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Coalition for Preemies – We Help Polish Parents of Preemies and Rescue Ukrainian NICUs

Maria Katarzyna Borszewska-Kornacka, MD, Elzbieta Brzozowska, Adriana Misiewicz, Joanna Nycz

"Coalition for Preemies is an organization operating in Poland for ten years - initially as a social movement that brought together people and institutions working for the health of premature babies in Poland, and from 2019 as a Foundation."

Coalition for Preemies is an organization operating in Poland for ten years - initially as a social movement that brought together people and institutions working for the health of premature babies in Poland, and from 2019 as a Foundation.

The goals of the Foundation have been unchanged for many years - to work for the smallest of the youngest - premature babies and their parents. Our goal is education - starting with the health of pregnant women and preventing premature births, ending with the health of premature babies, their development, and rehabilitation. We reach out to parents of premature babies to help them care for their premature babies and to the general public to help them understand that a premature baby is the most vulnerable person who needs our help. Nobody who has not encountered a premature baby in their environment knows what complications the baby and its loved ones face and how much effort is needed to ensure healthy development.

During the pandemic, we got involved with an international campaign initiated by EFCNI #zeroseparation. It aimed to restore the possibility of visiting preemies in neonatal departments for their parents. In Poland, as part of the #zeroseparation campaign, we included parents of preemies in the group "zero" for vaccination against COVID-19 – the group that could be vaccinated first together with medical staff. We wanted parents of premature babies to be protected from the virus as soon as possible and to be able to visit their children in hospitals. It was possible thanks to the immediate decision of the Ministry of Health after we sent a request on this matter.

In 2021, we launched advice for parents of premature babies with specialists as part of the "Ask for a premature baby" campaign - it consists of a telephone conversation or via online communicators. Parents can talk to a neonatologist, psychologist, pediatric neurologist, lactation consultant, and physiotherapist.

"Currently, we are involved in helping premature Ukrainian babies. Together with the Neonatus Foundation, the Tęczowy Kocyk Foundation, and the blogger MatkoweLove, we organized a fundraiser. With the collected money, we finance the purchase of the necessary equipment and medicines for Ukrainian neonatal units and transport the equipment to the neediest hospitals in Ukraine."

Currently, we are involved in helping premature Ukrainian babies. Together with the Neonatus Foundation, the Tęczowy Kocyk Foundation, and the blogger MatkoweLove, we organized a fundraiser. With the collected money, we finance the purchase of the necessary equipment and medicines for Ukrainian neonatal units and transport the equipment to the neediest hospitals in Ukraine. The President of our Foundation- prof. Maria Katarzyna Borszewska-Kornacka is in constant contact with the national consultant for neonatology in Ukraine, and therefore we know what their needs are. First shipments of medical equipment, drugs, and milk were sent to Lviv, Kyiv, Charkov, Brovary, Ivano-Frankovsk, and Dniepro

"The President of our Foundation- prof. Maria Katarzyna Borszewska-Kornacka is in constant contact with the national consultant for neonatology in Ukraine, and therefore we know what their needs are. First shipments of medical equipment, drugs, and milk were sent to Lviv, Kyiv, Charkov, Brovary, Ivano-Frankovsk, and Dniepro."

There is a fundraiser in the USA: https://fundly.com/relief-fund-for-nicus-in-ukraine?fbclid=IwAR3abHHFs6pszrQKuSnJ147xiFfSRigAgp1_w_OHNdWBo8cp2KH-uTJI2uI

It is also possible to donate to the Coalition for Preemies Foundation: https://www.koalicjadlawczesniaka.pl/numer-konta-fundacji-koalicja-dla-wczesniaka-i-dane-do-przelewow-z-zagranicy/

We have also started the "Package for a Newborn" campaign, the purpose of which is to equip Ukrainian babies born in Warsaw with necessities such as clothes for newborns, sizes 50-68, including bodysuits, rompers, socks, hats, nipples, small toys, cosmetics, and hygiene articles.

We also plan to prepare a warehouse of clothes/things useful for newborns, which will be issued in response to the specific needs of single Ukrainian mothers in Poland. From the warehouse, mothers will be able to receive rockers, carriers, scarves for carrying babies, prams, changing mats, bathtubs, and breast pumps.

Since the outbreak of war, we have had over a dozen requests to help in transferring newborns from Ukraine to Poland.

Initially, there were babies of US and UK citizens born in Ukraine, followed by several neonatal transfers or personal admissions of Ukrainian newborns from the border zone brought personally by parents.

Our triage center has different scenarios comprising both stabilization and subsequent transfer to different Polish neonatal/pediatric centers and diagnostic and treatment approaches on site.

Requests regarding medical transfers of premature babies were formulated predominantly by aid organizations, governmental or family activities, and not specifically by medical referrals.

Recently we have received several inquiries about the possibility of admission of newborns/small infants with chronic and/or rare genetic problems. Until now, the utility of the database created for the quick electronic exchange of medical data regarding the transfer of newborns from Ukraine to Poland seems suboptimal as there was perhaps no need for such transfers on a larger scale.

"Further information can be found on the Foundation website: https://www.koalicjadlawczesniaka.pl/aktualnosci/"

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Save the Date for the First Fragile Infant Forum for Integration of Standards— FIFI-S July 13-15, 2022

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"Storyteller" painting by Sharron Montague Loree, 1982

Letters to the Editor

National System for Neonatal Transfer and Distribution of Ukrainian Children Requiring Hospitalization During the State of War in Ukraine

The current situation in Ukraine revealed the need for international-based neonatal care. Such a situation might also be created by natural disasters and war in Ukraine as it exists currently. Due to absolute damage to the health care system in Ukraine, there is a need to accept patients from the neighboring country under a war state. To secure a smooth flow of infants from Ukraine requiring continuous hospital care, we have established a Polish electronic registry and an electronic free beds database.

