeling that, in this environment, I could truly make a difference. Being a student was much different than being a staff RT responsible for ventilating our tiny patients.

In hindsight, much of what was routine in 1990 is laughable today. Chest physio was regularly performed using a resuscitation mask

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to percuss the chest, and almost all babies under 30 weeks gestation (and sometimes older) were intubated and ventilated at rates of 40-60, peak inspiratory pressure (PIP) of 20 cmH₂O, and PEEP of 5 cmH₂O. The rate was always weaned before pressure, and blood gas pH was to be no less than 7.35. After a week of life, "chronic gases" were accepted, with a pH of no less than 7.30, something that never made sense to me. (We did not have a choice after pounding their tiny lungs for a week with these settings!)

The Sechrist[®] was our staple ventilator then, although we had a Healthdyne[®] or two and a few Baby Bears[®]. The pressure relief valve on the Sechrist[®] was manually adjusted and had to be checked once per shift. This was done by disconnecting the baby, removing the expiratory limb from the exhalation block, and occluding it and the patient wye. The pressure was monitored using an add-on attached to the top of the ventilator, and it typically took several seconds to register, during which time the baby invariably had a bradycardic spell. The more unstable the baby, the longer it seemed to take the monitor to give a reading; all the while, alarms blared as we loudly stated, "It's ok, it's here!"

The venerable BabyBird[®] had been phased out prior to my arrival. We did not have 24-hour RT coverage at one time. One night, one of my mentors, Dr. Martin Skidmore (we never use the term "Doctor"; he was always just "Martin") called in my former clinical instructor, Marilyn Hyndman, because he could not get one to work. Marilyn looked at the circuit, reversed a one-way valve, and shortly thereafter, the unit had an RT on site 24-7-365. It was the start of something very good.

Surfactant trials had just finished when I started, and it was still considered an investigational drug. We used bLES® (bovine lung extracted surfactant), a product developed in London, Ontario, that is essentially Infasurf® (calfactant). After administration, we described the babies as "blessed," an apt description given that FiO₂ decreased rapidly to 0.21 in almost all babies postadministration. We still use it today. Following some minor quality control issues with manufacturing, bLES® was unavailable, and we had to use Survanta® for the better part of a year. We were not impressed, and while it may have been due to differences in response, we seemed to have significantly more pneumothoraxes using it. Our colleagues across Canada also made this observation. (The Hospital for Sick Children, now "Sick Kids," would offer to trade us two bottles of Survanta® for 1 of the bottles of bLES® we still had in stock. Given Survanta's much higher price, this was quite significant!)

"Surfactant trials had just finished when I started, and it was still considered an investigational drug. We used bLES[®] (bovine lung extracted surfactant), a product developed in London, Ontario, that is essentially Infasurf[®] (calfactant)."

By the time I started working there, WCH had already established a reputation for having relatively low rates of chronic lung disease (CLD), {then known as bronchopulmonary dysplasia (BPD)} despite the rudimentary technology of the time. Synchronised ventilation was non-existent in the neonatal world, although several manufacturers tried to achieve it using various methods. We trialed all of them and found none of them reliable enough to use. When babies were bucking the ventilator, we increased the rate and over-rode them.

The term "PEEPaphobia" had not yet been coined, and using 5 cmH₂O as a standard and rarely altered level of PEEP was likely why pulmonary interstitial emphysema (PIE) was rampant. To make matters worse, PIE was treated by *reducing* PEEP to allow the lung to collapse down. Not surprisingly, the outcomes of babies with PIE were poor at best and terminal at worst. Eventually, PEEPs greater than 5 cmH₂O became more commonplace as our understanding of its importance grew. PIE was still a problem, but there was less of it.

"The term 'PEEPaphobia' had not yet been coined, and using 5 cmH2O as a standard and rarely altered level of PEEP was likely why pulmonary interstitial emphysema (PIE) was rampant."

Then, ventilation guidelines were drafted by respiratory therapists and forwarded to the physician group for approval. We use guidelines rather than policies because we feel it important to be able to colour outside the lines, as it were when tailoring a baby's ventilation. (Not surprisingly, we would start pushing those guidelines' boundaries as soon as they were approved!) I firmly believe the direct involvement of RTs in managing ventilation and creating the guidelines used is mainly responsible for our exemplary pulmonary outcomes.

The arrival of the Dräger Babylog 8000[®] marked a turning point in neonatal ventilation. Aside from the obvious advantage of providing truly synchronous ventilation for the first time, we could monitor the volumes a baby was receiving. It was a game-changer. We were shocked to see how large delivered volumes could be even using PIPs of 12 cmH₂O. At first synchronised intermittent mandatory ventilation (SIMV) mode was used, but we quickly adopted assist-control (A/C) as a first-line ventilation mode. To my knowledge, we were the first NICU in Canada to use A/C.

Around this time, we began questioning the wisdom of generally accepted ventilation parameters, namely tidal volume (Vt). In our estimation, 5 ml/kg was too large for our tiny babies. Our reason was that smaller, less mature lungs lacked the structure to put this volume without causing injury. 4 ml/kg became our preferred target, as low as 3 ml/kg in extremely premature, low birth weight babies. We also questioned the wisdom of using high FiO₂ on extremely premature babies, reasoning that oxidative stress is a much bigger issue in this population. A FiO₂ of 0.21 became our goal, and the parameters that allowed this had no deleterious effect on our CLD rate. Twenty-five weeks post-menstrual age (PMA) was considered extremely premature then, and parents were given the choice of not resuscitating at this gestation. While offered, resuscitation at 24 weeks PMA was strongly discouraged, and babies born at less

than 24 weeks PMA or whose birth weight was less than 500 grams were not resuscitated regardless of parental wishes.

Software updates to the Babylog 8000[®] soon arrived, and the ventilator was now called the Babylog 8000 plus[®]. The machine now offered pressure support (PSV) ventilation, volume targeted ventilation (dubbed "VG" [®]), the ability to adjust inspiratory and expiratory flows independently (called "VIVE" [®]), and in markets outside the U.S., high-frequency oscillation (HFO). Neonatal ventilation had at last caught up with the adult world!

"AC/VG" quickly became our go-to mode; again, it was the first in Canada. (I preferred PSV/VG whenever tolerated since it is a more lung-protective mode.) While many of our RTs pined for the ability to offer HFO to our patients, this was the first time we had access to a machine we could use to deliver it. (We never had a Sensormedics[®] oscillator, nor did we have an Infant Star[®] (a machine well known and loved by those who used it, which could provide a flow interrupter version of HFO.)

The Babylog 8000 plus[®] used a venturi on the exhalation limb to provide active expiration, and while not very powerful, that lack of power may be why it worked so well with our patient population. (One night, I had to decrease the frequency to 6 Hz in order to ventilate a larger baby. I silently prayed in front of the ventilator as I repeatedly silenced a "pressure measurement out of range" alarm. I am unsure if it was the ventilation or the prayers, but the baby pulled through!)

HFO was a new option for us; we were the first NICU in Canada to use HFO with this machine. It marked yet another turning point in our ventilatory practice. We observed that most of our small babies ended up on HFO, so one day, I decided to start HFO immediately; eventually, everyone else followed suit, and our chronic lung disease rates began to fall. Shortly before, we had begun to place babies on the ventilator immediately after intubation while still on the admission table; prior to that, our babies were hand-bagged until being transferred to the incubator.

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Initially, up to 15 Hz frequencies were used, especially with tiny babies. This may be due to the necessity of using higher frequencies with the much more powerful Sensormedics[®] oscillator. Eventually, 10Hz was rarely exceeded as we recognised the propensity of tiny babies to gas-trap. ("All tiny babies are either gas trapping or are about to" are words to practice by!) The "magic formula" on the admission table was a frequency of 10 Hz, mean airway pressure of 10 cmH₂O, and amplitude of 100% (amplitude was as percent, not cmH₂O), which was usually quickly weaned to 40%. (The power curve of the Babylog 8000 plus[®] was not linear, and there was a relatively small difference between 40% and 100% amplitude compared to between 10 and 40%.)

The Babylog 8000 plus $^{\mbox{\tiny B}}$ is no longer sold nor supported, but it is a testament to its reliability and robustness that we are still using

it as a slave for some of our jets. The technology has evolved, but HFO remains our first-line mode of ventilation.

In 1996, I returned to TIMT and obtained a post-diploma certificate in neonatology, after which I worked exclusively in the NICU as an advanced practice therapist. The increased autonomy accompanying the title gave me more license to push the boundaries and advance ventilatory practice. Unfortunately, the program I benefitted from is no longer offered.

There is one mode of ventilation our unit cannot claim to be the first to use: high-frequency jet ventilation (HFJV). I had used a rudimentary jet ventilator on a few adult patients during my time at Toronto General, but the machine was cobbled together in a lab at the University of Toronto. Shortly before the new millennia, Dr. Brian Simmons joined our team at WCH. Before he arrived in Toronto, Brian practiced in the NICU at "The Janeway" in St. John's, Newfoundland (known affectionately as "The Rock"), where he became familiar with using "the jet."

"There is one mode of ventilation our unit cannot claim to be the first to use: high-frequency jet ventilation (HFJV). I had used a rudimentary jet ventilator on a few adult patients during my time at Toronto General, but the machine was cobbled together in a lab at the University of Toronto."

One day in 1999, my now good friend Evan Richards from Bunnell Inc. showed up with a hugely intimidating hulk of a machine called the "LifePulse[®] 203" high-frequency jet ventilator. It was another turning point in the evolution of ventilation in our unit, and for me, it was love at first sight. I took it upon myself to learn all about HFJV and champion its use in our unit, and, to this day, I am the "go-to guy" for all things jet. *And, I am still learning!*

As with HFO, we altered HFJV parameters as we became more comfortable with the mode and the machine. Our NICU was a pioneer in the use of lower rates; 240 is almost always used. We have also been an innovator in using low PIP and long inspiratory time recruitment maneuvers (yes, it was me), and I continue to find new uses. One is when weaning MAP to maintain airway stability, and another is when high MAP is required for oxygenation, but there are concerns about cerebral blood return and/or cardiovascular compromise.

The Babylog 8000 plus[®] was replaced by the Dräger Babylog VN500[®], which, in most aspects, was an evolution of the earlier model, except for one notable exception: the introduction of volume targeting during HFOV. (My first column in Neonatology Today was on HFO/VG in the January 2019 issue.) By this time, the Perinatal and Obstetrics Programs (now the Women and Babies Program) had been relocated to our present location at the Bayview Campus of Sunnybrook Health Sciences Centre. Here, we now had the luxury of a unit approximately four times the size of the one at Women's College. Single-patient rooms with integrated

parental space represented a considerable improvement for our babies and their families, but they also presented new challenges to how our team worked.

The location changed, but our eagerness to try new technology did not. HFO/VG was no exception, and in another first, we were the first unit in Canada to use this adjunct. (It is still not used in many Canadian units.) Just as HFO became our first-line mode, we now use HFO/VG almost exclusively as a first-line mode. As with conventional ventilation, when using HFO/VG mode, we aim for low volumes and amplitudes. HFJV has seriously considered if it is above 2 ml/kg of VG and/or as amplitude approaches 20 cmH2O. If amplitude is low, volumes of 2.5 ml/kg or even 3 ml/kg may be tolerated, particularly if the need for higher volumes is expected to be short-lived. These may seem to be very low amplitudes for those unfamiliar with HFO/VG, but in clinical practice, it is quite remarkable how many babies will ventilate well with amplitudes of 10 cmH₂O or less.

"Just as HFO became our first-line mode, we now use HFO/VG almost exclusively as a first-line mode. As with conventional ventilation, when using HFO/VG mode, we aim for low volumes and amplitudes."

One significant improvement has been a dramatic decrease in infection rates; the cramped space at WCH gave us the dubious distinction of having one of the highest infection rates in the Vermont-Oxford collaborative. Indeed, an infection was considered a rite of passage! Before our move, I had initiated a change to our IV insertion practice. A caddy with IV supplies had been used. One was located on a shelf above one of the scrub sinks in each of our two rooms, and it was brought to the bedside when a baby had an IV inserted. Eliminating the caddies and instead using sealed plastic bags containing the items required for an IV start resulted in our IV sepsis rate plummeting. IV infections are now virtually non-existent.

Non-invasive ventilation (NIV) is now the darling of neonatal ventilation everywhere, and the NICU at Sunnybrook is no exception. Here, too, our use of NIV has seen innovation. Before introducing the Infant Flow® system and then the Sipap® variant thereof, we used nasal-pharyngeal tubes (NPTs) to provide NIV to our babies post-extubation. Our NPTs were shorter than those used by many other units (thus having lower resistance), and all babies were placed on what was referred to as "NPT-puffs," essentially non-invasive positive pressure ventilation (NIPPV), using the Sechrist[®], at a rate of 12, PIP of 12 cmH₂O and PEEP of 5 cmH₂O. Pressures were set with the baby disconnected and occluding the patient wye. Lacking any form of leak compensation, delivered pressure was invariably lower than set. It is quite likely that fewer babies would have failed extubation had pressures been set with the baby connected. Occasionally, someone would forget to turn the ventilator back on after changing the NPT, hence delivering CPAP, and if the baby tolerated it, they were "transitioned" to CPAP.

NIV pressures are more reliable today since the ventilators used feature leak compensation. NIPPV is not used as much as NPT puffs, but most babies are managed with CPAP. Most of our smaller babies are managed non-invasively with NIV-HFO, an option not available in the U.S., and we find a high degree of success using this mode. It is worth noting that our lowest rate of CLD was just over 8% before the widespread use of NIV. An endotracheal tube does not have to be a guarantee of CLD!

Now, "NIV-NAVA" is the new kid on the block. Given that much of the research on neurally adjusted ventilation in the neonatal population was done in the NICU at WCH (2), it may be a surprise that we have just recently acquired several Getinge Servo-N[®] ventilators. We are latecomers to the NIV-NAVA party.

We are at the bottom of this learning curve, but as with virtually every other ventilation mode, we question the parameters used. NIV-NAVA will find its place in our unit, but it will indubitably be used our way. (That will doubtless be a topic of another column.)

It may be the beat of a different drummer we march to, but march we do, and come what may, march we will!

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Pioneer Profile – Marshall H. Klaus, MD

Joseph B. Philips, III, MD



"Dr. Klaus was not content with private practice and took a pulmonary fellowship position with the Cardiovascular Research Institute at the University of California at San Francisco. He was mentored by some greats there, including Julius Comroe, MD, and John Clements, MD. It was there that he commenced his work on neonatal pulmonary physiology."

Marshall Klaus made enormous contributions to both neonatology and obstetrics. He was born and raised in Cleveland, Ohio, and attended Case Western Reserve University for both undergraduate and medical school education (1). He served his residency at what is now Rainbow Babies and Children's Hospital, then served in the Air Force, followed by a brief stint in private practice. Dr. Klaus was not content with private practice and took a pulmonary fellowship position with the Cardiovascular Research Institute at the University of California at San Francisco. He was mentored by some greats there, including Julius Comroe, MD, and John Clements, MD. It was there that he commenced his work on neonatal pulmonary physiology. Dr. Klaus was the lead author of a brief manuscript identifying the composition of pulmonary surfactant and demonstrating its characteristic hysteresis in a modified Wilhelmy balance (Figure 1) (2).

Dr. Klaus returned to Case Western as an Assistant Professor and continued his work on respiratory disorders in the newborn. **Figure 1**. Surface tension–area diagrams measured on a modified Wilhelmy balance. The left is dried lung foam, and the right is lung phospholipid extract (2).



He described the morphology of the alveolar lining layer and elaborated on the relationship of alveolar surface tension to the alveolar radius (3). He was a co-author of a report on the first attempt at surfactant replacement therapy using aerosolized dipalmitoyl phosphatidylcholine (DPPC), which failed because DPPC is a waxy solid at body temperature (4).

Stanford University recruited Dr. Klaus back to the West Coast, where he was among the first to use prolonged mechanical ventilation with endotracheal intubation in neonates (5). Among his collaborators was Philip Sunshine, a legend in his own right. While at Stanford, Dr. Klaus observed that mothers whose infants had been ventilated for extended periods had difficult and abnormal bonding with their babies and sometimes demonstrated bizarre behaviors toward their infants, sparking a lifelong interest in maternal-infant bonding.

"While at Stanford, Dr. Klaus observed that mothers whose infants had been ventilated for extended periods had difficult and abnormal bonding with their babies and sometimes demonstrated bizarre behaviors toward their infants, sparking a lifelong interest in maternalinfant bonding."

In 1967, he was recruited back to Case Western as Neonatal Director, where he remained for the rest of his illustrious career. Again, early work involved the respiratory system. Dr. Klaus contracted polio while a medical student, which left him with a flail arm and weak leg. He was averse to the use of mechanical ventilation unless necessary. This led to a publication showing that intermittent bag and mask ventilation was effective in managing infants with respiratory distress syndrome (RDS) (6). I recall using this technique early in my training and practice years for infants with CO₂ retention. Intermittent bagging was used to bring PaCO₂ levels down.



"In 1967, he was recruited back to Case Western as Neonatal Director, where he remained for the rest of his illustrious career. Again, early work involved the respiratory system...He was averse to the use of mechanical ventilation unless necessary. This led to a publication showing that intermittent bag and mask ventilation was effective in managing infants with respiratory distress syndrome (RDS)."

Another important innovation was developing a practical device for administering continuous positive airway pressure (CPAP) spearheaded by Dr. John Kattwinkel, one of Dr. Klaus' many mentees (7). This device was widely used for decades, and variations of it are still used in NICUs today. Another mentee, Richard Martin, MD, began his research career with Dr. Klaus, studying the effect of ČPAP on the Hering-Breuer reflex and expiratory time (8, 9). A third mentee, Dr. Avroy Fanaroff, published seminal observations concerning insensible water loss in low-birth-weight infants and showed that the use of a heat shield placed within the single-walled incubators in use at the time greatly reduced insensible losses and improved the thermal environment (10). Observations such as these led to the double-walled redesign of infant incubators. Thus, Dr. Klaus and his early trainees made major contributions to the medical care of premature infants. As important as these contributions were, however, they pale in comparison to the truly monumental and revolutionary advances he pioneered in mother-infant bonding, which led directly to what we now call family-centered care.

"As important as these contributions were, however, they pale in comparison to the truly monumental and revolutionary advances he pioneered in mother-infant bonding, which led directly to what we now call familycentered care."

As far back as his residency days, Dr. Klaus had noted the improved family satisfaction with patient care when unlimited family visitation was allowed (1). In those times, family visitation was typically limited to a half hour per week, usually on Sundays. As mentioned earlier, he had also observed at Stanford the sometimes abnormal behavior of mothers whose infants had received prolonged mechanical ventilation. Once established at Case Western, he paired up with John H Kennell, MD, to study mother-infant bonding, forever changing the course of newborn infant care.

Together with colleagues, they described in detail the initial

maternal behavior patterns when mothers were presented with their nude infants just after birth and noted that these patterns were different for term and preterm infants (11). The standard of care at the time was for mothers to have limited contact with their newborns. Klaus and colleagues showed that mothers who had extended contact with their infants spent significantly more time in the "en face" position and fondled their babies more often one month after birth than those who were in a standard-of-care group and that these differences persisted at one year of age (12, 13). It was further shown that speech patterns were different out to two years between the two groups, with the extended contact group having more complex and less commanding speech than the controls (14). The authors postulated that a "special attachment period shortly after birth" was essential for normal maternal-infant bonding. This led to suggestions for change to the standard practice of separating the mother from her baby for extended periods after birth (15, 16).

"The authors postulated that a 'special attachment period shortly after birth' was essential for normal maternalinfant bonding. This led to suggestions for change to the standard practice of separating the mother from her baby for extended periods after birth."

Along with Avroy Fanaroff, Klaus and Kennell showed that mothers who visited their premature infants less often were more likely to have disorders of mothering and to abuse or neglect their children more than those who visited more often (17). This observation led to the publication of suggested guidelines for the care of the parents with a normal or high-risk neonate with an emphasis on unrestricted visitation (18, 19). Their recommendation for early mother-baby skin-to-skin contact eventually led to the kangaroo care model and unrestricted nursery visitation, now the standard of care worldwide. Klaus and Kennell also published an important study on the mourning response to the death of their newborn baby (20).

"This observation led to the publication of suggested guidelines for the care of the parents with a normal or high-risk neonate with an emphasis on unrestricted visitation. Their recommendation for early mother-baby skin-to-skin contact eventually led to the kangaroo care model and unrestricted nursery visitation, now the standard of care worldwide."

Dr. Klaus was also an advocate for breastfeeding. He showed that more frequent breastfeeding led to increased milk intake and weight gain in babies in the first weeks after birth and that this



was also associated with lower serum bilirubin levels in the more frequent feeding group (21–23).

Working in Guatemala in collaboration with Dr. Roberto Sosa, Klaus and Kennell showed that the presence of a support person called a doula during labor led to significantly shorter labors, less need for augmentation of labor and cesarean section, and improved neonatal outcomes (24, 25). These observations were confirmed with a large randomized, controlled trial (RCT) in the United States and by a later review of eleven RCTs (26, 27).

Dr. Klaus authored several important books, the most notable of which is *Care of the High-Risk Neonate*, which he co-authored with Dr. Avroy Fanaroff and which most of us older neonatologists cut our teeth on and still recommend to trainees interested in newborn medicine (28). This book is now in its eighth edition. Other important books include *Maternal-Infant Bonding: The Impact of Early Separation or Loss on Family* (29), *The Amazing Newborn: Discovering And Enjoying Your Baby's Natural Abilities* (30), *Bonding: The beginnings of parent-infant attachment* (31), *Bonding: Building The Foundations Of Secure Attachment And Independence* (32), and *The Doula Book: How a Trained Labor Companion Can Help You Have a Shorter, Easier, and Healthier Birth* (33). He also produced a video, Amazing Newborn, showcasing the talents and abilities of newborn infants, proving there is more to the neonate than just brainstem responses (34).

"Working in Guatemala in collaboration with Dr. Roberto Sosa, Klaus and Kennell showed that the presence of a support person called a doula during labor led to significantly shorter labors, less need for augmentation of labor and cesarean section, and improved neonatal outcomes. These observations were confirmed with a large randomized, controlled trial (RCT) in the United States and by a later review of eleven RCTs."

Dr. Klaus mentored numerous trainees. Four of them were most notably honored with the Apgar Award, the highest award bestowed by the AAP Section on Neonatal Perinatal Medicine (SoNPM): Drs. Avroy Fanaroff, John Kattwinkel, Wally Carlo, and Richard Martin. SoNPM also annually bestows the Marshall Klaus Perinatal Research Awards of \$5,000 each plus travel expenses to trainees in four categories: Bench or Clinical Research (up to 12 per year), Health Services Research (up to 2 per year), and one each per year for Education Research and Necrotizing Enterocolitis Research.

Dr. Klaus received numerous obituaries upon his death, including from *Pediatric Research* (1), *Acta Paediatrica* (35), *The New Your Times* (36), Lamaze International (37), and numerous other news and society publications. He contributed as much as anyone ever to the evolution and modernization of newborn care and founded what we now call family-centered care.

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Streptococcus Salivarius: A Case Report of an Uncommon Cause of Neonatal Sepsis

Vishakha Nanda, MD, FAAP

"Streptococcus salivarius is a bacterium commonly found in human oral cavities. It is rarely associated with neonatal sepsis. We present a case of a term newborn with maternal chorioamnionitis who developed respiratory distress after birth and had a positive blood culture for this bacterium."

Abstract:

Streptococcus salivarius is a bacterium commonly found in human oral cavities. It is rarely associated with neonatal sepsis. We present a case of a term newborn with maternal chorioamnionitis who developed respiratory distress after birth and had a positive blood culture for this bacterium. Of interest, this bacterium was noted to be drug-resistant and intermediately sensitive to ampicillin. This case implies that Streptococcus salivarius should not be ruled out as a contaminant, and these patients may not always respond to first-line antibiotics like ampicillin and gentamicin and may need antibiotics like Vancomycin.

Introduction:

Early onset sepsis (EOS) in neonates is a potentially lifethreatening condition and contributes to significant morbidity in newborns. Neonates acquire these infections during or immediately after birth. Common causes include *Group B* streptococcus, *E. coli, Listeria monocytogenes*, and *Staphylococcus aureus*. (1)

Streptococcus salivarius is commonly found in the human oral cavity. It generally causes less serious infections in healthy individuals but is known to cause serious life-threatening infections in neonates, children, and immunocompromised adults—very few reported cases of neonatal sepsis (both early and late onset) are associated with this bacterium. Though isolated infrequently from blood cultures, it should not automatically be considered a contaminant, especially if a single organism of the *viridans streptococci* is isolated, if a repeat blood culture is positive, or if the patient is symptomatic.

Though some reports suggest that this infection responds to first-line antibiotics for early-onset neonatal sepsis, one case report identified that this bacterium does not respond well to first-line antibiotics and may need Vancomycin for treatment. Our patient's blood culture also revealed that the organism is intermediate sensitive to ampicillin and ceftriaxone and resistant to most antibiotics except Vancomycin.

Patient information:

The patient is a newborn male born to a 30-year-old Gravida 2 mother with one previous abortion. Pregnancy was complicated by gestational diabetes, chronic hypertension, and obesity. The mother was on diet control for gestational diabetes and prenatal vitamins. Pertinent prenatal labs included a negative Group B streptococcus screen, negative HIV screen (Human Immunodeficiency Virus), Hepatitis B surface antigen, Syphilis screen, Gonorrhea and Chlamydia, and negative prenatal genetic screen. The mother had an abnormal 3-hour glucose challenge test.

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Mother presented at 37 weeks 1 day of gestation with labor pains. She was given labetalol for elevated blood pressure, and an epidural was placed. Membranes ruptured for 14 hours prior to delivery. She developed fever, fetal tachycardia, and variable decelerations one hour prior to delivery and received ampicillin and gentamicin (concerning for maternal chorioamnionitis). The baby was delivered via emergency cesarean section because of non-reassuring fetal heart tones. The baby was born vigorous and had Apgar's scores of 8 and 9 at 1 and 5 minutes of life. The baby was noted to have respiratory distress soon after birth and was placed on Nasal CPAP (Continuous positive airway pressure). The baby was admitted to the special care nursery and continued on nasal CPAP.

On examination, the baby was noted to have tachypnea,

subcostal retractions, and desaturations. The rest of the examination was unremarkable. Complete blood count and blood culture were sent. The baby's labs and radiological findings are detailed in Table 1.

Laboratory test	Day	Results
Complete blood count 1	Day 1	WBC – 15.5; Hematocrit – 58.5; Platelets 184k
		Neutrophils 34% Band cells 5%
		Metamyelocyte 1% Myelocyte 1%
Blood culture # 1	Day 1	Gram positive cocci in chains
		Final report - Streptococcus salivarius.
		Sensitive only to Vancomycin and
		Intermediate sensitive to ampicillin and
		ceftriaxone.
Chest X-ray	Day 1	Diffuse ground glass airspace haziness
		bilaterally, 10 rib expansion, normal cardio
		thymic shadow
C- Reactive protein	Day 2	0.5
Blood culture # 2	Day 3	No growth
Spinal Fluid culture	Day 4	No growth
Spinal fluid	Day 4	Negative
meningitis PCR Panel		
Complete Blood count 2	Day 5	WBC 10; Platelets 206; Neutrophils 33%, No
		bands
Vancomycin trough	Day 5	Normal

Upon admission, the baby was placed on nasal CPAP (Continuous positive airway pressure) via the Ram cannula. The baby's respiratory distress improved over the next few days, and he was weaned to a high-flow nasal cannula on day 3 of life and to room air on day 4 of life. He continued to have occasional desaturations and intermittent tachypnea till day 7 of life.

The methicillin-resistant *staphylococcus aureus* screen done at admission was negative. The baby's blood culture at admission grew *Streptococcus salivarius*. The repeat blood culture senton day 3 was negative. Aspinal tap was performed, and the results were negative. The baby was treated for bacteremia in a symptomatic neonate. At admission, the baby was started with intravenous ampicillin and gentamicin (initial antibiotics). The baby's antibiotics were changed to Vancomycin based on the antibiotic sensitivity report of the blood culture.

The baby's activity and oral intake improved, and he had no other symptoms. He was discharged from the hospital after completing 10 days of Vancomycin and has been following up with his pediatrician.

Discussion:

Early onset sepsis is a life-threatening condition with an incidence of culture-proven EOS of approximately 0.5 cases per 1000 infants born at \geq 37 weeks gestation, compared with approximately 1 case per 1000 infants born at 34 to 36 weeks gestation, 6 cases per 1000 infants born at <34 weeks gestation and 20 cases per 1000 infants born at <29 weeks gestation, and 32 cases per 1000 infants born at 22 to 24 weeks gestation (1-2). About 60% of term infants with EOS require neonatal intensive care

for respiratory distress and/or blood pressure support. EOS may lead to death in about 2-3% of infants born at \geq 35 weeks' gestation (3).

"The methicillin-resistant staphylococcus aureus screen done at admission was negative. The baby's blood culture at admission grew Streptococcus salivarius. The repeat blood culture sent on day 3 was negative. A spinal tap was performed, and the results were negative. The baby was treated for bacteremia in a symptomatic neonate. At admission, the baby was started with intravenous ampicillin and gentamicin (initial antibiotics). The baby's antibiotics were changed to Vancomycin based on the antibiotic sensitivity report of the blood culture."

The immature immune system in neonates increases their risk for serious bacterial infections. Common causative organisms leading to EOS include *Group B streptococcus, E. coli, Listeria monocytogenes,* and *Staphylococcus aureus*. Less common causes of neonatal early-onset sepsis include *Streptococcus viridans group, Staphylococcus epidermidis, Staphylococcus haemolyticus, Staphylococcus saprophyticus,* and viruses like herpes simplex, SARS-COVID and enteroviruses (4).

Streptococcus salivarius belongs to the streptococcus viridans group; it is a normal oral flora in humans but can cause infections in immunocompromised individuals, including infective endocarditis, bacteremia, and pneumonia. It is a rare cause of neonatal sepsis, with very few cases reported in the literature (4).

Molinaro et al. (5) reported a case of a term newborn who was asymptomatic but underwent a septic workup given a mother with inadequately treated GBS prophylaxis. The blood culture grew *Streptococcus salivarius*, and repeat blood culture also grew the same organism. The spinal tap was negative, and the baby received 10 days of intravenous antibiotics.

Keerthi et al. (6) reported an former 35 weeker preterm neonate who presented on day 44 with late-onset sepsis with *Streptococcus salivarius* with fever and respiratory symptoms, and workup revealed pneumonia, negative septic screen labs, negative respiratory viral panel.

Bin et al. (7) recently reported a case of a term newborn who, on day 3 of life, developed a fever and no focal signs. He was started on ampicillin and cefotaxime for suspected Earlyonset sepsis. His Complete blood count was unremarkable, C - reactive protein was high, and the spinal tap was negative. Blood culture revealed *Streptococcus salivarius* is resistant to ampicillin and ceftriaxone and is sensitive only to Vancomycin. A repeat blood culture sent after the initial positive culture was also positive for *Streptococcus salivarius*.

"Streptococcus salivarius belongs to the streptococcus viridans group; it is a normal oral flora in humans but can cause infections in immunocompromised individuals, including infective endocarditis, bacteremia, and pneumonia. It is a rare cause of neonatal sepsis, with very few cases reported in the literature (4)."

Studies have identified that *Streptococcus bovis* and *Streptococcus salivarius* are phenotypically similar and may even lead to erroneous lab identification but can be differentiated by extended physiological characterization (8-9). Broome et al. (10) described criteria for defining significant isolates in blood and CSF cultures.

Gerber et al. (11) noted that bacteremia and meningitis are the most common presenting findings in Streptococcus bovis infection in infants. Gavin et al. (12) reported an otherwise healthy neonate presenting with fever, irritability, seizures, and decreased oral intake. The mother was GBS negative, and there was no chorioamnionitis; the baby was discharged on day 2 of life from the hospital and presented back within 8 hours. Initial blood and CSF culture grew *Streptococcus bovis* sensitive to penicillin and ampicillin.

"With newer early-onset sepsis guidelines and stewardship practices, it is important that this organism is not considered a contaminant and that not all streptococci are susceptible to first-line antibiotics for neonatal sepsis"

Corredoira et al. (13), in a prospective 16-year study on adult patients, studied the clinical significance of *Streptococcus salivarius* and *Streptococcus bovis* isolates. Herecommended that isolation of *Streptococcus salivarius* should not be considered contamination, and this bacteremia may occur in patients with high levels of mucosal disruption and/or serious disorders like neoplasms. They also noted penicillin resistance in 31% of *Streptococcus salivarius* isolates. Their study showed that among the viridans group streptococci, *Streptococcus salivarius* has the greatest rate of resistance to penicillins. Therefore, it is important to note that this bacterium may not be sensitive to the first-line antibiotics for early-onset sepsis. With newer early-onset sepsis guidelines and stewardship practices, it is important that this organism is not considered a contaminant and that not all streptococci are susceptible to first-line antibiotics for neonatal sepsis.

Conclusions:

This case implies that *Streptococcus salivarius* bacteremia should not be ruled out as a contaminant, and these patients may not always respond to first-line antibiotics, ampicillin and gentamicin, and need antibiotics like vancomycin.

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Appendices:

Informed consent

The mother signed an informed consent form to report this interesting case in the medical literature.

Disclosures: The authors have no disclosures

NT



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White Paper for the NANT Ignite Core Training and Mentoring Program for Neonatal Therapists

Jenene W. Craig, PhD, MBA, OTR/L, CNT

Executive Summary:

Neonatal staff mentoring programs are designed to improve healthcare providers' skills, knowledge, and job satisfaction in neonatal care settings. These programs have shown potential benefits in reducing neonatal mortality, enhancing professional development, and improving the quality of care. (1) The NANT Ignite Core Training and Mentoring Program aims to enhance the professional development of neonatal therapist (NT) practitioners through structured education and mentoring relationships. Effective mentorship strategies for NTs involve a combination of peer learning, continuous mentorship, inter-professional collaboration, and support for quality improvement initiatives. These strategies enhance clinical competencies and improve neonatal health outcomes by fostering a supportive and collaborative learning environment.

"Neonatal staff mentoring programs are designed to improve healthcare providers' skills, knowledge, and job satisfaction in neonatal care settings. These programs have shown potential benefits in reducing neonatal mortality, enhancing professional development, and improving the quality of care."

Because neonatal therapists play a critical role in providing riskadjusted, neuroprotective care services in the NICU environment, their specialized expertise is essential to maximizing the effectiveness of the multidisciplinary care team. (2) With growing recognition of the benefits of neonatal therapy, there is an increasing demand for these professionals, both in the United States and globally. However, barriers such as understaffing and limited access to experienced mentors can hinder the success of therapists and their respective units. Given staffing recommendations (2, 3) and the rising demand for NT, neonatal therapists have increasingly requested the benefits of peer-topeer mentoring. Healthcare mentoring programs are increasingly recognized as a vital strategy to address hospital staff shortages. Ignite's initiative aligns with the research recommendations of adjacent NICU practitioners such as nurses (4, 5), Neonatal Nurse Practitioners (1), and neonatologists (6), which advocate for formalized mentoring programs to improve job satisfaction and improved quality of care. Neonatal therapists have recognized the value of learning from one another, sharing best practices, and receiving Guidance from experienced professionals in the field. This collaborative approach has helped to advance the practice of neonatal therapy, foster professional growth, and ultimately improve the quality of care delivered to infants in the neonatal intensive care unit.

The following white paper provides an overview of the NANT Ignite Training & Mentorship Program, its goals, and the key strategies employed to enhance the professional development of neonatal therapists.

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Introduction:

The neonatal intensive care unit is a dynamic and complex environment that requires healthcare providers to possess a unique blend of clinical expertise, critical thinking skills, and emotional resilience. The National Association of Neonatal Therapists (NANT) is a professional organization for neonatal occupational therapists (OT), physical therapists (PT), and speech-language pathologists (SLP) (<u>https://neonataltherapists.com/</u>). Neonatal therapists are integral to the NICU's multidisciplinary care team and are pivotal in providing risk-adjusted, neuroprotective care services to the most vulnerable patient population. (2, 7–11) To address the evolving needs of this specialized field, NANT established the Ignite Core Training & Mentoring Program,

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designed to empower neonatal professionals with the knowledge, tools, and support necessary to deliver exceptional care.

This white paper presents a comprehensive overview of Ignite, exploring its development, key features, learning objectives, and its positive impact on neonatal care providers and the infants and families they serve. By examining the program's curriculum, pedagogical approach, and ongoing mentorship opportunities, this paper aims to demonstrate the program's effectiveness in cultivating a culture of continuous learning, professional development, and collaborative excellence within the neonatal therapy community.

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Background:

The American Occupational Therapy Association (AOTA), American Physical Therapy Association (APTA), and the American Speech-Language-Hearing Association (ASHA) have each published separate articles outlining skills, knowledge, and scopes of practice related to the neonatal intensive care unit (NICU). (8, 12-14) However, all three therapy disciplines—OT, PT, and SLP share common areas of foundational knowledge when providing risk-adjusted care services in the NICU, regardless of therapy discipline. Recognizing the need for a specialized organization to support neonatal therapists, the National Association of Neonatal Therapists (NANT) was established in 2009 by Founder and President, occupational therapist Sue Ludwig.

The National Association of Neonatal Therapists:

The National Association of Neonatal Therapists is a professional organization that serves neonatal occupational therapists, physical therapists, and speech-language pathologists. NANT supports neonatal therapists' professional and personal development by providing highly focused continuing education, resources, standards, mentoring, and connection while advancing the specialty globally.

The National Association of Neonatal Therapists aims to improve the quality of life and neurodevelopmental outcomes for babies who begin their lives in the neonatal intensive care unit (NICU) through the unique contributions of neonatal therapy.

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Over the years, NANT has expanded its offerings to support neonatal therapists nationwide and globally. NANT now includes members in 50 states, over 1,400 hospitals, and 30 countries. NANT has become a comprehensive resource for specialized education, shared best practices, and a thriving professional network in neonatal therapy. Through its dedicated efforts, NANT has established itself as a leading voice advocating for neonatal therapists' unique needs and contributions. NANT facilitates specialized education, shared resources, and peer-to-peer networking through its extensive offerings.

Neonatal Therapy:

As interdisciplinary care team members, neonatal OTs, PTs, and SLPs play a pivotal role in driving the delivery of familycentered, developmental care. They are often instrumental in the care process, from the point of infant admission to the NICU, throughout the stay, and in the discharge planning phase. The American Academy of Pediatrics (AAP) NICU Verification Program includes neonatal therapy services for Level II, III, and IV NICUs, with certified neonatal therapists (CNTs) preferred. (3) Neonatal therapists play a vital role in promoting the holistic well-being of infants in the neonatal intensive care unit. They collaborate closely with bedside nurses and families to implement comprehensive, evidence-based interventions. These interventions aim to foster healthy posture and movement patterns, mitigate pain and stress, and nurture age-appropriate sensory experiences. (15, 16) Neonatal therapists actively engage families in the infant's daily care activities, such as diapering, feeding, dressing, and bathing, providing hands-on support and anticipatory Guidance to develop parental confidence and competence. (17-19) The neonatal therapy team also helps to advance individualized care plans, which may include environmental modifications, positive touch, therapeutic handling for postural support and self-regulation, protection of the aerodigestive system, infant-driven feeding strategies, and parent education related to discharge needs. (15, 16, 18, 20) In many NICU settings, neonatal therapists are recognized as feeding specialists with advanced training in pre-



feeding strategies, breastfeeding support, and clinical feeding assessments. (17, 21) Additionally, highly skilled neonatal therapy professionals often have extensive expertise in evaluating an infant's neurologic integrity using skilled observations and standardized testing, providing therapeutic management of orthopedic conditions, conducting instrumental swallowing evaluations, and offering lactation support as Certified Lactation Counselors (CLC) or International Board-Certified Lactation Consultants (IBCLC).

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Neonatal therapy is optimally provided through an integrated collaborative care model across all levels of neonatal intensive care. In level III and IV NICU settings, neonatal therapists are additionally integral to neonatal follow-up clinics, providing neurodevelopmental testing and triage for early intervention services. (2, 15) The provision of therapy services in the NICU requires specialized orientation, training, continuing education, and mentorship. (2, 15) Furthermore, neonatal therapy services should be grounded in ethical practice and contribute to an environment that promotes a culture of safety, diversity, equity, inclusion, and justice.