Neonatal Registry of Children from Ukraine (NRD UA)

To control and gain the most important clinical information of the newborns transferred from Ukraine to Poland for continuous hospital care, the Neonatal Registry has been established. The electronic registry is provided in both Ukrainian and Polish languages at the following numbers: phone: +48780700527 and Viber: 0806365765. Preferable medical personnel should call the registry and provide the most critical information. It is essential to have in the registry all-important logistic information, e.g., time and location of the border crossing, to arrange the appropriate transport solution. Access to the NRD UA has limited personnel: Director of the Neonatal Triage Unit (NOT) Dr. Witold Błaż, National Consultant in Neonatology, Professor Ewa Helwich, and National Coordinator of the Neonatal Transport Professor Jan Mazela.

Neonatal DataBase (NBD)

In order to obtain full knowledge regarding admissions to neonatal intensive care units and monitor the number of available beds, this electronic database has been established. Each regional consultant received access to this database and was asked to update information regarding available beds in dedicated hospitals from each region. Information from this electronic database is freely available to the NOT Director. In such cases, there is easily available information about which hospitals have available beds, and infants can be transported as soon as possible and with the most optimized mode of transportation.

Neonatal Triage Unit (NOT)

The Neonatal Triage Unit is located in Rzeszow, just 70 m from the Ukrainian border. Its role is to admit newborns transported into Poland and registered in the NRD UA. This triage optimizes the transport time and allows the medical team to be prepared for clinical challenges. Infants are collected from the border by the dedicated neonatal transport team and brought to NOT in Rzeszow. After admission and initial stabilization, the Director of the NOT allocates the infant to a dedicated hospital based on the data from the NBD. He also orders the appropriate mode of transport: ground or air, according to established rules. Figure 1 presents the basic principles of the system.

Air Transport

The Polish Medical Air Rescue secures air Transport after a registration call from the NOT. This mode of transport is done by a dedicated airplane, and the local airport in Rzeszow is used for this purpose. In order to avoid irregularities during the air transport booking procedure, only dedicated personnel from NOT are performing this procedure. All needed information for booking and registering the dedicated air transport can be found at www.lpr.com.pl. Air transport is done only on distances longer than 200 km.

Ground Transport

All transports for a distance of less than 200 km will be done using a dedicated ambulance for neonatal transport.

Information Letter

In order to inform medical personnel in Ukraine and Poland regarding the main functional conditions of accepting infants from Ukraine into Polish hospitals, the following letter has been issued.

Дорогі друзі,

Нижче наведено інформацію, як зареєструвати новонароджених, які потребують госпіталізації та яких планується / необхідно доправити до Польщі.

Для підтримання контролю над прийомом та для отримання основної клінічної інформації про українських новонароджених, яких необхідно доправити до Польщі для продовження лікування, створено центральний неонатальний реєстр:

телефон: +48780700527

Viber: 0806365765 польською та українською мовою.

Операційні години - 8.00-16.00. Новонароджені повинні бути зареєстровані лікарем, який володіє інформацією, що стосується клінічного статусу пацієнта та знає місцезнаходження пацієнта, а також час запланованого перевезення та місце розташування запланованого пункту проходження кордону, якщо це можливо. Усі дані, необхідні для реєстрації новонароджених, представлені в таблиці 1. Доступ до НРД УА має національний консультант з неонатології - проф. Ева Хелвіч, директор відділення неонатальної патології новонароджених (НПН) - доктор Вітольд Блауж та Національний координатор логістики «N» - проф. Ян Мазела.

«Szanowni Państwo,

Przesyłamy informację opisującą jak należy zgłaszać noworodki wymagające hospitalizacji, przekazane do leczenia na terenie Polski.

W celu kontroli i pełnej wiedzy na temat ukraińskich noworodków przekazywanych na teren Polski do dalszego leczenia szpitalnego stworzono Noworodkowy Rejestr Dzieci z Ukrainy (NRD UA), który prowadzony jest pod numerem tel.: +48780700527 oraz Viber: 0806365765 w języku polskim i ukraińskim w godzinach od 8.00 do 16.00. Pacjentów wymagających leczenia na terenie Polski mogą zgłaszać do NRD UA lekarze z terenu Ukrainy lub Polski, którzy posiadają pełną wiedzę dotyczącą stanu klinicznego pacjenta oraz pełne informacje osobowe oraz logistyczne, w tym miejsce i czas planowanego przekroczenia granicy z Polską, o ile możliwe. Dane potrzebne do rejestru pacjenta w NRD UA zawarte są w tabeli 1. Dostęp do NRD posiada Noworodkowy Oddział Triażowy (NOT) – dr Witold Błaż, Konsultant Krajowy w dziedzinie Neonatologii - prof. Ewa Helwich, Krajowy Koordynator Transportu „N" z ramienia Nadzoru Krajowego - prof. Jan Mazela.»

«Dear Friends,

Below is information on registering newborns who require hospitalization and is planned/needed to be transferred to Poland. In order to maintain control of the admissions and obtain basic clinical information of the Ukrainian newborns to be transferred to Poland for continuous hospital care, there is a central neonatal registry: phone: +48780700527 and Viber: 0806365765 in Polish and Ukrainian language. Operational hours are 8.00-16.00. Newborns should be registered by a physician who is knowledgeable regarding the patient's clinical status and knows the location of the patient and the time of the planned transport, and the location of the planned border checkpoint, if possible. All data required for newborn registration is presented in table 1. Access to the NRD UA has National Consultant in Neonatology – Prof. Ewa Helwich, Director of the Neonatal Triage Unit (NTU) – dr Witold Błaż, and National Coordinator of the Neonatal Transport – Prof. Jan Mazela

Jan Mazela[1], Witold Błaż[2], Robert Gałązkowski[3], Piotr Czauderna[4], Maria Katarzyna Kornacka[5], Ewa Helwich[6]

1- Department of Neonatology Poznan University of Medical Sciences in Poznan, Poland, National Coordinator for Neonatal Transport

2- Department of Neonatology and NICU, Saint Jadwiga the Queen Clinical Provincial Hospital, University of Rzeszow

3- Polish Medical Air Rescue, Warszawa, Poland

4- Department of Surgery and Urology for Children and Adolescents, Medical University of Gdańsk

5- Department of Neonatology, Warsaw Medical University

6- National Consultant in Neonatology, Institute of Mother and Child, Warszawa

Dear Drs Mazela, Błaż, Gałązkowski, Czauderna, Katarzyna Kornacka, Helwich:

I want to thank you for taking on this project of immense importance. Although the ravages of war are clearly disturbing, the effects on neonatal/perinatal care are oftentimes overlooked. The mobilization of the Polish transport system in the face of this tragedy must succeed for these most at-risk individuals.

The free beds electronic database provides a structure in the face of a brutal conflict, disrupted healthcare, and resultant disparity. It must succeed.

As Neonatology Today's Central Europe Editor, we appreciate Dr. Mazela's efforts in supporting the journal. We will continue to support these humanitarian efforts to the extent we can and encourage those who may be able to provide logistics, means, and financial support to reach out to Dr. Mazela directly.

Mitchell Goldstein, MD, MBA, CML

Editor in Chief

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Neonatology Today is not aware of any erratum affecting the March, 2022 edition.

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

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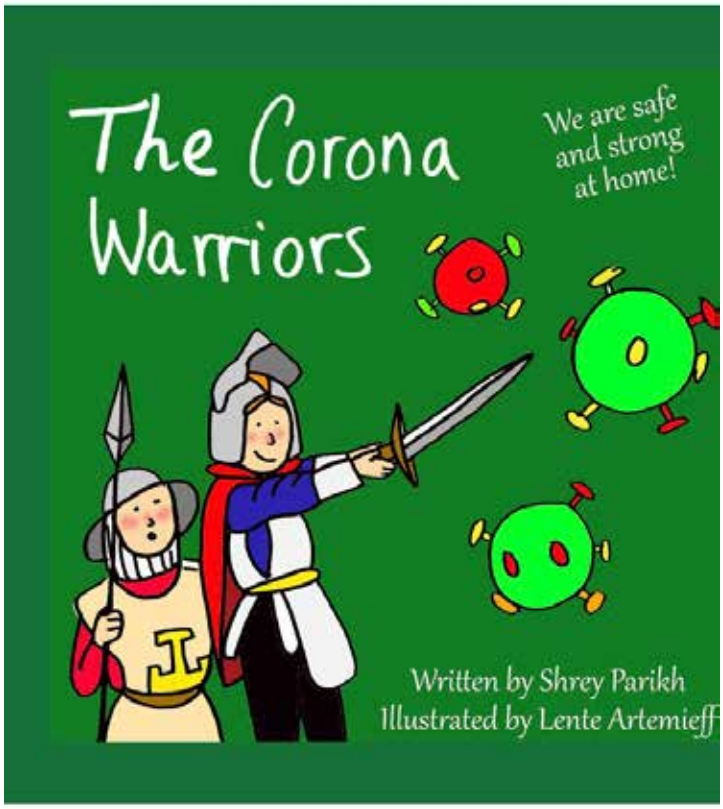

Neonatology Today welcomes your editorial commentary on previously published manuscripts, news items, and other academic material relevant to the fields of Neonatology and Perinatology.

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NT Behind the Scenes: Erica Komisar, Raising Resilient Adolescents, Beyond the Q&A, Part II

Kimberly Hillyer, DNP, NNP-BC

The following is an reloaded transcript for Neonatology Today of Dr. Kimberly Hillyer and author *Erica Komisar*. The following interview focused on her new book; ***Chicken Little the Sky isn't Falling: Raising Resilient Adolescents in the New Age of Anxiety***. This is the second part of the interview.

Click this link to go directly to our YouTube channel, Neonatology Today Media. Hit the subscribe and notification button to enjoy the direct viewing of the interview when it is available. We would love to hear your thoughts, so leave a comment.

"The following interview focused on her new book; Chicken Little the Sky isn't Falling: Raising Resilient Adolescents in the New Age of Anxiety. This is the second part of the interview."

Introduction

Thank you for joining us on today's segment of Neonatology Today Media. I am your host Dr. Kimberly Hillyer and today with have with us *Erica Komisar*. She is a clinical social worker, psychoanalysis, and parent guidance expert who has been in private practice in New York City for over 30 years. Her new book Chicken Little the Sky Isn't falling: Raising Resilient Adolescents in the New Age of Anxiety has come out.

Dr. Hillyer: Your book is entitled Chicken Little the Sky Isn't Falling: Raising Resilient Adolescents in the New Age of Anxiety. What was your inspiration?

Erica Komisar: So, the title was based on that childhood book 'Chicken Little the Sky is Falling,' and you know that cute little chicken that's running around saying the sky is falling, the sky is falling, and it was a book to say actually this is the sky isn't falling it feels like it's falling when your children are not doing well. We say, "we're only as happy as our least happy child." So, it certainly feels like the sky is falling, but again it was meant to be a somewhat hopeful title.

"I wrote this book because I was really responding to this mental health crisis and this epidemic of mental illness in children and adolescents."

I wrote this book because I was really responding to this mental health crisis and this epidemic of mental illness in children and adolescents. It really was my way of writing a book that kind of cut through a lot of misinformation and misunderstanding about raising adolescents and educating parents about things like brain science, meaning understanding what's actually going on in terms of your child's neurological development. That helps you to understand their behavior and also helps you to be more empathic.

But I think one big reason I wrote this book is that I had a very hard adolescence and was bullied and teased. My parents loved me a lot but did not know how to help me with that situation at school, so it was very personal for me. It's probably one of the reasons I did become a therapist because I did have some adversity in childhood that I had to overcome. I wanted to give parents the tools that I wish my parents had had.

Dr. Hillyer: So. Your first book was 'Being There, Why Prioritizing Motherhood in the First Three Years Matter.' Was there a connection between the two books?

Erica Komisar: Absolutely, so the first book was about the first three years of a child's life and really the brain development, the neurological development that is connected to secure attachment. Meaning mothers or primary attachment figures, sometimes today their fathers, are critical for the healthy emotional development of children in the first three years. By a thousand days or three years, 85% of a child's right brain or social-emotional brain is developed. We call it a critical window because a child is incredibly sensitive in that critical window to the environment and to stress in the environment.