In 2014, the NANT Professional Collaborative (NPC) developed The Neonatal Therapy Core Scope of Practice[®], which was founded on the shared foundational knowledge of occupational therapists, physical therapists, and speech-language pathologists. The NPC has since expanded this original core scope to delineate the key practice domains for these specialized neonatal intensive care unit clinicians. (15) These domains outline the primary areas of responsibility within neonatal therapy. However, it is not intended to represent the unique aspects of service inherent to each discipline. In support of validating and sustaining clinical practice and based on the Neonatal Therapy Core Scope of Practice, the NPC additionally developed neonatal therapy practice competencies (16), encompassing the shared foundational knowledge and skills necessary to work independently and safely in the NICU.

Neonatal Therapy Practice Domains:

Neonatal OTs, PTs, and SLPs have a shared foundational

knowledge encompassing six practice domains: the environment, family/psychosocial support, sensory system, neurobehavioral system, neuromotor and musculoskeletal systems, and oral feeding and swallowing. These domains are not inherently exclusive to any single discipline. (15,16) Neonatal therapists employ an integrative, collaborative care model, continually assessing and intervening grounded in evidence-based decisionmaking. (22) Ideally, therapeutic interventions are initiated at the earliest point in the lifespan, with therapists collaborating across disciplines and utilizing their unique perspectives to advance infant competencies, foster parental confidence, and facilitate the transition to the home environment.

"Neonatal OTs, PTs, and SLPs have a shared foundational knowledge encompassing six practice domains: the environment, family/ psychosocial support, sensory system, neurobehavioral system, neuromotor and musculoskeletal systems, and oral feeding and swallowing."

NANT leadership has long acknowledged the distinct challenges experienced therapists encounter when entering the neonatal intensive care unit and novice therapists transitioning from other clinical domains or academic settings into the fast-paced, highacuity environment of the NICU. Navigating the complexities of the NICU, applying evidence-based practices, and developing the essential critical thinking skills required to provide appropriate, individualized care for medically fragile infants can be daunting, even for the most seasoned clinicians. In response, the Ignite Program was designed in 2015 to bridge this critical gap, empowering therapists with the necessary knowledge, skills, and confidence to thrive in their new roles. (2, 23, 24) As the professional organization representing neonatal therapists, NANT is committed to providing a comprehensive training and mentorship program to support therapists at all stages of their careers.

The NANT Ignite Core Training & Mentoring Program:

The neonatal therapy field has grown substantially over the past few decades, yet there remains a significant disparity between the high expectations for neonatal therapists and the limited resources available to equip them with the necessary knowledge and competencies. While some clinicians were fortunate to have exceptional mentors who provided foundational training and inspiration to enhance the NICU environment for fragile, developing infants, many neonatal therapists enter the field without adequate preparation, often facing substantial stress and challenges. A critical issue that has gained increasing attention in the neonatal care landscape is the growing burden of burnout among healthcare providers, including neonatal therapists. In 2013, the availability of neonatal therapy teams varied greatly across NICUs - some had highly evolved teams, while others had none. Despite the industry gold standard being 1:1 mentoring by


experienced, highly trained neonatal therapists, NANT received hundreds of emails from therapists who lacked access to such mentors. A survey during that time found that only 15% of neonatal therapists were mentored for more than 6 months, while 36% had no direct mentorship. Some therapists had access to a nonspecialized clinician who could occasionally "come over to the NICU" if needed. Recognizing this critical gap, NANT established Ignite in 2015 to address these mentorship and training needs.

Program Overview:

Ignite is a comprehensive initiative designed to empower neonatal therapists with the knowledge, skills, and support they need to excel in their practice and contribute to advancing neonatal care. While designed specifically for neonatal therapists, the program welcomes other healthcare professionals working in the NICU. Over the years, Ignite has enjoyed the interprofessional participation of nurses, neonatologists, and allied health professionals, all united in their commitment to providing the highest standard of care for neonatal patients. To date, 1,117 neonatal professionals have completed the Ignite Program.

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Curriculum Structure:

Ignite is a 10-month self-paced program with 13 on-demand training webinars, and nine monthly all-access topic-specific Guidance calls with mentors. The monthly guidance calls are coled by three nationally recognized neonatal therapy mentors of each NT discipline to help therapists understand each discipline's shared foundational knowledge and unique perspectives (OT, PT, SLP). The program's more comprehensive set of features includes:

On-Demand Training - 17 contact hours (1.7 CEUs)

Virtual Mentorship - Live Group Guidance Calls

Community - Private Facebook Group

Resources - Practical Tools and Activities

As such, Ignite offers high-quality, interactive learning opportunities to acquire NICU knowledge and guided mentorship to contextualize practice and learning, all conveniently accessible from anywhere.

Recognizing the critical role of training and mentorship in cultivating a skilled and resilient neonatal care workforce, Ignite

has been meticulously crafted to provide a multifaceted learning experience. The program's curriculum covers a wide range of topics, including:

On-Ramp Resource Pack:

- Module 1: Implementing a Successful Neonatal Therapy (NT) Program
- Module 2: Theories and Models of Practice

Module 3: Family and Environment

- Module 4: The Neurobehavioral System
- Module 5: The Neuromotor System
- Module 6: The Sensory System

Module 7: Neurobehavioral System: Assessment and Interventions

Module 8: Family Assessment and Intervention

Module 9: Neuromotor Assessment & Intervention

Module 10: Environment & Sensory Assessment & Intervention

- Module 11: Basic Feeding Assessment & Intervention
- Module 12: Putting it all Together, Neonatal Therapy Interventions
- Module 13: Instrumental Feeding Assessments & Managing Dysphagia in the NICU

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Comprehensive Bibliography:

To enrich the learning experience, Ignite offers various mentoring opportunities. Peer-to-peer mentoring is made available via monthly guidance calls and private Facebook groups, which helps foster a sense of community and collaboration among neonatal care providers. The monthly group guidance calls serve as a crucial professional development component, allowing participants to engage directly with expert mentors, receive tailored support, and build a community of peers. In addition to the three core mentors, Ignite features guest subject matter experts who provide niche knowledge and insights. This holistic approach blends self-paced learning with interactive mentorship, ensuring neonatal therapists gain the theoretical foundation and practical Guidance needed to excel in their roles.

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Outcomes and Impact:

The Ignite Program has demonstrated significant positive impacts for neonatal therapist participants since its launch. Through Ignite, participants have reported many positive experiences, including a sense of connection and reduced isolation, enhanced confidence in their clinical practice, momentum in their professional development, and access to structured Guidance and standards for successful neonatal therapy practice. Participants have reported feeling more confident and skilled in their clinical practice and have expressed relief in knowing that their practice aligns with the neonatal therapy standards defined by NANT.

Ignite has gathered data demonstrating its positive impacts, including participant testimonials, such as the one available here: <u>https://www.facebook.com/watch/?v=437183485573776</u>.

Conclusion:

The NANT Ignite Core Training and Mentoring Program is uniquely positioned to influence neonatal therapist practitioners' professional development and well-being positively. The program seeks to bolster NT professional development, job satisfaction, and participant retention by leveraging evidence-based practices and aligning with national standards. This, in turn, can potentially enhance the overall stability and quality of care provided in neonatal settings. Through its comprehensive curriculum, personalized mentorship, and supportive community, the Ignite Program empowers neonatal therapists to continuously grow, innovate, and deliver exceptional care to the vulnerable infants and families they serve.

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The Indirect Impact of **RSV**



OVERVIEW

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

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

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

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

RSV PARENT SURVEY

340 parents who had at least 1 child sick with RSV



67% of parents said their child was hospitalized for RSV

RESULTS

7%

of parents said they

were fired as a result

of parents felt quilty

that they could not

do more to prevent

of parents had to rely

on family and friends

for sibling care.

transportation and

other responsibilities

their child's RSV.

of caring for their

child with RSV

69%

54%

FINANCIAL BURDEN More than ²/3

EMOTIONAL BURDEN

of parents said the

costs of RSV posed a

financial burden or

financial crisis.

of parents said

mental health

watching their child

suffer affected their

SOCIAL BURDEN

of parents had never

heard of RSV before

finding out their

child was sick.

68%

43%

RSV HEALTH CARE PROVIDER SURVEY

175 health care providers across various pediatric and neonatal subspecialties



67% worked in an outpatient facility

3% worked in a nospit

RESULTS

of providers agreed

that parents need

more information

99%

about RSV.

PARENT EDUCATION & AWARENESS

86%

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

TREATMENT CHALLENGES

Nearly ¼ of providers have been reluctant to test for RSV because no treatment exists.

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

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

MISCONCEPTIONS

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

CONCLUSION

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

The virus may lead to:

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

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

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

More RSV education

- Research and innovation for preventive interventions
- Access to prevention and treatment for all babies and children

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

infanthealth.org

When parents found out there was no treatment for RSV, only supportive care: • **48%** felt angry

32%

of parents reported

income while their

losing potential

child had RSV

• 46% felt helpless

42%

of parents said they struggled to care for their other children when one faced RSV Ð



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Transparent Leadership: A Bold Strategy or a Risky Gamble?

Rody Azar, MHA, RRT-NPS

"This article delves into open leadership's top ten benefits and drawbacks, offering a balanced perspective on its impact. From building credibility to managing resistance, we explore how transparency shapes modern workplaces."

Abstract:

In an era where trust and accountability define the success of businesses, open and transparent leadership has emerged as a game-changer. Imagine a workplace where employees feel valued, included, and motivated, where decisions are not hidden behind closed doors but shared to inspire collective growth. Transparency in leadership fosters trust, enhances collaboration, and strengthens organizational culture. Nevertheless, it is not without its challenges. How much information is too much? Can openness hinder authority and slow decision-making?

This article delves into open leadership's top ten benefits and drawbacks, offering a balanced perspective on its impact. From building credibility to managing resistance, we explore how transparency shapes modern workplaces. Whether you are a leader aiming to foster trust or an employee seeking clarity, this discussion sheds light on the power of transparency and the responsibility that comes with it. Read on to uncover how mastering this leadership style can drive innovation, accountability, and longterm success.

Introduction:

In today's fast-paced and dynamic business environment, leadership style is critical in shaping organizational success. Among various leadership approaches, open and transparent leadership has gained significant recognition for fostering trust, improving communication, and promoting a collaborative workplace culture. Transparency in leadership involves openly sharing information, encouraging honest feedback, and ensuring that employees clearly understand organizational goals, challenges, and decision-making processes.

The importance of transparency in leadership extends beyond internal organizational benefits. In an era where corporate ethics and accountability are increasingly scrutinized, businesses that embrace open leadership cultivate strong relationships with employees, customers, and stakeholders. Employees are more engaged when they feel included in decision-making processes, and stakeholders appreciate organizations that operate with integrity. However, while the advantages of transparency are numerous, they are not without challenges. Leaders must balance openness with discretion to protect sensitive information, maintain efficiency, and uphold the organization's strategic interests.

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This article explores the concept of open and transparent leadership by examining its top ten benefits and potential drawbacks. By understanding this leadership style's positive and negative aspects, organizations can implement transparency effectively and create a work environment that fosters growth, innovation, and long-term success.

Top 10 Benefits of Open and Transparent Leadership:

- 1. Build Trust and Credibility: Trust is the foundation of any successful organization. Transparent leadership fosters trust by demonstrating honesty and integrity strengthening employee and management relationships. Employees are more likely to support leadership decisions when they believe leaders have their best interests at heart.
- 2. Enhance Employee Engagement and Motivation: Employees who understand company goals and the

reasoning behind decisions feel more involved. Transparency gives them a sense of purpose, leading to higher motivation and job satisfaction and increased productivity and retention.

- 3. Encourage Collaboration and Teamwork: Open communication nurtures a cooperative work environment. Employees share ideas freely and feel confident working together, improving team synergy and collective problem-solving abilities. This leads to innovative solutions and better business outcomes.
- 4. Improve Decision-Making: Employees perform better when they have access to critical information. When leaders share company data, employees make more informed choices, leading to more efficient workflows and optimized performance.
- 5. Reduce Workplace Conflicts: Miscommunication and lack of information often lead to conflicts. A transparent leadership style ensures clear expectations and responsibilities, reducing misunderstandings and promoting a harmonious work environment.
- 6. Foster Innovation and Creativity: In an open environment, employees feel encouraged to take risks and contribute ideas without fear of retribution. This innovative-friendly atmosphere can give companies a competitive advantage in developing new products or services.
- 7. Strengthening Organizational Culture: A transparent workplace reflects a culture of openness, honesty, and inclusion. Employees who align with the company's values feel more connected to the organization, leading to a more positive and productive work environment.
- 8. Increase Accountability and Responsibility: Transparency ensures employees understand expectations and performance metrics. This fosters accountability as employees take greater ownership of their work, leading to a more responsible and self-driven workforce.
- **9.** Enhance Customer and Stakeholder Confidence: Customers and stakeholders appreciate businesses that operate with integrity. A transparent organization builds credibility, increasing consumer trust and stronger relationships with investors and partners.
- **10.** Facilitate Change Management: Organizational change can be challenging, but open leadership eases the transition by keeping employees informed. Transparency reduces uncertainty, builds confidence, and encourages employees to embrace change proactively.

Top 10 Drawbacks of Open and Transparent Leadership:

- 1. Risk of Information Overload: While transparency is beneficial, too much information can overwhelm employees, reducing efficiency. Leaders must find the right balance to ensure clarity without inundating employees with excessive details.
- 2. Potential for Misinterpretation: When leaders share complex information, there is a risk that employees might misinterpret it, leading to confusion and unnecessary concerns. Clear and structured communication is essential

to mitigate this issue.

- **3. Confidentiality Concerns:** Some business information, such as financial strategies or employee records, must remain confidential. Leaders must balance transparency with discretion to protect sensitive data.
- 4. Increased Vulnerability to External Threats: Oversharing company strategies or financial details can make an organization vulnerable to competitors and market shifts. Leaders must ensure that transparency does not compromise business security.
- 5. Challenges in Decision-Making Hierarchy: Transparency can blur leadership structures, making it difficult to enforce necessary decisions. A balance between openness and transparent decision-making authority is needed to maintain operational efficiency.
- 6. May Create Unrealistic Expectations: When leaders share every decision-making detail, employees may develop unrealistic expectations about their involvement in all aspects of leadership. Managing expectations effectively is crucial.
- 7. Can Lead to Resistance or Pushback: Not all employees or stakeholders are comfortable with complete transparency. Some may resist openness, fearing change or exposing organizational vulnerabilities. Managing resistance through strategic communication is key.
- 8. Time-Consuming Communication Process: Implementing transparency takes time and effort. Leaders must dedicate additional resources to communication, training, and documentation, which can slow down decision-making processes.
- **9. Emotional Impact on Employees:** Transparency about challenges or failures can create stress and anxiety among employees. Leaders must manage sensitive information carefully and provide support to prevent negative morale.
- **10. Difficulty in Balancing Transparency and Authority:** While transparency is essential, leaders must maintain their authority and ability to make executive decisions. Striking the right balance ensures that openness does not undermine leadership effectiveness.

Conclusion:

Open and transparent leadership provides numerous advantages, including trust-building, increased collaboration, and improved decision-making. However, it also presents challenges such as information overload, confidentiality concerns, and potential misinterpretation. Striking the right balance is key to maximizing the benefits while mitigating the drawbacks.

For organizations looking to implement transparency effectively, it is important to develop structured communication strategies. Leaders should be mindful of the type and amount of information shared, ensuring that it is relevant and constructive. Training programs can help employees adapt to a more transparent culture and understand how to use information responsibly.

Furthermore, a culture of transparency must be accompanied by strong ethical leadership. Leaders should model integrity and



accountability, fostering an environment where employees feel safe and encouraged to contribute. Open leadership should not be mistaken for complete disclosure; it should be used strategically to empower employees, drive innovation, and maintain operational efficiency.

"Furthermore, a culture of transparency must be accompanied by strong ethical leadership. Leaders should model integrity and accountability, fostering an environment where employees feel safe and encouraged to contribute. Open leadership should not be mistaken for complete disclosure; it should be used strategically to empower employees, drive innovation, and maintain operational efficiency."

Future research and case studies can further explore the longterm impact of transparent leadership across different industries. Organizations must tailor their transparency policies to fit their specific operational needs while focusing on employee well-being and business sustainability.

Ultimately, transparent leadership is a powerful tool when used effectively. It has the potential to transform workplace culture, improve relationships, and drive success in an increasingly competitive business environment.

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Certain diagnoses can make children and babies more vulnerable for serious complications from respiratory viruses - including prematurity, chronic lung disease, and heart conditions.

washing your hands with soap & water, using an alcohol-based hand sanitizer, and getting vaccinated.

The fewer germs your baby is exposed to, the less likely they are to get sick. Let people know you need their help to stay well. Limit visitors. Avoid crowds. Stay away from sick people.

Immunizations save lives. Stay up-to-date with your family's flu vaccinations and COVID-19 boosters. This helps our community stay safe by stopping the spread of deadly viruses.

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Ethics and Wellness: Fairness, Justice, and the Realities of Academic Neonatology

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

"Many professionals have encountered situations where they feel mistreated whether someone else is receiving undue credit or taking advantage of circumstances at another's expense. These experiences prompt a deeper reflection on the concepts of fairness and justice, which, despite their frequent conflation, are far from synonymous."

In academic neonatology, as in any profession, individuals seek a sense of belonging, opportunities for growth, and a feeling of being valued. However, the reality is that these aspirations are often elusive. Many professionals have encountered situations where they feel mistreated—whether someone else is receiving undue credit or taking advantage of circumstances at another's expense. These experiences prompt a deeper reflection on the concepts of fairness and justice, which, despite their frequent conflation, are far from synonymous.

"While justice aligns with objective principles and established frameworks, fairness is relative and considers the unique needs and circumstances of all parties involved. (1)"

Justice, as a concept, is rooted in legality and structured ethics. The term derives from the Latin *iustus*, meaning "lawful" or "rightful;" it has maintained a firm association with legal and ethical codes throughout history. In contrast, fairness originates from the Old English *fæger*, which initially meant "beautiful" or "pleasant" before evolving into a broader concept of equity and balance. While justice aligns with objective principles and established frameworks, fairness is relative and considers the unique needs and circumstances of all parties involved. (1)

In neonatology, the distinction between fairness and justice plays out in ways that can shape careers, institutions, and, ultimately, patient care. Consider a scenario where their institution acknowledges a young researcher's groundbreaking work, but the credit is publicly attributed to a more senior colleague. From a legal standpoint, this may not constitute an injustice if there is no formal intellectual property violation. However, from a moral and professional perspective, such an outcome feels deeply unfair, and the impact on the individual's career trajectory can be profound. (2)

"Similarly, justice might dictate that a clinician who inadvertently breaches an obscure hospital policy faces formal disciplinary action. However, fairness would recognize the mitigating factors: Was the rule well-communicated? Was the clinician acting in good faith to provide the best possible care?"

Similarly, justice might dictate that a clinician who inadvertently breaches an obscure hospital policy faces formal disciplinary action. However, fairness would recognize the mitigating factors: Was the rule well-communicated? Was the clinician acting in good faith to provide the best possible care? The balance between adhering to just policies and ensuring fair treatment is delicate, and failing to navigate it properly can lead to a work environment rife with resentment and disengagement. (3)

Alexander Hamilton famously asserted that "the first duty of society is justice." He could have chosen the word "fairness," but he did not—because fairness, while desirable, is not an absolute principle. It is fluid, dependent on perspective, and occasionally at odds with justice. (3) This tension is particularly evident in academia, where hierarchical structures often dictate who is recognized, rewarded, or reprimanded.

"Alexander Hamilton famously asserted that 'the first duty of society is justice.' He could have chosen the word 'fairness,' but he did not—because fairness, while desirable, is not an absolute principle. It is fluid, dependent on perspective, and occasionally at odds with justice. (3)"

The reality is that reconciling fairness and justice is as challenging as achieving perfect sensitivity and specificity in a clinical test. The ideal scenario—where both align perfectly—is aspirational but often impractical. Instead, institutions and leaders must consciously strive for a balance, ensuring that just decisions are tempered with fairness and that fairness does not undermine necessary structures of justice. (2, 4, 5) For academic neonatology to thrive, there must be an ongoing dialogue about how decisions are made and their implications for those affected. Mentorship, transparency, and institutional accountability can help bridge the gap between what is just and what is fair, fostering a culture where professionals feel valued and are treated with integrity. Ultimately, the pursuit of fairness and justice is not about achieving perfection—it is about ensuring that when the two diverge, efforts are made to navigate their complexities with wisdom and ethical consideration. (6)

"For academic neonatology to thrive, there must be an ongoing dialogue about how decisions are made and their implications for those affected. Mentorship, transparency, and institutional accountability can help bridge the gap between what is just and what is fair, fostering a culture where professionals feel valued and are treated with integrity."

Maintaining this balance becomes even more crucial in the everevolving landscape of neonatology, where cutting-edge research, clinical care, DEI, and education intersect. This is a significant investment—not only for the individuals navigating their careers but also for the patients and families who depend on a wellfunctioning, ethically sound system. (1, 5, 7, 8)

One practical approach to mitigating the disparity between fairness and justice is cultivating an environment where open discussions about ethical dilemmas are encouraged. Professional development programs should integrate training on ethical decision-making, conflict resolution, and bias awareness to ensure leaders at all levels can recognize and address potential inequities before they become systemic issues.

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Additionally, fostering a culture of acknowledgment and recognition can help rectify some of the fairness gaps that naturally arise in hierarchical institutions. Institutions should consider structured credit-sharing mechanisms for research contributions, transparent promotion and evaluation processes, and clear, well-communicated policies that minimize ambiguities leading to perceived injustices. (5)

At its core, academic neonatology is driven by compassion and a commitment to improving the lives of the most vulnerable patients. It stands to reason that the principles guiding our professional interactions should reflect these same values. While challenging, striving for fairness and justice in tandem is a task worth undertaking for the benefit of both the field and the individuals within it. (4, 9)

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Code Blue in The NICU

Joseph B. Philips, III, MD

"The moonlighter had just returned with our dinners when the code alarm sounded. Almost simultaneously, our pagers went off "Code infant 3312." We all knew who it was. The 23-week gestation, two-day-old baby had coded earlier in the afternoon and had been doing poorly since."

The moonlighter had just returned with our dinners when the code alarm sounded. Almost simultaneously, our pagers went off "Code infant 3312." We all knew who it was. The 23-week gestation, two-day-old baby had coded earlier in the afternoon and had been doing poorly since. Oxygen saturations were in the low 80s despite maximal support, and blood pressures were marginal on dopamine, dobutamine, and epinephrine drips. Upon entering the room, we found the infant with saturations in the 40s and a heart rate in the 50s. We quickly assumed our positions around the warmer. The resident began chest compressions, the respiratory therapist handbagged, the fellow at the head of the bed assessed the airway and ordered fluid pushes and medications, the bedside nurse administered the medications, and I, the attending physician, oversaw it all. The nursing staff also rapidly began their roles, one opening the crash cart and drawing up drugs, another charting, and multiple others observing and ready to assist if needed.

"We quickly fell into our all-too-familiar routine, counting "one, two, three" for chest compressions, followed by "breath." Over and over again."

We quickly fell into our all-too-familiar routine, counting "one, two, three" for chest compressions, followed by "breath." Over and over again. "Ten mils normal saline," said the fellow, followed by "epi, point 0 five" every five minutes. The intern took over the chest compressions after about 10 minutes, but the cadence remained the same. Blood was bubbling up the endotracheal tube, indicating the presence of a pulmonary hemorrhage. A nurse was dispatched to retrieve emergency-release blood from the blood bank. The saturation and heart rate were steadily falling. The mother was literally rolling on the floor, wailing, "Save my baby! Save my baby!" over and over again.

Despite several rounds of fluids and epinephrine plus a push of the blood, the baby continued to deteriorate. I knelt beside the mother, put my hand on her shoulder, and asked her to listen. She immediately stopped her wailing and looked me in the eye. I told her that her baby was dying, that we were going to stop CPR as it was not working, and that her baby's brain had been irreversibly damaged. She nodded in agreement.

"Stop," I said. The scene instantly shifted from the hustle and bustle of a code to a stony silence pierced only by the sobs of the mother whom the nurses had assisted into a recliner chair. The monitor was turned off, the ventilator and lines were disconnected, syringes and other debris were removed from the bed, and the baby was wrapped in a blanket and placed in mom's arms. The nurses began their familiar postmortem care routine. The fellow auscultated the baby's chest and confirmed the death.

"Stop,' I said. The scene instantly shifted from the hustle and bustle of a code to a stony silence pierced only by the sobs of the mother whom the nurses had assisted into a recliner chair."

We returned to the workroom and ate Chinese takeout. I had cashew shrimp. I conducted a debrief during our meal, asking everyone how they felt. The intern was visibly shaken, with a tear trickling down her cheek. It was July, and this was the first death of a patient in her charge since she had become a real doctor. "His life slipped through my hands when you told me to stop," she said. One of the upper-level female residents hugged her as she sobbed for a while before regaining her composure and resumed picking at her food.

For myself and the fellow, this death was one of many, but each death is new all over again and is a fresh reminder of our human frailty.

"For myself and the fellow, this death was one of many, but each death is new all over again and is a fresh reminder of our human frailty." Few outside our world would understand a situation like this. We were eating while a baby had just died and a mother was grieving. For her, life had just changed forever. For us, we had to nourish ourselves to have the strength to continue caring for the living. Nothing taught in medical school can prepare one for these moments. They must be experienced first-hand, processed, and reflected upon. Doing so is what gives us the strength to move forward.

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

"On January 27th, we, along with many organizations, were blindsided by the freezing of all Federal grants, both existing and new."

On January 27th, we, along with many organizations, were blindsided by the freezing of all Federal grants, both existing and new. Despite a Temporary Restraining Order last week to halt the freeze, funds for existing grants are still not being disbursed.

This extends to the state level, as programs run through State Departments of Health receive funding from Federal dollars, and colleges and universities that conduct research may be supported by Federal grants.

Like many non-profits that focus on maternal and infant health, we are deeply troubled that this money was being used to fund our Let's Talk Community Chats program in Atlanta. (1)

"Like many non-profits that focus on maternal and infant health, we are deeply troubled that this money was being used to fund our Let's Talk Community Chats program in Atlanta. (1)"

This program takes a community-based approach, working in collaboration with families to understand the benefits of infant-safe sleep practices in reducing Sudden Unexplained Infant Deaths and to help them access needed healthcare resources they may not have had. We train trusted community members, peers, and professionals and meet in local places convenient for the families we work with.

This Georgia program is now in its third year and is funded, at least for now, by a grant from the Department of Health and Human Services through its Office of Minority Health. The current political climate raises challenges for non-profits engaged in social services and equity-focused initiatives, and organizations such as ours will need to address these challenges. They include:

Uncertainty. We've seen how project funding can be suddenly stopped. There is also uncertainty about how programs dealing with health equity and multicultural approaches will be assessed.

The potentially changing landscape. Our goal is to reduce infant and maternal mortality by advancing equitable health outcomes and addressing preventable differences in these outcomes through accessible, evidence-based strategies. A pathway to achieving this is respect for families' lived experiences, which includes understanding their cultures, family practices, and, in short, their diversity.

The availability of alternate funding sources. Because of the uncertainties, appeals to foundations and other non-government granting entities will increase when they evaluate where they fit in the scheme of things and what they can provide.

Regardless of the challenges, we will remain unwavering in our mission to save babies' lives and support families. The Let's Talk program, our Straight Talk for Infant Safe Sleep training program for professionals, and our bereavement support services for those who have lost an infant will continue.

"Regardless of the challenges, we will remain unwavering in our mission to save babies' lives and support families. The Let's Talk program, our Straight Talk for Infant Safe Sleep training program for professionals, and our bereavement support services for those who have lost an infant will continue. "

About First Candle

First Candle, based in New Canaan, CT, is a 501c (3) committed to eliminating Sudden Unexpected Infant Death while providing bereavement support for families who have suffered a loss. Sudden Unexpected Infant Death (SUID), which includes SIDS and Accidental Suffocation and Strangulation in Bed (ASSB), remains the leading cause of death for babies one month to one year of age, resulting in 3,700 infant deaths nationwide per year.



We will seek to diversify our funding sources further and broaden our relationships with organizations at all levels that value what we do and are equally committed to saving babies' lives.

Now more than ever, we will rely on donations from individuals who understand the importance of our mission. You can donate here. (2)

"Now more than ever, we will rely on donations from individuals who understand the importance of our mission. You can donate here. (2)"

References:

- 1. https://firstcandle.org/lets-talk-community-chats/
- 2. https://fc.app.neoncrm.com/np/clients/fc/donation.jsp

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

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Corresponding Author

Alison Jacobson Executive Director Chief Executive Officer First Candle 21 Locust Avenue, Suite 2B New Canaan, CT 06840 Telephone: 1-203-966-1300 For Grief Support: 1-800-221-7437 Email: Alison@firstcandle.org

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Peer Reviewed

Advancing Neonatal-Perinatal Care: February Update: Section on Neonatal-Perinatal Medicine

Clara H. Song, MD, FAAP

"We are back with another update to inform you about SONPM! From upcoming events to important deadlines, here is everything you need to know."

✔ Your SONPM More-Than-Monthly Update—Keeping Us All Connected!

We are back with another update to inform you about **SONPM**! From upcoming events to important deadlines, here is everything you need to know.

◇ Stay on Top of Important Dates!

Check out the **#AAPneonatal Calendar** for details on upcoming events and key deadlines: <u>AAP Neonatal Calendar</u>

♦ Relive the Moments! Im

Take a look at our **#AAPneo photo gallery**, featuring highlights from SONPM events. (*Password: AAPneonatal*) SONPM Photo Gallery

◇ ICYMI—SONPM is 50!

Did you know? **SONPM is celebrating 50 years!** This is a milestone year, and we are excited to share this journey with all of you.

Big Event Alert: WNPPS 2025 – February 21-23!

"Did you know? SONPM is celebrating 50 years! This is a milestone year, and we are excited to share this journey with all of you."

Continent President Pre

The Workshop on Neonatal-Perinatal Practice Strategies (WNPPS) is SONPM's annual spring meeting, and we are thrilled to announce record-high registration numbers this year!

Do you still need to register? There is **still time** to join us for an incredible learning, networking, and collaboration weekend.

Register here:

2025 Workshop on Neonatal-Perinatal Practice Strategies - Scottsdale, AZ

Book your hotel at the discounted rate:

Workshop on Neonatal-Perinatal Practice Strategies - Start your reservation

Stay Connected & Join the Conversation!

The **SONPM Central Communication Committee (C3)** will be **live-tweeting** using **#WNPPS2025** and capturing all the weekend's best moments. Be sure to follow along and tag us!

Until next time, we are here for you. Keep in touch and stay engaged!

- On behalf of your **#SONPMexec Committee**:
- ◇ Past Chair: Munish Gupta @munishguptamd
- District 1 Rep: Wendy Timpson <u>@TimpsonWendy</u>
- D2 Rep: Shetal Shah <u>@NICUBatman</u>
- D3 Rep: Michael Posencheg <u>@MikePosencheg</u>
- D4 Rep: Misty Good <u>@mistygoodlab</u>
- **D5 Rep**: Craig Nankervis
- D6 Rep: Josh Petrikin @jepetrikin
- ◇ D7 Rep: John Loyd
- ◇ D8 Rep: Jessica Davidson @JessDavMD
- OP & Chair Elect: Alexis Davis @AlexisDNeoMD
- ◇ D10 Rep: Ravi Patel @ravimpatelmd
- Of Counsel: Marilyn Escobedo @Mokcita
- ◇ AAP Director: Jim Couto @jcouto2
- Chair: Clara Song @songMD

I am looking forward to seeing you all soon! 😹

Disclosures: No conflicts noted

NT

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NEONATOLOGY TODAY www.NeonatologyToday.net February 2025



Corresponding Author



Clara H. Song, MD, FAAP Neonatal Intensivist, Southern California Permanente Medical Group Chair Elect, Communication & Digital Media Chair; Women In Neonatology Steering Committee, All Pathways group Co-Chair: District IX California Chapter 4 Council Representative, Chair, American Academy of Pediatrics, Section on Neonatal-Perinatal Medicine Lean Six Sigma Black Belt

Email: E clara.h.song@kp.org

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Keeping Your Baby Safe

from respiratory infections

How to protect your little one from germs and viruses

This year's cold and flu season may be a dangerous one - especially for vulnerable infants and children. Fortunately, 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



based sanitizers

Provide Protective Immunity

 Give them your breast milk Stay current with

your family's mmunization

80

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



Take Care of Yourself

stay safe.

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

Immunizations Vaccinations save lives Protect your baby from flu pertussis RSV and COVID-19 by getting your immunizations.

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 scap 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/rsv



2024

RSV COVID-19 colds

flu

Request for Proposals 2025

Initiatives to Further the Strategic Aims of the Section on Neonatal-Perinatal Medicine (Fourth Funding Opportunity)

The Section on Neonatal-Perinatal Medicine (SONPM) of the American Academy of Pediatrics welcomes proposals for funding that address aims relevant to the following domains of its Strategic Plan:

- 1. <u>Education</u> Improve the knowledge, skills, and perspectives of neonatal-perinatal providers through high quality education, and ultramodern education delivery.
- 2. Member Value Find and address the needs and interests prioritized by SONPM members
- 3. <u>Optimal Care</u> Facilitate high quality research and quality improvement in neonatology to assure excellent clinical care
- 4. <u>Advocacy</u> Define an advocacy agenda for the neonate and develop the ability of SONPM members to achieve it
- 5. <u>Health of the Subspecialty</u> Envision, articulate, and engage SONPM members in supporting the neonatal-perinatal medicine profession
- 6. <u>Health of the Section</u> Ensure the long-term sustained organizational health of SONPM.

Eligible projects should include service, educational/clinical program or study that addresses at least one of the SONPM strategic aims and includes a measurable outcome.

SONPM Executive committee will rate proposals according to the following criteria:

- 1. Innovation
 - a. To what degree will the proposal result in a novel approach to an issue of importance to SONPM membership?
- 2. <u>Priority</u>
 - a. Is the proposal responsive to one of the aims of SONPM Strategic Plan under an existing domain/subdomain?
 - b. Will the proposal address an important recognized or unrecognized need for neonatologists and/or patients and families?
- 3. <u>Feasibility</u>
 - a. Is the project's team well-constituted and qualified to accomplish the goals laid out in the proposal?
 - b. Is the budget proper to the activities described?
- 4. Scalability
 - a. What is the likelihood that the project will gain greater relevance for a larger proportion of SONPM members?
- 5. Sustainability
 - a. Will the proposal lead to the creation of a program or deliverable that SONPM can continue to offer members?

- 6. Testability
 - a. Does the proposal include an adequate mechanism for measuring its effect and/or finding whether it meets its stated deliverables?
- 7. Stewardship
 - a. Is the budget reasonable?
 - b. Will the funding provide substantial value and a strong return on investment?
- 8. <u>Diversity</u>
 - a. What is the potential for the team and the project to add diversity to our SONPM leadership and work?
 - b. Has the proposal encouraged collaboration from invested partners (technology, industry, government, families, etc) that align with the SONPM vision and mission.

Applicants may request funds in the \$5,000 to \$25,000 range per grant. Applicants should ensure that requested funds are sufficient to achieve project goals and should remember that Stewardship of SONPM resources will be a key criterion for adjudication. *Salary support and indirect costs are ineligible expenses.* In total, SONPM will award funds of up to \$60,000 across all awards.

Proposals should include:

- 1. Cover letter
- 2. Project narrative (limit to 4, single-spaced pages)
- 3. Curriculum vitae for key personnel (including AAP member numbers and contact information)
- 4. Itemized budget
- 5. Budget justification.

All key MD personnel must be members in good standing of the American Academy of Pediatrics and the Section on Neonatal-Perinatal Medicine, at the time of application.

Application deadline for application is January 31, 2025.

Announcement of awards will occur after the Workshop in Neonatal-Perinatal Practice Strategies meeting in February 2025.

Award funding will begin on July 1, 2025, and end on June 30, 2027.

Projects should be completed within a two-year time frame.

Grant recipients will submit a project update after first year by June 30, 2026, and a final report to the SONPM Executive Committee by July 1, 2027.

Submit electronic applications to BOTH:

Clara Song <u>clarasong@me.com</u>

Jim Couto jcouto@aap.org

Please direct questions to Clara Song, AAP SONPM Chair clarasong@me.com

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

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

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

Within executive committee and SONPM broadly:

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

Within district:

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

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

Dear Section Members,

The SONPM is committed to developing the advocacy skills of our members. To that end, we will be supporting **5 scholarships** to next year's AAP Advocacy Conference—to be held in person, **March 2-4, 2025**, in **Arlington**, **VA** (at the Crystal Gateway Marriott).

The Advocacy Conference is energizing, inspiring and filled with practical content about an area we rarely cover in our formal neonatology training. Attendees to the Advocacy Conference will have the opportunity to participate in skills-building workshops, hear from distinguished guest speakers and learn about policy issues impacting children. You will then meet with your Congressional Offices to advocate for a timely child health topic. There is no better way to develop a strong relationship with your federal representatives in Washington than under the guidance of the AAP. You will be prepped and practice before these meetings.

To be eligible for the section AdvoCon scholarship, you must attend the entire conference, including the in-person Capitol Hill visits on March 4th. If selected, we will register you for the conference. As part of the award, the SONPM will reimburse you for up to \$1000 in expenses. However, the remainder of expenses such as registration and hotel are the responsibility of the awardee.

These scholarships are offered with the expectation that awardees will be able to use the skills and savvy gained at this meeting in neonatology-focused advocacy following their attendance. Follow-up contributions may include:

- Use the "Take Action" links through the AAP Advocacy Action Center
- Make a state or federal legislative visit/phone call/Zoom on a neonatal-perinatal issue
- Write up your experience at AdvoCon for your chapter or the SONPM newsletter
- Develop and deliver a lecture on advocacy to fellows/faculty/pediatricians
- Write/publish an op-ed on neonatal-perinatal policy issues
- Author an issue brief on a neonatal-perinatal issue in the Biden-Harris Transition Plan
- Participate in or lead an advocacy focus with the SONPM Advocacy Committee
- Serve as a neonatal-perinatal policy advisor to local health policy organizations
- Use the Donor Milk Toolkit for state advocacy
- This list is just to get you thinking--there are many more ways to advocate!

TO APPLY

Please submit the following information via email to Lily Lou

at <u>lilylou@mindspring.com</u> (SONPM Advocacy Committee co-chair), using subject line "AdvoCon scholarship," by **Dec 1**st, **2024**.

- 1. Name (First, Last, Designation)
- 2. Address (Street/City/State/Zip)
- 3. Phone
- 4. Email
- 5. AAP ID



REQUEST FOR RESEARCH GRANT LETTER OF INTENT (LOI) Submission Deadline March 1, 2025

The American SIDS Institute invites qualified investigators to submit a Letter of Intent (LOI) for a research grant related to sudden unexpected infant death (SUID). Applicants must have a faculty appointment or the equivalent at a U.S. based university, hospital, research institution, or medical examiner office, with one exception. Graduate students enrolled in a postdoctoral program may also apply as the PI, BUT the faculty advisor must be a Co-Investigator, with a biosketch and letter of support included. Topics of interest include, but are not limited to, pathology, physiology, neonatology, cardiology and epidemiology. The intent of this funding opportunity is to support innovative research leading to subsequent extramural grant funding regarding SUID or related causes of sudden unexpected death.

Priority will be given to research proposals related to one of the top ten US research priorities identified by the Global Action and Prioritization of Sudden Infant Death (GAPS) Project. These include:

- 1. Physiological mechanisms leading to death and how they interact with behavioral risk factors, e.g. prone (front)-sleeping.
- 2. The role of genetic factors in SUID.
- 3. Social and cultural factors affecting parental choices in sleep practices and responses to risk reduction campaigns.
- 4. Role of abnormal or immature brain anatomy and physiology.
- 5. Systematic collection and sharing of death scene data from SUID and non-SUID deaths to allow better case control studies
- 6. How infants control oxygen desaturation and arousal to allow a better understanding of SUID mechanisms.
- 7. Mechanisms for SUID at different ages.
- 8. Developing and evaluating new ways to make safe sleep campaigns more effective.
- 9. Identifying specific biomarkers to differentiate between natural causes, accidental asphyxia, and SIDS.
- 10. Better understanding of the risks of sharing any sleep surface with an infant, notably how it interacts with other factors, including feeding practices, to make it more or less risky.