The second critical window is where parents are a part of the environment. Being a big part of the environment has a great impact on children's brain development and emotional development. The second critical window is adolescence from nine to twenty-five. Which we know now that adolescence starts earlier as early as nine and ends later than we understood many generations ago; it ends at twenty-five. We know that because we have the technol-

ogy to know that.

Dr. Hillyer: So, in your first book, you described how parental attachment creates resiliency later on in life. How does this book address that issue?

Erica Komisar: So, you could think of the first critical window as laying down the foundation of emotional security that helps that child through life but certainly carries them into adolescence. They have the foundation of that security to cope with adversity in the future.

Children aren't born resilient that is a misunderstanding, and I think it's a misunderstanding. Again, we project onto very young children adult-like characteristics because we don't want to see them as vulnerable. If they're as vulnerable as they actually are, then it means that we have to give up more. I think that we project onto them that they're not vulnerable and that they are strong and resilient. You'll often hear parents say, "oh, you know my child can take it," and "children are, you know they bounce back," and "they'll be fine," and actually, children are not fine. That's what we're finding.

Basically, the first critical window of that emotional security gives that child who heads into adolescence an advantage, which is that they are ready to deal more with the storms of adolescence when they come. What we're finding today is that more children are heading into adolescence more fragile. Many of them with attachment disorders, many of them with untreated depression and anxiety. So, when you head into adolescence which is itself a trauma and a storm, you're more likely, you're more susceptible to breakdown.

"What we're finding today is that more children are heading into adolescence more fragile. Many of them with attachment disorders, many of them with untreated depression and anxiety. So, when you head into adolescence which is itself a trauma and a storm, you're more likely, you're more susceptible to breakdown."

Dr. Hillyer: Wow! As I think about myself growing up, I remember being taught, especially as a Black woman, that you need to be independent. You really need to be self-sufficient. So, with all these cultural concepts and factors, societal factors. How does your book address this?

Erica Komisar: I want to pick up on the word strong because I think there's a lot of emphasis in our society and maybe in particular in the Black community on creating, and I understand some of the history behind it, but by creating strength with self-sufficiency. I think it exists everywhere in America, in particular, that we're a very self-sufficient, independent, self-determination-driven culture. I think what it's doing is creating very rigid, fragile, defensively independent young people.

I think of interdependence as a way forward, which is that strength comes from the ability; well, we say in my field, in psychoanalysis, we say a strong ego. The strongest ego is an ego when someone that you love or cares for you is around that you can lean on them when you are in distress. In other words, giving our children strength means to make it possible for them to lean on us and be dependent on us when they can. Then to be flexible enough, to switch tacks when no one's around and to be able to lean on themselves. Then when someone's around, to create strength in relationships. So, it's more like flexibility. I think the best metaphor would be an oak tree, which is probably more likely to lose its branches in a hurricane because it's a hardwood, a rigid wood, and stands alone. Whereas a group of willows or softwood trees that bend in the wind don't lose their branches and stand together.

"In other words, giving our children strength means to make it possible for them to lean on us and be dependent on us when they can. Then to be flexible enough, to switch tacks when no one's around and to be able to lean on themselves."

I think of human beings like that in a way; this kind of hyper-focus on self-sufficiency and independence as a sign of strength is actually weakening our children. There's a wonderful article that was written in the Philadelphia inquirer by a colleague the other day about how dependency and neediness, and I write about this all the time too, but how dependency and neediness are seen as a curse word in our culture, is seen as a bad thing. It's stigmatized as opposed to saying if we don't need each other, where does our strength come from, right?

I think it's also the devaluing of nurturing and caretaking that is making our young people; the emphasis is in the wrong place. We want them to be interdependent, to be able to be independent when no one's around if someone's around. Or, if they need help that they can reach out, or they can say, "I need therapy," or "I want to go talk to my friend," or "I'm going to go talk to my mom and dad." You know, but it's this idea that they feel they have to be; it's shameful in our culture to need anyone or to be dependent.

So, I think that's an interesting concept, what is strength, what is emotional strength, and mental health? Margaret Moller, a very famous psychoanalyst, said that strength is built from being able to emotionally refuel whenever you need to with the relationships that are securing and mooring for you. That might be your mother, that might be your father, that might be your friends, that might be your therapist, but strength comes from emotionally refueling.

Dr. Hillyer: Wow, that is very powerful, and as you are talking about the interdependency, it reminds me of the article you wrote in the Wall Street Journal about Simone Biles and how she had to take a step back mentally during those last Olympics. Yet, her team rallied around her, but at the same time, society was, we were putting some really negative stuff out there on social media. How can we do better?

Erica Komisar: So, interesting is if you looked at social media, I mean, that's why I wrote that piece. If you looked at social media during that time, people were just horrible. Saying, "she knew what she was getting herself into." I mean, I don't even want to repeat it because they were awful comments. What I can say is it is part of our culture really to be not compassionate. We are not a compassionate culture; I mean, we're becoming a more compassionate culture. I think there are movements to become a more compassionate culture, but we have trouble being compassionate; it's a very harsh culture. we have to evolve as a culture, so we are more sensitive and empathic. Embrace and value caretaking and nurturing again

"What I can say is it is part of our culture really to be not compassionate. We are not a compassionate culture; I mean, we're becoming a more compassionate culture. I think there are movements to become a more compassionate culture, but we have trouble being compassionate; it's a very harsh culture. we have to evolve as a culture, so we are more sensitive and empathic. Embrace and value caretaking and nurturing again."

You could say our culture has a lot of good things to it. We were based on freedom and independence. All that comes from our culture, but we were also a very puritanical culture. It was based on puritanical, very rigid values. I think we have to evolve as a culture, so we are more sensitive and empathic. Embrace and value caretaking and nurturing again; we've really lost our way. I think because we've lost our way as a modern culture, our children, we always say in my field that children are the barometers of how a family is doing. I will say that children in our society are a barometer of how society is doing, and society is not doing okay because our children are not doing okay. If our children are not doing okay, society is not doing okay. A lot of people don't like the things I say because they're harsh truths. As my rabbi says, keep speaking the truth even if it's painful to people and even if you get lash back from it. But a lot of people don't like to hear the painful truth that we have to value nurturing and caretaking over everything again; otherwise, our children are lost.