Proposals related to the study of sudden unexpected intrauterine death, sudden death in children, or sudden death in epilepsy may also be responsive. However, applicants will need to clearly explain how their proposal will advance the understanding of SUID. Although priority will be given to human studies, animal studies may be responsive if justified and related to an animal model relevant to the research priorities listed above. Proposals for the development of new physiologic monitoring equipment or devices to facilitate safe sleep position or reduction of other sleep environment-related risks will not be responsive.

These grant awards are intended to be self-contained studies with a well-defined targeted hypothesis. Budgets may include technical salary support, but principal investigator salary support and indirect costs may not be requested. Awards will be for 2 years and limited to a total of \$80,000.

REQUIREMENTS FOR LOI

PROPOSAL

The proposal is limited to **2 pages**. Preliminary data are not required. Each proposal should include the following:



President Sherin Devaskar, MD

Secretary/Treasurer Michael Steiner, MD, MPH

Executive Director Laura Degnon, CAE

Academic Pediatric Association Jean L. Raphael, MD, MPH Michael Steiner, MD, MPH

American Academy of Pediatrics Mark Del Monte, JD Ben Hoffmann, MD

American Board of Pediatrics John Barnard, MD Michael Barone, MD, MPH

American Pediatric Society Cliff Bouge, MD Catherine Gordon, MD

Association of Medical School Pediatric Department Chairs John Frohna, MD Joseph W. St. Geme, III, MD

Association of Pediatric Program Directors Megan Aylor, MD Patricia Poitevien, MD, MSc

Society for Pediatric Research Christina Maria Alvira, MD Todd Florin, MD

Call for Nominations for the 2025 Joseph W. St. Geme, Jr. Leadership Award

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

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

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

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

Criteria for Selection

- 1. The individual must be a pediatrician who is perceived as a role model for others to emulate, as a clinician, an educator, and/or an investigator.
- 2. The individual must be a leader who has "created a future" for pediatrics and for children and has played an active role in one or more organizations sponsoring this award.
- 3. The individual should preferably have a record of broad sustained contributions to pediatrics that have had or will have a major impact on child health.
- 4. The individual must be currently active in pediatrics. **what defines "active" is at the discretion of each of the 7 organizations.*
- 5. The individual can be a retired member of any of the pediatric organizations sponsoring this award.
- 6. The individual must **not** be an active FOPO Board member. Full list of current FOPO Board members may be found at <u>www.fopo.org/leadership</u>.



American Academy of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN®

2025 WORKSHOP ON NEONATAL-PERINATAL PRACTICE STRATEGIES

February 21-23, 2025 Scottsdale, AZ



REGISTER TODAY!

Sponsored by the American Academy of Pediatrics (AAP) and the AAP Section on Neonatal-Perinatal Medicine (SONPM)

Registration now open! Join us in Scottsdale, AZ next February

The Workshop on Neonatal-Perinatal Practice Strategies is designed to inspire attendees to better demonstrate effective leadership skills, effectively resolve conflicts, and adeptly manage their practice setting to optimize the performance of multidisciplinary teams. Attendees will have ample networking opportunities to foster collaboration and support career development. Rooted in evidence-based medicine, participants will gain insights into strategies for interpreting and integrating published research to enhance clinical care. We encourage any pediatric professional caring for the fetus and newborn to join us at the workshop!

Earn up to 18.25 AMA PRA Category 1 Credits™ (includes the Neonatal Coding Seminar) and 10 MOC Part 2 points.

Neonatal Coding Seminar (Separate registration required) Friday, February 21, 2025 7:30am-3:00pm

- 4.75 CME Credits are offered for the morning portion of the seminar
- AAPC credits are also offered
- Lunch is included

Other highlights include:

- Women in Neonatology Seminar
- Clinical Leaders Group
- All Pathways: "Tips for Career Transitions" Session

Special Events:

- Welcome Reception
- Section on Neonatal-Perinatal Medicine Reception
- Workshop Luncheon

Please Note: Special events are not designated for CME credit.

Hotel & Travel Information



DoubleTree Resort by Hilton Hotel Paradise Valley - Scottsdale

5401 North Scottsdale Road Scottsdale, AZ 85250 Hotel Phone: 480/947-5400

Reservation Instructions

The room block is now open for reservations, please use the <u>direct hotel booking link</u> to book your room.

Visit Scottsdale

Get ready to experience pure vacation inspiration in Scottsdale! From the stirring beauty of the lush Sonoran Desert to our luxury resorts, chef-driven restaurants, and exciting activities and attractions, Scottsdale is bursting at the seams with the makings of a memorable getaway. For more information, <u>click here</u>.

Save \$150! Register by January 21, 2025 for Early Bird Rates

REGISTER TODAY

Special Offer for Course Registrants



INCLUDES THE JOURNAL NeoReviews



Save up to \$120 off retail rates!

Subscribe to 2025 NeoReviewsPlus for only \$220 if you purchase during course registration.* NeoReviewsPlus is a comprehensive neonatology package bringing together case-based self-assessment questions, with full online access to the *NeoReviews*[™] journal and valuable MOC & CME credit.

*Limited offer good only during course registration. Does not apply to renewals or previously purchased subscriptions and cannot be combined with any other offer. Discount savings is calculated off of non-member rates. All pricing and specifications subject to change without notice. Subscription access begins in January 2025.

NeoReviews[™] *a*nd NeoReviewsPlus[™] are supported, in part, through an educational grant from **Abbott Nutrition**, a proud supporter of the American Academy of Pediatrics

Continuing Medical Education

The American Academy of Pediatrics (AAP) is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.

The AAP designates this live activity for a maximum of 18.25 AMA PRA Category 1 Credit(s)TM. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

This activity is acceptable for a maximum of 18.25 AAP credits. These credits can be applied toward the AAP CME/CPD Award available to Fellows and Candidate Members of the AAP.

This activity is approved for 10.00 MOC Part 2 by the American Board of Pediatrics through the AAP MOC Portfolio Program. All points will be awarded (or must be claimed) based on the MOC activity completion date, which is the date MOC requirements were met. All deadlines and MOC point values should be confirmed by checking the ABP Activity Catalog within each physician's ABP Portfolio. Consult your ABP portfolio at www.abp.org for details about your specific certification requirements. For questions about how to access this activity, contact MOCPortfolio@aap.org.

This program is accredited for 18.25 NAPNAP CE contact hours of which 0.00 hrs contain pharmacology (Rx) content, (0.00 related to psychopharmacology) (0.00 related to controlled substances), per the National Association of Pediatric Nurse Practitioners (NAPNAP) Continuing Education Guidelines.

PAs may claim a maximum of 18.25 Category 1 credits for completing this activity. NCCPA accepts AMA PRA Category 1 Credit(s)TM from organizations accredited by ACCME or a recognized state medical society.

This program is approved as a learning event for American College of Medical Practice Executives (ACMPE) continuing education hours. A cumulative total of 50 ACMPE continuing education credit hours is among the requirements for attaining the Certified Medical Practice Executive (CMPE) credential. To maintain CMPE or Fellow status, you must earn 50 hours of qualifying credit hours every three years.

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Letters to the Editor Letter to the Editor: "How Can Washington Invest in Saving Moms?"

Dear Editor:

Your article "How Can Washington Invest in Saving Moms?" sheds light on a crucial conversation that is well-known but underappreciated. Many in and outside medicine are aware of the US maternal crisis. However, with a problem that is deep-rooted in racial disparities, it can be intimidating and overwhelming to dive into.

This article effectively highlights ongoing disparities in maternal and infant health and underscores the importance of leveraging existing federal and state initiatives to reduce these inequities. You reference efforts such as the "White House Blueprint for Addressing The "Maternal Health Crisis" and the NIH's call-toaction initiative "Maternal Mortality Moonshot" program, which encourages readers to engage in thought-provoking dialogue about how we can affect the current trajectory of obstetrical and neonatal health outcomes. While this discussion is too difficult to explore in any one piece of writing entirely, we think your article provides readers with a baseline to begin.

"Quickly searching the US maternal health crisis on a search engine provides individuals with reassuring data from reliable sources. The CDC and ACOG have published updates on the topic describing how maternal deaths have decreased for mothers across multiple ethnicities when looking at annual data since 2018."

Why Should We Care?

Quickly searching the US maternal health crisis on a search engine provides individuals with reassuring data from reliable sources. The CDC and ACOG have published updates on the topic describing how maternal deaths have decreased for mothers across multiple ethnicities when looking at annual data since 2018. Upon further digging, these improvements in maternal health likely occurred due to the influence of the Pregnancy Checklist from 2016-2018, the Preventing Maternal Deaths Act of 2018, and the expansion of the Maternal Mortality Review Committee (MMRC). These factors helped increase maternal mortality surveillance, leading to more accurate data tracking. Nevertheless, regardless of these advancements, the light should not be dimmed on the fact that there is a significant outcome gap that still exists for mothers of color.

The problem of racial disparities in maternal and infant health

cannot be overstated. Black mothers remain 3x more likely to die from pregnancy-related causes and 2x as likely to lose their newborn shortly after birth compared to their White counterparts. These alarming statistics speak to systemic inequities deeply rooted in access to care, socioeconomic determinants, and implicit bias in healthcare delivery. Therefore, we must continue advocating for funding government initiatives that desire to address the root problems.

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Your manuscript's publishing is occurring at the most opportune time with the recent induction of a new US administration. Increasing public awareness of these federally-funded programs will hopefully encourage Washington to maintain them. This may be deemed a difficult task, so discussing other avenues in which the current administration can implement positive change was commendable.

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Proposed Improvements to the Research

The article does an excellent job of highlighting key areas to address maternal and infant health disparities, particularly the alarming rates at which Black mothers and their babies face complications. The proposed actions are meaningful and actionable, but there are further opportunities to enhance these "The article does an excellent job of highlighting key areas to address maternal and infant health disparities, particularly the alarming rates at which Black mothers and their babies face complications. The proposed actions are meaningful and actionable, but there are further opportunities to enhance these recommendations."

- 1. Expand data stratification- While improving data collection is mentioned, a more granular approach could strengthen its impact. Stratifying data by geography, socioeconomic status, and healthcare access would better illuminate localized disparities and tailor interventions to specific communities.
- 2. Integrate patient perspectives- Incorporating the voices of Black mothers and other marginalized groups in policymaking and research design could ensure that solutions align with their lived experiences. Patient advisory councils or focus groups could provide valuable insights into unmet needs and barriers.
- 3. Standardize cultural competency training- The article touches on the importance of provider training programs, but it could go further by advocating for standardized, evidence-based curricula that can be scaled across healthcare systems. These programs should include implicit bias training and community-specific modules.
- 4. Leverage technology and innovation- Investing in advanced analytics and artificial intelligence can help identify maternal and infant health outcome patterns, enabling more proactive and personalized care. This could also support early identification of risk factors in high-need populations.
- 5. Broadening postpartum care policies- Expanding Medicaid coverage is a great first step, but integrating mental health support and community-based resources into postpartum care would provide more comprehensive support for mothers.
- 6. Support public awareness campaigns- Raising awareness through culturally sensitive campaigns could help improve health literacy and empower mothers to seek timely care.

By building upon the article's recommendations and focusing on these areas, policymakers can further strengthen their approach to eliminating maternal and infant health disparities.

Thank you for your attention to this deep-rooted, systemic issue.

Sincerely,

Mylene Alcayde OMS-III, Alexander Abdou OMS-III, and Samuel Kades OMS-III

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Dear Mylene Alcayde, Alexander Abdou, and Samuel Kades,

Thank you for your thoughtful and well-articulated response to our article, *How Can Washington Invest in Saving Moms?* Your engagement with this critical issue and insightful recommendations for improving maternal and infant health equity are greatly appreciated.

We fully agree that while recent improvements in maternal health outcomes are encouraging, they should not overshadow the persistent racial disparities that continue to impact Black mothers and their infants at disproportionate rates. As you highlight, the progress made through initiatives like the *Preventing Maternal Deaths Act* and expanded *Maternal Mortality Review Committees* demonstrates the value of targeted policy interventions. However, much work must be done to ensure that all mothers receive equitable, high-quality care.

"As you highlight, the progress made through initiatives like the Preventing Maternal Deaths Act and expanded Maternal Mortality Review Committees demonstrates the value of targeted policy interventions. However, much work must be done to ensure that all mothers receive equitable, high-quality care."

Your proposed enhancements— expanding data stratification, integrating patient perspectives, and standardizing cultural competency training—offer valuable pathways for strengthening future policy and research. Incorporating the lived experiences of Black mothers in decision-making, leveraging technology to identify risk patterns, and broadening postpartum care policies are



all essential components of a comprehensive strategy to close these outcome gaps.

"As you highlight, the progress made through initiatives like the Preventing Maternal Deaths Act and expanded Maternal Mortality Review Committees demonstrates the value of targeted policy interventions. However, much work must be done to ensure that all mothers receive equitable, high-quality care."

We are particularly encouraged by your emphasis on sustaining public awareness and advocacy efforts, especially in the context of a new administration. Continued federal and state investment is vital, and raising awareness of these programs is key to ensuring their longevity and effectiveness.

"We are particularly encouraged by your emphasis on sustaining public awareness and advocacy efforts, especially in the context of a new administration. Continued federal and state investment is vital, and raising awareness of these programs is key to ensuring their longevity and effectiveness."

Your response underscores the importance of collaborative discourse in addressing systemic inequities in maternal and infant health. We appreciate your contribution to this conversation and look forward to continuing the dialogue on how best to drive meaningful change in perinatal care.

Sincerely,

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Mitchell Goldstein, MD, MBA, CML

Editor in Chief



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Erratum (Neonatology Today January, 2025)

There were no reported erratum for January, 2025.

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

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

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Gravens by Design: Words Matter: The Impact of Language on Family Presence in NICU

Paige Terrien Church, MD, Mia Malcolm

Abstract

The essential nature of parental presence in the Newborn Intensive Care Unit (NICU) is irrefutable, and parental presence remains elusive. While numerous barriers to parental presence exist, not all are immovable. One modifiable factor is the microethical climate, specifically, the words used to describe their baby to the family and the words used to describe the baby or family context to fellow staff members. This brief review will provide a background in microethics, a description of how the human brain learns novel words, and the impact on family presence.

"Parent presence contributes to earlier discharge, greater likelihood of breastfeeding at discharge, and better regulation skills after discharge. Further, skin-to-skin care has demonstrated positive impacts that extend into young adulthood. Despite the known essential nature, parental presence is not universal, and multiple barriers have been identified."

Introduction

Families are essential to the health and well-being of their children (1). In the Newborn Intensive Care Unit (NICU), the essential nature of parental presence is irrefutable. Parent presence contributes to earlier discharge (2), greater likelihood of breastfeeding at discharge (2), and better regulation skills after discharge (3). Further, skin-to-skin care has demonstrated positive impacts that extend into young adulthood (4). Despite the known essential nature, parental presence is not universal, and multiple barriers have been identified. Parents in the NICU, similar to their preterm baby, are preterm themselves, experiencing parenthood earlier and differently than anticipated (5). Parents in the NICU are often overstimulated, unable to communicate in the NICU vernacular, and sometimes lack the tools they need to overcome major barriers (5). Barriers to parental presence include infectious concerns, transportation, financial barriers with time off

of work and/or costs associated with transportation, and childcare (2, 6). In addition, there are barriers to mental health, with many parents experiencing anxiety, depression, and trauma (1, 7), which may result in a variety of behavioral responses, including hyper/hypervigilance, difficulty separating from their baby at the bedside, and unequivocal avoidance (5).

While certain aspects of the trauma of the NICU may be unavoidable, there are sources of the trauma experienced in the NICU that are modifiable. One specific aspect is the microethical environment in the NICU (8). Bioethics references the sweeping care decisions involving care systems and pivotal care decisions, such as whether to intubate. In contrast, microethics describes the everyday ethics in the minute moments of day-to-day care (8, 9). It includes the choice of words used to convey information to or about an infant or family and how these words are spoken. It includes what is said and how it is said (9).

The focus of this paper is on the choice of words healthcare professionals use and the impact of these words on family understanding of their child, as well as our understanding of families, and lastly, how all of this impacts the family presence at the bedside. While the infant may be the bedside patient, the family is now recognized as being equally patient as the infant, and it is now a major focus of NICU care. The key to this focus is first, recognizing that parents are growing as parents in this novel and frightening environment (1, 2, 5) and second, understanding the essential nature of families in caring for the infant in the NICU (2. 4). As such, the environment, the culture, and the language we use and model with families carry tremendous significance.

"The focus of this paper is on the choice of words healthcare professionals use and the impact of these words on family understanding of their child, as well as our understanding of families, and lastly, how all of this impacts the family presence at the bedside."

Language and Culture of NICU

As with all healthcare domains, the Neonatal Intensive Care Unit (NICU) has evolved to have its vocabulary, language, and culture.

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This language and culture are taught to providers as they orient to and become educated in the medicine of the infants that require care in the NICU and the existing technology and care practices. Providers transfer delicate and exquisite data and information about the infant and their family through a dialect characterized by acronyms, words, and phrases.

"Families find themselves in this unusual and often traumatic environment without warning, orientation, or education. They race to understand their newfound context, and with this comes a crash course in the vocabulary, language, and culture of the NICU."

Families find themselves in this unusual and often traumatic environment without warning, orientation, or education. They race to understand their newfound context, and with this comes a crash course in the vocabulary, language, and culture of the NICU. Families also come with their own culture. language. education, and context, which are often minimized for the sake of the fast-paced NICU culture. Often, there is no specific repository in the chart for this equally important and delicate data, which is transferred between providers verbally (10). As such, the choice of words can significantly impact understanding for all involved. For parents, this understanding may drive pivotal care decisions and/ or shape their perception of their child and future. For staff, how the family or infant context is shared and the specific words used to do so will shape a collective understanding of the family, and it may be one based on reality, conjecture, bias, misunderstanding or a mixture of all things (10).

"Relational frame theory, with its explicit and implicit creation of associations between words, is also a source of parental trauma. As such, it represents a modifiable source of trauma, as the choices of words by healthcare professionals can be more intentional."

Relational Frame Theory (or Why Words Matter)

The developmental theory called relational frame theory describes the significance of words and the power of words to shape understanding (8, 11). Humans learn new words through both explicit and indirect instruction. Explicit teaching of a new word is intentional. The brain, however, will also learn associations between words without explicit teaching. This bidirectional implicit and explicit instruction of words is relevant for new vocabularies (8). As vocabularies are formed, adding new combinations of words creates new associations and understandings and is equally bidirectional, playing a proposed role in psychopathology for adults (11). Relational frame theory, with its explicit and implicit creation of associations between words, is also a source of parental trauma (8). As such, it represents a modifiable source of trauma, as the choices of words by healthcare professionals can be more intentional.

Outcomes of prematurity

Words matter as they describe to parents their future should their child survive. Critical to understanding outcomes in development is how the outcome is described, which varies amongst fields of medicine. In neonatology, outcomes are often distilled into a binary phenomenon. In developmental pediatrics, however, outcomes are often reported along a spectrum, focusing on function rather than 'impairment' (12). With this in mind, much of what is reported in the literature, and then to parents, reflects the presence or absence of a disorder, resulting in impacts on function in two or more environments (13). Less reported and less understood in neonatology is the concept of the spectrum, with behavior presenting in the expected or typical manner, variant with skills demonstrated within a window of expected but at the margins of expectations, and then problem behavior, reflecting undesirable behavior that is mediated by the environment (13). While this is often used for how children present, it describes all behavior in many ways.

"Less reported and less understood in neonatology is the concept of the spectrum, with behavior presenting in the expected or typical manner, variant with skills demonstrated within a window of expected but at the margins of expectations, and then problem behavior, reflecting undesirable behavior that is mediated by the environment."

The words used to describe the outcomes of children hospitalized in the NICU have been characterized in a binary manner by what the child will not/cannot do rather than what they can do (12). Historical and ongoing outcomes of prematurity have included the presence or absence of cerebral palsy, cognitive impairment (defined as a demonstration of learning skills that falls below 1 or 2 standard deviations on formal developmental testing), and neurosensory impairment (vision or hearing) (13). Collectively, these have been referred to as the presence or absence of neurodevelopmental impairment (13). The likelihood of these outcomes is relatively rare, depending on the gestation reported and specific outcome reported (13). Parents, however, report more pressing early import outcomes, such as feeding, sleeping, and respiratory concerns (12). Further, outcomes that emerge later in childhood with challenges in school have been identified as
common, including attentional weakness, executive dysfunction, subtle language processing challenges, motor challenges such as developmental coordination disorder, mental health issues with increased anxiety and depression, and socioemotional immaturity (13). Equally important, however, is an understanding that these children also demonstrate tremendous strengths, not captured in the literature but reported by parents (14).

Less recognized as an 'outcome' of preterm birth is that of the parents. They are also preterm, becoming parents before expected dates (5). The trauma experienced is shared across the family, and 45% of parents have reported clinically significant depression, anxiety, and trauma while in the NICU (7). These noxious experiences have been reported to pose a barrier to parental presence in the NICU, further exacerbating an already strenuous attachment process. Parental mood, anxiety, and trauma persist beyond discharge and pose a challenge to bonding, attachment, and parenting (7, 13).

"Less recognized as an 'outcome' of preterm birth is that of the parents. They are also preterm, becoming parents before expected dates. The trauma experienced is shared across the family, and 45% of parents have reported clinically significant depression, anxiety, and trauma while in the NICU."

This combination of the preterm neurodevelopmental strengths and challenges and characteristic pattern of development has been referred to as the behavioral phenotype of prematurity (15). It has been used to describe the preterm survivor specifically, but in actuality, it also describes the family unit, with their strengths and trauma (13). Each family's individual patterns of the emergence of strength and challenge are variable. Some experience trauma in the NICU and recover as they leave and transition to home. Others experience trauma from the NICU later with flashbacks and intrusive memories consistent with post-traumatic stress disorder (13). Others still experience some pattern prior and then new trauma as they transition to home, navigating a different version of the healthcare system for their infant.

Family Presence in the NICU and the Impact of '-Ism'

While the infant has historically been the focus of NICU care, the family is increasingly recognized as an equally important focus (1, 2). The essential role of parents in the care of the infant has been demonstrated with breast milk provision (16), skin-to-skin care (4, 16), auditory exposure (17), and greater behavioral regulation after NICU with parental presence in day-to-day care (16). Despite this essential role, parental presence is hindered by barriers such as transportation, traffic, financial burdens with parking and time off work, work requirements and lack of parental leave, concern for infection, and parents' mental health (1, 2, 5–7). Experiential avoidance is a stress-behavioral response to conditions that are difficult, painful, or traumatizing (18). This experiential avoidance

related to traumatic exposure is modifiable, to a degree, and one key aspect is through our unit language and culture.

"Despite this essential role, parental presence is hindered by barriers such as transportation, traffic, financial burdens with parking and time off work, work requirements and lack of parental leave, concern for infection, and parents' mental health."

Historically, discussions about the infant and outcome have centered on survival and the absence of neurodevelopmental impairment (12–14). Neonatologists and pediatricians specializing in NICU care have led many of these discussions. As such, the experience and exposure to the care of children across a lifespan, particularly children who may be neurodiverse, is limited (19). The result is reliance upon the neonatal outcome literature for data on outcomes, and this literature, as noted above, is riddled with impairment-focused outcomes rather than function or parent-designated important outcomes (12–14).

"This association created for parents as they learn about cerebral palsy (or any other outcome) is now forever linked to a negative or subpar outcome when, in fact, parents may report that other outcomes are more or less desirable. Once linked, however, the association is formed and cannot be undone. The associations assigned by medicine assign value, and it may not align with the values of the families, thus being a source of trauma."

Further, the presence of ableism in medical culture and training is undeniable (20). Ableism refers to the perpetuation of a belief that there is a 'normal' when it comes to the standard for a body type and function, and anything less than this normative standard is inferior (21). This bias exists both explicitly as demonstrated in health care allocation or articulated by providers as that those with a disability experience a lower quality of life (20, 22). It also exists implicitly with the unconscious choice to use value-based language such as 'risk' and cerebral palsy together, thereby conveying an ableist bias to the condition of cerebral palsy (8). This association created for parents as they learn about cerebral palsy (or any other outcome) is now forever linked to a negative or subpar outcome when, in fact, parents may report that other outcomes are more or less desirable. Once linked, however, the association is formed and cannot be undone. The associations assigned by medicine assign value, and it may not align with the values of the families, thus being a source of trauma (8).

Additional exacerbations include sources of bias and discrimination, including a lack of understanding or respect for other cultures, languages, gender identity and expressions, health literacy, and racism. As they struggle to learn about their baby, parents in the NICU are also tasked with sharing their family context (10). There is no formalized structure for this process, and family preference for what is shared, how it is shared, and with whom may be captured in fragments in the chart, but more often is shared by verbal report (10), offering further opportunities for miscommunications, personal insertions, and misunderstanding due to bias, confusion, and exhaustion. Words like 'difficult' are both assigned to and used to describe parents, providing a negative association of this family. The use of 'difficult' as a descriptor is not problematic in itself; it is the context in which it is used. 'Difficult' more accurately describes a situation; it reflects parental stress and trauma due to their current circumstance (5) and their attempts at coping with limited tools, support, or guidance. Phrases like 'Parent is absent' provide additional opportunities for inaccurate and harmful associations to be made, i.e., somehow linking that the parental absence is negligent/negligence rather than reflective of one of the many barriers to being in the NICU or perhaps a need for self-care or self-preservation. The vernacular of the NICU seems benign, but it shapes team understanding, separates and often excludes parents from the team, and provides additional sources of trauma. The ideal would be a central family context in the medical chart described by Dahan et al. (19), providing the family context as told by the family to the team, minimizing opportunities for misperceptions.

"Additional exacerbations include sources of bias and discrimination, including a lack of understanding or respect for other cultures, languages, gender identity and expressions, health literacy, and racism."

Lastly, for families, the words we use to describe the infant daily have an impact. Through the NICU binary lens, the infant is either sick or well. Instead, the infant develops in an artificial and stressful environment (23, 24), which results in permutations in developmental trajectories (13, 23, 24). An example of this is the NICU reference of 'respiratory distress syndrome (RDS)' to refer to premature infants and the associated lung immaturity and surfactant deficiency. Developmentally, preterm infants at 24 or 28 weeks should not yet have mature surfactant, and yet, the absence of it becomes a disease state. Parents are then led to perceive their infants as fragile, sick, and unwell when, in reality, they are growing in an alternative environment and will experience illness for certain, but the infant receiving developmental support as they grow and mature characterizes many days. Choices of words, such as 'failure to extubate,' drive home this narrative of the child as a failure, being at fault for a treatment course success

or lack thereof, or being unwell.

"Choices of words, such as 'failure to extubate,' drive home this narrative of the child as a failure, being at fault for a treatment course success or lack thereof, or being unwell. ."

Conclusion

Families are essential in the NICU to care for their babies (1, 2, 4, 16). Parents of preterm infants are preterm themselves in navigating this environment (5). Both the infant and their parents are developing in the NICU, which is unnatural and often stressful and traumatizing. The culture and the language of the NICU have deep roots in medical care and, with that, ableism, bias, and elitism. With greater awareness of factors associated with health equity, the NICU can modify its language to create an environment that would be more welcoming and less traumatizing-creating an essential aspect of all charts to include a 'Family Snapshot' (10) as told by the family for the team offers a tool to facilitate steps to change and greater awareness. Explicitly referring to infants as developing and, as such, as having strengths and challenges as they grow in the unnatural NICU environment empowers parents to see the children as they are rather than as diseased, feeble infants. Shifts in neonatal research to focus on important functional outcomes identified by parents, including feeding, sleeping, and behavioral regulation, would then offer more salient, less ableist data to be reported to families as they learn about their infant (12, 14, 19). Descriptions of neurodevelopmental diversity in value-neutral ways allow parents to determine the value of this outcome and make decisions reflective of the family values rather than medical bias. In doing so, parents can mature in a safer environment, be more present for their infant whilst in the NICU, and be more effective as parents for their child's future.

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NT



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Mia Malcolm Parent advocate Member Graven's Conference Planning Committee





INFANT AND FAMILY-CENTERED DEVELOPMENTAL CARE (IFCDC)

STANDARDS AND SAMPLE RECOMMENDATIONS FOR INFANTS IN THE INTENSIVE CARE UNIT



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

POSITIONING & TOUCH FOR THE NEWBORN

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



SLEEP AND AROUSAL INTERVENTIONS FOR THE NEWBORN

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

SKIN-TO-SKIN CONTACT WITH INTIMATE FAMILY MEMBERS

- FAMILY MEMBERS

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



REDUCING AND MANAGING PAIN AND STRESS IN NEWBORNS AND FAMILIES • Are parents supported to be present and interactive during

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

MANAGEMENT OF FEEDING, EATING AND NUTRITION DELIVERY

 Are the desires of the m/other central to the feeding plan? Is this consistently reflected in documentation with input of the m/other?



 Does the feeding management plan demonstrate a feeding & nutrition continuum from in-hospital care through the transition to home & home care?

WANT TO KNOW MORE ABOUT THE STANDARDS AND RECOMMENDATIONS? VISIT: HTTPS://NICUDESIGN.ND.EDU/NICU-CARE-STANDARDS/

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38[™] ANNUAL GRAVENS CONFERENCE On the Environment of Care for High Risk Babies and Their Families

Tuesday, March 4 th 2025			
Time	Session/Event	Location	
4:00 pm-7:00 pm	Registration Desk Open	Lobby II	
7:00 pm-9:00 pm	Welcome Reception Cash bar only	Exhibit Hall-Island	
	Wednesday, March 5 th 2025	5	
Intro/welcome, breaks, and awards do not count for CME/CE			
Time	Session/Event	Location	
6:30 am-7:15 am	Run/Walk/Crawl on the Beach	Meet Poolside	
7:00 am-8:00 am	Continental Breakfast Provided	Exhibit Hall-Island	
7:00 am-5:00 pm	Registration Desk Open	Lobby II	
	8:00 am-12:30 pm		
	Moderator: Joy Browne	חוכ	
Time	Session/Event	Presenter	
8:00 am-8:15 am	Welcome & Introductions	Joy Browne	
8:15 am-9:00 am	What Makes A Safe Space?	LaToshia Rouse	
9:00 am-9:45 am	Pain: Not so Simple	Brian Carter	
	9:45 am-10:15 am		
Break in Exhibit Hall Drinks and snacks provided			
10:15 am-11:00 am	Newborn Circadian Rhythms	Robert White	
11:00 am-11:45 am	Palliative Care-During and After the NICU	Renee Boss	
11:45 am-1:00 pm			
Lunch on Own			



1:00 pm to 5:00 pm		
Plenary Sessions in Grand Ballroom		
	Moderator: Robert White	
1:00 pm-1:45 pm	Advocacy for the Busy Newborn Care	Lily Lou
	Professional	
1.15 nm-2.10 nm	Gravens Beginnings: Beflections on	John Hartline and Bob Cicco
1.40 pm-2.10 pm	How it Got Started	
	Not eligible for CME/CE*	
2:10 pm-2:35 pm	Roots and Wings and the Ties That Bind	Kari Graven
	Us: Memories of My Uncle Stan	
	Not eligible for CME/CE*	
	2:30 pm-2:45 pm	
	Gravens Award Presentation	
	2:45 pm-3:15 pm	
	Break in Exhibit Hall	
2:15 pm 4:00 pm	Drinks and snacks provided	lim Crow and Bridget Devern
5.15 pm-4.00 pm	Technologists and Clinicians to	Jill Glay and Bluget Davern
	Understand Al in the NICU	
4:00 pm-4:45 pm	Integration Panel & Discussion with All	All Wednesday Speakers
	wednesday Speakers	
4:45 pm-5:00 pm	Final Thoughts & Take-Home Messages	Robert White
6:30 pm-8:30 pm		
Reception, Stan Graven toast & Poster Walk in Exhibit Hall		
Food stations, complimentary wine, and cash bar		
Poster Authors Available		
o: 10 pm Door Prize Baffle with Vincent Smith		

Gravens
on the Environment of Care for High Risk Newborns
The start has been been ath anoth

Thursday, March 6th 2025

Intro/welcome, breaks, and awards do not count for CME/CE				
Time Session/Event			Location	
6:30 am-7:15 am Run/Walk/Crawl on the B		Beach	Meet Poolside	
7:00 am-8:00	7:00 am-8:00 am Continental Breakfast Pro		rovided	Exhibit Hall-Island
Bagels provided in honor7:00 am-5:00 pmRegistration Desk Open			Lobby II	
8:00 am-1:00 pm Themed Tracks				
Track A Developmental & Family-Centered Care Location: Beach/Gulf Moderator: Joy Browne			Track B Newborn ICU Design Location: Palm/Bay Moderator: Robert White	
Time	Topic/Pres	senter	Time	Topic/Presenter
8:00 am- 8:10 am	Announcer to the Sess Implement Three IFCD Joy Browne	ments and Introduction ion: "Evidence and ation Strategies for OC Standards"	8:00 am- 8:10 am	Introduction & Announcements: Robert White
8:10 am- 8:45 am	Parent Pers	spective: Mia Malcolm	8:10 am- 8:55 am	Our Journey Towards More Parental Closeness; Work in Progress: Geert Lingier and Kris De Coen
 8:45 am- 9:30 am development in Infants: Amy Salisbury 		8:55 am- 9:40 am	New Unit Presentation - Phoenix Children's Hospital: Gregg Martin	
9:30 am-The effects of handling in moderate10:15 amto late preterm infants receiving		9:40 am 10:25 am	Hope, pride, and other enjoyments: Design for nuanced positive	



neonatal intensive care: emotions in family-centered patient Nancy Brashear care: Jay Yoon 10:15 am-10:45 am Break (Exhibitors Break Down) Drinks and snacks provided 10:25 am-10:55 am Break (Exhibitors Break Down) Drinks and snacks provided 10:45 am-Recognizing and understanding 10:55 am-The Impact of Circadian Lighting on 11:30 am traumatic stress in NICU parents: 11:40 am Retinal Development in Preterm **Richard Shaw** Infants: Jim Greenberg 11:30 am-Implementation Panel: 11:40 am-The Healthcare Sustainability 12:15 pm 12:25 pm Rose Bigsby, Michael Hynan, and Movement, the NICU, and You: What Debra Paul Should We Know and What Can We Do?: Troy Savage **Discussion with Audience** 12:15 pm-12:25 pm-Once Upon a Renovation: Sharing 12:45 pm 12:55 pm Stories from HSHS St. John's NICU's Post Occupancy Evaluation to Advance NICU Design: Julia Jude 12:45 pm-Summary & Presentation of New 12:55 pm-Crowdsourcing, Summary & Next Standards: Joy Browne and Carol 1:00 pm 1:05 pm Steps: Robert White Jaegar Rest, Play, & Network



Friday, March 7th 2025

Intro/welcome and breaks do not count for CME/CE			
Time	Session/Event	Location	
6:30 am-7:15 am	Run/Walk/Crawl on the Beach	Meet Poolside	
7:00 am-8:00 am	Continental Breakfast	Lobby II	
7:00 am-5:00 pm	Registration Desk Open	Lobby II	
	8:00 am-12:15 pm		
	Workshops		
(Continuing	g Education Credits will only be awarded for in-person at	tendance)	
	8:00 am-9:15 am		
	J Workshops and Topics		
Workshop/Room	Topic/Presenter		
J-1 Workshop:	The Impact of Social Determinants of Health on Infant and	Maternal Health	
Beach	Using a Reproductive Justice Lens: Kathryn Malin and Rebecca Koerner		
	(Moderator: Paige Church)		
J-2 Workshop: Gulf	Parents As Participants, Not Recipients: Molly Fraust-Wylie and Mia Malcolm		
	(Moderator: Malathi Balasundaram)		
J-3 Workshop: Palm	Optimizing the Pathway Home by Reducing the Risk from Respiratory Syncytial		
Virus: Mitchell Goldstein (Moderator: Judy Smith)			
J-4 Workshop: Bay	Al is Coming for You!!: Jim Gray, and Bridget Davern (Mode	erator: Elizabeth	
	York)		
J-5 Workshop:	The Silent Barrier, Bridging Communication Gaps: Nancy	Brashear	
Island I	(Moderator: Joy Browne)		
9:15 am-9:45 am			
	Drinks and snacks provided		
	9:45 am-11:00 am		
H Workshops and Topics			
Workshop/Room	Topic/Presenter		



H-4 Workshop: Bay	Beyond instant gratification: Designing for simple, tiny activities that enhance
	our happiness: Jay Yoon (Moderator: Mardelle Shepley)
H-5 Workshop:	Implementation of Infant & Family Centered Developmental Care Standards in
Island I	a BPD Program: Gina Porto and Sue Horner (Moderator: Malathi Balasundaram)
	11:00 am-11:30 am Brook
	Drinks and snacks provided
	11:30 am-12:45 pm
	I Workshops and Topics
Manda Isan (Dalama	Tania (Dresenter
worksnop/Room	lopic/Presenter
I-1 Workshop:	Planning for Supporting Social Determinates, Language Differences, and
I-1 Workshop: Beach	Planning for Supporting Social Determinates, Language Differences, and Mental Health Needs in The NICU and Beyond: LaToshia Rouse (Moderator: Molly Fraust-Wylie)
I-1 Workshop: Beach I-2 Workshop: Gulf	Planning for Supporting Social Determinates, Language Differences, and Mental Health Needs in The NICU and Beyond: LaToshia Rouse (Moderator: Molly Fraust-Wylie) The Ethics of Ambiguity: Life and Death in the NICU: Evan Richards
I-1 Workshop: Beach I-2 Workshop: Gulf	Iopic/Presenter Planning for Supporting Social Determinates, Language Differences, and Mental Health Needs in The NICU and Beyond: LaToshia Rouse (Moderator: Molly Fraust-Wylie) The Ethics of Ambiguity: Life and Death in the NICU: Evan Richards (Moderator: Vincent C. Smith)
I-1 Workshop: Beach I-2 Workshop: Gulf I-3 Workshop: Palm	Planning for Supporting Social Determinates, Language Differences, and Mental Health Needs in The NICU and Beyond: LaToshia Rouse (Moderator: Molly Fraust-Wylie) The Ethics of Ambiguity: Life and Death in the NICU: Evan Richards (Moderator: Vincent C. Smith) The Imperfect Baby-Helping Parents Cope with NICU Stress:
I-1 Workshop: Beach I-2 Workshop: Gulf I-3 Workshop: Palm	Planning for Supporting Social Determinates, Language Differences, and Mental Health Needs in The NICU and Beyond: LaToshia Rouse (Moderator: Molly Fraust-Wylie) The Ethics of Ambiguity: Life and Death in the NICU: Evan Richards (Moderator: Vincent C. Smith) The Imperfect Baby-Helping Parents Cope with NICU Stress: Kelly Welton-Lewis (Moderator: Mitch Goldstein)
I-1 Workshop: Beach I-2 Workshop: Gulf I-3 Workshop: Palm I-4 Workshop: Bay	Iopic/Presenter Planning for Supporting Social Determinates, Language Differences, and Mental Health Needs in The NICU and Beyond: LaToshia Rouse (Moderator: Molly Fraust-Wylie) The Ethics of Ambiguity: Life and Death in the NICU: Evan Richards (Moderator: Vincent C. Smith) The Imperfect Baby-Helping Parents Cope with NICU Stress: Kelly Welton-Lewis (Moderator: Mitch Goldstein) The Road to Excellence is Paved with Wrong Turns: Improving the Way We
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I-1 Workshop: Beach I-2 Workshop: Gulf I-3 Workshop: Palm I-4 Workshop: Bay I-5 Workshop: Island I	Planning for Supporting Social Determinates, Language Differences, and Mental Health Needs in The NICU and Beyond: LaToshia Rouse (Moderator: Molly Fraust-Wylie) The Ethics of Ambiguity: Life and Death in the NICU: Evan Richards (Moderator: Vincent C. Smith) The Imperfect Baby-Helping Parents Cope with NICU Stress: Kelly Welton-Lewis (Moderator: Mitch Goldstein) The Road to Excellence is Paved with Wrong Turns: Improving the Way We Honor our Bedside Mistakes: Louisa Ferrara-Gonzalez (Moderator: Kathleen Kolberg) Following Through after the NICU: A Population Health Management Approach: Jonathan Litt (Moderator: Paige Church)
I-1 Workshop: Beach I-2 Workshop: Gulf I-3 Workshop: Palm I-4 Workshop: Bay I-5 Workshop: Island I	Planning for Supporting Social Determinates, Language Differences, and Mental Health Needs in The NICU and Beyond: LaToshia Rouse (Moderator: Molly Fraust-Wylie) The Ethics of Ambiguity: Life and Death in the NICU: Evan Richards (Moderator: Vincent C. Smith) The Imperfect Baby-Helping Parents Cope with NICU Stress: Kelly Welton-Lewis (Moderator: Mitch Goldstein) The Road to Excellence is Paved with Wrong Turns: Improving the Way We Honor our Bedside Mistakes: Louisa Ferrara-Gonzalez (Moderator: Kathleen Kolberg) Following Through after the NICU: A Population Health Management Approach: Jonathan Litt (Moderator: Paige Church)



2:00 pm-5:00 pm Abstracts		
Abstracts (Continuing Education Credits will only be awarded for in-person attendance)		
Time	Abstract Session	Location
2:00 pm-3:15 pm	A: Developmental Care Moderator: Elizabeth York 1. H-HOPE (Hospital to Home: Optimizing the	Beach
	Preterm Infant Environment): Infant, Parent, and Parent-Infant Interaction Outcomes (Rosemary White-Traut #6) 2 Eactors Contributing to Stress in NICLU Infants and	
	 Their Mothers (Susan Horner #50) 3. It's Time for Kangaroo Care: A Quality Improvement Project to Improve Time Spent Skin-To-Skin in the Sunnybrook Health Sciences Centre Neonatal 	
2:00 pm-3:15 pm	B: Family Support Moderator: Mia Malcolm	Gulf
	 Trauma-Informed and Resilience-Promoting Care Trainings for NICU Providers (Alyssa Morris #13) Using a Trauma Informed Approach to Share Lessons Learned During My Transition from NICU Professional to NICU Parent (Jessie Barnes #30) 	
	 Empowering parents through targeted journaling to promote engagement and reduce stress (Erik VerHage #2) 	
2:00 pm-3:15 pm	C: Feeding/Lactation Moderator: Robert White	Palm
	 Family-Driven Feeding: A Quality Improvement Initiative (Jessica Duby & Adeline Launay, #8) Implementation of the Hunger Vital Sign Tool to Assess Food Insecurity (Sheri Andersen #38) 	



	3. Transforming Preterm Oral Feeding with Innovative	
	Algorithms: Insights from a Quality Improvement	
	Initiative (Rena Rosenthal & Jean Chow #27)	
2:00 pm-3:15 pm	D: Potpourri	Bay
2.00 pm 0.10 pm	Moderator: Mitch Goldstein	Duy
	1. Implementation of a Multidisciplinary	
	Individualized Neurodevelopmental Program for	
	SPBOLIT Program (Ashley Lucke #51)	
	2 Introducing Psychological Support for NICLI	
	Fellows to Improve Trainee Mental Health (Tasnia	
	Osmani #46)	
	3. Weekly Multidisciplinary Rounds to Guide an	
	Intensive Inpatient Neonatal Neurodevelopmental	
	Program (Ashley Lucke, Melissa Jecker, Victoria De	
	La Garza, and Holly Paulos #52)	
	3:15 pm-3:45 pm	
Break		
	Break	
	Break Drinks and snacks provided	
Time	Break Drinks and snacks provided Abstract Session	Location
Time 3:45 pm-5:00 pm	Break Drinks and snacks provided Abstract Session A: Developmental Care	Location Beach
Time 3:45 pm-5:00 pm	Break Drinks and snacks provided Abstract Session A: Developmental Care Moderator: Joy Browne	Location Beach
Time 3:45 pm-5:00 pm	Break Drinks and snacks provided Abstract Session A: Developmental Care Moderator: Joy Browne 1. Infant Voice Exposure Through a Reading Program:	Location Beach
Time 3:45 pm-5:00 pm	Break Drinks and snacks provided Abstract Session A: Developmental Care Moderator: Joy Browne 1. Infant Voice Exposure Through a Reading Program: Comparing Experiences in an Open Bay to a Single-	Location Beach
Time 3:45 pm-5:00 pm	Break Drinks and snacks provided Abstract Session A: Developmental Care Moderator: Joy Browne 1. Infant Voice Exposure Through a Reading Program: Comparing Experiences in an Open Bay to a Single- Family Room NICU (Malathi Balasundaram #18)	Location Beach
Time 3:45 pm-5:00 pm	Break Drinks and snacks provided Abstract Session A: Developmental Care Moderator: Joy Browne 1. Infant Voice Exposure Through a Reading Program: Comparing Experiences in an Open Bay to a Single- Family Room NICU (Malathi Balasundaram #18) 2. Characteristics of Communication in Interpreted	Location Beach
Time 3:45 pm-5:00 pm	Break Drinks and snacks provided Abstract Session A: Developmental Care Moderator: Joy Browne 1. Infant Voice Exposure Through a Reading Program: Comparing Experiences in an Open Bay to a Single- Family Room NICU (Malathi Balasundaram #18) 2. Characteristics of Communication in Interpreted and Non-Interpreted NICU Family Meetings (Nikita	Location Beach
Time 3:45 pm-5:00 pm	Break Drinks and snacks provided Abstract Session A: Developmental Care Moderator: Joy Browne 1. Infant Voice Exposure Through a Reading Program: Comparing Experiences in an Open Bay to a Single- Family Room NICU (Malathi Balasundaram #18) 2. Characteristics of Communication in Interpreted and Non-Interpreted NICU Family Meetings (Nikita Kalluri #34)	Location Beach
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Time 3:45 pm-5:00 pm	Break Drinks and snacks provided Abstract Session A: Developmental Care Moderator: Joy Browne 1. Infant Voice Exposure Through a Reading Program: Comparing Experiences in an Open Bay to a Single- Family Room NICU (Malathi Balasundaram #18) 2. Characteristics of Communication in Interpreted and Non-Interpreted NICU Family Meetings (Nikita Kalluri #34) 3. Family Well-being Outcomes for Infants with Severe Bronchopulmonary Dysplasia: Comfort and	Location Beach
Time 3:45 pm-5:00 pm	Break Drinks and snacks provided Abstract Session A: Developmental Care Moderator: Joy Browne 1. Infant Voice Exposure Through a Reading Program: Comparing Experiences in an Open Bay to a Single- Family Room NICU (Malathi Balasundaram #18) 2. Characteristics of Communication in Interpreted and Non-Interpreted NICU Family Meetings (Nikita Kalluri #34) 3. Family Well-being Outcomes for Infants with Severe Bronchopulmonary Dysplasia: Comfort and Quality of Life Surrounding Transition to Home	Location Beach
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Time 3:45 pm-5:00 pm 3:45 pm-5:00 pm	Break Drinks and snacks provided Abstract Session A: Developmental Care Moderator: Joy Browne 1. Infant Voice Exposure Through a Reading Program: Comparing Experiences in an Open Bay to a Single- Family Room NICU (Malathi Balasundaram #18) 2. Characteristics of Communication in Interpreted and Non-Interpreted NICU Family Meetings (Nikita Kalluri #34) 3. Family Well-being Outcomes for Infants with Severe Bronchopulmonary Dysplasia: Comfort and Quality of Life Surrounding Transition to Home (Kathleen Hannan & Igor Shumskiy #35) B: Family Support	Location Beach Gulf



	 Development of a Belgian perinatal palliative care intervention: Supporting infants with severe perinatal diagnoses, their families and healthcare providers (Laure Dombrecht & Ellen Roets #1) Video-Enhanced Education to Encourage Maternal Engagement in a Ugandan NICU: A Pilot Trail (Jessica Duby, Fahima Khan, & Olive Kabajaasi #11) 	
3:45 pm-5:00 pm	 C: Discharge planning Moderator: Vincent C. Smith 1. Implementation of Discharge Path Tool to Achieve Discharge Readiness in NICU families (Sherri Spaw #47) 2. Empowering Families for Better Outcomes: A Statewide QI Initiative to Improve NICU Discharge Readiness (Patoula Panagos-Billiris #49) 3. Implementation of Emotional Readiness Tool to Achieve Discharge Readiness in NICU families. (Taylor Wiseman Deall #48) 	Palm
3:45 pm-5:00 pm	 D: Developmental Care/Family Support Moderator: Mitch Goldstein 1. Post COVID - an approach to bringing families back to face-to-face participation (Emily Whitesel #16) 2. TBA 3. Sustaining a Nurturing Culture in The NICU (Lisa Sampson & Eugene Ng #28) 	Bay
3:45 pm-5:00 pm	 E: Design Moderator: Judy Smith 1. Examining the Single-family Room: Disruptive and Supportive Design for Family-centered Clustered Care in the NICU (Herminia Marchy & Laurie Hay #42) 2. Implementing a NICU Nourishment Center through Community Collaboration (Christine Neugebauer & Emilia Garcia #21) 	Island I



	 Hospitable NICUs – Providing safe spaces for babies, families, and staff (Beth Gould Nolson & Luisa King #5) 	
Rest, Play, & Network		







Saturday, March 8th 2025

Intro/welcome and breaks do not count for CME/CE Time Session/Event Location 6:30 am-7:15 am Run/Walk/Crawl on the Beach Meet Poolside Continental Breakfast Provided 7:00 am-8:00 am Lobby II 7:00 am-5:00 pm **Registration Desk Open** Lobby II 8:00 am-12:00 pm **Plenary Sessions in Grand Ballroom** What is your Why? Finding Meaning and Doing Meaningful Work Moderator: Vincent C. Smith and Molly Fraust-Wylie Session/Event Time 8:00 am-8:15 am Welcome & Introductions: Vincent C. Smith and Molly Fraust-Wylie 8:15 am-8:45 am Parent Perspective on how a NICU Stay Changed My Life: Molly Fraust-Wylie Not eligible for CME* 8:45 am-9:30 am What Drives Motivation: Autonomy Mastery Purpose: Erick Rideout 9:30 am-10:15 am Break 10:15 am-11:00 am Equitable engagement of families during prolonged NICU hospitalization to optimize the transition home: Susan Hwang and Laurie Sherlock 11:00 am-11:30 am Parent Panel: Laurie Sherlock and LaToshia Rouse Moderators: Molly Fraust-Wylie and Mia Malcom 11:30 am-12:00 pm Wrap Up & Final Thoughts: Robert White and Joy Browne **Farewell Until Next Year!** 39th Annual Gravens Conference March x 2026 (Welcome Reception 7:00 pm-9:00 pm March x 2026)

Note: Speaker and topic may change



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Hand to Hold

Hand to Hold is dedicated to providing early intervention mental health support before, during, and after a NICU stay, ensuring that all NICU families thrive.

When a baby requires specialized care in the neonatal intensive care unit (NICU), it profoundly impacts the family. The emotional toll is immense, disrupting traditional parent-baby bonding, often leading to postpartum depression, anxiety, and PTSD. Hand to Hold's support, recommended by the World Health Organization (WHO) and the American Academy of Pediatrics (AAP), is essential in providing the care and resources families need to cope with the NICU experience.

100+ hospitals in 39 states rely on Hand to Hold's support resources.

93% of NICU Managers agree Hand to Hold's support resources allow them to spend more time focusing on the care of the baby.

100% of NICU Managers agree Hand to Hold helps provide a better understanding of how to support NICU parents.

> Ways we can help you support the families in your care:

> > In-Person NICU Support











Hand to Hold bridges the gap by offering early intervention mental health support to NICU and bereaved parents, helping to alleviate the emotional challenges of a traumatic birth, a NICU stay, and/or infant loss. Our support is always provided at no cost to the parent in both English and Spanish.



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To qualify to be nominated to the RC-Peds for this position, the candidate:

- must be a board-certified pediatrician or pediatric subspecialist with a background in education and expertise in graduate medical education.
- should have at least three years of experience as a program director of an ACGME-accredited pediatrics residency program or pediatric subspecialty fellowship or three years of experience as a designated institutional official. The nominee's program must be in good standing with a status of Continued Accreditation.
- must have a current or past association with graduate medical education.
- should participate in major specialty societies.
- must be skilled in the use of computers (communication with staff is primarily through email, and members will use electronic systems for receipt of agenda materials, program reviews, reimbursement of expenses, and peer evaluations).
- must demonstrate fairness, the ability to work collaboratively, and express views clearly and concisely.
- must be able to attend an observation meeting, April 10-11, 2025, prior to the start of the term.
- must devote sufficient time to prepare for and participate in three RC meetings per year (January, April, and September), two-three days per meeting, as well as contribute to RC-Peds subcommittee work as assigned.
- ideally, will not hold the same subspecialty certifications as the members of the RC-Peds at the time of appointment. The RC-Peds strives to maintain a balance of specialties; it is preferable that individuals from the following specialties are not nominated:
 - General Pediatrics
 - Internal-Medicine Pediatrics
 - Pediatric Hospital Medicine
 - Pediatric Emergency Medicine
 - Neonatal-Perinatal Medicine
 - Pediatric Critical Care Medicine
 - Pediatric Endocrinology
- must not be at the same institution as any member of the RC-Peds at the time of appointment.
 - Same-Institution Disqualification: Although the RC-Peds may have multiple members from the same state, they may not be from the same institution. Accordingly, individuals must not be nominated from the following institutions:
 - UC Davis (Davis, CA)
 - Stanford University (Stanford, CA)
 - University of Colorado (Aurora, CO)
 - Advocate Children's Hospital (Park Ridge, IL)
 - Mayo Clinic (Rochester, MN)
 - Columbia University College of Physicians & Surgeons (Yonkers, NY)
 - Goryeb Children's Hospital-Atlantic Health System (Morristown, NJ)
 - University of North Carolina School of Medicine (Chapel Hill, NC)
 - Cincinnati Children's Hospital Medical Center (Cincinnati, OH)
 - University of Texas Health San Antonio (San Antonio, TX)
 - University of Washington/Seattle Children's (Seattle, WA)

The RC-Peds expects the AAP to consider diversity and inclusion when submitting its nominations.

ONCE UPON A PREEMIE ACADEMY



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- + Solutions for Addressing Inequities and Implicit Bias In the NICU
- + Black NICU Mother's Mental and Emotional Health
- + Black Preemie Parents as Partners in Preemie Care

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- + Gain actionable tools to drive health and racial equity solutions in your organization!

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Respiratory Syncytial Virus

Really Serious Virus

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



www.nationalperinatal.org/rsv

Why Pregnant and Nursing Women Need Clear Guidance on **THE NET BENEFITS OF EATING FISH**



But **mixed messages** from the media and regulatory agencies cause pregnant women to sacrifice those benefits by eating less fish than recommended.

> **GET THE FACTS** ON FISH CONSUMPTION FOR PREGNANT WOMEN, INFANTS, AND NURSING MOMS.



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

Leadership

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

Advocacy

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

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

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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.**

> Make a Difference in the Life of a Student in Need Today! Please visit <u>emilyshane.org</u>

Sponsor a Child in the SEA Program

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



1 session	\$15
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1 semester	\$540
1 year	\$1,080
Middle School	\$3,240

he Emily Shane Foundation is a 501(c)3 nonprofit charity, Tax id # 27-3789582. Our flagship SEA (Successful Educational Achievement) rogram is a unique educational initiative that provides essential mentoring/tutoring to disadvantaged middle school children across Los Angeles and Ventura counties. All proceeds directly fund the SEA Program, making a difference in the lives of the students we serve.

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 selfesteem led him to stumble, but he soon found the courage to tackle his subjects with vigor. He became more curious about the world around him and began to yearn for a new life despite his financial limitations. Against all odds, he became one of the top students in Iran and earned a scholarship to study medicine in Europe. Even though he was culturally and socially naïve by European standards, an Italian family in Rome helped him thrive. The author never shied away from the challenges of learning Italian, and the generosity of Italy and its people became part and parcel of his formative years. By the time he left for the United States of America, he knew he could accomplish whatever he imagined.

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COVID-19

2024

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KEEP PATIENTS UP-TO-DATE WITH CHANGES IN POLICIES SO THEY KNOW WHAT TO EXPECT. LISTEN TO THEIR CONCERNS.





Provide culturallyinformed 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.

myNICUnetwork.org



National Perinatal Association NICU Parent Network

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

Respiratory Syncytial Virus:

How you can advocate for babies this RSV season



Peer Reviewed

First Candle: Honoring Our Babies: Insights, Research, and Support from the Latest SUID Conference

Alison Jacobson



Saving babies. Supporting families.

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

"This past week, we presented at the Isabel Davis Center for Safe Children Conference, Beyond the Crib: Innovations in SUID Prevention and Research, supported by Baylor College of Medicine and Texas Children's Hospital."

This past week, we presented at the Isabel Davis Center for Safe Children Conference, Beyond the Crib: Innovations in SUID Prevention and Research, supported by Baylor College of Medicine and Texas Children's Hospital. I had the privilege of sharing how First Candle supports grieving families while our Director of Education and Bereavement Support, Barb Himes, presented our Let's Talk Community Chats as a successful prevention program.

The conference featured some truly fascinating research, and one session in particular focused on bereavement. Dr. Rick Goldstein, Director of the Robert's Program on Sudden Unexpected Death in Pediatrics and Associate Professor at Harvard Medical School, presented his work on prolonged grief among parents who have lost a child suddenly and unexpectedly, with no apparent cause. His session was eye-opening and insightful.

Each session began with parents sharing the heart-wrenching stories of their baby's death. Unfortunately, many of these stories included troubling experiences with law enforcement during the death scene. We were, however, encouraged by Dr. Savannah Lusk, who has developed a training program for law enforcement on how to interact respectfully with grieving parents. Seeing such meaningful work being done to address these issues was moving.

The conference also included a memorial service to honor babies

lost too soon, where everyone lit an electric candle and shared who they were honoring. Pictures of our babies and SIDS Quilts, dating back to the 1970s, were displayed, creating a powerful and emotional tribute to the lives we carry in our hearts.

"The conference also included a memorial service to honor babies lost too soon, where everyone lit an electric candle and shared who they were honoring. Pictures of our babies and SIDS Quilts, dating back to the 1970s, were displayed, creating a powerful and emotional tribute to the lives we carry in our hearts."

The conference brought together top researchers in Sudden Unexpected Infant Death, including **Drs. Rachel Moon**, **Fern Hauk**, **Nino Ramirez**, and **Russell Ray**. Even more encouraging was the presence of many young researchers eager to contribute to the field.

A particularly special moment for me was witnessing **Dr. Hannah Kinney** receive the inaugural Hannah Kinney Lifetime Achievement Award. Dr. Kinney is a pioneer in SUID research, and she was the first person I reached out to when my son passed. Seeing her honored for her extraordinary contributions was deeply moving.

Conferences like this are crucial for highlighting important research and offering a space where families can come together to support each other.

We are excited to host the **ISPID International Conference** on Stillbirth, SIDS, and SUDI this October, where parents, advocates, healthcare providers, and researchers will discuss further advancements in research, community advocacy, and bereavement support. <u>You can learn more, register to attend,</u> and submit an abstract here.

This past week reaffirmed how vital it is to continue supporting

About First Candle

First Candle, based in New Canaan, CT, is a 501c (3) committed to eliminating Sudden Unexpected Infant Death while providing bereavement support for families who have suffered a loss. Sudden Unexpected Infant Death (SUID), which includes SIDS and Accidental Suffocation and Strangulation in Bed (ASSB), remains the leading cause of death for babies one month to one year of age, resulting in 3,700 infant deaths nationwide per year.



families through education, research, and compassionate care. Together, we can create a future where fewer families experience these heartbreaking losses.

"This past week reaffirmed how vital it is to continue supporting families through education, research, and compassionate care. Together, we can create a future where fewer families experience these heartbreaking losses."

Disclosure: The author is the Executive Director and Chief Executive Officer of First Candle, a Connecticut-based not-for-profit 501(c)3 corporation.



Corresponding Author



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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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+ Jenné Johns, MPH Once Upon A Preemie Academy

+ Dawn Godbolt, Ph.D. National Birth Equity Collaborative

+ Chavis A. Patterson, Ph.D. Children's Hospital of Philadelphia

+ Shanté Nixon Connect2NICU



+ Deidre McDaniel, MSW, LCSW Health Equity Resources and Strategies

+ Dalia Feltman, MD, MA, FAAP Univ. of Chicago Pritzker School of Medicine

+ Terri Major- Kincade, MD, MPH Pediatrician and Neonatologist



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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 <u>www.rsvgold.com/awareness</u> 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.







Vational Perinatal Association PERINATAL MENTAL HEALTH

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SCREEN DADS TOO

10% of fathers experience depression and anxiety during the perinatal period.



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National Coalition for Infant Health: Congenital Syphilis: An Increasing Crisis

Susan Hepworth, Lindsay Cox, MPM, 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.

Cases of <u>congenital syphilis</u> have surged over the past decade, increasing <u>tenfold</u> since 2012. The condition, which can cause severe health complications or even death in newborns, is largely preventable. (1, 2)

Task Force Recommends Stronger Screening Guidelines:

The crisis, according to the U.S. Preventive Services Task Force, can best be addressed with early syphilis screening for all pregnant mothers. That advice came in an <u>"A" grade draft recommendation</u>, underscoring the effectiveness of early detection in preventing serious outcomes. (3)

Steering Committee

The National Coalition for Infant Health is supported by a volunteer steering committee, all of whom contribute significantly to lives of premature infants through work and parenting. Skeering committee members represent national nonprofits, academic institutions, and parent organizations, and they provide leadership as well as help to mobilize partners in the field of prematurity.



preemiework

Screening for <u>syphilis</u> – a sexually transmitted infection – during the first prenatal visit allows for prompt treatment of the mother, vastly reducing the risk of transmission to the baby. (4)

Reducing Mother-to-Child Transmission Saves Lives:

Syphilis is highly treatable in both adults and infants. If antibiotic treatment for pregnant women is completed 30 days before delivery, the risk of congenital syphilis in the newborn is dramatically reduced. Up to <u>10 days of antibiotics</u> and hospitalization may be required for infected newborns. (5)

Expectant mothers must get tested and treated because, left unaddressed, <u>congenital syphilis</u> can result in lifelong disability, seizures, severe anemia, and death, even in infancy. Heartbreakingly, these cases account for nearly 100 stillbirths annually. (6)

"Expectant mothers must get tested and treated because, left unaddressed, congenital syphilis can result in lifelong disability, seizures, severe anemia, and death, even in infancy. Heartbreakingly, these cases account for nearly 100 stillbirths annually. (6)"

Disparities in Care Worsen the Crisis:

Not all communities are affected equally. Black, Hispanic, Native American, and Alaska Native mothers are up to <u>eight times</u> more likely to have babies with congenital syphilis compared to white mothers. <u>Inadequate access</u> to care accounts for much of this disparity. (7, 8)

Not only are <u>cases of syphilis</u> in adults higher in these communities, but socioeconomic barriers to quality prenatal care may cause those cases to go undetected, putting both mother and child at risk. (9)

Unfortunately, more than half of cases of congenital syphilis occur in babies born to people who tested positive during pregnancy but who did not receive adequate treatment to clear the infection. When treatment is started promptly, no differences in recovery rates between races are observed.

Stopping the Surge Requires Swift Action:

Addressing these disparities requires increasing access to serologic testing and treatment, particularly in underserved areas and among uninsured patients. In addition to prenatal screenings, community health advocates and case managers play a key role


in assuring that patients in need are connected with appropriate services.

Likewise, expanding awareness about the condition and encouraging expectant mothers to inquire about testing and treatment are also critical to turning the tide.

"With early detection and proper intervention, most cases of congenital syphilis can be prevented, protecting both newborns and their parents from devastating harm."

With early detection and proper intervention, most cases of congenital syphilis can be prevented, protecting both newborns and their parents from devastating harm.

References:

- 1. <u>https://www.cdc.gov/syphilis/about/about-congenital-</u> syphilis.html
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Disclosures: The authors have no relevant disclosures.

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Mitchell Goldstein, MD, MBA, CML Professor of Pediatrics Loma Linda University School of Medicine Division of Neonatology Department of Pediatrics Email: mgoldstein@llu.edu

National Coalition for Infant Health Values (SANE)

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

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

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

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



Your Pregnancy and Substance Use

4 Things you can do to improve your health and lower your risk for complications



Get Prenatal Care

Start early. Go to all your visits. Empower yourself with information so you can make smart decisions. Build relationships with providers who understand Substance Use Disorders (SUDs) and know how to help. Partner with them to reach your goals. But remember, you do not need to be abstinent from substance use to get care. Go now.

Reduce Your Use



There are simple things you can do to limit the harm substances might do.

- Use fewer substances
- Use smaller amounts
- Use less often
- Learn how to use safer

Reducing or quitting smoking is a good place to start. Set your goals, then ask for help. One of the best things you can do is to stop using alcohol. We know that even small amounts are risky. And when combined with benzos and opioids, alcohol can kill.

Use Medications for Opioid Use Disorder (MOUD) if you are opioid dependent

Methadone and Buprenorphine (Subutex® or Suboxone®) are the "Standard of Care" during pregnancy because they:

- Eliminate the risks of illicit use
- Reduce your risk for relapse
- Can be a positive step towards recovery



Take Good Care of Yourself

You deserve a healthy pregnancy & childbirth.

- Eat healthy and take your prenatal vitamins
- Find the right balance of rest and exercise
- · Surround yourself with people who care

Your Health Matters



Academy of Perinatal Harm Reduction



www.perinatalharmreduction.org www.nationalperinatal.org

Why Pregnant and Nursing Women Need Clear Guidance on THE NET BENEFITS OF EATING FISH



But **mixed messages** from the media and regulatory agencies cause pregnant women to sacrifice those benefits by eating less fish than recommended.



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

for this unique dyad?

What is the best

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





TRAUMA-INFORMED

Both parents and providers are confronting significant...

- FEAR
- GRIEF
- UNCERTAINTY

LONGITUDINAL DATA

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

MENTAL HEALTH
 POSTPARTUM CARE DELIVERY



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

Partnering for patient-centered care when it matters most.





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<u>Peer Reviewed</u>

Revolutionizing Newborn Care: Overcoming Barriers to Lasting Change

Samantha Butler, PhD, Kaitlyn Ludder, M.Sc, Joy Browne, PCNS, IMH-E, Dorothy Vittner, PhD, RN, FAAN



"A lack of evidence rarely hinders change in high-acuity healthcare settings. Instead, it is often obstructed by long-standing traditions, institutional hierarchies, and the deeply ingrained belief that 'this is how we've always done it."

Introduction

In a busy intensive care unit (ICU), a nurse lowers the lights, silences the beeping monitors, and gently positions a fragile newborn in skin-to-skin contact with their parent. These small yet profound adjustments can reduce stress, stabilize vital signs, and support neurodevelopment. As the nurse glances around, a moment of hesitation sets in. They consider if their colleagues see this as essential, evidence-based care, or an unnecessary deviation from routine protocols. A lack of evidence rarely hinders change in high-acuity healthcare settings. Instead, it is often obstructed by long-standing traditions, institutional hierarchies, and the deeply ingrained belief that "this is how we've always done it." Care of newborns has evolved through dramatic paradigm shifts, introducing lifesaving interventions such as surfactant therapy, delayed cord clamping, and Family-Centered care. Still, despite growing recognition of the long-term impact of the hospital environment on development, individualized, neuroprotective interventions remain inconsistently applied. (1, 2)

Why does change in developmentally focused newborn care face such resistance? How do entrenched habits and systemic barriers hinder the adoption of evidence-based practices? Most importantly, how can intensive care practices change so that every newborn and family receive care that ensures survival and optimizes longterm development? Historical resistance, cognitive dissonance, and institutional constraints are known to hinder evidence-based changes in hospital-based practice. The complexities of change in newborn intensive care can be best understood by exploring systemic and psychological barriers to change.

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Examining theoretical frameworks of change management helps to understand how change occurs in healthcare settings. Applying quality improvement (QI) methods and interdisciplinary collaboration fosters sustainable practice transformation while addressing resistance to change. This article explores strategies for embedding change into policy and practice, ensuring that new approaches become lasting improvements rather than temporary initiatives. Integrating these perspectives provides a roadmap for bridging the gap between theory, research, and bedside practice. It illustrates how hospital environments can evolve into cultures prioritizing immediate medical outcomes and the long-term wellbeing of infants and their families. Lessons from the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) serve as examples of successfully implemented changes in newborn care.

The Need for Change in Newborn Care

Preterm birth is a leading cause of infant morbidity and mortality, with approximately 380,000 infants born preterm in the United States annually. (3) Congenital heart disease (CHD) is the most common cause of infant mortality in the United States, affecting approximately 40,000 newborns each year. (4) Each year, approximately 500,000 infants receive care in Newborn Intensive Care (NICU) and Cardiac Intensive Care Units (CICU) across the United States. (5)

Infants with CHD and those born preterm are at increased risk of long-term cognitive, emotional, and social challenges due to a combination of medical fragility and environmental factors such as excessive noise, frequent painful interventions, disrupted sleep, and limited parental contact. (4, 6-10) Research indicates that these neurodevelopmental risks are not solely due to medical complexity but are exacerbated by the clinical environment itself. While the CICU and NICU are designed to provide life-saving treatments, they also introduce significant stressors for the infant and family that can negatively impact neurodevelopment and attachment. Medical stabilization is prioritized over sensorybased and family-integrated interventions. Medical complexities present additional challenges and require invasive procedures, prolonged sedation, extensive use of medical devices, and restriction from parental intimate contact. (11) Despite significant progress in newborn intensive care, individualized developmental care practices remain inconsistently applied across intensive care units (ICUs). (2)

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Evidence strongly supports the benefits of individualized, neuroprotective care and intimate parent-infant experiences in intensive care. (12) NIDCAP is a structured approach to individualized developmental care designed to support optimal neurodevelopment in high-risk infants and families. (13) The approach emphasizes minimizing noxious stimuli, supporting parental involvement, and tailoring medical care to align with each infant's behavior. Studies have demonstrated that NIDCAP improves neurodevelopmental outcomes, reduces stress responses, enhances brain development, and strengthens parent-infant bonding. (14–17)

The specific gaps in intensive care settings underscore the urgency of neuroprotective care for hospitalized infants. A change toward integrating individualized developmental care into all newborn intensive care is imperative. Understanding the theoretical perspectives and useful strategies for change will assist individuals, hospitals, and systems in addressing educational and practice issues that ultimately benefit infants and families.

Historical Resistance to Change in Newborn Care

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Change in healthcare is notoriously difficult due to institutional resistance, hierarchical decision-making, ingrained clinical routines, concerns for immediate medical stabilization, resource limitations and rigid workflows. Understanding these complexities is essential for implementing and sustaining meaningful change in newborn care. For example, not too long ago, it was widely believed that newborns did not experience pain, leading to major surgeries performed without anesthesia. (18-20) Despite accumulating evidence of physiological stress responses for newborns, pain management protocols were slow to gain acceptance. (21) Similarly, Kangaroo Care (skin-to-skin care), an intervention now known to improve thermoregulation, neurodevelopment, and parental bonding, faced early skepticism and delayed implementation. (22) Delayed cord clamping and surfactant therapy, which have been shown to enhance newborn outcomes, also met significant resistance before becoming standard practice. (23, 24) Major shifts, such as the acceptance of germ theory or the necessity of newborn pain management, only occurred after overwhelming evidence made resistance untenable. (25-27) These historical shifts illustrate that adopting best practices in newborn care demands persistent advocacy, continuous education, and the courage to challenge entrenched medical traditions. Only through unwavering commitment to evidence-based advancements can meaningful progress be achieved, ensuring that the best possible care becomes the standard rather than the exception.

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An Individual's Cognitive Barriers to Change

Clinicians frequently encounter cognitive barriers that make change difficult. Environmental constraints in high-tech CICUs and NICUs, including frequent alarms, bright lighting, and invasive procedures, can make developmental interventions challenging. The medical complexity of patients often necessitates extensive sedation, ventilation, and surgical interventions, further limiting opportunities to promote family involvement and apply neuroprotective strategies. Clinicians trained in efficiency and rigid protocols may struggle to reconcile their medically based priorities with the principles of individualized, neuroprotective care. This inner conflict can create hesitation, frustration, and resistance to implementing change. This phenomenon is better known as cognitive dissonance. (28) Dissonance occurs when an individual experiences psychological discomfort due to a conflict between their beliefs, values, or behaviors and new information or expectations that challenge them. For example, a nurse may experience cognitive dissonance when attempting to reconcile a structured care schedule by spending additional time facilitating skin-to-skin contact or feeding based on an infant's hunger cues. The resulting inner conflict can generate feelings of guilt or frustration, as the clinician recognizes that a strict focus on clinical tasks may unintentionally undermine the holistic, familyintegrated care that individualized developmental care promotes and that infants deserve. Dissonance is further compounded by the high-stakes nature of medical care, where the urgency of lifesaving interventions often takes precedence over developmental and relational aspects of care.

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Organizational and Systemic Barriers to Change

Institutional and systemic barriers further hinder the adoption of new practices. A significant obstacle to the widespread adoption of developmental care is the deeply entrenched culture of traditional medical models, with embedded structures, norms, and traditions that emphasize immediate medical stabilization over long-term developmental considerations. This creates resistance to change even when new evidence suggests improvements. Despite compelling evidence supporting individualized developmental care's long-term benefits, many hospitals prioritize acute interventions over preventive and developmental strategies.

Institutional theory explains how organizations often maintain traditional medical models due to institutional isomorphism, the tendency of institutions to conform to established norms rather than adopt innovative practices. (29, 30) To overcome barriers to change, structured management strategies must address institutional norms, prioritize education, encourage interdisciplinary

collaboration, and integrate evidence-based policies into routine practice.

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Variability in developmental care practices across ICUs further complicates change implementation. A collaborative learning assessment across six pediatric heart centers documented substantial variation in how developmental care was approached, with differences in pain management protocols, environmental modifications, cue-based care, and family engagement noted. (31) Some centers excelled in integrating family involvement through structured developmental rounds, while others lacked consistent parental participation and skin-to-skin contact guidelines. Similarly, NICUs have been noted to have varied protocols for skin-to-skin care, the inclusion of family in infant care practices, feeding based on hunger cues, and pain management following signs of stress. (1, 32–34)

The Diffusion of Innovations Theory explains how new ideas, practices, and technologies spread within and between organizations, highlighting why some institutions adopt evidencebased practices more readily than others. (35) The variability in developmental care practices across ICUs can be attributed to factors such as institutional readiness for change, leadership support, resource availability, and the influence of early adopters within a healthcare system. Hospitals that lack consistency in implementing neurodevelopmental care may be at different stages of the innovation adoption curve (innovators, early adopters, early majority, late majority, or laggards).

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Addressing organizational and systemic barriers is the first step; translating evidence into action requires structured change management approaches that facilitate lasting transformation in clinical practice. By applying established change theories, healthcare institutions can move beyond recognizing the need for developmental care and begin implementing strategies that drive sustainable improvements in newborn neurodevelopmental outcomes.

Theoretical Models for Effective Change

Understanding the theoretical perspectives and useful strategies for change will assist individuals, hospitals, and systems in addressing educational and practice issues that ultimately benefit infants and families. Several theories provide valuable insights into the common barriers to change and the structured approaches needed to promote, implement, and sustain effective systems change. These models highlight the importance of collaboration, education, and continuous evaluation in overcoming resistance to change and fostering sustainable transformation in healthcare settings.

As mentioned earlier, Cognitive Dissonance Theory (28) describes the psychological discomfort that arises when new evidence contradicts established beliefs and routines. Clinicians may experience this dissonance when reconciling rigid clinical protocols with individualized developmental care. This theory can inform hospital interventions by incorporating reflective practice sessions, where healthcare providers (HCP) openly discuss and reconcile conflicting priorities. Hospitals can help HCP navigate discomfort and align their clinical practice with best evidence-based standards by providing structured education, mentorship, and reinforcement strategies.

The Paradigm Shift Model suggests that resistance to change decreases when a new approach demonstrates effectiveness and is widely accepted and integrated as the standard of care within an institution. (36) In hospitals, this model can guide change by ensuring that new practices, such as developmental care protocols, are introduced and reinforced through leadership support, ongoing training, and incorporation into hospital policies. Hospitals can reduce resistance and facilitate widespread adoption by normalizing individualized, neuroprotective care within standard operating procedures.

Kotter's Eight-step Change Model (37) is a structured, leadershipdriven framework for guiding organizational transformation. It emphasizes the importance of establishing urgency, building a guiding coalition, developing and communicating a vision, and systematically embedding change within an organization's culture. This model is widely used in healthcare settings to facilitate largescale system improvements, policy shifts, and organizational restructuring. This model can be applied by establishing dedicated change leadership teams that drive initiatives, such as NIDCAP implementation, create urgency around developmental care improvements, establish a guiding coalition of champions, communicate a clear vision, and systematically implement and reinforce new care models.

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The Consolidated Framework for Implementation Research (CFIR) (38) provides a comprehensive, theory-informed approach to understanding factors that influence successful interventions in healthcare and other complex environments. Organized into five domains (intervention characteristics, outer setting, inner setting, characteristics of individuals, and implementation process), CFIR is an analytical tool to assess facilitators and barriers to implementation, ensuring evidence-based practices are effectively adopted and sustained. Hospitals can use CFIR to systematically evaluate existing barriers, develop targeted interventions, and measure outcomes to refine strategies over time. Within developmental care, this framework could assess the feasibility of skin-to-skin contact and sound reduction interventions, evaluate organizational culture and HCP readiness, and guide the structured adoption of evidence-based developmental care practices through stakeholder engagement, training, and continuous evaluation.

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Another useful change theory is the Diffusion of Innovations (35), which explains how new ideas, practices, or technologies spread within a social system over time. Innovations are thought to be influenced by factors such as relative advantage, compatibility, complexity, trialability, and observability. In a hospital setting, this theory can help guide the adoption of developmental care practices by identifying early adopters, sometimes called champions, among HCP, addressing barriers to change, and leveraging peer influence to promote widespread acceptance. In newborn care, clinical champions, often nurses, therapists, psychologists, researchers, and physicians who are well-versed in developmental care play a vital role in advocating for and normalizing evidence-based interventions. Hospitals can facilitate a gradual but sustained integration of developmental care into routine ICU practice by demonstrating and educating the benefits

of interventions such as skin-to-skin contact, individualized care plans, and sound reduction, and ensuring they align with existing workflows. Hospitals can use this theory by identifying and supporting robust, well-liked, early adopters to champion developmental care initiatives, facilitating peer-to-peer learning and creating platforms for knowledge-sharing that accelerate institutional adoption.

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Lewin's Change Management Model (39) is a three-stage framework that explains how organizations can successfully implement and sustain change. The model consists of Unfreeze, where the need for change is established by challenging existing practices and preparing HCP for a new approach; Change, where new behaviors, processes, or interventions are introduced and actively supported; and Re-freeze, where the changes become embedded into the organization's culture through reinforcement and policy integration. In a hospital setting, this model could guide the adoption of developmental care practices in the ICU. The Unfreeze stage might involve identifying outdated practices and educating HCP on the long-term benefits of skin-to-skin contact, sound reduction, and individualized care plans, while addressing potential resistance. During the Change phase, these practices are implemented through training programs, workflow adjustments, and pilot studies. Finally, the Refreeze stage ensures sustainability by integrating developmental care into hospital protocols, reinforcing compliance through continuous education, and monitoring outcomes to maintain long-term improvements in patient care.

The Theory of Planned Behavior (40) further reinforces that attitudes, subjective norms, and perceived control significantly influence the likelihood of adopting new practices. In the hospital, fostering a culture where interdisciplinary collaboration is valued ensures that all healthcare team members, including nurses, physicians, developmental specialists, parents, spiritual care providers, social workers, patients, families, and environmental support HCP, feel supported to implement best practices. Hospitals can apply this theory by fostering positive attitudes toward developmental care through education, reinforcing the expectation that all HCP members engage in best practices, and removing barriers that limit perceived control over implementing individualized care.

The Collaborative Learning Model (41) demonstrates how engaging multidisciplinary teams in peer evaluations and site visits allows institutions to learn from high-performing centers and rapidly adopt best practices. This model can be applied in hospitals by facilitating structured learning collaboratives, where teams from different units or hospitals share successful interventions, receive direct feedback on their implementation efforts, and refine strategies based on real-world experiences.

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These theories highlight that successful and sustainable change in hospital practice requires a structured, multi-faceted approach that combines strategic planning, leadership engagement, HCP support, and continuous evaluation. By applying evidence-based change models and addressing organizational and systemic barriers, hospitals can move from awareness to action, fostering an environment where developmental care becomes the standard. A structured approach for change ensures that every newborn receives the highest quality, developmentally appropriate care while embedding a lasting culture of excellence in newborn individualized developmental care.