Dr. Hillyer: I can see that, and I definitely understand it. Thankfully your book brings together information that parents can implement, especially with a child. How can parents advocate and collaborate with the schools?

"Some of them have to do with, and I would say, the easiest advocacy for most parents is to go to your school. Start with your school. Meaning whatever school your kids go to, advocate for things like more mental health workers in the school."

Erica Komisar: I talk about policy recommendations, particularly with adolescents. Some of them have to do with, and I would say, the easiest advocacy for most parents is to go to your school. Start with your school. Meaning whatever school your kids go to, advocate for things like more mental health workers in the school. If you wait for children to show signs of difficulty, you kind of miss the boat. Even if you have to do fundraisers in your community, raise the money for another social worker so kids can have one-on-one sessions with someone in school where they don't have to pay for it. Parents don't have to pay for it directly because a lot of parents can't afford it directly, and there aren't enough mental health services outside of schools, but more mental health services in schools that catch things early that are preventative, that are not just what we call medically-oriented or symptom-oriented.

If you wait for children to show signs of difficulty, you kind of miss the boat. There are signs that are preventative signs that they show very early. Even if you see a child is struggling socially, that might be one of the first signs where a child is missing too much school because they're sick because they're developing a school phobia. If a child's grades have dropped from A-'s and B+'s to C's and D's. If a child seems to be more aggressive, and aggression is a sign of stress, it's part of the fight-or-flight part of our HPA access. Meaning it's part of how we, in an evolutionary way, respond to stress is to become aggressive, right. If we see a predator, we fight. If a child becomes distractible, you know, all these kids are being diagnosed with ADHD; I think it's like a quarter of American kids are diagnosed with ADHD. I'm like, it's not a condition, it is a symptom of anxiety. What we call a hyper-vigilance of the right part of the brain, the limbic system, and the threat sensing part of the brain is on high alert.

No one is asking why are these kids on high alert. What is the stress, and what are the psychosocial stressors for that particular child? Is it that their family has marital conflict; is it that there's alcoholism in the family; is it that their mother is depressed or distracted or absent, or their father is abusive? I could go on and on. Is it even that they've moved house, and no one took into consideration that the transitions are hard for kids? There are all kinds of psychosocial stressors that create stress for children, both external ones and internal ones. We're not asking those questions. We're just diagnosed, slapping diagnoses, and medicating kids because we just want to silence their pain and move on. So, that is another thing schools can look for is not just to say your kid has ADHD but to say your child is showing signs of being distracted. Is there something going on at home that might be causing the

stress that would make them be more distracted? Instead, they say your child has ADHD, so we want to slap labels on things, but we don't want to actually understand what they mean, right. We want to just get rid of the symptom that's part of our culture too.

"There are all kinds of psychosocial stressors that create stress for children, both external ones and internal ones. We're not asking those questions. We're just diagnosed, slapping diagnoses, and medicating kids because we just want to silence their pain and move on."

Schools can be more vigilant about referring children for psychotherapy. Talk-psychotherapy, feelings-based talk psychotherapy, not just CBT therapy which just gets rid of symptoms but really gets to the root of what's causing the symptoms. Also, schools can start later because adolescents have something called sleep-wake phase delay, which is that they produce melatonin later in the evening, at least two hours after an adult, and they feel sleep pressure two hours later than you do. When you force them to go to sleep too early, they get something called sleep anxiety, which is then they get anxious that they can't fall asleep. Parents think it's a discipline issue that kids don't go to sleep early when they're adolescents, but they actually don't feel sleep pressure until at least midnight or one in the morning. So, schools need to start later because a child who's not well-rested is more susceptible to depression and anxiety. I mean, I have so many recommendations for schools, but those are just a couple of them.

Dr. Hillyer: Those are great recommendations, and I really hadn't thought about it. How I could participate, being a part of the PTA in the school, and how to utilize some of those tools.

Erica Komisar: I mean the other thing is that more trained teachers can do the training too. Teachers can train in mindfulness training, and they can be facilitators even if they're not mental health workers. They can facilitate expression, social, and emotional groups in the morning, meaning when you come to school. There are some schools in New York who are doing the processing of emotions before the day begins. So, they go around in a circle and homeroom, and they have everybody say how they feel that day. If there's something going on that's making them feel rotten, or are they happy or are they sad. So, they can really discuss what's going on inside and outside of their lives.

Mindfulness training, meaning teaching them to do even ten-minute meditations before school starts and visualization and breathing exercises, and emote ways to regulate their emotions. But the most important thing is to give them adults that they can turn to who really care and want to understand and want to listen. Sometimes with parents, if there's not a culture of openness in a family, it takes time to create a culture of openness, but I encourage parents to try to express their feelings first so kids feel comfortable expressing their own because a lot of the kids that are going into the school system do not come from homes where their parents are not that emotionally intelligent. That's the truth. A lot of emotional repressions. A lot of situations where for one reason or another, they don't feel comfortable. There's not an open enough experience of communication, so they have to have adults that they can turn to process their emotions and their feelings. I try to get parents to be that, but teachers can also be that.

Dr. Hillyer: One section that really stood out for me in your book was the section where you were asking us as parents to look into the mirror and how we need to be truthful with our feelings. I know a lot of times, I will say to someone who's asking me how am I doing, "I am fine," and if I can't be truthful with my own feelings. How am I supposed to teach that to my kids?