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Bridging the Gap Between Theory Application, Research and Practice

One of the most persistent challenges in implementing developmental care frameworks is the gap between research and clinical practice. Several efforts to link research and practice are widely available through guidelines and position statements. There are many research-based guidelines for developmental care implementation in the NICU. (12, 42–44). For example, those established by the Vermont Oxford Network (45) and the Gravens Infant and Family Centered Developmental Care Standards Competencies and Best Practices (46) provide a specific framework for intensive care to guide practice. Additionally, guidelines from the American Heart Association (AHA) and the Cardiac Neurodevelopmental Outcome Collaborative (CNOC) support neurodevelopment in infants with CHD (47, 48) and provide a framework for improving consistency.

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Regardless of the availability of these evidence-based standards and guidelines, widespread implementation remains a challenge. Research has demonstrated that translating evidence into practice requires dedicated knowledge brokers, individuals or teams who facilitate communication between researchers and clinicians to ensure that findings are adapted into usable clinical workflow. (49) These knowledge brokers play a crucial role in integrating developmental care into daily practice by interpreting research in a way that resonates with frontline HCP. This approach can be operationalized by establishing a multidisciplinary developmental care committee to oversee the integration of best practices. Additionally, developmental care rounds can serve as a platform for collaboration, allowing teams to assess patient needs, implement individualized neuroprotective strategies, and ensure ongoing interdisciplinary communication that supports patient outcomes and HCP engagement. (50)

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Quality Improvement as the Key to Bridging Gaps in Developmental Care Implementation

Quality Improvement (QI) science is a structured, data-driven approach to systematically improving healthcare processes, patient outcomes, and efficiency through continuous assessment and iterative changes. It is a powerful tool for integrating evidencebased developmental care practices like NIDCAP into routine clinical workflows. (12, 51) Institutional resistance, competing clinical priorities, and logistical challenges often impede progress. Using QI science provides structured methodologies to bridge these gaps and offers a roadmap for sustainable change.

As discussed in the section on change theory, successful and sustainable implementation of new practices requires strategic planning, leadership engagement, HCP empowerment, and continuous evaluation. QI science encompasses all these components and offers a systematic framework that aligns with the key principles of change management in the hospital setting. QI methodologies provide the structure necessary to move developmental care from theory to practice.

For developmental care to be effectively embedded within QI initiatives, hospitals must define measurable outcomes that assess its impact on patient care. Key Performance Indicators (KPIs) are quantitative metrics used to measure performance that can serve as critical benchmarks for evaluating the effectiveness of NIDCAP-driven and other neuroprotective interventions. (52) Auditing bedside developmental care practices can provide data to refine interventions and track progress over time. Other KPIs include tracking behavioral or stress responses to caregiving interventions and monitoring length of hospitalization to provide insight into the efficiency and effectiveness of developmental care interventions. Measures of the frequency and depth of parental engagement, including skin-to-skin contact and shared decisionmaking, can be recorded as KPIs.

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The Plan-Do-Study-Act (PDSA) cycle, a widely recognized QI approach, has been instrumental in incrementally implementing and sustaining developmental care models within hospitals. (53) The PDSA cycle is a QI methodology that involves planning a change, doing a small-scale test, studying the results, and acting on the findings to refine and expand implementation for sustainable improvement. This iterative process aligns with change theories by emphasizing the need for structured planning, small-scale testing, and continuous reassessment to facilitate long-term adoption. By incorporating leadership buy-in and interdisciplinary collaboration, core tenets of change management theories, hospitals can use the PDSA cycle to drive measurable improvements in developmental care.

QI ensures that developmental care principles become deeply embedded within hospital workflows, reinforcing a

culture of continuous learning and adaptation, an essential component of effective and sustainable change. To advance the implementation of developmental care in the ICU, hospitals have increasingly relied on QI-driven initiatives to standardize neuroprotective interventions. A key focus of these efforts has been improving environmental conditions, optimizing infant positioning, and increasing family involvement to promote positive neurodevelopmental outcomes.

While the literature contains many studies, Table 1 notes examples of using QI to improve developmental care efforts.

"QI ensures that developmental care principles become deeply embedded within hospital workflows, reinforcing a culture of continuous learning and adaptation, an essential component of effective and sustainable change."

Implementing developmental care in the NICU and CICU presents unique challenges due to the complexity of medical care, reliance on invasive procedures, and frequent need for prolonged sedation and ventilation. However, applying QI methodologies enables the successful integration of neuroprotective interventions. QI studies emphasize that structured, theory-driven approaches that align leadership, staff engagement, policy reinforcement, and interdisciplinary collaboration are essential for sustainable change. While developmental care challenges vary between NICU and CICU settings, structured interventions remain critical for success. Early adoption, leadership support, standardized education, and evidence-based care protocols have been key drivers in advancing developmental care models. Change management theories guide these transformations, ultimately fostering sustainable, institutionalized models that enhance neurodevelopmental outcomes and prioritize long-term infant well-being.

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Future Directions for Quality Improvement in Developmental Care

Building on the success of existing QI initiatives, future efforts should focus on expanding education, refining data collection, enhancing leadership advocacy, and ensuring policy integration to drive long-term, sustainable improvements in developmental care. As change management theories suggest, creating a structured, multidisciplinary approach with ongoing evaluation and reinforcement is essential to transforming hospital culture and ensuring that developmental care becomes the standard rather than an optional practice.

Expanding education and training by embedding developmental care principles into mandatory nursing, physician, and interdisciplinary training programs is a key priority. This could include integrating neuroprotective strategies and programs such as NIDCAP into medical school curricula, residency training, and training for physical and occupational therapists in nursing school. It is also essential as continuing education courses for NICU and CICU HCP. Leveraging e-learning platforms, hands-on workshops, and interdisciplinary simulation-based training will help reinforce evidence-based neuroprotective practices while improving HCP confidence and adherence. Scaling successful QI strategies across additional aspects of developmental care will be critical. Simulation-based training programs should be expanded beyond infant holding to include infant-led feeding protocols, optimizing sleep environments, parental education, and facilitating ICU-tohome transitions.

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Data-driven decision-making must also be enhanced by developing advanced analytics for care evaluation. This includes leveraging electronic medical records (EMRs) to track developmental interventions, patient progress, and long-term neurodevelopmental outcomes. However, a significant challenge is that developmental care efforts are often not systematically recorded in EMRs, making auditing and real-time data collection for quality improvement time-consuming and resource intensive. Standardizing documentation of individualized care strategies, such as skin-to-skin contact, sleep-promoting interventions, and infant-led feeding, is essential to facilitate benchmarking across institutions and ensure these interventions are recognized as equally important as other medical variables in patient care.

Institutions must establish executive-level support for developmental care initiatives to ensure continued advocacy and leadership engagement. Hospital administrators and policymakers should be involved in allocating resources, endorsing QI initiatives, and integrating developmental care metrics into hospital-wide performance evaluations. Interdisciplinary leadership committees dedicated to neurodevelopmental care can provide structured oversight, ensuring that ongoing HCP education, unit-wide training, and performance tracking remain institutional priorities.

A significant challenge in healthcare QI is maintaining momentum beyond initial change efforts. Hospitals should embed developmental care into institutional policies and accreditation



Table 1: Examples of Implementation of Developmental Care (DC) Through QI						
Author	Population	Goal	Interventions	Outcomes	Change Theory	
Moody et al. (2017) (54)	NICU, Infants < 32 weeks gestation and those with higher medical complexity	Evaluate NIDCAP's impact on length of hospital stay and standardize bedside audits.	Early initiation of NIDCAP; em- bedding NIDCAP into routine practice; measurable benefit analysis; reinforcement of insti- tutional commitment; conduct- ing developmental audits over five years; structured bedside rounds; interdisciplinary educa- tion sessions	Infants enrolled in NIDCAP earlier were discharged sooner and at a younger age; improved adherence to best practices; higher medical complexity was less likely to receive consis- tent DC.	Change manage- ment; institutional buy-in; QI; standard- ized care protocols.	
Ballweg (2001) (55)	NICU, infants, families, and HCP	Enhance HCP ad- herence to NIDCAP best practices.	Implement structured edu- cational programs, bedside coaching, real-time feedback mechanisms, leadership engagement to reinforce new practices.	Improved infant physi- ological stability; increased parental involvement; ad- herence to evidence-based guidelines.	Change theory; education; leader- ship engagement; structured reinforce- ment.	
Ludwig et al. (2008) (56)	NICU, infants, families, and HCP	Improve infant growth, reduce stress, and enhance family engagement	Implementation of standard- ized neurodevelopmental strat- egies; culture of DC; fostering interdisciplinary teamwork; securing leadership support to sustain changes.	Observed improvements in infant growth; reduced stress responses; enhanced family engagement; adher- ence to DC practices.	Change manage- ment; interdisci- plinary teamwork; leadership support.	
Butler et al. (2025) (57, 58)	CICU, infants, families, and HCP	Support safe infant holding following NIDCAP recom- mendations	Development of holding guidelines based on NIDCAP; simulation-based training; multidisciplinary team; patient- specific risk stratification; leadership support; integra- tion of structured educational programs into professional development; champions to normalize practices; train the trainer approach to education.	Normalization of safe practices; improved HCP confidence; adherence to DC.	Change manage- ment; leadership advocacy; develop- mental champions.	
Butler et al. (2024) (51)	CICU infants, families, and HCP	Improve adher- ence to DC guide- lines and NIDCAP model of care	Initiation of NIDCAP; Multi- disciplinary approach; strong leadership support; creation of standardized DC guidelines; interdisciplinary education sessions; structured bedside rounds; ongoing audits of care to review and enhance DC.	Improvements in light- ing and sound regulation, infant positioning, caregiv- ing facilitation, and family participation; Infants with increased medical com- plexity were less likely to receive NIDCAP-consistent care.	Quality improve- ment; targeted interventions for high-risk infants.	

standards to sustain long-term improvements. This can be achieved by aligning developmental care initiatives with national QI collaboratives, state mandates, and regulatory organizations. Policies incentivizing evidence-based developmental care practices can drive widespread adoption and ensure that familycentered, neuroprotective care is not just a recommendation but a mandated standard.

needs, including opportunities for mobility, sensory engagement, and age-appropriate interaction, which are often overlooked in intensive care settings. Establishing QI collaboratives can facilitate shared learning, dissemination of best practices, and greater standardization of developmental care interventions for children of all ages.

Developmental care efforts must extend beyond the neonatal period to support older infants and toddlers frequently admitted for long-term stays. These patients have unique developmental

Conclusion

Despite strong evidence supporting individualized developmental care, integration into hospital practice remains inconsistent.

"Standardizing documentation of individualized care strategies, such as skin-to-skin contact, sleep-promoting interventions, and infant-led feeding, is essential to facilitate benchmarking across institutions and ensure these interventions are recognized as equally important as other medical variables in patient care."

Gaps in intensive care settings underscore the urgent need for structured, neuroprotective interventions prioritizing survival and long-term developmental outcomes. Addressing organizational and systemic barriers through structured change management strategies and QI methodologies can transform developmental care from an optional enhancement into a fundamental standard of care.

"The future of newborn and cardiac intensive care must embrace a paradigm shift prioritizing thriving over survival. The time for action is now. By advancing education, fostering interdisciplinary collaboration, and integrating neurodevelopmental care into hospitalwide initiatives, healthcare systems can transform the standard of care for the most vulnerable infants. Every newborn deserves an environment that supports not only survival but lifelong well-being."

Applying change management theories and evidence-based frameworks can help healthcare institutions implement and sustain developmental care practices, even in medically complex environments. Training healthcare providers in strategies like those included in the NIDCAP approach enhances implementation and adherence to best practices. Additionally, embedding developmental care into policy frameworks, performance metrics, and regulatory standards will ensure widespread adoption.

The future of newborn and cardiac intensive care must embrace a paradigm shift prioritizing thriving over survival. The time for action is now. By advancing education, fostering interdisciplinary collaboration, and integrating neurodevelopmental care into hospital-wide initiatives, healthcare systems can transform the standard of care for the most vulnerable infants. Every newborn deserves an environment that supports not only survival but lifelong well-being.

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Respiratory Viruses:



What parents need to know this RSV and flu season



Like COVID-19, RSV (Respiratory Syncytial Virus) and flu affect the lungs and can cause serious breathing problems for children and babies. Talk to your family about the risks.



Certain diagnoses can make children and babies more vulnerable for serious complications from respiratory viruses - including prematurity, chronic lung disease, and heart conditions.



You can limit the spread of viruses by wearing a mask, washing your hands with soap & water, using an alcohol-based hand sanitizer, and getting vaccinated.



The fewer germs your baby is exposed to, the less likely they are to get sick. Let people know you need their help to stay well. Limit visitors. Avoid crowds. Stay away from sick people.



Immunizations save lives. Stay up-to-date with your family's flu vaccinations and COVID-19 boosters. This helps our community stay safe by stopping the spread of <u>deadly viruses</u>.



Babies older than 6 months can get a flu shot and COVID-19 vaccinations. There is no vaccine for RSV, but monthly antibody shots during RSV season can help protect them.





Respiratory Syncytial Virus DID YOU KNOW?



The Gap Baby: An RSV Story







Kids under age 5 experience

> 500,000 emergency room visits for RSV each year

57,000 hospitalizations for RSV each year

Notified National Coalition for Infant Health

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Neonatology Today's now has a digital presence. The site is operational now and defines the future look of our digital web presence. By clicking on this https://www.neonatologytoday.org/web/., researchers can download individual manuscripts both in digital format and as part of the original PDF (print journal). While the PDF version of Neonatology Today will continue in its present form, we envision that the entire website will be migrated to this format in the next several months. We encourage you to take a look, "kick the wheels," and let us know where we still need to improve... We are working towards making the website more functional for subscribers, reviewers, authors and anyone else. Although we have not yet applied for inclusion in the National Library of Medicine Database (Pub-Med), this new format meets several of the important metrics for this ultimate goal. As of December, 2020, NT has its own account with Cross-Ref and will assign DOI to all published material.

As we indicated last month, we look forward to a number of new features as well.

- An online submission portal: Submitting a manuscript online will be easier than before. Rather than submitting by email, we will have a devoted online submission portal that will have the ability to handle any size manuscript and any number of graphics and other support files. We will have an online tracking system that will make it easier to track manuscripts in terms of where they are in the review process.
- 2. Reviewers will be able to review the manuscript online. This portal will shorten the time from receipt of review to getting feedback to the submitting authors.
- 3. An archive search will be available for journals older than 2012.
- 4. A new section called news and views will enable the submission of commentary on publications from other journals or news sources. We anticipate that this will be available as soon as the site completes the beta phase
- 5. Sponsors will be able to sign up directly on the website and submit content for both the digital and PDF issues of Neonatology Today.

Neonatology Today will continue to promote our Academic True Open Model (ATOM), never a charge to publish and never a charge to subscribe.

If there are any questions about the new website, please email Dr. Chou directly at:

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╞ Hemolytic disease of the fetus & newborn is a rare blood disorder. When the mother's and infant's the baby's red blood cells. HDFN can lead to: Severe anemia Jaundice Fetal or infant death To reduce their baby's risk pregnant mothers should talk to their health care provider to: Identify potential blood incompatibilities Monitor the baby Treat the condition if it occurs NCTH National Coalition for Infant Health LEARN MORE >

Which Infants are More Vulnerable to Respiratory Syncytial Virus?

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

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

*Source: Respirator Syncytial Virus and African Americans

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



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

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

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SHARED DECISION-MAKING

What is the best for this unique dyad?

S EEK PARTICIPATION ELP EXPLORE OPTIONS A SSESS PREFERENCES R EACH A DECISION

E VALUATE THE DECISION



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- Both parents FEAR and providers
- GRIEF are confronting
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We need to understand more about outcomes for mothers and infants exposed to COVID-19, with special attention to:

MENTAL HEALTH



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A Multidisciplinary Approach to Perinatal Cardiology Volume 1

Edited by P. Syamasundar Rao and Dharmapuri Vidyasagar



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 <u>website</u>, where you can also access a free <u>30-page sample</u>.



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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 PPROM Foundation, Denver, CO.



PROVIDING INTRAPARTUM SUPPORT CEUs offered: 1

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

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



PROVIDING POSTPARTUM SUPPORT CEUs offered: 1

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

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



SUPPORTING STAFF AS THEY SUPPORT FAMILIES CEUs offered: 1

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

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

Cost

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

Contact help@myperinatalnetwork.org to learn more.

Faculty

Linda Baker, PsyD

Psychologist at Unstuck Therapy, LLC, Denver, CO.

Jerasimos (Jerry) Ballas, MD, MPH

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Tracy Pella, MA

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

Erin Thatcher, BA

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

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Means balancing the risks of...

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- SEPARATION AND TRAUMA



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SHARFD **DECISION-MAKING**

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





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Both parents and providers are confronting significant...

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- GRIEF
- UNCERTAINTY

LONGITUDINAL DATA

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

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 POSTPARTUM CARE DELIVERY



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Alliance for Patient Access: Fourteen States Set to "Transform Maternal Health"

Josie Cooper

The Alliance for Patient Access (allianceforpatientaccess.org), founded in 2006, is a national network of physicians dedicated to ensuring patient access to approved therapies and appropriate clinical care. AfPA accomplishes this mission by recruiting, training and mobilizing policy-minded physicians to be effective advocates for patient access. AfPA is organized as a non-profit 501(c)(4) corporation and headed by an independent board of directors. Its physician leadership is supported by policy advocacy management and public affairs consultants. In 2012, AfPA established the Institute for Patient Access (IfPA), a related 501(c)(3) non-profit corporation. In keeping with its mission to promote a better understanding of the benefits of the physicianpatient relationship in the provision of quality healthcare, IfPA sponsors policy research and educational programming.





"Funding for the Transforming Maternal Health model is being provided to states via their Medicaid and Children's Health Insurance Programs, often called the CHIP program. (1) Most state Medicaid programs cover low-income pregnant women and young children, while CHIP can provide coverage for children through age 18."

Federal officials announced that 14 states and Washington, DC, will share \$17 million to implement a new maternal health model.

A New Model of Care

Funding for the <u>Transforming Maternal Health</u> model is being provided to states via their Medicaid and Children's Health Insurance Programs, often called the CHIP program. (1) Most state Medicaid programs cover low-income pregnant women and young children, while CHIP can provide coverage for children through age 18.

"Experts are seeking methods to improve outcomes while reducing health care costs – a tall order considering the U.S. spends more per capita on maternal health than any other country yet still has a maternal mortality rate that's more than double other high-income countries. (2)"

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Laying the Foundation for Success

During the first three years of the pre-implementation model, states will receive technical support to establish access, infrastructure, and workforce capacity.

"Building a network of midwives, doulas, and perinatal community health workers is one example. (3) Broader access to these providers has been shown to reduce cesarian sections for low-risk pregnancies and shorten labor time, for example. (4) Moreover, continuing the care relationship beyond birth can result in lower rates of postpartum anxiety and depression."

Building a network of <u>midwives</u>, doulas, and perinatal community health workers is one example. (3) Broader access to these providers has been shown to reduce <u>cesarian sections</u> for low-risk pregnancies and shorten labor time, for example. (4) Moreover, continuing the care relationship beyond birth can result in lower rates of postpartum anxiety and depression.

Implementing Patient-Centered Care

During the following seven years, states will execute their "wholeperson approach to pregnancy, childbirth, and postpartum care."



sitioning-fee-for-service-value-based-reimbursements

The goal is for each woman to have a customized care plan that addresses her physical and mental health and any social needs she may have during pregnancy. This support could include a range of services, from counseling for a substance use disorder to remote monitoring of hypertension.

"By the program's fifth year, states are expected to transition from fee-forservice models, which are historically transactional, to value-based payment systems, which are more oriented toward encouraging holistic approaches to improving patient outcomes. This shift aligns with CMS' broader goals for healthcare delivery and encourages closer attention to patient-centric and culturally sensitive care. (5)"

Shifting to Value-Based Care

By the program's fifth year, states are expected to transition from fee-for-service models, which are historically transactional, to value-based payment systems, which are more oriented toward encouraging holistic approaches to improving patient outcomes. This shift aligns with CMS' <u>broader goals</u> for healthcare delivery and encourages closer attention to patient-centric and culturally sensitive care. (5)

Underserved populations facing higher risks of maternal complications will be prioritized, helping to close the gap between outcomes for these mothers and the broader average. The models will target these disparities toward more equitable maternal care.

Policymakers and stakeholders alike will keep a close eye on implementing this model and its transformative approach to addressing systemic gaps in maternal care.

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- <u>https://www.commonwealthfund.org/publications/issue-briefs/2024/jun/insights-us-maternal-mortality-crisis-international-comparison#:~:text=ln%202022%2C%20there%20were%2022,deaths%20per%20100%2C000%20live%20births.</u>
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Disclosure: Josie Cooper is the Executive Director of the Alliance for Patient Access. This article was also published at healthpolicytoday.org.





Help Our Youth Share Their Story

The International Children's Advisory Network. Inc., (ICAN) is a worldwide network of children's advisory groups, known as Kids Impacting Disease Through Science (KIDS) and Young Persons Advisory Groups (YPAGS). These dedicated youth member groups work in unison around the world to provide a voice for children and families in medicine, research, and innovation. Every year ICAN hosts a summit that brings these groups together in shared experience and camaraderie. ICAN is a tax exempt organization as described in Section 501(cl3 of the Internal Revenue Code.

We want as many children to come to the summitt as possible. However, attending the Summit is not always possible for our families who often experience financial hardships. So iCAN pays for lodging, most food, and a transportation stipend in addition to summit activities. As more youth join iCAN, we need your help more than ever! Your tax-deductible donation of \$1,000 will help bring a child to the Summit, to make it possible for that child to share their voice, and to interact with medical professionals and other kids like them. We will acknowledge you as an individual donor or you may dedicate the donation in honor of a loved one, as you wish.



Immunizing Yourself Against COVID-19

COVID-19 vaccines have been shown to:

- Lessen the severity of symptoms¹
- Reduce risk of mortality²
- Reduce disease transmission³
 - Make communities healthier and safer⁴



COVID-19 vaccines are available for children, adolescents and adults. There are 3 types to choose from.



mRNA VACCINES

New to market, but research has been ongoing since the 1990s.



Instruct cells to make COVID-like proteins that trigger the immune system to fight the virus.



PROTEIN SUBUNIT VACCINES

Used for three decades against the flu, whooping cough and hepatitis B.

••••

Deliver harmless versions of the COVID protein that train the immune system to fight the virus.

VECTOR VACCINES

Used for decades against chickenpox, malaria and tuberculosis.

••••

Use a modified virus, such as a common cold, to teach the body to fight off COVID.

COVID vaccines are recommended for everyone ages 6 months and older, and boosters for everyone ages 5 years and older, if eligible.⁵

Safe and Sound

COVID vaccines have been:



Thoroughly tested

through multi-phase trials with tens of thousands of participants⁶



Proven safe and effective for adults as well as children⁷

Vetted and approved by the US FDA and EMA and endorsed by the WHO⁸⁻¹⁰

- https://www.mayoclinic.org/diseases-conditions/coronavirus/symptomscauses/syc-20479963
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- 6. https://doh.wa.gov/emergencies/covid-19/vaccine-information/safety-and-effectiveness

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Vaccines are available at your:



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Neighborhood pharmacy



https://doh.wa.gov/emergencies/covid-19/vaccine-information/safety-and-

- https://www.fda.gov/emergency-preparedness-and-response/coronavirusdisease-2019-covid-19/covid-19-vaccines
- https://www.ema.europa.eu/en/human-regulatory/overview/public-healththreats/coronavirus-disease-covid-19/treatments-vaccines/vaccines-covid-19/ covid-19-vaccines-authorised
- http://www.bccdc.ca/Health-Info-Site/Documents/COVID-19_vaccine/WHO-EUA-qualified-covid-vaccines.pdf



Talk to your **health care provider** or **pharmacist** about which vaccine is right for you.






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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

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iCAN in Action: iCAN's February Highlights: ATE Recap, Features on Webinars, iCAN Challenge of 10, and Our 2025 Summit

Sabina Schmidt Goldstein-Becerra



Get involved today and Join the iCAN **Parent Council!**

"iCAN, the International Children's Advisory Network, is the premier global pediatric platform empowering the patient voice in healthcare, driven by youth for vouth. As a worldwide consortium of 40 KIDS' (Kids Impacting Disease through Science) advisory groups spanning four continents, including one virtual chapter, iCAN's dedicated youth member groups work in unison around the world to provide a voice for children and families in medicine, research, science, and innovation, to foster greater global understanding about the importance of the pediatric patient and caregiver voice in healthcare, clinical trials, and research."

iCAN, the International Children's Advisory Network, is the premier global pediatric platform empowering the patient voice in healthcare, driven by youth for youth. As a worldwide consortium of 40 KIDS' (Kids Impacting Disease through Science) advisory groups spanning four continents, including one virtual chapter, iCAN's dedicated youth member groups work in unison around the world to provide a voice for children and families in medicine, research, science, and innovation, to foster greater global understanding about the importance of the pediatric patient and caregiver voice in healthcare, clinical trials, and research. On average, our youth are ages 8-18 years old, most of whom are living with chronic, rare, and complicated diagnoses, though a few of our youth have no medical diagnoses or medical conditions. iCAN values and understands that all patients, even the youngest, often have ideas that can help improve their healthcare experiences. To foster diversity, all children from anywhere may freely join iCAN. iCAN also supports young adults and the voice of parents, many of whom have young people who cannot share their voices. We continue to be a collaboration between the American Academy of Pediatrics (AAP) Section on Advances in Therapeutics and Technology (SOATT), Georgia Institute of Technology (the GT Pediatric Innovation Network), local AAP Chapters, children's hospitals, local academia, and other non-profits.

"We aim to get our youth where they need to be to have their voices heard. Our amazing youth make a difference in pediatric healthcare through interactions with industry, by presenting original research at conferences, by innovating new solutions, by empowering the pediatric patient voice in healthcare worldwide, and by telling their stories at conferences and to organizations like the FDA, iACT, NIH, NORD, CDC, and AAP."

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healthcare outcomes for all pediatric patients.

"February's *Ask the Experts*- The Power of Ethical Research: A Conversation with Stacy"

Thanks to our incredible guest, Stacy, this month's Ask the Experts session was an inspiring and eye-opening discussion. Her expertise in research ethics and pediatric clinical trials helped our young participants understand the critical role of Institutional Review Boards (IRBs) and why ethical oversight is essential in ensuring patient safety.

Stacy is a certified IRB Professional specializing in pediatric clinical trials. Her deep knowledge of regulatory frameworks, ethical guidelines, and research protocols has supported

Connecticut Children's commitment to high-quality pediatric care. However, beyond her professional expertise, her connection to clinical research made this session so powerful.

Stacy shared the deeply personal story of her sister's journey after being diagnosed with a tumor at a young age. She spoke about the difficult choices her family faced and how that experience shaped her lifelong commitment to ensuring that children in clinical trials are protected, fully informed, and empowered to make decisions about their participation. Her story served as a potent reminder that behind every clinical study are real children and families navigating life-changing decisions—and that ethical research is not just a regulatory requirement but a responsibility to those who entrust science



with their care.

One of iCAN's members, Carl from KIDS Connecticut, added to the conversation by sharing his first-hand experience with IRBreviewed research. Carl had participated in a clinical trial but quickly realized he was uncomfortable with the amount of blood being taken. Learning that he had the right to withdraw at any time was a defining moment for him, reinforcing the importance of ensuring that young participants truly understand their rights in research.

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However, Carl's role in research goes far beyond being a participant. He has actively shaped clinical trial protocols by working alongside researchers and IRB professionals to review study designs and improve patient-facing materials. Through his work with iCAN, Connecticut Children's IRB, and Dr. Smith, Carl has helped make research studies more ethical, transparent, and patient-centric. His contributions—including reviewing advertisements and informed consent documents—ensure that research is not only scientifically rigorous but also considerate of the experiences and well-being of young patients.

Carl's leadership embodies iCAN's mission: to elevate the voices of young people in research and healthcare. At iCAN, we believe that kids and families should be active partners in shaping the future of medicine—not just as study subjects but as advisors, innovators, and changemakers. Stacy's session reinforced the importance of giving young people a seat at the table, whether in reviewing clinical trial materials, improving the patient experience, or advocating for ethical research practices.

Beyond research ethics, Stacy encouraged the kids to stay curious, ask questions, and explore different career paths in science, medicine, and research. She shared invaluable advice about shadowing professionals, gaining hands-on experience, finding mentors, and opening up new possibilities for our young leaders. Her insights helped them see the many different ways they can contribute to the future of pediatric healthcare.

This session was a powerful reminder that ethical research is not just about policies and regulations but about people. It is about ensuring every child participating in a study feels informed, respected, and safe. It is about creating a future where young voices are heard and valued.

We are incredibly grateful to Stacy for her time, wisdom, and generosity. Her passion for ethical research left a lasting impact, and we look forward to collaborating again!

Want to be part of our next Ask the Experts session?

Please reach out to sabina@icanresearch.org.

Mark your calendars- iCAN invites you to another installment of Ask the Experts on March 15!

<u>"Speak with Impact: Expert Communication Strategies with Michael Piperno"</u>



We are excited to introduce Michael Piperno for our upcoming *Ask the Experts* session on March 15 at 8 AM PST | 11 AM EST | 5 PM CET.

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

Michael Piperno is a communication coach who helps people work together better. He teaches them to speak clearly, give effective presentations, and build strong relationships. With 30 years of experience as an actor, teacher, writer, and senior executive, Michael knows how to help people improve their communication skills.

"Michael specializes in helping mid- to senior-level professionals become better leaders and achieve their goals. He shows them how to share their ideas, understand others, listen carefully, and inspire those around them. He also helps teams prepare for important meetings and solve communication issues."

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Michael holds a Master of Science in strategic communication from Purdue University and a bachelor's degree in communication studies and speech and theatre arts from Montclair State University.

Secure your spot by registering here today!

iCAN KID and Parent Spotlight

<u>Michael and Michelle's Journey: Navigating Pediatric Gene</u> <u>Therapy Trials</u>



Life Sciences, Drug Discovery & Development, Cell and Gene Therapy

Watch the recording here.

Monday, February 24, 2025

Ground-breaking scientific advances in cell and gene therapy (CGT) have transformed the landscape of treatment for rare diseases in recent decades. With an increasing number of CGTbased clinical trials, the potential to offer curative treatments for children and their families living with rare, life-altering conditions

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has never been more promising.

Michelle Burgess and her son, Michael, both active members of KIDS Lurie, recently shared their experiences at a webinar focused on the latest developments in CGT and its impact on pediatric patients. This webinar provided an invaluable opportunity to learn from leading experts, gain insights into regulatory requirements, and understand the evolving landscape of CGT for pediatric rare diseases. Michelle and Michael's contributions helped shape a meaningful discussion on improving outcomes through early intervention and innovative gene-editing approaches.

Michael, a teenager living with sickle cell disease, and Michelle, a dedicated parent committed to patient-centric care, provided a powerful perspective on the challenges and hopes surrounding gene editing as a potential cure. With over 8,000 known rare diseases and limited treatment options, the urgency for innovative therapies is paramount. Approximately 80 percent of rare diseases are monogenic, many of which manifest in childhood, making early intervention through CGT a promising approach to improving patient outcomes. Michelle and Michael discussed the importance of treating children at the earliest stages and the ethical considerations involved in first-in-human trials for young pediatric patients and neonates.

"Approximately 80 percent of rare diseases are monogenic, many of which manifest in childhood, making early intervention through CGT a promising approach to improving patient outcomes." When doctors first discussed curative therapies, including gene editing, Michelle embarked on a journey to learn as much as possible. From May to October, she engaged in extensive discussions with highly knowledgeable, thorough, honest, and transparent doctors. Understanding the day-to-day realities of undergoing gene editing therapy was crucial, as it had significant implications for their family. She highlighted the impact on employment, caring for other children, and navigating FMLA to support Michael's treatment. Throughout the process, she found the medical team to be incredibly supportive.

"From May to October, she engaged in extensive discussions with highly knowledgeable, thorough, honest, and transparent doctors. Understanding the day-to-day realities of undergoing gene editing therapy was crucial, as it had significant implications for their family. She highlighted the impact on employment, caring for other children, and navigating FMLA to support Michael's treatment. Throughout the process, she found the medical team to be incredibly supportive."

Michael had completed all his preliminary testing and was ready to begin treatment when another child was selected for the available spot. Although initially disappointed, he remained grateful for the opportunity to participate in gene editing and potentially be cured. However, the timeline for his treatment was delayed due to insurance approvals, which meant he had not yet undergone cell harvesting. The prolonged process is now affecting his senior year, requiring him to transition to remote learning.

Michelle emphasized the challenges of making quick decisions about participating in clinical trials, particularly given the extensive informed consent process. She suggested that companies create real-life videos featuring past participants to illustrate what day-to-day life looks like during the trial, the emotional burden, and available resources. Families need support, follow-up opportunities, and adequate time to process information, as these decisions are life-changing. While the commitment to a trial can be exhaustive for doctors, families require clear, compassionate guidance.

One of the most crucial aspects of informed decision-making is understanding the risks. Michelle and Michael were informed that participation in the clinical trial would require a 15-year commitment. Michelle stressed the importance of receiving information in plain, simple language, particularly regarding potential risks. She cited the case of two individuals who developed leukemia five years post-trial and the necessity of explaining what leukemia is and its potential consequences. In contrast, the insurance-approved gene editing pathway had zero reported cases of participants developing leukemia. Michael had to weigh the honesty of the risks against his willingness to accept potential complications. Another significant consideration was the potential impact on his future ability to have children, which was clearly explained.

Michael shared that he just wants to move forward with the process and get it over with, as the uncertainty has been difficult. Michelle reinforced that families need comprehensive support and guidance throughout the process, as these decisions carry lifelong implications.

By sharing their journey, Michael and Michelle shed light on the realities of navigating pediatric gene therapy trials. Their experiences highlight families' challenges in making life-altering decisions, the need for accessible and transparent information, and the importance of ensuring that young patients have a voice in their care. Through their courage and openness, they are helping to bring iCAN's mission to the forefront-ensuring that the perspectives of children and families are heard, valued, and integrated into the future of pediatric treatment.

iCAN KIDS Walter Payton: 2025 Challenge of 10 - Giving Back & Leading the Future

Last year, we launched the iCAN Challenge of 10 to celebrate a decade of making a difference in pediatric healthcare, innovation, and research. Now, in our 11th year, we are excited to continue this tradition, encouraging chapters and members to give back, raise awareness, and take action-using the power of 10!

What is the iCAN Challenge of 10?

The iCAN Challenge of 10 is an initiative where iCAN members complete acts of service or engagement in denominations of 10-whether it's donating 10 items, volunteering 10 hours, raising \$10 per person, or performing 10 random acts of kindness. Each chapter or individual can tailor their challenge to create a meaningful impact.

This year, our iCAN KIDS Chapter at Walter Payton College Preparatory in Chicago has chosen to donate 10 care packages to young patients at Lurie Children's Hospital and families staying at The Ronald McDonald House.

Their 2025 Challenge: Care Packages for Pediatric Patients

Each care package will include:

1 iCAN Youth Council Coloring for Change coloring book (with a personalized note from KIDS Walter Payton)

1 decorated letter of encouragement or affirmation for pediatric patients and their families

- 1 book for comfort and inspiration
- 1 stuffed animal to provide warmth and companionship
- 1 blanket for a sense of home and security
- 1 backpack to hold all the thoughtful items

Their members are working together to craft, decorate, and secure in-kind donations to make these care packages extra special!

To support their iCAN Challenge of 10, click here: https://gofund. me/df3e9a50





Amplifying Youth Voices: Abby Clark Represents iCAN at the 2025 US HAEA Rare Disease Forum

Click Here to Watch

"Earlier this month, Abby Clark, iCAN's Director of Operations, spoke on the "Amplifying Youth Voices" panel at the 2025 US Hereditary Angioedema Association (HAEA) Rare Disease Forum. This annual event brings together representatives from leading healthcare non-profits to drive meaningful conversations about the future of rare disease advocacy and youth engagement."

Earlier this month, Abby Clark, iCAN's Director of Operations, spoke on the "Amplifying Youth Voices" panel at the 2025 US Hereditary Angioedema Association (HAEA) Rare Disease Forum. This annual event brings together representatives from leading healthcare non-profits to drive meaningful conversations about the future of rare disease advocacy and youth engagement.

Abby joined a distinguished panel alongside Kepler Jeudy (Program Director of Next Step) and MaryAnn Emerick (Manager of Youth and Community Services at Huntington's Disease Society of America) to discuss strategies for developing impactful programming for youth, fostering community engagement and ensuring that the core mission—the "why" behind advocacy remains at the forefront of every initiative. A key message that resonated deeply throughout the discussion was iCAN's unwavering commitment to being kid-driven. Abby spoke about how iCAN continuously meets the needs of young patients, using them as our North Star in everything we do. Our youth voice is not just included—it is leveraged to shape all programming, initiatives, and research engagement efforts. This commitment ensures that the voices of young patients and their families drive meaningful change in pediatric healthcare, making patient engagement efforts more impactful and relevant.

"As organizations like iCAN, HAEA, and other non-profits continue to drive critical change, amplifying youth voices in research is more important than ever. These collaborative efforts ensure that young patients are not just participants but leaders in shaping a more inclusive and patient-centered future."

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Thank you to Lisa Facciolla and lanice Viel Santiago for their dedication to making this event a success. Through shared knowledge, community-driven initiatives, and unwavering commitment, we empower the next generation to lead the charge in the pediatric space.





iCAN's 2025 Annual Research and Advocacy Summit

Presented by Jumo Health

The Delta Hotel

475 Av. du Président-Kennedy, Montréal, QC H3A 1J7, Canada July 14-17



Get ready for an unforgettable experience at the 2025 iCAN Summit in the vibrant city of Montreal! From July 14-17, join us at the incredible Delta Hotel (Marriott) in the heart of Montreal's entertainment district. This is your chance to be part of a movement shaping pediatric healthcare's future. The Delta Hotel offers a family-friendly, fully accessible environment, making it the perfect setting for our community, industry leaders, clinicians, researchers, and more to come together, collaborate, and ignite change.

Mark your calendars—registration opens on Thursday, February 20! Stay tuned for more details as we prepare to make an extraordinary impact on pediatric care.

Our annual Summit serves as a transformative platform for innovation, compassion, and collaboration in pediatric healthcare. We invite you to be part of this life-changing event by contributing in two meaningful ways:

- 1. Sponsor the 2025 Summit: Your sponsorship will ensure an impactful experience for all attendees.
- 2. Sponsor a Child to Attend: Your sponsorship directly impacts a child's life by granting them the opportunity to attend the Summit in Canada. Your support will cover travel, accommodation, and participation, offering them a world of learning and empowerment.

Together, we are shaping a brighter future for pediatric healthcare. Your contribution—big or small—significantly impacts prioritizing the patient voice and driving positive change. Your generosity and dedication are deeply valued. Let us unite in Canada to create a summit experience that empowers the pediatric community for years to come.

Let us work together to make our 2025 Summit even bigger by bringing more kids to share their voices! To contribute to the funding for next year's Summit, please <u>click here</u> to sponsor or donate.

Disclosures: There are no reported disclosures

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Peer Reviewed

Fellows Column: The Canary in the Cold Cut: How the 2024 Boar's Head Deli Meat Listeria Outbreak Warns of Looming Foodborne Threats

Phat Tran, OMS III

"As of January 10, 2025, there have been 60 hospitalizations and 10 deaths linked to the Boar's Head multi-state outbreak. According to the U.S. Centers for Disease Control and Prevention (CDC), Listeria monocytogenes and its associated infection of listeriosis continues to be the third leading cause of foodborne illness mortality in the US despite its relatively small number of cases compared to other foodborne illnesses, such as salmonella (1)."

"This is no fairy story and no joke; the meat will be shoveled into carts, and the man who did the shoveling will not trouble to lift out a rat even when he saw one." (Sinclair, 1905). Over a century later, this reality described by Upton Sinclair in his 1905 book "The Jungle" may still ring true as the US Department of Agriculture (USDA) concluded a massive law enforcement investigation into the billion-dollar processed meat company Boar's Head in the aftermath of a deadly outbreak of Listeria monocytogenes linked to their deli meat products. As of January 10, 2025, there have been 60 hospitalizations and 10 deaths linked to the Boar's Head multi-state outbreak. According to the U.S. Centers for Disease Control and Prevention (CDC), Listeria monocytogenes and its associated infection of listeriosis continues to be the third leading cause of foodborne illness mortality in the US despite its relatively small number of cases compared to other foodborne illnesses, such as salmonella (1). Listeriosis infections can affect anyone, but pregnant patients and newborns are at significantly higher risk of severe complications and mortality. For example, according to the World Health Organization, pregnant women are 20 times more likely to contract listeriosis infections (9). As it stands now, the 2024 Boar's Head listeria outbreak is the second largest outbreak of Listeria monocytogenes recorded in the United States history, occurring only 13 years after the biggest listeria outbreak in the United States in 2011, with Jensen Farms' cantaloupes.

Listeria monocytogenes outbreaks have increased sharply worldwide in the past decade, breaking and setting records in case numbers and mortality in many countries. In 2017, South Africa experienced the world's largest listeriosis outbreak, traced to contaminated ready-to-eat processed meat from a single company. This incident resulted in over 1,060 cases and 216 deaths, with neonates (aged \leq 28 d) accounting for 43% of cases. A year later, in 2018, South Korea faced its first-ever listeria outbreak, linked to contaminated crab meat and bean sprouts, which resulted in 294 symptomatic cases, of which 64 were confirmed. Spain followed suit in 2019, suffering its largest outbreak due to contaminated chilled roasted pork, which led to 222 cases, including three deaths and five miscarriages. The European Centre for Disease Prevention and Control (ECDC) published its 2022 epidemiological listeria report, revealing an alarming 2,770 confirmed cases across the EU and EEA-the highest on record. These events underscore a trending increase in the frequency and intensity of listeria outbreaks worldwide year by year, impacting both developed and developing nations.

"Listeria monocytogenes outbreaks have increased sharply worldwide in the past decade, breaking and setting records in case numbers and mortality in many countries. In 2017, South Africa experienced the world's largest listeriosis outbreak, traced to contaminated ready-to-eat processed meat from a single company. This incident resulted in over 1,060 cases and 216 deaths, with neonates (aged ≤28 d) accounting for 43% of cases."

As a third-year medical student, one thing my medical school instilled in me is a growth mindset, where you try to proactively learn from past mistakes to improve and avoid repeating the same mistakes. From an initial perspective, one might say that the world struggles with developing a proactive growth mindset when handling listeria outbreaks, given its growing surge in outbreak frequency, occurrence, and deaths worldwide year by year. "In fact, this is really the history of regulations in the United States. Most food regulation changes occur in light of issues such as outbreaks," said Martin Bucknavage when speaking about the Boar's Head listeria outbreak (8), a senior food safety extension associate at Penn State's Department of Food Science. However, I would argue that this perspective warrants reconsideration. I contend that the surge of listeria outbreaks is a direct showcase of the world proactively, instead of reactively, improving upon its mistakes and that this growing trend in listeria outbreaks worldwide was inevitable and will continue in growth due to a combination of advancing food safety technology and policy, transitioning consumers' preferences, and lax regulations in place for trending food products, particularly in the United States. I believe the Boar's Head listeria outbreak is the canary in the coal mine or the canary in the 'cold cut' for the looming surge of foodborne illness outbreaks that will be announced soon.

A few months before the 2011 US cantaloupe listeria outbreak, the Food Safety Modernization Act (FSMA) was signed into law, shifting the United States food safety system from a traditional reactive approach to a more preventive one, including the modernization of foodborne illness detection and screening. While the FSMA was not fully implemented until 2013, this legislation demonstrated the proactivity regarding foodborne illnesses and safety. Other major countries worldwide adopted a similar proactive and preventive



Listeria monocytogenes Pathogenesis

1A. Has surface proteins called "internalins"(InIA & InIB) which binds host's GI epithelial cells' cadherin

2A. Utilizes host-mediated immune response of phagocytosis by host's vacuoles to enter the cell

3B. Has a pore-forming cytotoxic protein called "listeriolysis O" (LLO) and phospholipase proteins (PIcA & PIcB) to break out of the host's vacuoles

4C. Be free to replicate in the host

5DE. Utilizies host's intracellular cytoskeleton filaments to connect its own actin monomers to form the actin "rocket tail" which allows them to move freely and disseminate between cells.

Ultimately causes the bacterial infection "listeriosis"

(Rogalla, 2023)



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Worldwide Surge in Major Outbreaks: Timeline (2011-2024)



approach, such as the European Union's 2006 European Hygiene Package and South Korea's 2016 Special Act on Imported Food Safety Management and Food Sanitation Act. One of the critical advancements in food safety technology resulting from these legislative efforts of modernization and proactivity has been the widespread adoption of whole-genome sequencing (WGS) in the early 2010s. This technology has played a crucial role in rapidly and accurately identifying the source of outbreaks, enabling swift preventive actions such as shutting down contaminated facilities, recalling affected products, and notifying consumers to discard potentially harmful items. For example, in October 2024, WGS was used during routine testing by the USDA in BrucePac's products, which detected possible listeria contamination, prompting a recall of over 11 million pounds of ready-to-eat meat and poultry items (3). WGS has played a significant role in linking cases of listeria illnesses that might have previously been considered isolated incidents, resulting in more instances being grouped and classified as outbreaks. WGS played a crucial role in identifying the 2017 South African listeria outbreak, the 2018 South Korean outbreak, and the 2019 listeria outbreak in Spain, among other minor outbreaks (4). This advanced screening has contributed to the surge in reported listeria outbreaks worldwide, which will likely continue.

"WGS has played a significant role in linking cases of listeria illnesses that might have previously been considered isolated incidents, resulting in more instances being grouped and classified as outbreaks. WGS played a crucial role in identifying the 2017 South African listeria outbreak, the 2018 South Korean outbreak, and the 2019 listeria outbreak in Spain, among other minor outbreaks (4). This advanced screening has contributed to the surge in reported listeria outbreaks worldwide, which will likely continue."

Another key factor behind my belief in the inevitability of past listeria outbreaks and my anticipation of the rise in future listeria outbreaks is the transition in consumers' preferences in their diet, accelerated by the COVID-19 pandemic. As consumers increasingly prioritize convenience due to their fast-paced lifestyles, there is a growing demand for healthy, fresh, and fast foods. (6,7). Addressing this increasing demand are ready-to-eat products whose market grows yearly, such as deli meats, cold cheese, fresh produce, and online meal kit delivery services. These services combine all the ingredients into a box, complete with a recipe card, or deliver pre-cooked frozen meals directly to your doorstep on a weekly or monthly basis. Over the past decade, the meal kit delivery industry has experienced explosive growth, with the number of companies increasing by 3000% (2).

Many ready-to-eat products are stored and sold in refrigerated or frozen conditions, the perfect environment for listeria to contaminate and thrive. More concerning is that, unlike most food products in the United States, the majority of meal kit delivery services are not regulated by the FDA and are not required to follow FDA safety requirements in place to limit the spread of foodborne illnesses, such as listeria. Experts say that federal regulators have no oversight over whether meal kit ingredients are shipped in refrigerated trucks or whether they reach customers at a safe temperature. Meal kit deliveries, often shipped via third-party carriers like FedEx and UPS, can be delayed in unrefrigerated trucks or left outside for hours on doorsteps (5). Due to the relatively new nature of meal kit delivery services, the government has also not clearly stipulated how foods in meal kits should be packed or cooled to avoid cross-contamination or spoilage. While a listeria-specific outbreak directly linked to a meal kit delivery service has not yet occurred, though there have been near misses with Reser's branded foods and BrucePac products recalls these past months, other foodborne outbreaks have been reported, such as the 2022 HelloFresh E. coli outbreak. Given these services' conditions and rapid growth, I believe it is only a matter of time before a major listeria outbreak is tied to one of these meal kit companies.

The Boar's Head outbreak serves as a clear warning. Without efforts to address the lax regulatory frameworks surrounding new food products and services, we will continue to see an increase in preventative foodborne illness outbreaks. The increasing demand for fast, fresh, and convenient foods and advancing food safety technologies create opportunities and challenges. If we fail to close regulatory gaps and minimize food safety blind spots, the Boar's Head outbreak will not remain an isolated incident but a harbinger of an impending public health crisis.

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- 2000 word limit not including references or title page. Exceptions will be made on a case by case basis
- QI/QA work, case studies, or a poster from a scientific meeting may be submitted..
- Submission should be from a medical student, resident, fellow, or NNP in training.
- Topics may include Perinatology, Neonatology, and Younger Pediatric patients.
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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 your 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.
- Drink more water and eat healthy foods.
- Seek mental health support.
- Sleep when you can.

Get Immunized

WARNING

Vaccinations save lives. Protecting your baby from COVID-19, flu and pertussis lowers their risks for complications from respiratory infections.

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 feel sick or 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. www.nationalperinatal.org/rsv





RSV

flu

COVID-19 colds







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Peer Reviewed

Hospital Lacks Fundamental Intrapartum and Resuscitation Measures and Lists Death as Stillbirth Despite Signs of Life in the Newborn

Maureen Sims, MD, Barry Schifrin, MD

"A 26-year-old primigravida with a history of hypertension, gastroesophageal reflux, and a BMI of 38, presented at 39 weeks' gestation for induction of labor due to chronic hypertension. Prenatally, she was treated with benazepril and then metoprolol with excellent control of her BP. Her laboratory tests, including GBS, were unremarkable."

A 26-year-old primigravida with a history of hypertension, gastroesophageal reflux, and a BMI of 38, presented at 39 weeks' gestation for induction of labor due to chronic hypertension. Prenatally, she was treated with benazepril and then metoprolol with excellent control of her BP. Her laboratory tests, including GBS, were unremarkable.

On admission, the cervix was 1 cm dilated and 50% effaced with the fetal head at -2 station—unfavorable features for the induction of labor in a primigravida. The estimated fetal weight (EFW) was 3400 grams, and her BP was in the normal range. Labor induction began with several doses of Cervidil, a cervical ripening agent. This produced no progress, and at about 20 hours after admission, Pitocin was begun and raised intermittently but also intermittently discontinued and restarted because of the recurrent but inconsistent variable decelerations. About 32 hours after admission, membranes were ruptured artificially with egress of fluid, lightly stained with meconium. Shortly thereafter, epidural anesthesia was provided. Nineteen hours after the administration of Pitocin (39 hours elapsed time), the cervix is 4/80/-2. The tracing reveals a stable baseline of 135 bpm, moderate variability, and accelerations between occasional decelerations. Three hours later (42 hours elapsed time), the cervix was 7/100/-1 with recurrent variable decelerations with contractions. Two hours and 15 minutes later (44 1/4 hours elapsed), the cervix was fully dilated, but the head (with molding, caput, malposition, left occiput posterior) was still at -1 station and unengaged. The mother was instructed to begin pushing. The pushing efforts not only failed to produce descent of the fetal head but did induce repetitive, increasingly severe variable decelerations for which the Pitocin was discontinued, but the pushing maintained to the point where severe fetal bradycardia ensued, and the decision was made to proceed with emergency cesarean section.

With the decision to move to operative delivery, the fetal monitoring tracing was discontinued, with the last recorded FHR 60 bpm.

The anesthesiologist was called from home. There was no further recording of the FHR in the 34-minute interval until the delivery by cesarean section. In deposition, several participants referred to an FHR during this interval at 130 bpm. This was most certainly the mother's HR, as testified to by the simultaneous recording of the maternal heart rate.

After about 45 hours of labor, it took just over 30 minutes to effect a stat, emergency cesarean section under general anesthesia. The obstetrician admitted that the procedure was delayed due to the delayed arrival of the anesthesiologist. The anesthesiologist vouchsafed that he had arrived within 30 minutes of the call, notifying him of the need for an emergency cesarean section, a time of availability stipulated within his contract with the hospital.

At birth, the female infant delivered from the left occiput position (LOP – a malposition) weighed 3771 grams with a length of 53.2 cm and head circumference of 34.9 cm with prominent molding and caput—Apgar's 0,0,0 baby. Despite more than ample warning of the problem of both the labor and the FHR tracing, the operating room was staffed only by labor and delivery nurses who issued a code blue at the time of the birth of the lifeless baby. It took until 6 minutes after birth for an Emergency Room (ER) physician to arrive, having heard an overhead page of a code blue in the labor and delivery room. The anesthesiologist was tending to the mother and not free to attend to the baby.

"Apgar's 0,0,0 baby. Despite more than ample warning of the problem of both the labor and the FHR tracing, the operating room was staffed only by labor and delivery nurses who issued a code blue at the time of the birth of the lifeless baby."

Documentation of any resuscitative activities during the first 6 minutes of life is absent. The ER physician's documentation reflects that on his arrival, a copious amount of meconium-stained fluid was being extracted via an oro-gastric catheter, and chest compressions were being administered along with the bag and mask positive pressure ventilation (PPV). In his deposition, he stated that the PPV failed to promote any chest rise, and the preductal oxygen saturation (O2 sat) was improving; the pupils were dilated and reacted sluggishly. He instructed the nurses to continue chest compressions as he suctioned the airway and increased the airway pressure for the mask PPV. At 8 minutes, he intubated and increased the inflating pressure until he saw the chest rise. Equipment needed for an umbilical venous catheter (UVC) or interosseous cannulation (IO) was unavailable in the OR. Once the necessary equipment became available, however, attempts to place them failed. The endotracheal tube (ET)



became dislodged; PPV maintained respirations. The O2 sat was noted to peak at 55% with the increased pressure from the PPV. At 9 minutes of age, a general pediatrician arrived and, within 2 minutes, successfully intubated the baby. Beginning at 13 minutes of age, multiple administrations of epinephrine via ET failed to produce a cardiac response. At 34 minutes, IO was successfully inserted through which normal saline and multiple doses of epinephrine were administered, again without response. The baby was pronounced dead 60 minutes after birth.

A postmortem exam revealed no anomalies or infection. The microscopic evaluation of the lungs showed scattered intraalveolar brown pigmented material. [ASPIRATION?] The placenta was not examined.

"A postmortem exam revealed no anomalies or infection. The microscopic evaluation of the lungs showed scattered intra-alveolar brown pigmented material. [ASPIRATION?] The placenta was not examined."

The hospital and the obstetrician were sued, but the ER physician was not included in the lawsuit. The case was settled without going to trial.

The allegations:

- The hospital should have ensured that a qualified resuscitation team was available in a timely manner.
- The resuscitation team should have been assembled well before delivery to ensure that prebriefing was carried out. Risk factors need to be identified, and management plans need to be developed. A team leader needs to be identified, and each resuscitation team member's various roles assigned the various tasks required to perform a full resuscitation. There were ample clinical signs and risk factors for the Labor and Delivery nurses to call for the resuscitation team in a timely manner.
- The resuscitation team should have included individuals with full resuscitation skills, including the capacity to perform a resuscitation according to the NRP.
- The team needed to be skilled at intubation, suctioning meconium, placing umbilical venous lines, and providing and administering medication, including epinephrine.
- Appropriate equipment needed to be immediately available for resuscitation in accordance with the NRP guidelines outlined in the NRP manual.
- The standard of care required proper suctioning and positive pressure ventilation.
- The standard of care required minute-by-minute assessment and documentation of Sophia's vital signs and oxygen saturation.
- The UVC should have been inserted within 5 minutes after birth.
- The nurses should have ensured a venous blood draw was obtained immediately upon a UVC placement to inform the

clinicians how best to manage the resuscitation.

- The standard of care required that the guidelines set forth by the NRP be followed.
- Although the fetus was severely compromised during the intrapartum period and warranted a much more timely cesarean section., This was not an intrauterine death. She was alive at birth. Not only was her oxygen saturation improving but had reached 55%, but her pupils were reactive, though "sluggish."

In addition to the obvious problems with the resuscitation, there were numerous allegations against the obstetrical personnel, including:

- Failure to correctly interpret and timely respond to the abnormalities in the FHR tracing during labor, especially during the 2nd stage of labor where unrestrained maternal pushing produced increasing hypoxic-ischemic challenges for the fetus.
- Failure to appreciate and timely respond to the diminished feasibility of safe vaginal delivery. In addition to the problems with the tracing, the prospects for safe vaginal delivery diminished significantly as the duration of labor increased. Proper recognition of the futility of attempting to deliver vaginally would have prompted an earlier decision for cesarean section, less delay in the onset of the cesarean section, and an improved condition in the newborn.
- Failure to appreciate the logistics of intervention under the circumstances prevailing at the hospital. Given the lack of immediate availability of the anesthesiologist, it was required that the anesthesiologist be mobilized earlier, even under the circumstances where he may not be needed.
- These failures caused the fetus, neurologically responsive and with no obvious hypoxemic, mechanical, or infectious threat at the outset of labor, to be in extremis at the time of birth, creating the need for a full resuscitation.
- It is my opinion that the conduct of labor, the failed preventive measures, and the inadequate resuscitation conspired to cause this entirely preventable neonatal death.

Discussion:

In this case, the numerous signals that the normally responsive fetus initially deteriorated for several hours before the sentinel events were ignored. There was both excessive uterine activity and decelerations even before the onset of pushing during the 2nd stage of labor. It should have been anticipated that decelerations in the 1st stage of labor would be exacerbated with the onset of pushing. Irrespective, there was no effort to curtail the frequent contractions / pushing as a resuscitative measure for the fetus. Even when the Pitocin was discontinued, pushing was maintained, despite the lack of optimism about the feasibility of safe vaginal delivery. There could be no surprise that continued pushing with a lack of descent would eventually precipitate a prolonged fetal bradycardia, demanding an emergency (stat) cesarean section.

The provision of care requires an understanding of the limitations of local circumstances, including the time necessary to recruit personnel should an emergency cesarean section be required. The circumstances of this case, including the very prolonged labor, the failure of the fetal head to descend during maternal pushing, the deepening decelerations with overshoot and tachycardia, should have given ample time for the mobilization of the anesthesiologist and other necessary personnel, and a cesarean section conducted under less urgent circumstances.



"It should have been anticipated that decelerations in the 1st stage of labor would be exacerbated with the onset of pushing. Irrespective, there was no effort to curtail the frequent contractions / pushing as a resuscitative measure for the fetus. Even when the Pitocin was discontinued, pushing was maintained, despite the lack of optimism about the feasibility of safe vaginal delivery. There could be no surprise that continued pushing with a lack of descent would eventually precipitate a prolonged fetal bradycardia, demanding an emergency (stat) cesarean section."

The Neonatal Resuscitation Program (AAP, AHA) publishes and regularly updates guidelines on neonatal resuscitation. Despite such clear-cut guidance, the hospital failed to pay proper heed. Multiple deficiencies in obstetrical, pediatric, and nursing care led to the death of this baby.

"The circumstances of this case, including the very prolonged labor, the failure of the fetal head to descend during maternal pushing, the deepening decelerations with overshoot and tachycardia, should have given ample time for the mobilization of the anesthesiologist and other necessary personnel, and a cesarean section conducted under less urgent circumstances."

In its defense, the hospital argued that the fetus was stillborn and any alleged failures in neonatal resuscitation were irrelevant. This dispute, based on the definitions below, was never adjudicated. Reasonably, since the newborn appeared to show at least some signs of life at 6 minutes (reactive pupil, improving oxygen saturations), despite having no discernible heart rate, she should be classified as a neonatal death rather than a fetal death.

Definitions:

Live birth: The complete expulsion or extraction from the mother of a product of human conception, irrespective of the duration of the pregnancy, which, after such expulsion or extraction, breathes or shows any other evidence of life, such as the beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, regardless of whether the umbilical cord has been cut or the placenta is attached. Heartbeats are to be distinguished from transient cardiac contractions; respirations are to be distinguished from fleeting respiratory efforts or gasps.

Fetal death: Death before the complete expulsion or extraction from the mother of a product of human conception, irrespective of the duration of pregnancy, that is not an induced termination of pregnancy. The death is indicated by the fact that, after such expulsion or extraction, the fetus does not breathe or show any other evidence of life, such as the beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles. Heartbeats are to be distinguished from transient cardiac contractions; respirations are to be distinguished from fleeting respiratory efforts or gasps.

Infant death: Live birth (as above) that results in death before 1 year of life (<365 days)

Neonatal death: Death before 28 days of life

Postneonatal death Death at 28 days to 364 days of life

Suggested reading:

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- **3. Sims, ME**, Schifrin B Failure to Safely Deliver Timely and A Botched Resuscitation Lead to Adverse Outcome Neonatology Today 2021; 16: 26-28

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Medical News, Products & Information

Compiled and Reviewed by Benjamin Hopkins, DO

Beyond tongue-tie: How to manage breastfeeding issues when baby does not have ankyloglossia

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American Academy of Pediatrics

By Jennifer Thomas, M.D., M.P.H., FAAP, and Emily Hannon, M.D., FAAP

Study: Beyond tongue-tie: How to manage breastfeeding issues when baby does not have ankyloglossia

Current as of February 1, 2025

A 2024 AAP <u>clinical report</u> offers comprehensive, evidence-based guidance on managing breastfeeding difficulties in newborns with ankyloglossia.

It is important, however, for pediatricians to recognize that not all breastfeeding challenges stem from ankyloglossia and to consider other potential issues when evaluating a baby without tongue-tie.

Below are some causes of breastfeeding difficulty that are not related to ankyloglossia.

Infant factors

Oral anatomy

Beyond tongue-tie, other anatomical variations such as higharched palates, cleft lip or palate, and micrognathia can affect breastfeeding.

Suck-swallow-breathe pattern

Premature infants or those with neurological conditions may struggle with the coordination of sucking, swallowing and breathing.

Some infants may have difficulty with the rhythm of suckling, leading to inefficient feeding and fatigue.

Maternal factors

Anatomy

Variations in nipple shape or size can impact latch and milk transfer. Flat or inverted nipples may require specific techniques or aids to facilitate breastfeeding.

Additionally, certain breast surgeries, such as reductions or augmentations, may impact milk production and breastfeeding success.

Breastfeeding technique

The mother's and infant's positioning and latch technique are critical. Inadequate latch can lead to poor milk transfer, nipple pain and damage.

Milk supply

Both oversupply and undersupply of milk can cause challenges. Hormonal imbalances, previous breast surgeries or insufficient glandular tissue may contribute to these issues.

Low milk supply may result in poor infant weight gain and overly frequent feeding, while oversupply can lead to breast engorgement, fast let-down and infant discomfort during feeding.

The most common cause of low milk supply is infrequent or ineffective breastfeeding. Milk production works on a supply-and-demand basis; if the breasts are not emptied regularly, milk production will decrease. Infrequent or short feeding sessions can impact milk production and infant weight gain.

Health issues

Postpartum depression or anxiety can interfere with breastfeeding. Conditions such as polycystic ovary syndrome, thyroid disorders and retained placental fragments can interfere with the hormonal signals required for milk synthesis.

Pain and discomfort

Nipple pain or breast infections like mastitis can discourage breastfeeding and require prompt attention.

Medications

While most medications are compatible with breastfeeding, some can interfere with milk production or may be contraindicated during breastfeeding. It is essential to review maternal medications when assessing breastfeeding difficulties.

How pediatricians can help

Although the list of potential breastfeeding issues may seem daunting, pediatricians can be proactive in addressing breastfeeding challenges or concerns and offer continuous encouragement and support, including the following.

- Provide resources about breastfeeding techniques, the importance of skin-to-skin contact and the normal course of breastfeeding.
- Monitor breastfeeding parents and babies regularly to identify and address breastfeeding issues promptly.
- Schedule follow-up visits to evaluate the baby's weight gain, feeding frequency and duration to ensure adequate nutrition and growth.

- Recommend consultations with lactation specialists who can provide personalized support and address specific breastfeeding challenges.
- Encourage parents to join breastfeeding support groups where they can share experiences and gain encouragement from other breastfeeding families.

AAP clinical report outlines how to detect biliary atresia by 2-4 weeks of life

NEWS PROVIDED BY

American Academy of Pediatrics

By Sanjiv Harpavat, M.D., Ph.D., FAAP

Study: AAP clinical report outlines how to detect biliary atresia by 2-4 weeks of life

Current as of February 18, 2025

What is the most common reason for liver transplant in children? The answer is biliary atresia, according to data from the United Network for Organ Sharing.

Biliary atresia accounts for 60% of liver transplants in infants younger than 1 year and 30% of all liver transplants in pediatric patients.

Primary care providers (PCPs) play an es-

sential role in improving outcomes in this devastating disease by identifying infants before 1 month of age and referring them for treatment with Kasai portoenterostomy. Earlier surgery is the only proven way to delay or prevent the need for liver transplant.

The new AAP clinical report Identifying Infants with Biliary Atresia by 2-4 Weeks of Life: Guidance for the Primary Care Provider outlines steps to quickly identify infants who have biliary atresia.

The clinical report, from the Section on Gastroenterology, Hepatology and Nutrition, the Committee on Fetus and Newborn, and the Section on Surgery, is available at https://doi.org/10.1542/peds.2024-070077 and will be published in the March issue of Pediatrics.

Why is biliary atresia so difficult to identify?

Infants with biliary atresia often go unnoticed initially because they usually appear healthy. The first sign is jaundice, which is visually indistinguishable from the physiological jaundice seen in healthy newborns.

As a result, infants with biliary atresia typically are referred for surgery after the 2 month well-child visit. This delay is problematic because infants treated with Kasai portoenterostomy before 30-45 days of life have the best outcomes. During the operation, the obstructed bile ducts are removed, and the liver is connected to the intestines in an attempt to stop bile from backing up into and damaging the liver.

PCPs can use a common blood test - direct or conjugated bilirubin level - to identify infants who may have biliary atresia.

Identifying infants at the 2-4 week wellchild visit

Every child should see the PCP in the first 2-4 weeks of life, according to the Bright Futures Periodicity Schedule. This is the ideal period for the PCP to ask three questions.

- 1. Is the infant jaundiced? Sometimes jaundice is easier to notice by looking in the eyes instead of at the skin. If an infant has jaundice beyond 2 weeks of life, there may be a liver problem.
- Does the infant have pale stools? If 2. so, this is a sign that bile is trapped in the liver and not reaching the intestine.
- 3. Did the infant have a direct or conjugated bilirubin that was high while in the newborn nursery? To answer this question, records from the nursery may need to be reviewed. A high initial level could be a sign of liver disease.

If the answer to any of the questions is yes, PCPs can check a direct or conjugated bilirubin level. If the level is 1 milligram/deciliter (mg/dL) or higher, a liver disease such as biliary atresia may be present. PCPs then can contact a pediatric specialist to discuss next steps and plan for possible urgent referral.

Key actions for pediatricians

- At the 2-4 week well-child visit, ask three questions: Is jaundice present? Are the stools pale? Was an initial direct or conjugated bilirubin level high?
- If the answer to any of these questions is yes, consider checking a direct or conjugated bilirubin level.
 - If a direct or conjugated bilirubin level is 1 mg/dL or higher at 2-4 weeks of life, a liver disease

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such as biliary atresia may be present. PCPs can contact pediatric gastroenterology to discuss next steps.

AAP president urges House to reject budget resolution with 'devastating' cuts to Medicaid, CHIP, SNAP

NEWS PROVIDED BY

American Academy of Pediatrics

By Sean Stangland

Study: AAP president urges House to reject budget resolution with 'devastating' cuts to Medicaid, CHIP, SNAP

Current as of February 24, 2025

AAP President Susan J. Kressly, M.D., FAAP, calls upon U.S. lawmakers to reject a budget resolution that would have "devastating consequences for children and families."

According to <u>reporting by The Hill</u>, the budget resolution that could be voted upon Tuesday by the House of Representatives calls for cuts of \$1.5-\$2 trillion, including \$880 billion in cuts by the Energy and Commerce Committee which oversees Medicaid.

"We oppose the proposed funding cuts to programs like Medicaid and the Children's Health Insurance Program (CHIP) — which cover nearly half of all U.S. children — as well as the Supplemental Nutrition Assistance Program (SNAP)," Dr. Kressly <u>said</u> Monday in a news release.

<u>As of October 2024</u>, 37 million children and teens were enrolled in Medicaid or CHIP, which accounts for 47.4% of all participants in both programs. In 2023, SNAP served an average of 42.1 million Americans a month.

Many children from low-income families and children with disabilities or chronic health conditions depend on Medicaid and CHIP, Dr. Kressly said, and "programs like SNAP work to support families experiencing food insecurity, helping them to put food on the table and supporting children's lifelong health.

"Protecting these programs invests in the health and well-being of America's children, which is directly related to our future healthy workforce and economic prosperity," she said.

The Academy also joined leading national children's organizations in <u>sending a letter Monday</u> to every member of the House of Representatives, urging them to vote against the resolution.

"By reducing vital support for Medicaid and CHIP, you would not just be cutting a budget line – you would be limiting the health prospects of our children, leaving them without the care they need to grow into healthy adults," the letter reads.

The House bill differs from a competing budget resolution passed last week in the U.S. Senate by a 52-48 vote; that bill includes \$1 billion in cuts to Medicaid. If the House passes its bill, the reconciliation process will begin to shape the ultimate budget bill.

The House of Representatives approved the resolution late Tuesday by a vote of 217-215.

Unvaccinated child dies of measles amid outbreak in Texas

NEWS PROVIDED BY

American Academy of Pediatrics

By Steve Schering

Study: Unvaccinated child dies of measles amid outbreak in Texas

Current as of February 26, 2025

An unvaccinated school-aged child has died after testing positive for measles amid an outbreak in west Texas, health officials <u>confirmed</u> Wednesday.

The Texas Department of State Health Services (DSHS) said the child was hospitalized last week in Lubbock and is the first known death related to the outbreak.

"As a pediatrician, I'm heartbroken to learn that a child has died from measles," AAP President Susan J. Kressly, M.D., FAAP, said in a <u>statement</u>. "This is a tragic and devastating loss, and our thoughts are with the family and community affected. One death from a preventable disease is one too many."

As of Feb. 25, 124 cases of measles have been <u>confirmed</u> in Texas since the outbreak began in late January. Most of the cases are unvaccinated children, and 18 people have been hospitalized.

Thirty-nine cases involve children ages 0-3 years, while 62 cases have been reported in children ages 5-17 years. Eighteen cases involve people 18 years of age or older, while five cases are of an unknown age.

During a press briefing Wednesday, Lara W. Johnson, M.D., FAAP, chief medical officer at Covenant Children's Hospital in Lubbock, Texas, said about 20 patients have been hospitalized with measles. Many received supplemental oxygen to help them breathe, she said.

"Measles is a very severe illness that has a mortality rate of about 3%," Dr. Johnson said. "Knowing we have a large outbreak, unfortunately, statistically, there's a significant risk of having a death. I hope we don't see anymore, but we're fairly early in this outbreak. We've seen the numbers increasing pretty dramatically with each update."

While respiratory issues are a key concern among those hospitalized, Dr. Johnson said neurological issues can occur with the measles virus and may show up years after initial infection.

New subscribers are always welcome! NEONATOLOGY TODAY To sign up for a free monthly subscription, just click on this box to go directly to our subscription page Gaines County has the most reported measles cases with 80. The county had a nearly 18% vaccine exemption rate among kindergartners for the 2023-'24 school year. according to DSHS statistics. Additional cases have been reported in Terry (21), Dawson (seven), Yoakum (five), Dallam (four), Martin (three), Ector (two), Lubbock (one) and Lynn (one) counties.

The AAP and the Centers for Disease Control and Prevention (CDC) recommend children receive the measles-mumps-rubella (MMR) vaccine at age 12-15 months and again at 4-6 years. Children can receive the second dose earlier if it is at least 28 days after the first dose. Each dose of MMR lowers the risk of infection and severity of illness, if infected. Families should contact their pediatricians for more information about vaccination.

"The reason many parents in the U.S. have not had to worry about measles in decades is because of widespread immunization with this safe and effective vaccine," Dr. Kressly said. "However, when immunization rates drop in a community, the disease can spread, putting our most vulnerable ---especially young children - at risk."

In large outbreaks in the U.S. in the late-1980s and early 1990s, there were more than 150 deaths, said Sean T. O'Leary, M.D., M.P.H., FAAP, chair of the AAP Committee on Infectious Diseases.

"Prior to widespread vaccination in the U.S., there were 400 to 500 deaths per year (and that was among a smaller U.S. population)," he said. "Worldwide, in recent years, there are more than 100,000 deaths per year, and prior to widespread vaccination, there were over a million deaths per vear worldwide."

The Houston Health Department identified two confirmed cases of measles in adults associated with recent international travel. Both individuals reside in the same household and were not vaccinated. These are the first reported measles cases in Houston since 2018.

The New Mexico Department of Health reported nine measles cases have been identified in Lea County, which borders Gaines County, Texas. Of those, four cases involve children ages 5-17 years, while five cases involve adults ages 18 and older.

In an update Monday, DSHS said one person from the outbreak area in west Texas visited several locations in the San Marcos and San Antonio area the weekend of Feb. 14-16 while contagious, including Texas State University in San Marcos and the University of Texas at San Antonio main campus. Due to the highly contagious nature of measles, additional cases are likely to occur in the affected communities.

The measles virus is transmitted by contact with infectious droplets or by airborne spread when an infected person breathes, coughs or sneezes. Measles virus can remain infectious in the air up to two hours after an infected person leaves an area.

Illness onset (high fever, cough, runny nose and red, watery eyes) begins a week or two after someone is exposed. A few davs later, a rash breaks out as flat, red spots on the face and then spreads down the neck and trunk to the rest of the body. A person is contagious about four days before the rash appears to four days after.

Other measles symptoms may include small spots in the cheek area inside the mouth, diarrhea and ear infection. Measles can lead to pneumonia, swelling of the brain, deafness, intellectual disability and death.

Most children who get measles are not up to date on recommended vaccines or are not old enough to get measles vaccine.

The CDC measles website, which is expected to be updated weekly, reports 93 measles cases as of Feb. 20 across eight jurisdictions (Alaska, California, Georgia, New Jersey, New Mexico, New York City, Rhode Island and Texas).

The CDC has reported three outbreaks (defined as three or more related cases) in 2025, and 92% of cases (86 of 93) are outbreak-associated. Last year, 285 measles cases (16 outbreaks) were reported by 33 iurisdictions across the United States. For comparison, 59 measles cases (four outbreaks) were reported in 2023.

AAP analysis: 49% of children insured by **Medicaid or** CHIP

NEWS PROVIDED BY

American Academy of Pediatrics

Bv AAP Research

Study: AAP analysis: 49% of children insured by Medicaid or CHIP

Current as of February 27, 2025

An estimated 37 million U.S. children (49%) were enrolled in Medicaid or the Children's Health Insurance Program (CHIP) as of October 2024, according to an AAP analysis of data from the Centers for Medicare & Medicaid Services (CMS).

The portion of children ages 0-18 covered by Medicaid/CHIP ranged from 18% in Utah to 71% in New Mexico (see map). Other states with the highest portion of children receiving care through these public programs included the District of Columbia (70%), Louisiana (63%), Kentucky (59%), New York (59%) and North Carolina (57%), according to the AAP analysis. In 26 states, at least half of children are enrolled in Medicaid/CHIP.





Percent of state children enrolled in Medicaid/CHIP as of October 2024



The analysis also showed that children and adults comprise roughly an equal number of Medicaid/CHIP enrollees (48% vs. 52%).

Data are based on the CMS Medicaid and CHIP Performance Indicator Projects. Each month, all states and the District of Columbia are required to provide data to the CMS, which is reported in the Medicaid & CHIP Enrollment Report. Data from U.S. territories are not available in this reporting system.

Total enrollment figures represent the unduplicated number of people enrolled in Medicaid and CHIP as of the last day of the reporting period. AAP staff divide the enrollment figures by the number of children in each state based on Census estimates to determine the percentage of children covered by Medicaid/CHIP.

AAP president: Cancellation of federal flu vaccine meeting 'alarming'

NEWS PROVIDED BY

American Academy of Pediatrics

By Sean Stangland

Study: AAP president: Cancellation of federal flu vaccine meeting 'alarming'

Current as of February 27, 2025

The cancellation of an annual meeting that shapes flu vaccines for the following year is "alarming," according to AAP President Susan J. Kressly, M.D., FAAP, and comes during "one of the worst flu seasons in years," she said.

The Food and Drug Administration's (FDA's) Vaccines and Related Biological Products Advisory Committee (VRB-PAC) was scheduled to meet March 13 to discuss strains used in vaccines for the 2025-'26 flu season. News of the cancellation reached VRBPAC members' email inboxes on Wednesday afternoon with no explanation.

Andrew Nixon, spokesperson for the U.S. Department of Health and Human Services (HHS), confirmed the cancellation Thursday and said in an emailed statement that the FDA "will make public its recommendations to manufacturers in time for updated vaccines to be available for the 2025-2026 influenza season."

Dr. Kressly said Thursday that the timing of the annual VRBPAC meeting is crucial to preventing a flu season that could overwhelm health care providers.

"The American Academy of Pediatrics urges health authorities to immediately reschedule the meeting to ensure vaccine decisions are made without delay," Dr. Kressly said in a statement. "It takes up to 6 months to produce and distribute the vaccine so it's available before the influenza virus starts to circulate next season." The AAP <u>recommends</u> everyone 6 months and older get vaccinated against the flu.

"Any delays that disrupt the supply of influenza vaccine for next year could negatively impact the health of children," said Kristina Bryant, M.D., FAAP, Professor of Pediatrics at the University of Louisville.

Bryant added this season is a powerful reminder of what happens when children are not protected with flu vaccine. "Nationally, influenza immunization rates have been falling for several years. In Jefferson County, Kentucky, where I live, less than 30% of kids received a flu vaccine this year. We saw multiple outbreaks of flu in schools that led to school closures or transition to virtual learning."

As of the week ending Feb. 15, there had been <u>86 pediatric flu deaths</u> during the 2024-'25 flu season. The Centers for Disease Control and Prevention estimates there have been at least 33 million illnesses, 430,000 hospitalizations and 19,000 deaths from the flu this season.

"Vaccination remains our most effective tool to prevent the most severe consequences of influenza, including hospitalization," Dr. Kressly said.

AAP leaders combating misinformation amid measles outbreak, stress importance of vaccination

NEWS PROVIDED BY

American Academy of Pediatrics

By Steve Schering

Study: AAP leaders combating misinformation amid measles outbreak, stress importance of vaccination

Current as of February 27, 2025

While health officials continue to monitor and treat those affected by a measles outbreak in Texas that has led to the death of one child, clinicians also are addressing misinformation regarding how to prevent infection and the cause of the outbreak.

As of Feb. 24, the Texas Department of State Health Services (DSHS) has reported 124 confirmed cases of measles in the South Plains and Panhandle regions of the state. A majority of those infected are unvaccinated children. On Wednesday, DSHS reported an unvaccinated schoolage child died after being hospitalized with measles.

Families hoping to protect their children from measles are encouraged to speak with their pediatrician to receive a measles-mumps-rubella (MMR) vaccine, if needed. Two doses of MMR are 97% effective against measles. With more infections expected to be reported, health care officials are reminding families that vaccination is the best way to prevent spread of measles.

While there is no specific antiviral treatment for measles, the World Health Organization recommends two doses of vitamin A be administered by a health care professional 24 hours apart for children and adults with measles. The supplement restores low vitamin A levels that can occur even in well-nourished children and can help prevent eye damage and blindness.

Many U.S. experts concur with administering vitamin A to all children in the United States with measles, regardless of hospitalization status, <u>according to the AAP Red</u> *Book*.

Clinicians, however, are working to debunk claims that vitamin A can prevent measles.

"Vitamin A is recommended for children diagnosed with measles to help prevent complications, particularly in children who are hospitalized," said Sean T. O'Leary, M.D., M.P.H., FAAP, chair of the AAP Committee on Infectious Diseases (COID). "It should not be used to try to prevent measles, and high doses of vitamin A are potentially very harmful. The only effective way to prevent measles is the MMR vaccine." Larger, prolonged doses of vitamin A can cause nausea and vomiting, headache and fatigue, joint and bone pain, blurry vision and skin and hair problems. They also can lead to dangerously high pressures inside the skull that push on the brain, liver damage, confusion, coma and other problems.

"Vitamin A, at any dose, does not protect you from measles," said James D. Campbell, M.D., M.S., FAAP, vice chair of COID. "No one should take, and no parent should give to their child, vitamin A in hopes of preventing measles. It will not do that."

According to Dr. Campbell, vitamin A is a micronutrient, meaning only small amounts are needed to stay healthy.

"Those small amounts are what is found in a healthy diet and in recommended doses of over-the-counter multivitamin supplements," Dr. Campbell said. "Larger doses, especially larger doses given over prolonged periods, are very dangerous. In summary, MMR vaccine prevents measles. Vitamin A does not."