Erica Komisar: So, one thing is maybe don't ask the question, how are you doing? Ask the question, how are you feeling today because how we're doing is different than how we're feeling. I mean, that's the first thing, but I think adults have to model it. I always think that when teachers are leading these groups in the morning, they have to start with themselves. Somebody has to open up, and it's a little bit of, I'll show you mine if you show me yours, it's that game. So, if the teacher says I'll start, "so I'm feeling kind of anxious this morning because I had a hard time commuting. There was a driver that got close to my car, and it scared me, and I'm feeling a little shaken up this morning." Then you go around, and then the next kid says, and "I'm feeling angry because my dad yelled at me this morning, and I didn't deserve it." You know, and you go around the circle, and you'd be surprised, once you kind of crack the door open little kids want to express themselves, they do want to express themselves. It's very little nudging to get them to open up. Sometimes with parents, if there's not a culture of openness in a family, it takes time to create a culture of openness, but I encourage parents to try to express their feelings first so kids feel comfortable expressing their own.

Dr. Hillyer: So, what I'm hearing is how important it is to really be able to express your feelings. You want to be able to see that true self. What kind of culture are we creating if we're not able to get to that? You have the CDC in 2019 saying that the second leading cause of death in Blacks ages fifteen to twenty-four is suicide. Then you have a strong Black woman, Miss USA Cheslie Kryst being a prime example of that.

Erica Komisar: Yeah, again, it gets back to what kind of culture are we creating for our children when we don't model for them, kind of vulnerability. That vulnerability is strength vulnerability is the willow in the storm. So, we're strong only if we're comfortable with our vulnerability and we trust people enough to be interdependent. That creates strength, but we are not strong if we stand alone. We're never strong if we stand alone.

I mean, teasing and bullying are a major problem in schools today. It was in my day. As I said, I was teased and bullied by this group of girls, but in my day, there wasn't social media; there wasn't technology, and so it remained contained in a way. It was not that it was good, but it remained contained. Today it's really terrible because it doesn't remain contained. It can actually become a very big and traumatic issue. The idea is that we have to think about what do we teach our kids when they are teased and bullied. Do we teach them to stand alone? Do we teach them to stand together with their peers? The answer is, and the best answer is when parents have a child who's being teased and bullied, it's helpful to reinforce that child's own community. Because when children stand alone, when in the face of others' aggression, they are more vulnerable than it's better if they have groups. It's better

even if that group is two other kids who are nerdy like you are. Whatever it is, we are stronger when we stand together with other people than when we stand alone. When you ask someone how are they doing, and they don't feel comfortable telling you, that person believes that they are stronger if they stand alone.

Dr. Hillyer: And we're teaching generation after generation how important it is to stand alone. Then with you tying in how social media is factoring in with the standing alone, individuals are just posting what's picture-perfect and not really displaying the whole truth. How do we as a society be able to show our children that it's okay to not just be that picture-perfect smile that they see on social media?

"Well, I think social media does promote idealization. So, one of the tasks of adolescence, well, the biggest task is to find your place in the adult world. But one of the other big tasks I think is when we're talking about idealizing is the de-idealizing of your parents, to not see them as perfect, and to let go of perfection in yourself. It's how we treat our own imperfections that helps our children to know that they can have imperfections."

Erica Komisar: Well, I think social media does promote idealization. So, one of the tasks of adolescence, well, the biggest task is to find your place in the adult world. But one of the other big tasks I think is when we're talking about idealizing is the de-idealizing of your parents, to not see them as perfect, and to let go of perfection in yourself. It's how we treat our own imperfections that helps our children to know that they can have imperfections.

When you're in middle adolescence, which is about 14 to 18. When you're in middle adolescence, you're very self-conscious. There's a lot of self-consciousness, the pimple on your nose, you think everybody just sees that pimple on your nose, and you are a big pimple, that's all you are. There's a lot of, and it has to do with brain development; the amygdala is very the threat sensing part of the brain is very active. The PFC, or the emotional regulation part of the brain, lags behind in development, so there's a lot of hyper-criticism, self-criticism, self-consciousness, and sensitivity to others' criticism. It's the worst time for social media because social media presents images that aren't even real. We know now that they are manipulated photos. Photos can be manipulated to look better than they are.

The idea is that adolescents, who struggle with their bodies, their skin, and their hair, and they're sort of, I would say, they're not fully formed adolescence. I know; I went through a terrible period of just feeling awkward with my looks, my teeth, my nose, and my hair. Everybody you know has that period, and to then see these images of these perfect models. Look, in our day, in my day, it was the fashion magazines that made you feel that way, but the difference is you had to go out of your way to pick up a fashion magazine, and then you could put it down and walk away. The problem is your phone is always with you, and that means it's like having an open fashion magazine all the time with skinny perfect and perfect this. First of all, it's not real, so first, you have to teach your kids that those are not real images. Those are touched-up images, meant to manipulate you into buying things and joining things. That's the first thing, but also for you to not need to be perfect. You know it's is as women, if we don't wear our makeup every day, if we kind of dress sloppy sometimes, if we have a pimple and we just go, "oh well" I have a pimple, "oh well" I'm having a bad hair day. That's okay. Everybody has. It's how we treat our own imperfections that helps our children to know that they can have imperfections, and it's okay. That's it, it's really modeling.

"Everybody has. It's how we treat our own imperfections that helps our children to know that they can have imperfections, and it's okay. That's it, it's really modeling."

Dr. Hillyer: Thank you for saying that. I think it's very important that us, as parents be able to understand that it's okay to make mistakes and that what we're modeling isn't perfection. Another part that I wanted to touch bases on is what we were discussing as far as bullying is concerned. How do we deal with that in social media? Especially in a time where the new term of "Cancel Culture" has such a negative connotation to it. How do we teach our teams that it's not about canceling them but being held accountable?

Erica Komisar: Again, I take a lot from my faith, and we talk a lot in Judaism about the idea that we're not meant to be punitive; we are meant to be forgiving. I think in Christianity, that's talked about too, the idea of forgiveness. We as a culture have gotten so far away from forgiveness.