Additional misinformation claims the outbreak was caused by the MMR vaccine, which public health officials have debunked. According to the Centers for Disease Control and Prevention (CDC) and DSHS, genotype testing has linked the outbreak to a genotype of measles virus called D8 that is <u>circulating</u> in Europe.

The AAP and CDC recommend children receive the measles-mumps-rubella (MMR) vaccine at age 12-15 months and again at 4-6 years. Children can receive the second dose earlier if it is at least 28 days after the first dose. Each dose of MMR lowers the risk of infection and severity of illness, if infected.

Families in an outbreak area also can talk to their pediatrician about whether the vaccine can be given to children ages 6-12 months, said Lara W. Johnson, M.D., FAAP, chief medical officer at Covenant Children's Hospital in Lubbock, Texas, where the child died from measles. Immunization has been used starting at 6 months of age with good efficacy in previous measles epidemics in the United States, according to the AAP *Red Book*.

The measles virus is transmitted by contact with infectious droplets or by airborne spread when an infected person breathes, coughs or sneezes. Measles virus can remain infectious in the air up to two hours after an infected person leaves an area.

Illness onset (high fever, cough, runny nose and red, watery eyes) begins a week or two after someone is exposed. A few days later, a rash breaks out as flat, red spots on the face and then spreads down the neck and trunk to the rest of the body. A person is contagious about four days before the rash appears to four days after.

Other measles symptoms may include small spots in the cheek area inside the mouth, diarrhea and ear infection. Measles can lead to pneumonia, swelling of the brain, deafness, intellectual disability and death.

Most children who get measles are not up to date on recommended vaccines or are not old enough to get measles vaccine.

WHO, St. Jude launch groundbreaking international delivery of childhood cancer medicines

NEWS PROVIDED BY

World Health Organization

By WHO Media Team & St. Jude Children's Research Hospital



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Study: WHO, St. Jude launch groundbreaking international delivery of childhood cancer medicines

Current as of February 11, 2025

The World Health Organization (WHO) and St. Jude Children's Research Hospital have commenced distribution of criticallyneeded childhood cancer medicines in 2 of 6 pilot countries, through the <u>Global</u> <u>Platform for Access to Childhood Cancer</u> <u>Medicines</u>. Currently, these medicines are being delivered to Mongolia and Uzbekistan, with next shipments planned for Ecuador, Jordan, Nepal and Zambia. The treatments are expected to reach approximately 5000 children with cancer across at least 30 hospitals in these countries within this year.

The Global Platform is a first initiative of its kind. Countries in the pilot phase will receive an uninterrupted supply of qualityassured childhood cancer medicines at no cost. In low- and middle-income countries (LMICs), childhood cancer survival rates are often below 30%, significantly lower than those in high-income countries. Six additional countries have been formally invited to join the platform.

The initiative is poised to become the largest, with the goal of reaching 50 nations in

the next 5 to 7 years. It aims to eventually provide medicines for the treatment of approximately 120 000 children with cancer in LMICs, significantly reducing mortality rates.

"For too long, children with cancer have lacked access to life-saving medicines," said Dr Tedros Adhanom Ghebreyesus, WHO Director-General. "This unique partnership between WHO and St. Jude is working to provide quality-assured cancer medicines to paediatric hospitals in low-and middle-income countries. WHO is proud to be part of this joint initiative with St. Jude, bringing health and hope to children around the world."

Every year, an estimated 400 000 children worldwide develop cancer. The majority of these children, living in resource-limited settings, are unable to consistently obtain or afford cancer medicines. It is estimated that 70% of the children from these settings die from cancer due to factors such as lack of appropriate treatment, treatment disruptions or low-quality medicines.

"A child's chances of surviving cancer are largely determined by where they are born, making this one of the starkest disparities in global healthcare," said James R. Downing, MD, president and CEO of St. Jude. "St. Jude was founded on Danny Thomas' dream that no child should die in the dawn of life. By developing this platform, we believe this dream can someday be achieved for children stricken by cancer, irrespective of where they live."

(pediatrix

St. Jude and WHO announced the platform in 2021 to ensure children around the world have access to lifesaving treatments. The platform brings together governments, the pharmaceutical industry and non-governmental organizations in a unique collaborative model focused on creating solutions for children with cancer. The co-design approach addresses the broader needs of national stakeholders, with a focus on capacity building and longterm sustainability.

The platform provides comprehensive end-to-end support, from consolidating global demand to shaping the market, assisting countries with medicine selection and developing treatment standards. It represents a transformative model for the broader global health community working together to tackle health challenges, in particular for children and noncommunicable diseases. To accomplish this, St. Jude and WHO partner with UNICEF Supply Division, and the Pan American Health Organization (PAHO) Strategic Fund.



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Keeping Your Baby Safe from respiratory infections



Cold and flu season can be dangerous - especially for vulnerable infants and children. Fortunately, 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 hand sanitizers.

Provide Protective Immunity

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



Limit Contact with Others

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

Take Care of Yourself

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

RSV

flu

COVID-19 colds

Get Immunized

NARNING

Vaccinations save lives. Protecting your baby from RSV, COVID-19, flu, and pertussis lowers their risks for complications from respiratory infections.

Never Put a Mask on Your Baby

- Because babies have smaller airways, a mask can make it harder for them to breathe.
- Face masks and their straps pose a risk of suffocation and strangulation.
- Remember, a baby can't remove their mask if they're having trouble breathing.

If you feel sick or 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 viruses 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. www.nationalperinatal.org/rsv







The Moral Agency of High Reliability Organizing

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

Abstract

Academicians and outside experts have modified HROs better to understand high-reliability organizing and fit corporate business models. During this process, the moral agent who provided the reliability part of HRO has been injured, and HROs have not met their promise. In this paper, we discuss the importance of moral agency for the operation of an HRO and the effect of corporate behaviors similar to corporate psychopathy.

"The world is a horrible place. Those of us who know this cannot describe our experiences; we find it difficult to recount or describe our experiences. Our minds would die, no one would listen. Those who do not know this cannot believe or will not believe these experiences. The danger lies not from those who have experienced the horror, nor those who have not felt it or cannot. The danger lies in those who will not learn about the horror – an act"

Introduction

The world is a horrible place. Those of us who know this cannot describe our experiences; we find it difficult to recount or describe our experiences. Our minds would die, no one would listen. Those who do not know this cannot believe or will not believe these experiences. The danger lies not from those who have experienced the horror, nor those who have not felt it or cannot. The danger lies in those who *will not learn* about the horror – an act of almost willful disbelief. They seem to commit to their firmly held belief that such horrors couldn't or don't happen. There is tenacity in their *actions* on that belief, preventing their understanding in a way that could alleviate such horror. The world does not need to be as horrible.

We introduce our article in this manner to return HRO to its roots – HRO is what we learned from people who died. Colleagues of the authors died in their presence. The blood from which HRO lessons were learned also covered the hands of the authors. The authors were often the first to be with families and friends who witnessed these horrors.

"The authors' moral agency grew from a different dichotomy of right and wrong. It did not develop because of precision, by strictly following the rules, being algorithmically and programmatically correct. Their moral agency emerges from accuracy, fidelity to the emerging situation that brings us closer to our moving objective."

The authors' optimism emerged from the deaths that did not happen, the horror prevented. What drives their sense of agency is not visible to those who have not participated in these horrors. The authors' moral agency grew from a different dichotomy of right and wrong. It did not develop because of precision, by strictly following the rules, being algorithmically and programmatically correct. Their moral agency emerges from accuracy, fidelity to the emerging situation that brings us closer to our moving objective.

HRO is an act of earnest individuals who learn by doing, who will engage uncertainty. The female entertainment group on a sinking cruise ship (1-4), second year pediatric residents in a solo resuscitation (5), RCPs and LVNs in a pediatric subacute care facility (6)Chaplains in a prison (7, 8), or elementary school staff evacuating children after an on-campus shooting (9). We can describe more.

High Reliability Organizing does not keep score of errors or days since the last incident; distant leaders receive reports in real time. It is not the privilege of "masculine" objectivity over "feminist" subjectivity. (10). The High Reliability Organization did not develop from conferences, mnemonics, cute phrases and clichés, dramatic analogies, awards given or earned. HRO develops from the realization that any action can lead to death, *and any member operation can prevent that death*. HRO comes from the awareness that we can *engage a situation without a plan* (11), that *errors act as guides* into uncertainty(12). HRO comes from the acknowledgment that failure *is an option*, and that failure is to stop too soon.

To protect us from physical threats, the sympathetic nervous system drives our bodies to *operate on the hostile or adverse environment*. In doing so, the environment dispassionately *operates on the emotions and the human mind*. The cognitive and

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behavioral consequences of these emotional experiences can be latent or delayed. Horrible experiences become challenging to recall while we share with others readily becomes associated with shame or guilt.

The sympathetic nervous system operates with physical responses as well as mental and emotional changes to protect us from emotional and psychological threats. Whereas the behaviors we use for physical protection can be intentionally modulated, our emotional and cognitive functions operate from inaccessible, unconscious brain regions. Such wounds readily become scars with latent, surreptitious effects on behaviors, cognition, and emotion. These behavioral, cognitive, and emotional scars easily become normalized.

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The horror described in the opening paragraph does not have a measure of magnitude. What it does have is that what is routine for one operator can induce horror in another unpredictably. Although the range of stimuli is great, the brain's response is narrow.

An environmental physical, cognitive, or emotional threat activates the brain for the motor and cognitive means of protection. Such situations distort, in real time, cognitive functions. (13) The experience can leave residual wounds that become scars, affecting performance and the individual's life. In this paper, we discuss systemic and structural elements that contribute to moral injury.

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When we view our world this way, we can identify people and organizations oriented toward *effective performance* amidst adversity. These people view others with shared connectivity as assets who work together and engage in adverse environments. This type of person and organization increases the personal and organizational capacities that protect exploration of new environments for sustenance, knowledge, and even beauty. Their logic and knowledge take different forms because they actively engage a dangerous world. In the final analysis, they will create sustained, safe environments for us.

This is not to dismiss those who avoid extreme adversity. Some who avoid these situations operate quite capably when tested. (1, 14). Avoidance of hostile and adverse environments is also necessary for *efficient productivity*. To actively avoid a dangerous world, organizations, particularly corporations, create barriers to hazards that could impair production and identify risks that can or cannot be managed. In the final analysis, corporations will have created an abundance of life-enhancing goods and services.

Organizing for effectiveness in hazardous contexts is quite different from efficient production in a safe, stable environment. A structural or hierarchical organizational approach for a stable economic environment, we can have adverse systemic effects on the individual. Paradoxically, a fluid, operational approach for a hazardous environment will support the individual.

"Environmental pressure on the person or organization is transferred to behaviors. When the behaviors no longer work (you don't know what will work or what to do),"

Faced with a threat, the responses of the human sympathetic nervous system (1, 14), human survival behaviors (1, 14, 15), and organizational behaviors have elements that can be adaptive and maladaptive depending on the time and situation. We have described the maladaptive responses under the insurance term "inherent vice" (1). "Inherent vice" means "any existing defects, diseases, decay or the inherent nature of the commodity which will cause it to deteriorate with a lapse of time" (16). "The decay of a perishable cargo is not a cause; it is an effect" (17) Maladaptive behaviors develop when the individual or organization has not learned to modulate protective survival behaviors or when maladaptive behaviors have arisen through inaction (18) and reinforced through operant conditioning. Environmental pressure on the person or organization is transferred to behaviors. When the behaviors no longer work (you don't know what will work or what to do), the pressure is transferred from action (behaviors) to the mind (thoughts and emotions). At that moment our minds may switch from the inherent value, or strength, of stress, fear, and threat responses to their inherent vice: stress-impaired cognition, drive fear-circuit behaviors, and amygdala-driven behaviors. (19, 20)This becomes visible in an organization when sufficient individuals, whether executives, administrative, managerial, or line workers, begin to self-organize into a maladaptive response.

At the organizational level, we see a difference between the business organization and an HRO.

- Moral Agency.
- The Business Model
- Corporate Psychopathy

Moral Agency

Moral agency entails the capacity to deliberate over possible courses of action and their consequences and act based on this


deliberation. Not all agents are moral agents.

High reliability emerges from individuals who converge over a discrepancy or at a disruption. The underlying, or overlying, culture of HRO supports immediate engagement which grows into enactment.(18, 21). The individual gives the organization the ability to rapidly react and respond, maintaining close engagement with the situation.

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John Boyd, an influential US Air Force military tactician, developed aerial combat tactics based on a rapid loop method for decision-making, the "OODA Loop" named for its four cycling elements: Observe, Orient, Decide, Act, Observe the results of your action. (22)The "Orient Function" can be problematic; on the surface, it alludes to "orient to the situation." However, it has a more significant meaning that draws in corporate culture and an operator's sense of agency.

In Organic Design for Command and Control (23) Orientation represents images, views, or impressions of the world shaped by genetic heritage, cultural tradition, previous experiences, and unfolding circumstances. As an active cyclic process, the OODA Loop is interactive of "many-sided implicit cross-referencing projections, empathies, correlations, and rejections that is shaped by and shape the interplay of genetic heritage, cultural tradition, previous experiences, and unfolding circumstances."

For Boyd, the power of his method lay in an individual's use of the OODA Loop with shared 'orientations'. Leaders and subordinates would interact with each other and the external world.

Arrange the setting and circumstances so that leaders and subordinates alike are given the opportunity to continuously interact with the external world, and with each other, in order to more quickly make many-sided implicit cross-referencing projections, empathies, correlations, and rejections as well as create the similar images or impressions, hence a similar implicit orientation, needed to form an organic whole (24).

In the United States, the American Medical Association vetted depictions of physicians in movies and television. A television show about paramedics was being developed. The medical advisor, Ronald Stewart, believed the depictions of paramedics must have accuracy to demonstrate the close, collegial interactions of paramedics, nurses, and doctors. This was the first television show depicting these interactions, which has since become standard in the US. Stewart wanted to point out that high-risk medical care across different environments mandated close interaction, much like Boyd described above (personal communication, DvS). This is the sense of agency that the individual has a sense of personal influence in the situation.

The organization's culture may not allow a response-based approach to learning, which is fundamental to the sense of agency. Without achieving the capability for response-based organization, the operator will not achieve the expert skill level, remaining at the proficient level (25).

Novices in an HRO, such as the fire service or nursing, are encouraged to make decisions, trusting that senior staff will be observing. Patricia Benner et al. (26) observed that this "allows them to absorb information as fact. This trust sets up qualities of freedom and exhilaration in learning that are only available to those who do not yet comprehend the contingent nature of the situation and what is known about it.

Moral Values and Agency

Interdependent actions, as described above, are supported by tacit communication, which emerges from trust and values. For Boyd, human values (he termed 'moral values') made for group cohesion, which was more valuable to success than material superiority (26). Benner also found that moral agency increased the effectiveness of nursing work, constituting a community for coordinated and concerted action (Proficiency: A Transition to Expertise (27)).

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Moral agency and the development of expertise in nursing develop together through increased practice skills and insights gained from experience. Engagement becomes driven, bringing the nurse more attuned to the profession. Nurses with difficulty understanding the ends of practice, interpersonal skills, and skills at problem engagement did not achieve the level of expertise. In nursing, moral agency aspects develop at the expert level (27).

- Clinical grasp and response-based practice
- Embodied know-how
- Seeing the big picture
- Seeing the unexpected

Boyd describes his concepts of moral strength in "Observations Related to Moral Conflict," *Patterns of Conflict* (23).

- Moral values: Human values that permit one to carry on in the face of menace, uncertainty, and mistrust
- Moral strength: Mental capacity to overcome menace, uncertainty, and mistrust
- Moral authority: A person or body that can give one the courage, confidence, and esprit to overcome menace, uncertainty, and mistrust
- Moral victory: Triumph of courage, confidence, and esprit (de corps) over fear, anxiety, and alienation when confronted by menace, uncertainty, and mistrust
- Moral defeat: Triumph of fear, anxiety, and alienation over courage, confidence, and esprit when confronted by menace, uncertainty, and mistrust

Moral Agency

Moral agency describes the capacity to deliberate over possible courses of action and their consequences. Based on this deliberation, the moral agent is free to act (28). Moral agency is also based on experienced-based moral perception in practical situations and the nurse's capacity to respond quickly and effectively (27).

The Business Model:

Businesses must gain compliance from their members and have an appropriate flow of information. A business's profit motive can interfere with an HRO's safe and reliable operations. That sentence is from the view of a person who could die in operations. A different point of view comes from the business model—cost avoidance. To an organization aspiring to become an HRO, cost avoidance is a prelude to collapse.

Cost avoidance is strong during the stability of a white noise environment, supporting the conventional for-profit business model. However, it falls when a catastrophic event abruptly appears within the stability of white noise or when a red noise forcing function begins its slow movement of long-standing change. The costs avoided have shredded any support from backup systems or safety nets. Safety is a cost we cannot control, banking safety for a rainy day.

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Corporations thrive in stable environments. With slight environmental variance and the burden of regulation, corporations develop rules to conform to the law and identify standards to maintain quality. Just as cost avoidance damages safety and reliability, strict rules create strong but wrong rules, crippling safety and reliability while facilitating moral injury.

Corporate Compliance

Corporations control the actions of their members. Otherwise, it would be an association where members act freely for their selfinterest. Corporations can be simple, but the actions of larger corporations, such as 'complex organizations,' will affect a larger geographic area and a more significant population.' Compliance is gained through centralized power (29).

Organizations exhibit three kinds of power over employees, often combined, but one kind will predominate. Employees have three types of involvement (29).

Kinds of power:

• Coercive power. Maslow describes restriction of movement or controlling how members can meet their needs (30).

- Remunerative power. Control over rewards through wages, commissions, fringe benefits, and services.
- Normative power. Allocation of symbolic rewards of esteem and prestige, administrative titles, and titles associated with promotions.

Kinds of involvement:

- Alienative. An intense, negative orientation.
- Calculative. A low-intensity orientation that can be negative or positive
- Moral. High intensity with a positive orientation.
 - Pure moral commitment internalizes norms and identity with authority and is internally directed as a "mode of conformity."
 - Social commitment responds to pressures from primary groups and their members; it is "other-directed."

We can think of prisons using coercive power over people with alienative involvement. Corporate businesses use the remunerative power of pay to control calculative individuals working for money, a utilitarian involvement. Colleges, universities, and churches allocate symbolic awards and administrative titles such as instructor, assistant professor, and professor. These individuals have a moral involvement in normative rewards.

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This comes in handy when identifying what is important to employees and when. Coercive methods are more indicative of problematic leadership or unreliable systems.

Matching the kind of authority power with the employee's involvement improves employee motivation. However, it is not so simple, as employees will have different involvement types at different times. Wrong matching leads to punishing a normative employee who would take the punishment as a sign they are right – the worse the punishment, the more normative the employee becomes.

Nevertheless, this endeavor to control behavior, rather than influence behavior, comes from a belief in the power of coercion (supported by observations of its immediate effect, movies, and television) and the belief in the power of force.

Stress reduction for people of higher authority is a more nefarious reason to control human behavior. The elements of stress are novelty, uncertainty, and uncontrollability. Control of behavior reduces novelty as the person with higher authority will then observe familiar behavior in subordinates. One of the authors (DvS) and his associate (Ronald M. Perkin) used reverse methods to teach endotracheal intubation to residents. Sitting to the side, they watched for unexpected activity, a disruption that signaled the resident had hit a snag. At that point, the attending physician would move closer to find the problem.



Compliant behavior also reduces uncertainty as the individual with authority, at the minimum, sees the team working in a concerted, familiar, and, therefore, predictable manner. Far worse is the control of behavior, observed with raised voices and pointed remarks. The greater the person's stress, the more structured the person becomes in controlling people's behavior.

"The degree of stress experienced by consulting physicians in an ICU room could be observed by how often they turned the display knob on a mechanical ventilator. They would observe the chest, turn the knob, read the numbers, observe the test, and repeat. What they saw on the ventilator was not a new setting but different displays."

The degree of stress experienced by consulting physicians in an ICU room could be observed by how often they turned the display knob on a mechanical ventilator. They would observe the chest, turn the knob, read the numbers, observe the test, and repeat. What they saw on the ventilator was not a new setting but different displays. This was like the "producer's knob" in a recording studio. Not connected to anything, it would thwart "non-knowledgeable" participants from detrimental influence (31). In experimental situations simulating life in combat, those recruits who remained at their radio post had focused on repairing a "nonfunctional" radio needed for evacuation. Those recruits unfamiliar with radio repair stopped using the radio and self-evacuated (32).

Quantum models of cognition and decision-making are based on contextuality, which is how conditions of uncertainty interfere with a person's inferences and decisions (33). Classical logics assume discrete elements and time measures. Logics used in HROs and quantum theory allow for partial truths (modal logics) and accept conflicting information (paraconsistent logics) (34). Cognitive decision-making models assume we can immediately know the antecedent state of mind before the inquiry. In quantum cognition, the act of deciding *creates* the cognitive state.

This model of the act creating the cognitive state is like Niko Tinbergen's approach to animal behavior. The act of deciding creates the behavior. The antecedents remain unidentified since we do not investigate until we see the behavior. Therefore, Tinbergen looked at the function of behavior. Raymond Novaco, studying anger, followed Tinbergen's approach to identify the function anger has for an individual [personal communication, DvS].

Quantum cognition investigates the 'function' of a decision, as Tinbergen investigated the 'function' of behavior (15). Deciding can also create an emotional state of fear or gastric distress (tonic immobility), strongly influencing social interactions and collaborative decision-making (35).

The control of behavior has the attraction of explaining human behavior in empirical and secular terms. Instead, each of us wrestles with what, in that moment, is right or wrong, good or bad (30). We cannot see the future when every moment is contingent on prior events and the concurrent, contextual environment.

There is no single trajectory or algorithm for a decision, leaving the individual conflicted until the moment of decision (33). Irving Janis and Leon Mann identified the effects of such conflict on decision-making (36). Some may find their answer in modern religions or some form of spirituality, their form of moral wrestling. Others find guidance in those who do not conform to the norms of their disciplines - those with moral agency (30).

Information Flow

The typology of corporate compliance has a strong influence on information flow. One of the authors (DvS) characterized emergency services, and later HRO, as a mix of authority migration and information flow (5). It is a small step to appreciate coercive power, and alienated employees have limited, unreliable information flow and no authority migration. While this may seem trite, some with authority view employees as lazy and dishonest, needing coercive guidance. This occurs in universities, professional medical centers, and religious institutions.

Information flow increases as the organization relies on remunerative power to encourage utilitarian, calculative employees. With greater professionalism or treating all employees as professionals, normative power encourages the development of moral normative employees with a sense of moral agency.

In 1977, one of the authors (DvS) was detailed at a fire station where some of the first paramedics in the state were assigned. The rescue ambulance journal had an entry describing a victim kicked in the groin, but the words were crude slang terms. Later, I asked my fire captain, William Corr, why the medics did not use medical terms. We judge people by their use of language. Further, I asked why some of them, with 30 years as firefighters, did not take the promotion test and use their longevity and WWII veteran's points to be promoted for a higher salary and then retire at higher pay.

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Capt. Corr responded, "Davey, those men went through the Depression. They fought in the war. They are able to provide shelter and food for their families. They have a car. They are successful. They are the most successful people in their families."

When I encounter someone looking down on others, whether due to race, gender, economic status, or whatever, I tell the story. That secretary, LVN, CNA, or whoever is the most successful person in their family. They may be the only one in their family with a secure full-time job, the only one who attended college. They are the most successful person in their family. We should respect them for that. We should respect them for their success...for being the most successful person in their family.

Information flow also increases with proximity. Foreign object debris (FOD) on the deck of a US Navy nuclear-powered aircraft carrier could damage a jet engine, causing a fatal crash. About



five times a day, the crew walked the deck, a FOD walk, to pick up such debris. As captain, one of the authors (TAM) would join the walk as often as possible, walking amongst the seamen. At some point on that long walk, the seaman on either side of him would feel compelled to talk. The author reduced the authority gradient, built morale, and opened the flow of information.

"Information is valuable in the HRO, and anomalous information is the most useful. Anyone can identify overt decompensation in a patient's system. Using time as a dimension, the HRO seeks out information when the patient or system compensates, making identifying it more difficult. Moving earlier makes the compensated system covert; only the subtle and nuanced signal is identified. "

Information is valuable in the HRO, and anomalous information is the most useful. Anyone can identify overt decompensation in a patient's system. Using time as a dimension, the HRO seeks out information when the patient or system compensates, making identifying it more difficult. Moving earlier makes the compensated system covert; only the subtle and nuanced signal is identified. This is the critical point, as such anomalous information is weak noise to the HRO but can be disregarded as noise in the corporate model.

Ron Westrum studied organizational information flow as a cultural classification (37). He found a continuum of safety cultures in three main categories: pathological, bureaucratic, and generative (38).

- Pathological organizations contain fear and threat; people often hoard or withhold information, often for political reasons, or information is distorted for manipulation.
- Bureaucratic organizations protect departments; people are territorial, maintaining the autonomy of their section, insisting on their own rules, and following the organization's main rule book or the department's rule book. Of note, this is a method the Office of Strategic Services taught civilians for sabotaging a factory in Nazi-occupied Europe (39)
- Generative organizations focus on the mission, working toward a common goal, subordinating everything that interferes with performance.

HRO and the Business Model

Some business leaders want to see a business model for HRO before they adopt it as part of their program. HRO must directly and concretely support and benefit the business. They must see clear causality between HRO elements and measurable improvement in their business performance (5).

Other business leaders want HRO to guarantee safety. However, high-reliability organizations were initially developed to operate in environments where internal harm can come from operations or the business situation itself. HRO in the native state does not distinguish safety from business operations – there is safety through operations and operations through safety. Because

an injured member reduces the team's performance, the HRO embeds safety into operations (5).

It is instructive to look at the actions the US Navy has taken. In 1954, the Navy lost 536 people, and 776 aircraft were destroyed in flight accidents. The Navy did not isolate safety as a separate entity: safety was an essential means to maintain operations integral to the Navy's function. Rather than search for a proven intervention, the Navy studied itself, identified weaknesses, corrected them, and then searched for more weaknesses. One seldom-discussed effect on accident reduction was the change in the assignment of aviators and the selection of command leaders, from those with connections to those with the most qualifications. The actions and approach to problem-solving of the US Navy

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Corporate Psychopathy

Organizations can meet the legal requirements of a country, allowing them to pursue the single-minded pursuit of profit. The organization can focus solely on profit maximization. As examples, organizations, as described above, can:

- Contain "fear and threat, information is hoarded or withheld, often for political reasons, or information is distorted for manipulation.
- Treat employees as alienative, having an intense, negative orientation who respond best to coercive behavioral measures.
- Treat employees as calculative, gaining compliance through wages and benefits. The organization protects itself and maintains autonomy, setting its own rules internally and conforming to the letter of the law externally.
- Organizations can also have callous unconcern for those who are not customers and incapable of maintaining good customer relations, relying on call centers to avoid customer service. An organization is expected to use deceitfulness in business negotiations. Some organizations, not all, disregard neighbors' safety or invest in factories in thirdworld countries to avoid costs for health and safety. In that, they fail to conform to social norms. When caught, the organization does not seem to experience guilt (40).

The last bullet point is derived from the World Health Organisation's (WHO) ICD-10's Manual of Mental Disorders DSM-IV. Joel Bakan (41) based the bullet material on a personality diagnostic checklist measured against WHO's six criteria for human psychopathy.



The authors are not qualified to diagnose anyone with psychopathy, whether human or corporation. The authors can identify some organizational traits expected in a for-profit corporation. The authors also have the expertise to evaluate whether characteristics shared by a corporation and human psychopath will support the principles of HROs.

HROs encourage the development of moral agency in all members. The profit orientation of a corporation can contaminate the culture of an HRO. Witness the medical literature on burnout and moral injury. It is not the only reason that fire departments, law enforcement agencies, and the military do not run on a cost-savings basis, nor are they directed to turn a profit.

Such organizations can, however, reduce costs through HRO principles. They can demonstrate that prevention is cheap in the long run, and people perform better in the HRO environment when treated as assets rather than commodifying employees.

Corporation as Moral Agent

Can institutions be moral agents? Moral refers to an individual's ability to make moral choices based on right and wrong and to be held accountable for these actions.

The above discussion reinforces those who see the evil in corporate management and brings challenges from those familiar with moral corporations. This paper aims to identify these elements, allowing individuals to have a more informed understanding.

The moral agent must have the deliberative capacity, accept the role of the moral agent, and accept moral responsibility for the institution's actions. Legal responsibility is ascribed in the legal system beyond the purview of moral agency. For moral responsibility, we have *prospective responsibility* where the institution performs an action given certain conditions. Then, there is retrospective responsibility from acts of commission or omission that can bring praise or blame. Does the institution have the capacity for ethical reasoning? It may be less institutional and more of a specific group of solidarity that shares similar morals, a 'collective responsibility' (28)

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Another view is to ask if the institution can meet the necessary abilities of a moral agency: intentionality, autonomy, and an ability to act. One can question intentionality and autonomy because they require the ability to be aware on behalf of the agent. Indirectly, these attributes would be derived from individuals within the corporation with moral responsibility (42).

Wim Dubbink and Mollie Painter-Morland argue that the corporate form is primarily a legal agent maintained as a legal fiction, an instrument of the state. The state may then conduct corporate actions following national social welfare goals (42).

"High-reliability organizing is an organizational system that convergently evolved from enlightened programs operating in dangerous contexts. The transformation of HRO to a business model has sapped its vitality through adaptation for the better understanding of business leaders and management science academicians."

Corporate Psychopathy, Moral Agency

It is beyond the scope of this particular article to discuss the events when a moral agency, a necessity for the function of an HRO, meets corporate psychopathy, a natural behavior of a capitalized institution. However, this may explain burnout, attrition, and moral injury in dedicated 'social warriors.'

Conclusion

High-reliability organizing is an organizational system that convergently evolved from enlightened programs operating in dangerous contexts. The transformation of HRO to a business model has sapped its vitality through adaptation for the better understanding of business leaders and management science academicians.

This has placed a compelling, cost-efficient program in service of organizations, some of whom have moral agency while others have corporate psychopathy. Moral agents have suffered, and the expectations of the served populations will not be met.

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Keeping Your Baby Safe from respiratory infections



Cold and flu season can be dangerous - especially for vulnerable infants and children. Fortunately, 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 hand sanitizers.

Provide Protective Immunity

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



Limit Contact with Others

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

Take Care of Yourself

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

RSV

flu

COVID-19 colds

Get Immunized

NARNING

Vaccinations save lives. Protecting your baby from RSV, COVID-19, flu, and pertussis lowers their risks for complications from respiratory infections.

Never Put a Mask on Your Baby

- Because babies have smaller airways, a mask can make it harder for them to breathe.
- Face masks and their straps pose a risk of suffocation and strangulation.
- Remember, a baby can't remove their mask if they're having trouble breathing.

If you feel sick or 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 viruses from spreading.
- Watch out for symptoms like fever, confusion, or trouble breathing.
- Ask for help caring for your baby and yourself while you recover.

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TAKE THE NECESSARY STEPS TO ELIMINATE INEQUITIES



How to Care for a Baby with Signs of Withdrawal



Use the Right Words

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

Treat Us as a Dyad

Parents and babies need each other. Help us bond. Whenever possible, provide my care alongside my parents and teach them how to meet my needs.



Support Rooming-In

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



Promote Kangaroo Care

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

Try Non-Pharmacological Care



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

Provide Lactation Support

Human milk is important to my gastrointestinal health and breastfeeding is recommended when my parent is HIV-negative and receiving medically-supervised care. Help my family reach our pumping and feeding goals.



Treat My Symptoms

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



inata

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Review Committee for Pediatrics (RC-Peds) Nominee Qualifications



To qualify to be nominated to the RC-Peds for this position, the candidate:

- must be a board-certified pediatrician or pediatric subspecialist with a background in education and expertise in graduate medical education.
- should have at least three years of experience as a program director of an ACGME-accredited
 pediatrics residency program or pediatric subspecialty fellowship or three years of experience as a
 designated institutional official. The nominee's program must be in good standing with a status of
 Continued Accreditation.
- must have a current or past association with graduate medical education.
- should participate in major specialty societies.
- must be skilled in the use of computers (communication with staff is primarily through email, and members will use electronic systems for receipt of agenda materials, program reviews, reimbursement of expenses, and peer evaluations).
- must demonstrate fairness, the ability to work collaboratively, and express views clearly and concisely.
- must be able to attend an observation meeting, April 10-11, 2025, prior to the start of the term.
- must devote sufficient time to prepare for and participate in three RC meetings per year (January, April, and September), two-three days per meeting, as well as contribute to RC-Peds subcommittee work as assigned.
- ideally, will not hold the same subspecialty certifications as the members of the RC-Peds at the time of appointment. The RC-Peds strives to maintain a balance of specialties; it is preferable that individuals from the following specialties are not nominated:
 - General Pediatrics
 - Internal-Medicine Pediatrics
 - Pediatric Hospital Medicine
 - Pediatric Emergency Medicine
 - Neonatal-Perinatal Medicine
 - Pediatric Critical Care Medicine
 - Pediatric Endocrinology
- must not be at the same institution as any member of the RC-Peds at the time of appointment.
 - Same-Institution Disqualification: Although the RC-Peds may have multiple members from the same state, they may not be from the same institution. Accordingly, individuals must not be nominated from the following institutions:
 - UC Davis (Davis, CA)
 - Stanford University (Stanford, CA)
 - University of Colorado (Aurora, CO)
 - Advocate Children's Hospital (Park Ridge, IL)
 - Mayo Clinic (Rochester, MN)
 - Columbia University College of Physicians & Surgeons (Yonkers, NY)
 - Goryeb Children's Hospital-Atlantic Health System (Morristown, NJ)
 - University of North Carolina School of Medicine (Chapel Hill, NC)
 - Cincinnati Children's Hospital Medical Center (Cincinnati, OH)
 - University of Texas Health San Antonio (San Antonio, TX)
 - University of Washington/Seattle Children's (Seattle, WA)

The RC-Peds expects the AAP to consider diversity and inclusion when submitting its nominations.

"Even in the middle of taking this course, I could see myself changing the way that I spoke to parents. After taking this course, I am much better at emotionally supporting our NICU families."

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Peer Reviewed

Inpatient Prenatal Consultation

Scott D. Duncan, MD, MHA

"As mentioned in the article from December 2024, Neonatology Today has published nearly 30 articles in the past five years on coding, including using Current Procedural Terminology (CPT) and International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10), documentation support and clinical documentation improvement, and the impact on facility and provider reimbursement."

As mentioned in the article from December 2024, Neonatology Today has published nearly 30 articles in the past five years on coding, including using Current Procedural Terminology (CPT) and International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10), documentation support and clinical documentation improvement, and the impact on facility and provider reimbursement. As noted, in future articles, we will attempt to provide a more structured approach, "beginning at the beginning," while interspersing timely articles addressing hot topics, annual changes, and tips to improve coding, documentation, and revenue. We hope you enjoy the updated format and discover some tips! To begin, at the beginning, let us consider the inpatient perinatal consult.

"We hope you enjoy the updated format and discover some tips! To begin, at the beginning, let us consider the inpatient perinatal consult."

Question

Dr. Smith requests that the neonatologist meet with a recently admitted pregnant woman who presented with preterm labor and PROM at 25 completed weeks of gestation. The neonatologist spends 60 minutes on the mother's floor/unit meeting with the

patient, discussing anticipated neonatal care, resuscitation, and documenting in the medical record. For that day's services, the neonatologist reports:

- 99222: Initial Hospital inpatient, straightforward or low MDM, Α. 55 minutes met or exceeded
- В. 99233: Subsequent Hospital inpatient, straightforward or low MDM, 50 minutes met or exceeded
- C. 99253: Inpatient consultation for a new or established patient, low MDM, 45 minutes met or exceeded
- D. 99254: Inpatient consultation for a new or established patient, moderate MDM, 60 minutes met or exceeded



"Codes 99252-99255 are used to report consultations provided to inpatients when the patient has not received any face-toface professional services from a qualified healthcare provider of the same specialty and subspecialty who belongs to the same group practice during the stay (this also applies to APRNs and PAs)."

<u>Answer</u>

D. 99254: Inpatient consultation for a new or established patient, low MDM, 60 minutes met or exceeded

Codes **99252-99255** are used to report consultations provided to inpatients when the patient has not received any face-to-face professional services from a qualified healthcare provider of the same specialty and subspecialty who belongs to the same group practice during the stay (this also applies to APRNs and PAs).

СРТ	MDM	Time
99252	Straightforward	At least 35 min
99253	Low	At least 45 min
99254	Moderate	At least 60 min
99255	High	At least 80 min
If the encounter exceeds 95 min, add +99418 (for each 15 minutes of prolonged inpa- tient/observation time)		
Table 1 – Inpatient Consultation Codes		

"Suggestions related to medical management should also be documented in the consultation note. The examples above use time as the basis for the correct CPT code (vs. Medical Decision Making); therefore, time spent on the day of service, including face-to-face time, should be recorded."

Question

The correct ICD-10 codes include all the following except:

- A. **O42.012**: Preterm premature rupture of membranes, onset of labor within 24 hours of rupture, second trimester
- B. 060.02: Preterm labor without delivery, second trimester
- C. P07.24: Extreme immaturity of the newborn, 25 weeks completed
- D. Z3A.25: 25 weeks gestation of pregnancy



<u>Answer</u>

C. P07.24: Extreme immaturity of the newborn, 25 weeks completed

P codes are restricted to the newborn chart and are never to be used in the maternal chart! Also, note the use of Z3A.XX. These codes are restricted to use on the maternal chart and reflect the currently completed weeks of pregnancy.

Question

The mother has remained hospitalized and is now 32 completed

"P codes are restricted to the newborn chart and are never to be used in the maternal chart! Also, note the use of Z3A.XX. These codes are restricted to use on the maternal chart and reflect the currently completed weeks of pregnancy. "

weeks of gestation. She has been on a course of antibiotics and completed a course of betamethasone. Dr. Jones requests a follow-up consultation. The neonatologist spends 40 minutes on the mother's floor/unit meeting with the patient and her family, discussing anticipated neonatal care, and documenting the medical record. For that day's services, the neonatologist reports:

A. 99221: Initial Hospital inpatient, straightforward or low MDM, 40 min met or exceeded



- **B. 99252**: Inpatient consultation for a new or established patient straightforward MDM, 35 min met or exceeded
- C. 99253: Inpatient consultation for a new or established patient with low MDM, 45 min met or exceeded
- D. 99232: Subsequent Hospital inpatient, moderate MDM, 35 min met or exceeded



<u>Answer</u>

D. 99232: Subsequent Hospital inpatient, moderate MDM, 35 min met or exceeded

Only one consultation code may be reported by a consultant per admission. Follow-up consultations or consultations addressing a different problem performed by a qualified healthcare provider of the same specialty and subspecialty who belongs to the same group practice during the same admission are reported using subsequent inpatient hospital care codes 99231-99233.

СРТ	MDM	Time
99231	Straightforward or Low	At least 25 min
99232	Moderate	At least 35 min
99233	high	At least 50 min
If exceed 65 min, add +99418 (each 15 minutes of pro- longed inpatient/ observation time)		

Table 2 – Subsequent Hospital Inpatient Codes

Documentation Tip

Consultations require a written report for proper coding and billing. Documentation must support all code assignments, including appropriate diagnosis. In documentation of a consultation, the referring physician's name must be included in the note. Appropriate maternal history and current conditions should be noted for maternal consults, and pertinent information should be reviewed with the family. Suggestions related to medical management should also be documented in the consultation note. The examples above use time as the basis for the correct CPT code (vs. Medical Decision Making); therefore, time spent on the day of service, including face-to-face time, should be recorded.

References:

Coding for Pediatrics 2025, 30^{th} Edition. American Academy of Pediatrics

Current Procedural Terminology 2025, Professional Edition. American Medical Association

Disclosures: The authors have no disclosures

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Respiratory Viruses:

What parents need to know this RSV and flu season



Like COVID-19, RSV (Respiratory Syncytial Virus) and flu affect the lungs and can cause serious breathing problems for children and babies. Talk to your family about the risks.

Certain diagnoses can make children and babies more vulnerable for serious complications from respiratory viruses - including prematurity, chronic lung disease, and heart conditions.

You can limit the spread of viruses by wearing a mask, washing your hands with soap & water, using an alcohol-based hand sanitizer, and getting vaccinated.

The fewer germs your baby is exposed to, the less likely they are to get sick. Let people know you need their help to stay well. Limit visitors. Avoid crowds. Stay away from sick people.