I don't know if you heard about this whole Whoopi Goldberg thing that's going on. It's interesting because as a Jew, I would say Whoopi Goldberg has been kind of barbecued publicly when she should have actually been a partner in this idea. I don't know if you know what's happening with her, but it's just an example of how she was suspended because she made some Anti-Semitic quote-unquote Anti-Semitic comment. I think that it's really important that we allow people, as long as they aren't heinous things that we allow people to make mistakes and that we partner with them. We allow people to make mistakes and take responsibility and move on from them; that we don't say one strike, you're out. Because what that does is it creates that perfectionistic example for our children. That if you make a mistake, you could be canceled. If you say the wrong thing or do the wrong thing, you could be totally thrown out socially, and that's a terrifying idea. That you can't stumble, that you can't fall, that you can't learn from your mistakes is a terrifying idea that is actually contributing to a lot of their anxiety. It's real, unfortunately, because the culture has become so intensely hypervigilant that it's a scary culture.

"If you say the wrong thing or do the wrong thing, you could be totally thrown out socially, and that's a terrifying idea. That you can't stumble, that you can't fall, that you can't learn from your mistakes is a terrifying idea that is actually contributing to a lot of their anxiety. It's real, unfortunately, because the culture has become so intensely hypervigilant that it's a scary culture."

Dr. Hillyer: You were talking about your faith, and I know for me, one of the key things that I try and teach my kids is that out of all things that, God is Love. I did notice that there was a little section in your book in which you leaned on your faith. I remember seeing a phrase that really stuck with me that said "if you don't believe in God, it's okay. Lie to your kids about that." Why is that important?

Erica Komisar: Well, there's a Harvard study that came out that says that belief in some religion, it doesn't matter which really religion, some faith-based raising of children creates more resilience to stress in those children. So, I think there were a thousand families that were part of the study. I think it's a thousand or more, and of those thousand families, the children who came out the most resilient are the ones who were attending at least one service a week or at least were given some sense of faith.

Being raised in a faith-based environment, the reason for that being that faith is obviously about the idea of some guiding supportive figure in your life other than your parents, but it's more than that it's the community, it is. Community is a big part of it, and its community service because most faiths have some idea of giving to others, sort of communal support. So, there's a lot more to faith than just empathy and compassion. Those are all principles of most religions. There's a lot of advantages that are not just believing in God; it has a lot to do with community. Those kids do better than the kids who are told that when you die, ashes to ashes, dust to dust, and you're nothing. I say in an article I wrote for the Wall Street Journal that Nihilism is fertilizer for anxiety and depression.

Dr. Hillyer: Wow, Erica, you've really dropped some great gyms on us today. I know one of the things that you talked about was that a chapter you would have put in your book would have been about COVID. So, can you tell me some of the tools that you would suggest to us parents post-COVID to give to our adolescents?

Erica Komisar: Well, again, I'm not sure that COVID is all bad. In some ways, it has been devastating to our youth, and in some ways, it's been perspective-giving. In terms of people spending more time with their families, spending more time working from home. Not dropping their kids off in institutional daycare for 12 hours a day like they used to. Really kind of reflecting on relationships being the most important thing. A lot of people quit their jobs. So, I think there might actually be positives that comes out of COVID. That's the optimist in me. I don't think it's all negative. I think that there's going to be a lot of changes in society and family structures because of COVID. That will be an interesting kind of chapter, as you say what happens a decade after COVID. I mean, obviously, there's going to be some negative. It's left a lot of kids in a fearful state, we're going to have to deal with that for many years, but there's also been a lot of good that's come out of it too.

Dr. Hillyer: Yeah, I know; I feel the effects on my life as well. Out of the negatives, I recognize the very real positive aspect that my husband gets from being able to work from home and pick up our son every day from school from kindergarten.

Erica Komisar: I think children are very sensitive to not being the center of their parent's universe. I think what's happened in the past 50 years is that a lot of good has come out of the women's movement. It's a lot of good when I'm a benefactor of a lot of that good. But I think a lot of what's happened is that children used to be the center of parents' universe, and I think careers now, and other personal endeavors have become the center of our universe as adults. I think we can try to lie to ourselves and say that our children are still the center of our universe, but I think how we base what is the center of our universe is how much time we spend on that endeavor or with that relationship.

I think children are very sensitive to the discrepancy between what parents say and what they actually do. So, if the parent says, "I love you more than anything," but I only spend 90 minutes a day with you, "but I love you," children are very sensitive. They know when they're not the center of their parents' universe, and they need to be. Children need to be the center of their parents' universe, it doesn't mean we all have to work and we have to make money, and I get it, I mean, my husband and I both have to work and make money. I have always been quote-unquote a working mom, but in the early years when my kids were little, we sacrificed a lot financially to allow me to be able to be there as much as possible.

So, nothing's perfect, no one's perfect, but I think the idea is that children are very sensitive to when their parents are distracted. I'll just give you one more example, I sing, and when my kids were little, I sang in the temple. Now when I was younger, I used to sing like an amateur; I was an amateur opera singer. But whenever I would sing to my kids, they would like it for a minute. Then they would say stop it, mommy, stop it because they don't want you then your narcissism which is expressed through singing. Anything that expresses your own narcissism, they're very sensitive to. They want the attention back on them, and that's a real key to health with children is that they are the center of your interest and the center of your universe. A lot of that has to be met with the amount of time that we spend with them, and how much attention we give them and whether we turn off our devices. Whether we're really interested in them because you can't fake interest, that's the problem. You can't fake it.

Dr. Hillyer: So, I understand what you're saying about children really being intuitive and really wanting you to be that center of attention around their world. But, jumping to my profession, for example, what happens when you have a family who's in the neonatal intensive care unit? They could be there for days, weeks, or months and maybe that child at home just isn't really understanding what's going on. How do we, as healthcare providers, give these families the tools to help navigate and help that child at home who no longer is the center of the world.

Erica Komisar: So again, loss is something that happens. Adver-

sity is something that happens. It is an adversity to have a child who's in a neonatal unit, and it's an adversity to the child you already have, right? So, the child who's at home, who's now lost time with you and that you've disappeared and gone. You are spending days and hours at the hospital, and it's a tremendous loss for that child. So again, children are not born resilient, they're born vulnerable. That means that they rely on you to help them to process the loss and their emotions.