Immunizations save lives. Stay up-to-date with your family's flu vaccinations and COVID-19 boosters. This helps our community stay safe by stopping the spread of deadly viruses.

Babies older than 6 months can get a flu shot and COVID-19 vaccinations. Now there are new vaccines for RSV for adults and antibody shots for babies that can help protect them.



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More than



of infants hospitalized for RSV had no underlying conditions.

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Peer Reviewed

Genetics Corner: Mini-Review: Rapid Whole Genome Sequencing (rWGS) and Whole Exome Sequencing (rWGS and rWES) in the NICU—Current Applications, Challenges, and Future Directions

Hua Wang M.D., Ph.D., Kimberly Hillyer DNP, RN, LNC, NNP-BC

"Rapid whole genome sequencing (rWGS) and rapid whole exome sequencing (rWES) have transformed neonatal intensive care unit (NICU) diagnostics by enabling timely genetic diagnoses in critically ill neonates. With a 30–50% diagnostic yield and turnaround times as fast as 48–72 hours, these technologies have significantly influenced clinical management, leading to targeted therapies, surgical decisions, and informed palliative care."

Abstract

Rapid whole genome sequencing (rWGS) and rapid whole exome sequencing (rWES) have transformed neonatal intensive care unit (NICU) diagnostics by enabling timely genetic diagnoses in critically ill neonates. With a 30–50% diagnostic yield and turnaround times as fast as 48–72 hours, these technologies have significantly influenced clinical management, leading to targeted therapies, surgical decisions, and informed palliative care. Largescale studies have demonstrated that rWGS and rWES contribute to improved patient outcomes, with diagnosis-driven interventions occurring in up to 80% of cases. However, the widespread adoption of these approaches remains limited due to challenges, including the lack of standardized clinical guidelines, complexities in variant interpretation, ethical considerations surrounding secondary findings, and inconsistent insurance reimbursement policies. This mini-review explores the current applications of rWGS and rWES in the NICU, examines key barriers to implementation, and proposes a framework for standardized protocols and equitable access. Establishing evidence-based criteria, integrating genomic workflows into neonatal care, and addressing financial and ethical concerns will be essential for optimizing the clinical utility of rapid genomic sequencing in critically ill newborns.

I. Introduction

The Growing Role of Genomic Medicine in the NICU:

Integrating genomic medicine into Neonatal Intensive Care Units (NICUs) has transformed the precision medicine landscape. With many infants admitted to the NICU in critical condition,

exome sequencing (rWGS and rWES) have emerged as the possibility of severe and life-limiting problems enables early molecular diagnosis, which can prompt discussions about withdrawal or targeted treatment as soon as possible. Many neonates with multiple congenital anomalies, unexplained metabolic disorders, or complex multisystem conditions often undergo extensive diagnostic workups involving multiple imaging studies, biochemical tests, and genetic assessments. These traditional approaches can be time-consuming and delay targeted interventions.

"Many neonates with multiple congenital anomalies, unexplained metabolic disorders, or complex multisystem conditions often undergo extensive diagnostic workups involving multiple imaging studies, biochemical tests, and genetic assessments. These traditional approaches can be time-consuming and delay targeted interventions."

Historically, genetic testing in the NICU has relied on conventional methods such as karyotyping, chromosomal microarray (CMA), and targeted gene panels. While these techniques have been instrumental in identifying chromosomal abnormalities and single-gene disorders, they have limitations in diagnostic yield and turnaround time (1). Karyotyping, which can detect large chromosomal aberrations, lacks the resolution to identify smaller pathogenic variants. CMA improves upon Karyotyping by detecting copy number variations but cannot identify single-nucleotide variants or deep intronic mutations. Targeted gene panels for known genetic conditions are restricted to that gene set and may miss unexpected diagnoses.

Rapid whole genome sequencing (rWGS) and whole exome sequencing (rWES) produce a broad approach, allowing the analysis of thousands of genes. These advanced sequencing methods significantly enhance the speed and accuracy of diagnosis, enabling clinicians to implement precision-based treatments and optimize neonatal care. In life-threatening, time-critical scenarios, adopting rWGS and rWES into routine NICU practice can reduce diagnostic crusades, improve clinical decision-making, and ultimately enhance survival and long-term outcomes for critically ill neonates.

Advancements in Rapid Genomic Sequencing:

Rapid whole genome sequencing (rWGS) and rapid whole

powerful diagnostic tools to address these challenges, offering higher diagnostic yields (30–50%) and shorter turnaround times (48–72 hours) compared to conventional genetic testing (2, 3). Multiple studies have demonstrated that early genomic diagnosis through rWGS, rWGS, and rWES significantly influences clinical management, guiding targeted treatments, surgical decisions, and even palliative care for neonates with life-threatening conditions (4-6).

"Multiple studies have demonstrated that early genomic diagnosis through rWGS, rWGS, and rWES significantly influences clinical management, guiding targeted treatments, surgical decisions, and even palliative care for neonates with lifethreatening conditions (4-6)."

A large-scale national cohort study in the United Kingdom reported a 38% diagnostic rate for rapid trio genome sequencing in NICUs, resulting in clinical management changes in 80% of diagnosed cases (7-9). Similarly, a U.S. study of 184 critically ill neonates found that rWGS and rWES yielded clinically actionable results in 43% of cases, with medical management changes occurring in nearly half (2).

Estimated Incidence and Economic Impact of Genetic Diseases in the NICU:

The true incidence of single-locus genetic diseases in neonates remains uncertain, but estimates suggest they affect approximately 5.3% of newborns, varying by population and geography (6). Data from multiple NICU studies indicate that the incidence of genetic diseases may be as high as 15% among critically ill infants (10). The economic burden of genetic disorders in neonates is substantial—healthcare costs for children with genetic diseases are nearly five times higher than for those with other chronic conditions (6). In the U.S., NICU admissions exceed 400,000 annually, costing over \$17 billion (3). Given these financial and clinical implications, identifying and diagnosing genetic disorders early through rapid sequencing is crucial for optimizing care and resource allocation.

"Despite its transformative potential, the implementation of rWGS, rWGS, and rWES in NICUs remains inconsistent due to the lack of standardized protocols, institutional guidelines, and reimbursement policies."

Challenges and Ethical Considerations:

Despite its transformative potential, the implementation of rWGS, rWGS, and rWES in NICUs remains inconsistent due to the lack of standardized protocols, institutional guidelines, and reimbursement policies. The absence of a universal consensus on when to initiate rWGS and rWES, which neonates qualify for testing, and how to interpret results leads to disparities in access, misinterpretation of genetic findings, and ethical dilemmas related to variant classification and secondary findings. Ethical concerns include parental consent in high-stress NICU environments, challenges in managing secondary findings, and potential disparities in access to genomic medicine based on socioeconomic factors (11).

Objectives of This Mini-Review:

This review aims to explore the current applications of rWGS, rWGS, and rWES in the NICU, highlight existing challenges, and propose a framework for developing standardized protocols to optimize their clinical utility. Addressing these issues will ensure equitable access to genomic testing, improve diagnostic efficiency and ultimately enhance patient outcomes in critically ill neonates.

II. Current Applications of Rapid Whole genome sequencing and Whole exome sequencing (rWGS and rWES) in the NICU:

Rapid Whole genome sequencing (rWGS) and whole exome sequencing (rWGS and rWES) have become an essential diagnostic tool in the neonatal intensive care unit (NICU), particularly for critically ill neonates with suspected monogenic disorders. The ability of rWGS, rWGS, and rWES to provide a timely molecular diagnosis within 48–72 hours allows for informed decision-making in cases where traditional genetic testing takes weeks or even months. Using rWGS, rWGS, and rWES has demonstrated a high diagnostic yield (30-50%), significantly impacting medical management, including targeted treatments, surgical interventions, and palliative care strategies.

1. Indications for rWGS and rWGS and rWES in the NICU:

The primary indication for rWGS and rWES in neonates includes cases where a rapid genetic diagnosis can influence medical management. Current studies and clinical guidelines suggest the following key indications for rWGS, rWGS, and rWES in the NICU:

a) Neonates with Severe Congenital Anomalies

- Infants presenting with multiple congenital malformations (e.g., heart defects, skeletal anomalies, craniofacial dysmorphism) often undergo multiple diagnostic tests without a clear etiology. rWGS and rWES can provide a definitive diagnosis in up to 40% of cases, reducing the need for invasive procedures and unnecessary imaging.
- For example, in a multicenter study involving neonates with congenital anomalies, rWGS and rWES identified pathogenic variants in genes associated with CHARGE syndrome, Kabuki syndrome, and RASopathies, allowing for early targeted interventions (4)

b) Neonates with Multisystem Involvement

 Critically ill neonates exhibiting symptoms affecting multiple organ systems (e.g., neurological, cardiac, and renal) may have an underlying monogenic disorder. rWGS and rWES have been particularly valuable in diagnosing:



Genetic Test	Turnaround Time (TAT)	Diagnostic Yield	Advantages	Limitations
Karyotyping	7–14 days	3–5%	Detects large chromosomal abnor- malities	Low resolution
Chromosomal Microarray (CMA)	5–7 days	10–15%	Detects copy number variations (CNVs)	Cannot detect single nucleo- tide variants (SNVs)
Gene Panel Testing	2–4 weeks	20–40%	Targeted testing for known disease genes	Limited by panel design
rWGS and rWES	48–72 hours	30–50%	High diagnostic yield, rapid results, broad coverage	May miss deep intronic vari- ants
Whole Genome Se- quencing (rWGS)	48–72 hours	~50–60%	Detects SNVs, CNVs, and intronic variants	High cost, large data burden

In a study conducted in a U.S. NICU, rWGS and rWES identified a genetic diagnosis in 37% of neonates with multisystem disease, leading to a change in management in 83% of those cases (Mestek-Boukhibar et al., 2018).

c) Neonates with Unexplained Metabolic Crises

- Inborn errors of metabolism (IEMs) are a leading cause of neonatal encephalopathy, metabolic acidosis, and failure to thrive. Traditional metabolic panels may fail to capture atypical or novel metabolic disorders, whereas rWGS and rWES can provide a precise molecular diagnosis such as:
 - Mitochondrial disorders (e.g., Leigh syndrome, POLG-0 related disease)
 - Metabolic conditions requiring urgent treatment (e.g., 0 urea cycle disorders, organic acidemias)
- A study showed that rWGS and rWES successfully identified metabolic conditions such as biotinidase deficiency and pyridoxine-dependent epilepsy, allowing for immediate metabolic interventions and improved outcomes (4)

d) Neonates with Early-Onset Neurologic Disorders

- Neonatal seizures, hypotonia, or unexplained neurodevelopmental delays can be early manifestations of genetic epilepsies or neuromuscular diseases.
- rWGS and rWES have been instrumental in diagnosing conditions such as:
 - SCN1A-related Dravet syndrome 0
 - STXBP1-related developmental and epileptic 0 encephalopathy
 - Congenital myasthenic syndromes (Srivastava et al., 0 2023).
- A study demonstrated that in neonates with early-onset epilepsy of unknown cause, rWGS and rWES provided a genetic diagnosis in 52% of cases, significantly impacting treatment strategies (2)VzcG9uc2UuYXBwLnBpbmc8LZG/.

Diagnostic Yield and Impact on Clinical Management: 2

Numerous large-scale studies have reported that rWGS and rWES lead to a genetic diagnosis in 30–50% of critically ill neonates (4). More importantly, the clinical utility of rWGS and rWES extends beyond diagnosis to actual management changes, including:

a) Targeted Therapies

A genetic diagnosis can lead to precision medicine

approaches, such as:

- mTOR inhibitors for TSC1/2 mutations in tuberous 0 sclerosis complex.
- Betaine supplementation for MTHFR deficiency. 0
- Pyridoxine (Vitamin B6) therapy for pyridoxine-0 dependent epilepsy

b) Surgical Decision-Making

Identifying an underlying genetic disorder can help avoid unnecessary surgeries or guide optimal surgical timing.

c) Prognostic Insights and Palliative Care

- rWGS and rWES can help guide palliative care discussions by providing an accurate prognosis.
- For lethal or progressive conditions (e.g., Zellweger spectrum • disorder, Walker-Warburg syndrome), rWGS and rWES can help families make informed decisions about life-sustaining interventions.

"rWGS and rWES should be prioritized over single-gene and panel-based approaches when considering a broad differential diagnosis. However, rapid whole genome sequencing (rWGS) may be preferable when non-coding variants or structural rearrangements are suspected."

3. Comparison with Other Genetic Testing Modalities:

rWGS and rWES have several advantages over traditional genetic testing in the NICU:

rWGS and rWES should be prioritized over single-gene and panel-based approaches when considering a broad differential diagnosis. However, rapid whole genome sequencing (rWGS) may be preferable when non-coding variants or structural rearrangements are suspected.



rWGS and rWES have become a cornerstone of genomic medicine in NICUs, enabling rapid and precise diagnoses for neonates with suspected genetic disorders. Its applications span congenital anomalies, metabolic crises, multisystem diseases, and early-onset neurologic conditions. By expediting diagnosis and directly influencing medical management, rWGS and rWES have significantly improved clinical outcomes in critically ill neonates. However, despite its growing utility, there is a lack of standardized guidelines for when and how to implement rWGS and rWES in the NICU, underscoring the need for evidence-based protocols.

"By expediting diagnosis and directly influencing medical management, rWGS and rWES have significantly improved clinical outcomes in critically ill neonates. However, despite its growing utility, there is a lack of standardized guidelines for when and how to implement rWGS and rWES in the NICU, underscoring the need for evidencebased protocols."

III. Challenges and Limitations of Rapid Whole Genome Sequencing and Whole exome Sequencing (rWGS and rWES) in the NICU:

Despite the growing adoption of rapid whole genome sequencing (rWGS) and whole exome sequencing (rWES) in neonatal intensive care units (NICUs), several challenges and limitations hinder its widespread implementation. These challenges range from the lack of standardized protocols and guidelines to issues related to variant interpretation, ethical considerations, financial constraints, and operational barriers. Addressing these challenges is critical to optimizing the use of rWGS and rWES in neonatal genomic medicine and ensuring equitable access across different healthcare systems.

1. Lack of Standardized Protocols and Criteria for rWGS and rWES Utilization:

One of the major obstacles to rWGS and rWES implementation in NICUs is the absence of standardized criteria for when and how to order testing. Different hospitals and institutions have varying inclusion criteria, leading to inconsistent application and potential disparities in patient access. Some NICUs offer rWGS and rWES only for critically ill neonates with multisystem disease, while others include neonates with unexplained congenital anomalies, metabolic crises, or suspected monogenic disorders.

• In the U.S., a review of NICU genetic testing practices found that some hospitals use an algorithmic approach (e.g., requiring a neonatologist-geneticist consultation before rWGS and rWES are approved), while others leave testing decisions entirely to the neonatologist (2)

Without a universal standard, certain neonates who may benefit

from rWGS and rWES might not receive timely testing, while others may undergo unnecessary genomic testing, raising concerns about cost-effectiveness and clinical utility.

2. Variant Interpretation and Reporting Challenges:

a) Variants of Uncertain Significance (VUS) and Incomplete Penetrance

While rWGS and rWES have improved diagnostic accuracy, not all genetic variants detected are immediately interpretable. Variants of uncertain significance (VUS) remain a major limitation, particularly in cases where the pathogenicity of a detected variant is unclear (5).

b) Laboratory Discrepancies in Variant Classification

Different genetic testing laboratories may use slightly different criteria for variant classification, leading to potential discrepancies in reporting. A pathogenic variant reported by one lab may be classified as VUS by another, complicating patient management.

• Efforts such as ClinGen and Matchmaker Exchange aim to standardize variant interpretation; however, variant classification remains an evolving challenge in clinical genomics.

"The NICU is a clinical setting where there is an understanding that the neonatology team will perform interventions and testing in the child's best interest, and general consent is standard. However, using genomic and exome sequencing in neonates raises ethical dilemmas regarding parental consent, secondary findings, and the long-term implications of genetic results."

3. Ethical Considerations and Parental Consent Issues:

The NICU is a clinical setting where there is an understanding that the neonatology team will perform interventions and testing in the child's best interest, and general consent is standard. However, using genomic and exome sequencing in neonates raises ethical dilemmas regarding parental consent, secondary findings, and the long-term implications of genetic results. With the stressful emotions that occur for families with a critically ill neonate, approaching the complex genomic information for informed consent can pose a significant challenge when its longterm implications are not just for the patient but also other family members (12).

a) Parental Consent and Informed Decision-Making

Obtaining informed consent for rWGS and rWES in the NICU is



Clinical Factor	Check box
Multiple congenital anomalies (≥2 organ systems affected)	
Single severe anomaly with atypical features	
Persistent metabolic crisis (acidosis, hyperammonemia, or hypoglycemia)	
Neonatal seizures with no clear etiology	
Severe hypotonia or progressive neuromuscular symptoms	
Respiratory failure requiring >48 hours of ventilation without cause	
Unexplained cardiomyopathy, severe arrhythmia, or heart failure	
Severe pulmonary hypertension without structural lung disease	
Family history of genetic disorder with similar presentation	
Non-diagnostic genetic tests (CMA, metabolic panel, karyotype) in a high-risk case	
Parental consanguinity with an undiagnosed critically ill neonate	

Checkbox Interpretation: If the > = 2 boxes are checked, rWGS and rWES should be considered.

challenging because:

- Parents are often in high-stress situations, making complex genetic discussions difficult.
- Consent forms are sometimes lengthy and technical, creating barriers to comprehension.
- Some institutions use opt-in approaches (where parents must actively agree to test), while others implement opt-out models (where testing proceeds unless parents decline), raising ethical concerns about autonomy.

"rWGS and rWES can uncover secondary findings unrelated to the neonate's current condition, such as adult-onset disorders, carrier status, and pharmacogenomic variants. The American College of Medical Genetics and Genomics (ACMG) provides guidelines on returning actionable secondary findings, but there is no consensus on what should be reported in neonates."

b) Secondary and Incidental Findings

rWGS and rWES can uncover secondary findings unrelated to the neonate's current condition, such as adult-onset disorders, carrier status, and pharmacogenomic variants. The American College of Medical Genetics and Genomics (ACMG) provides guidelines on returning actionable secondary findings, but there is no consensus on what should be reported in neonates.

- A study of NICU genomic testing found that 4% of cases revealed medically actionable secondary findings, raising ethical concerns about disclosure and long-term follow-up.
- Some institutions restrict rWGS and rWES analysis to disease-specific panels to avoid incidental findings, while others allow for full exome analysis, increasing the risk of uncovering uncertain or unexpected variants.

4. Financial and Insurance Barriers:

The cost of rWGS and rWES remains a significant challenge for many hospitals and families. Although sequencing costs have decreased, insurance reimbursement policies vary widely.

In a study of 1,200 NICU patients undergoing genomic sequencing, cost savings were observed in cases where an early diagnosis prevented unnecessary testing and prolonged hospital stays. However, hospitals that lack financial support for genetic testing programs struggle to offer rWGS and rWES widely (11).

5. Turnaround Time and Operational Barriers:

Although rWGS and rWES are marketed as a rapid test, realworld implementation faces logistical hurdles:

- Sample Processing Delays
- Data Interpretation Bottlenecks
- Lack of Genetic Specialists:

While rWGS and rWES have significantly improved genetic diagnosis in NICUs, several challenges remain in their widespread adoption. The lack of standardized protocols, complexities in variant interpretation, ethical dilemmas, financial constraints, and operational barriers limit its full potential. Addressing these limitations requires the development of clear clinical guidelines, improved genetic counseling models, and increased accessibility to sequencing technologies. As genomic medicine continues to evolve, establishing best practices for rWGS and rWES in NICUs will be crucial for optimizing neonatal care.

IV. Recommendations for Standardization of Rapid Whole

genome sequencing and whole exome sequencing (rWGS and rWES) in the NICU:

Given the lack of standardized protocols for implementing rapid Whole genome sequencing and whole exome sequencing (rWGS and rWES) in neonatal intensive care units (NICUs), it is critical to establish evidence-based guidelines to optimize patient selection, streamline workflows, and ensure equitable access. Standardization would help maximize the clinical benefits of rWGS and rWES while minimizing financial, ethical, and operational challenges. Below are key recommendations for improving the integration of rWGS and rWES in the NICU setting.

1. Establishing Evidence-Based Guidelines for Patient Selection

Institutions should adopt standardized criteria for ordering rWGS and rWES to avoid inconsistent application and disparities in access. Several studies have suggested common clinical indications that warrant rWGS and rWES in critically ill neonates.

2. Implementing a Standardized Testing Workflow

Hospitals should develop a transparent workflow to ensure rapid, efficient, and cost-effective integration of rWGS and rWES into NICU care. This includes:

3. Developing Ethical and Parental Consent Guidelines:

Given the complexities of genetic testing in neonates, standardized ethical guidelines and parental consent frameworks are essential.

a) Streamlining Parental Consent in High-Stress NICU Settings

- Developing concise, tiered consent models that balance ethical considerations with practical constraints.
- Providing genetic counseling by trained NICU-specific counselors, improving parental understanding, and reducing decisional regret
- Offering opt-in and opt-out models based on institutional policies, ensuring informed decision-making while avoiding undue burden on families.

b) Standardized Policies for Secondary Findings

- Aligning reporting policies with ACMG secondary findings guidelines, ensuring medically actionable variants are disclosed
- Establishing a formalized parental opt-in option for nonactionable or adult-onset conditions.

A review of NICU rWGS and rWES practices found that institutions with standardized consent protocols saw a 35% increase in parental confidence regarding testing decisions, emphasizing the importance of structured consent processes (3)

4. Improving Insurance Coverage and Cost-Effectiveness:

To expand access to rWGS and rWES, payers must recognize its cost-saving potential and clinical impact.

A multicenter study demonstrated that early use of rWGS and rWES in neonates resulted in a net cost savings of \$1,900 per patient due to reductions in unnecessary procedures and shorter hospital stays (3, 4)

A key barrier to effective rWGS and rWES implementation is the lack of training among NICU providers on genetic testing protocols.

a) Genetic Education Initiatives

 Developing rWGS and rWES training modules for neonatologists, emphasizing patient selection, test interpretation, and genetic counseling

b) Integrating Geneticists and Genetic Counselors in NICU Teams

- Embedding genetic counselors in NICU teams to assist with pre-test consent, post-test interpretation, and parental support
- Creating rapid genetic consultation services, ensuring realtime support for neonatologists interpreting rWGS and rWES results

A survey of NICU physicians found that 78% had no formal training in genomic medicine, underscoring the urgent need for structured education programs (3, 4)

Standardized protocols are essential to realize the potential of rWGS and rWES in NICUs fully. Implementing clear criteria for patient selection, structured workflows, ethical guidelines, financial advocacy, and provider training will enhance the efficiency, accessibility, and effectiveness of rWGS and rWES. Future efforts should focus on multicenter collaborations, data sharing, and Al-driven interpretation tools to optimize neonatal genomic medicine further. We can ensure that rWGS and rWES become a standard, equitable, and cost-effective diagnostic tool for critically ill neonates worldwide by addressing these key challenges.

"Standardized protocols are essential to realize the potential of rWGS and rWES in NICUs fully. Implementing clear criteria for patient selection, structured workflows, ethical guidelines, financial advocacy, and provider training will enhance the efficiency, accessibility, and effectiveness of rWGS and rWES. Future efforts should focus on multicenter collaborations, data sharing, and Aldriven interpretation tools to optimize neonatal genomic medicine further. We can ensure that rWGS and rWES become a standard, equitable, and cost-effective diagnostic tool for critically ill neonates worldwide by addressing these key challenges."

5. Training and Education for NICU Providers:



V. Conclusion & Rapid Whole genome sequencing and whole exome sequencing (rWGS and rWES) decision checklist for NICU:

Summary of Key Points

- Rapid Whole genome sequencing and whole exome sequencing (rWGS and rWES) is a valuable tool in the NICU, offering a 30–50% diagnostic yield and leading to direct changes in clinical management.
- Despite its benefits, challenges remain, including a lack of standardized protocols, variant interpretation complexities, ethical concerns, and insurance barriers.
- Standardizing clinical criteria for rWGS and rWES in the NICU is crucial for optimizing diagnostic efficiency and ensuring equitable access. By defining which neonates benefit most, clinicians can prioritize high-yield cases, streamline workflows, and improve outcomes in critically ill infants.
- Future research should focus on prospective validation of these criteria to further refine testing strategies in neonatal genomic medicine.

To facilitate decision-making in the NICU, we propose a rWGS and rWES checkbox system (based on the published data) to determine when rWGS and rWES should be ordered.

This checkbox ensures that rWGS and rWES are used strategically for neonates most likely to benefit, reducing unnecessary testing while prioritizing high-impact cases.

"This checkbox ensures that rWGS and rWES are used strategically for neonates most likely to benefit, reducing unnecessary testing while prioritizing high-impact cases."

Final Thoughts:

Integrating rWGS and rWES into NICU workflows requires a structured approach, balancing clinical urgency, diagnostic yield, and resource allocation.

- A standardized checklist can streamline testing decisions, ensuring timely diagnoses and improved patient outcomes.
- Future research should validate these criteria prospectively, refining protocols to enhance further genomic medicine's efficiency and impact in neonatal care.

By adopting these standardized rWGS and rWES criteria, NICUs can achieve earlier diagnoses, reduce unnecessary testing, and improve precision medicine applications in critically ill neonates.

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Which Infants are More Vulnerable to Respiratory Syncytial Virus?

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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%



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

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Family Centered Care: Synopsis of Partnering With Parents to Change Measurement and Reporting of Preterm Birth Outcome

Morgan Kowalski

"Rebecca Pearce shares her experience of being unable to find meaningful and reliable information about the outcomes of extremely preterm infants after the birth of her twins at 25 weeks gestation and the loss of one of her daughters."

This is a synopsis of <u>"Partnering With Parents to Change Measurement and Reporting of Preterm Birth Outcomes"</u> written by Rebecca Pearce, Anne Synnes, MDCM, MHSc, Mei Mei Lam, MD, Lindsay L. Richter, MSc, Fabiana Bacchini, Melissa Jones, Thuy Mai Luu, MDCM, MS, and Annie Janvier, MD, PhD on behalf of the PARENTS' VOICE NETWORK

Rebecca Pearce shares her experience of being unable to find meaningful and reliable information about the outcomes of extremely preterm infants after the birth of her twins at 25 weeks gestation and the loss of one of her daughters. As a NICU parent of a 25-weeker myself, I can attest that Rebecca's struggle to find relevant and accessible information on this subject felt impossible at the time of my son's birth, exacerbating an already traumatic and complicated parenting experience.

Healthcare professionals and researchers traditionally determine information collected during neonatal follow-up visits, considering feasibility, viability, availability, and cost but without considering what information is meaningful to parents. To address this gap in care, CNFUN (Canadian Neonatal Follow-Up Network) set out to identify and measure outcomes that parents identified as important.

CNFUN secured funding for this work from the Canadian Institutes for Health Research strategy for patient-oriented research. The main principles are that patients are meaningful partners throughout the research continuum, the research aims to improve patient outcomes, improve healthcare systems and practices,



and involve a multidisciplinary team. Alongside CPBF (Canadian Premature Babies Foundation), CNFUN developed the Parent-Centered Evidence-Based Care for Premature Graduates study, or Parents' Voice study, to capture the voices of a large number of diverse parents, examine the perspectives of parents in more detail, and address potential biases by involving parents in all aspects of the research.

"CNFUN secured funding for this work from the Canadian Institutes for Health Research strategy for patient-oriented research. The main principles are that patients are meaningful partners throughout the research continuum, the research aims to improve patient outcomes, improve healthcare systems and practices, and involve a multidisciplinary team. Alongside CPBF (Canadian Premature Babies Foundation), **CNFUN** developed the Parent-Centered **Evidence-Based Care for Premature** Graduates study, or Parents' Voice study, to capture the voices of a large number of diverse parents, examine the perspectives of parents in more detail, and address potential biases by involving parents in all aspects of the research. "

In their first study, CNFUN and CPBF engaged over 1,000 parents of children born before 29 weeks gestation, finding that parents often viewed their child as less impaired than follow-up clinic staff. Perceptions of severity were also studied, with parents feeling that the need for a cochlear implant was less severe. At the same time, cerebral palsy or a language delay diagnosis was viewed as more severe. In subsequent studies, it was found that parents value functionality over diagnosis and prioritize information about how their child is feeding, sleeping, behaving, and breathing over information about neurodevelopment. Additionally, parents expressed a desire for more practical advice around caring for their child, optimism, and a more balanced perspective from healthcare professionals.

Once Parents' Voice study results were shared with parents, clinicians, and researchers involved in the study, seven areas of actionable consensus statements for prematurity follow-up were identified as (1) child well-being, (2) quality of life or function, (3) socioemotional and behavior outcomes, (4) respiratory, (5) feeding, (6) sleeping, and (7) caregiver well-being and mental health. Once these parent-identified domains were agreed on

and validated in a workshop consisting of parents, clinicians, and researchers, questionnaires and tools for each area of importance were recommended and published in a scoping review for measuring family, parent, and patient outcomes.

The impact of this collaborative effort was more significant than the identification and recommended measurement of parent-identified areas of importance in follow-up clinics: changes in language around states of health were made to eliminate judgment. For example, healthcare professionals say "severe hearing impairment" instead of "use of hearing aids or cochlear implants." Additionally, parents involved in the study, including Rebecca Pearce and Fabiana Bacchini, were identified as significant contributors to knowledge dissemination across many audiences, including obstetricians, neonatologists and pediatricians, ethicists, and families, with lived experience adding meaning to the information being shared. Success and meaningful change were reached by respectful and total collaboration between parents and healthcare professionals.

"Additionally, parents involved in the study, including Rebecca Pearce and Fabiana Bacchini, were identified as significant contributors to knowledge dissemination across many audiences, including obstetricians, neonatologists and pediatricians, ethicists, and families, with lived experience adding meaning to the information being shared. Success and meaningful change were reached by respectful and total collaboration between parents and healthcare professionals."

This research is significant to me because of my own lived experience in the NICU follow-up clinic with an extremely preterm infant. I remember feeling defensive of my son as he was evaluated and subsequently fell short of age-appropriate neurodevelopmental milestones. I wished we could have also discussed how he overcame the odds by surviving, eating by mouth, and breathing independently. In the future, I would love to see similar studies conducted for parents of infants with varying diagnoses and gestational ages because they, too, deserve to receive information they care about.

Resources:

- 1. <u>Neurodevelopmental Impairment: Who Defines It? By Annie</u> Janvier, MD, PhD, FRPC
- 2. <u>Outcomes of Children Born Extremely Preterm: Why Parents'</u> Voices Project is Important
- 3. Preemie Chat
- 4. Parent Voices and Evidence-Based Neonatal

<u>Care: Where we've been and where we need to go</u> Video by CHILD-BRIGHT Network

5. <u>Parental and Medical Classification of Neurodevelopment in</u> <u>Children Born Preterm</u>

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The Evidence for Prune Juice in the NICU: **No Firm Conslusions**

Gustave Falciglia, MD, , Leslie Caldarelli, MD, Joseph Hageman, MD, Mitchell Goldstein, MD, MBA, CML

"Anecdotally, we have taken care of infants in the neonatal intensive care unit (NICU) who received prune juice and even ordered it ourselves."

Introdution:

Anecdotally, we have taken care of infants in the neonatal intensive care unit (NICU) who received prune juice and even ordered it ourselves. Examples include term-corrected preterm infants with bronchopulmonary dysplasia and intermittent bradycardic and hypoxemic episodes exacerbated by a bowel movement or enterally fed infants with opiate-induced constipation. However, what is the evidence for this practice? Which infants get prune juice in the NICU? Why? What amount? At what gestational age? How does it work? Moreover, what are the risks?

Literature on Prune Juice in Infants in the NICU:

A literature search of "prune" and "neonate" or "NICU" or "infant" yields 521 citations. (1) The overwhelming majority of citations pertain to Prune Belly Syndrome, also known as Eagle-Barrett Syndrome. Only two articles were relevant, and both were tangential at best. A case report of food protein-induced enterocolitis syndrome (FPIES) in a seven-month-old infant described an infant who presented with projectile emesis due to the rare condition following repeated prune exposure. (2) Another described toxic heavy metal accumulation in infant foods due to plant absorption, processing, or packaging. (3)

Unfortunately, many of the aforementioned questions remain unanswered. What evidence or guidelines are available to guide the clinician? The American Academy of Pediatrics (AAP) Committee on Nutrition addressed the topic in a 2001 publication entitled "The Use and Misuse of Fruit Juice in Pediatrics". (4) They recommended exclusive breast milk or formula until 6 months because juice provided excess carbohydrates and negligible amounts of protein or fat. There are 18g/dL of carbohydrates in prune juice compared to around 7g/dL in breast milk or formula. (4, 5) A similar recommendation reiterated this position in 2017. (6)

Constipation in the Infant:

Clinicians are not prescribing prune juice for nutrition to infants in the NICU. They are prescribing it to alleviate constipation. Though studies for the use in infants in the NICU are lacking, pediatricians and hospital resources for parents, such as the Children's Hospital of Philadelphia and the Mayo Clinic websites, (7, 8) recommend a small amount of prune juice for symptoms of constipation after consulting with the pediatrician. Though the guidance is not intended for a population of infants in the NICU, our collective experience of infants receiving prune juice is not unique. A mother on an online parental support group commented that her son "has always had a pooping problem, so he has been on prune juice since the NICU". (9)

"Clinicians are not prescribing prune juice for nutrition to infants in the NICU. They are prescribing it to alleviate constipation. Though studies for the use in infants in the NICU are lacking. pediatricians and hospital resources for parents, such as the Children's Hospital of Philadelphia and the Mayo Clinic websites, (7,8) recommend a small amount of prune juice for symptoms of constipation after consulting with the pediatrician."

Infants in the NICU can develop constipation. The differential in an infant without congenital obstruction (e.g., imperforate anus or intestinal atresia) includes Hirschsprung's, hypothyroidism, cystic fibrosis, ileus, electrolyte abnormalities (hypercalcemia or hypokalemia), and medication effects such as opiate-induced constipation. (10) When an organic cause of constipation is ruled out, prune juice may be given. There are no randomized control trials in infants; however, a blinded randomized trial in 84 adults demonstrated that prune juice reduced symptoms of constipation and reduced the frequency of hard stools without leading to diarrhea or an increase in loose stools. (11)

Prune Juice:

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Prune juice is derived from prunes, which are dried plums. The major macronutrients are carbohydrates, which include fiber, glucose, fructose, sorbitol, and inositol. Most of the glucose and fructose are absorbed in the small intestine. (12) Fiber is not absorbed in the small intestines; the sorbitol is only slowly absorbed. Both pass into the large intestine, where colonic bacteria may ferment them into short-chain fatty acids, which may then be absorbed. What is not absorbed softens the stool through osmosis. (4) Prunes also have a laxative effect. In adults, they increase stool frequency. (12)

Prune juice also contains a variety of micronutrients.¹² Minerals include potassium, copper, manganese, magnesium, boron, and iron. These values may vary depending on where the plant is grown or how they are processed. They contain Vitamin K and B6, riboflavin, niacin, and variable amounts of Vitamin C (depending on fortification). Besides gastrointestinal benefits, there are animal and adult human studies to suggest that they may preserve bone mineral density, which may be because of boron, which reduces urinary excretion of calcium and magnesium. (12)

No Firm Answers:

Infants in the NICU occasionally receive prune juice for constipation; however, little data guides the use. At what age can neonatologists safely consider prune juice for constipation? How much should be administered, how frequently should it be administered, and in which patients should it be considered? The risks and benefits remain unknown. Despite the unknowns, constipation in critically ill infants may carry additional risks. Bradycardic and hypoxemic episodes may occur with bowel movements. Severe hypoxemic episodes are associated with long-term neurodevelopmental outcomes; therefore, there is a benefit in mitigating these events. (13)

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Why does prune juice remain unstudied? Randomized control trials require funding. There are no patents with which to reward pharmaceutical company investments in research. The volume of prune juice is unlikely to entice fruit or fruit juice companies to invest in a trial. Or are we embarrassed to admit to the practice of administering prune juice to infants in the NICU? Regardless, our patients would benefit from improved data. A survey of practices across the country would be a good start.

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Neonatology and the Arts

This section focuses on artistic work which is by those with an interest in Neonatology and Perinatology. The topics may be varied, but preference will be given to those works that focus on topics that are related to the fields of Neonatology, Pediatrics, and Perinatology. Contributions may include drawings, paintings, sketches, and other digital renderings. Photographs and video shorts may also be submitted. In order for the work to be considered, you must have the consent of any person whose photograph appears in the submission.

Works that have been published in another format are eligible for consideration as long as the contributor either owns the copyright or has secured copyright release prior to submission.

Logos and trademarks will usually not qualify for publication.

This month we continue to landscapes, feature artistic works created by our readers on the next to last page as well as photographs of birds on rear cover. Dr. Zahera Etter provides Still More Lavender. a For this edition, our art was graciously provided by Colleen Kraft, MD. It is a work called "Pool Player" done by her son Tim. Our bird is from a photo taken by Mita Shah, MD in New York, A Cool Cardinal



Lily Martorell, MD

Arts Editor Associate Professor Loma Linda University Children's Hospital Loma Linda, CA

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Manuscript Submission: Instructions to Authors

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

2. All material should be emailed to:

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

3. There is no charge for submission, publication (regardless of number of graphics and charts), use of color, or length. Published content will be freely available after publication. There is no charge for your manuscript to be published. NT does maintain a copyright of your published manuscript.

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

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

6. An abstract may be submitted.

7. The main text of the article should be written in formal style using correct English. The length may be up to 10,000 words. Abbreviations which are commonplace in neonatology or in the lay literature may be used.

8. References should be included in standard "NLM" format (APA 7^{th} is no longer acceptable). Bibliography Software should be used to facilitate formatting and to ensure that the correct formatting and abbreviations are used for references.

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.



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



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.

Invitation to Apply:

Seeking content development experts for an AAP Project Advisory Committee (PAC)

The White Zone – Developing A Perinatal Loss Toolkit for LMICs

The Need: Over 2.4 million neonatal deaths and 2.6 million stillbirths occur each year; 98% occur in Low- and Middle-Income Countries (LMICs). While programs such as Helping Babies Breathe (HBB) and Essential Newborn Care (ENC 1 and 2) have revolutionized how providers in LMICs train in and provide neonatal resuscitation and post-delivery care for small and sick newborns, gaps remain in how to best offer end-of-life care and post-loss psychosocial care in these settings.

The Babies: HBB and ENC 1 begin with assessing if a baby is crying and conclude with the "Red Zone" where a baby who is unable to sustain an appropriate heart rate and/or respirations is provided with PPV support as someone attempts to get help. Within the HBB/ENC framework, we could imagine several babies for whom an extension of this framework to include palliative/perinatal loss guidelines could be helpful:

- 1. A stillbirth for whom no resuscitation is attempted. (Stillbirth)
- 2. A baby who proceeds through the red zone but never has a heartbeat or breathing despite the best resuscitative efforts of the team. (Stillbirth)
- 3. A baby who proceeds through the red zone who, after 20 or so minutes still has a very low heartbeat and/or gasping breathing. (Anticipated neonatal death)
- 4. A preterm baby who is too small for ongoing support, based on local resource constraints or resuscitation guidelines, despite a sustained heart rate and breathing. (Anticipated neonatal death)

The Approach: Create a suite of resources that could accompany ENC 1 and 2, focused on end-of-life care and perinatal loss. These resources would be less algorithmic than ENC, as local practices around death vary significantly – meaning there is not one "right" way to approach this care. Rather, the "White Zone Toolkit" would combine structured guidance about symptom management as well as reflective tools for implementing contextually and culturally appropriate post-loss care. This could consist of, but is not limited to, the following:

- 1. Structured guidance on what physiologic changes may happen at the end of life (ex: gasping) as well as pharmacologic and non-pharmacologic options for symptom management.
- 2. Reflective questions about if/when to offer seeing or holding of the baby.
 - Data shows that many women want to see and/or hold their infant following stillbirth or neonatal death but are often not offered that opportunity based on historic cultural norms.
- 3. Reflective questions about cultural traditions around loss and if/how these practices can be supported by those attending the delivery.
- 4. Anticipatory guidance guides on how mothers may still produce milk and how to manage those symptoms.
- 5. Anticipatory guidance on potential maternal mental health needs. Reflective questions on how to approach mental health and psychosocial support after loss.
- 6. Access to a set of adaptable practice scenarios that could help providers gain experience in handling perinatal loss and communicating with families surrounding perinatal loss.