Life isn't perfect, and sometimes we're dealt cards, and our kids are dealt cards that are not fair. It's addressing the unfairness with your child. It's letting them express their sadness. It's encouraging them to express their anger that this baby has come into the world; and "can't the baby go back mommy," "I don't want that baby," "I hate that baby," "I wish that baby would die," "I wish you'd come home again." Not to say to your child, "don't say that." We don't want to stop your child from expressing emotion because they just introvert that emotion. They'll become depressed because when we invert our anger and our sadness, that leads to depression. We want to encourage our children to express how they feel, whatever it is rage or sadness, and help them to process it and say that it's natural that you feel that way, and anytime you feel that way come to mommy. Check-in every day and talk about how we're feeling, so it's processing.

"We don't want to stop your child from expressing emotion because they just introvert that emotion. They'll become depressed because when we invert our anger and our sadness, that leads to depression. We want to encourage our children to express how they feel, whatever it is rage or sadness, and help them to process it and say that it's natural that you feel that way, and anytime you feel that way come to mommy. Check-in every day and talk about how we're feeling, so it's processing."

So, think of yourself as a parent, as a neonatal nurse. It's teaching parents that it's okay that the children that they have are angry and sad and that they have to give them opportunities to express. Even what is in the parent's mind, the worst possible thing, which is that that older child or the toddler wishes that baby would die. That if they say that it's not the end of the world. That if they've got to get it out and they've got to hear compassion from you. I understand it's hard; it's such a hard thing that we that this beautiful baby that is your sibling is not isn't is not able to come home and play. That mommy needs to be you need to be able to process how hard it is. So that's how you help children with adversity. You don't make it go away because you can't. You can't always be in two places at once, but you have to process their feelings.

Dr. Hillyer: Thank you so much, Erica, for your time today. I really enjoyed this conversation that we've had, and I think that your book is extremely important and I think that it gives parents the tools that they need to help their adolescents as they navigate through this complex world that we're living in now. I'm going to reread your book and tell everyone to read it as well. So, I want to once again thank you again for joining us on Neonatology Today Media platform, and we appreciate it.

Disclosure: Erica Komisar is the author of Chicken Little, the Sky Isn't Falling: Raising Resilient Adolescents in the New Age of Anxiety

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As a Neonatal Nurse Practitioner, she has worked for Loma Linda University Health Children's Hospital (LLUH CH) for twenty years. During that time, she has mentored and precepted other Neonatal Nurse Practitioners while actively engaging in multiple hospital committees. She was also the Neonatal Nurse Practitioners Student Coordinator for LLU CH. A secret passion for informatics has led her to become an EPIC Department Deputy for the Neonatal Intensive Care at LLUH CH.

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Erica Komisar is a clinical social worker, psychoanalyst, parent coach and author. With 30 years of experience in private practice, she works to alleviate pain from individuals who suffer from depression, anxiety, eating, and other compulsive disorders. By helping them live better lives and have richer, more satisfying relationships, she assists them in achieving their personal and professional goals and living up to their potential.

A graduate of Georgetown and Columbia Universities and The New York Freudian Society, Erica is a psychological consultant bringing parenting and work/life workshops to clinics, schools, corporations, and childcare settings including The Garden House School, Goldman Sachs, Shearman, and Sterling and SWFS Early Childhood Center.

Erica is also the author of the book Being There: Why Prioritizing Motherhood in the First Three Years Matters and has appeared on major media networks such as CBS, ABC, FOX, and NPR. She is a regular contributor to the Wall Street Journal, Washington Post, New York Daily News, and FOX 5 NY. She is a Contributing Editor to the Institute for Family Studies. Her upcoming book, Chicken Little The Sky Isn't Falling: Raising Resilient Adolescents in the New Age of Anxiety will be released in Fall 2021.

She lives in New York City with her husband, optometrist, and social entrepreneur Dr. Jordan Kassalow with whom she has three teenage and young adult children.

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High-Reliability Organizing (HRO) for the Color of Noise: Forcing Functions, Collaboration, and Safety

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Abstract:

The aviation industry operates in an environment where forcing functions and catastrophes can be deadly to the public and not easily explained away. The industry formed a safety improvement collaboration known as CAST, the Commercial Aviation Safety Team. Within ten years, the fatal accident rate decreased from the pre-CAST rate by more than 80% while also improving productivity. Signals carry information while noise interferes with information. This distinction is one of predictability versus unpredictability. Noise as a stochastic variation may represent unrecognized influences in the system. By existing in a world of stochastic variation, biological systems must maintain dynamic stability far from equilibrium. The meaning of the types of environmental stochastic noise comes from the characteristics of their fluctuations that cause unpredictable events and the energy of their 'forcing functions.' Frequencies with the power to force a system or population to respond to the environment are forcing functions. White noise environments follow the Gaussian distribution and are amenable to prediction, algorithms, rules, and protocols. Red and pink noise develop from autocorrelation, the feedback from the past influencing the present or a system interacting with other systems. Red noise environments with low frequency forcing events have a greater influence on the system than white noise. Red noise environments contain ill-structured problems requiring the use of heuristics and experience. Considered a response to reddened frequencies, we can discuss safety as information about long-period events and forcing functions or as the forcing function itself. The threat of punishment and litigation incentivized pilots, as it currently does healthcare professionals, to hide their errors and near misses and not report the errors and near misses of others.

"Frequencies with the power to force a system or population to respond to the environment are forcing functions."

Introduction:

"We don't fight fires; we solve problems the public cannot or will not solve themselves." William J. Corr, Captain, LAFD, and WWII US Navy veteran, South Pacific, held an expanded view of the fire service. He uniquely presaged the ideas of red noise forcing functions, and pink noise 'flicker' catastrophes could arise from any mundane problem. Corr expected and modeled attending to and reporting relevant, contextual details. Karl Weick observed that managing details without context is micromanagement (personal communication). Corr and Weick indirectly articulated what the authors also learned through experience – that context can amplify details into forcing functions. We must remain vigilant, monitoring and responding as necessary. Today, we might describe this as residing in the white noise environment but mentally operating in the pink noise space.

"The aviation industry operates in an environment where forcing functions and catastrophes can be deadly to the public and cannot be easily explained away. In the early 1990s, despite many safety improvement efforts, the previously declining accident rate had stopped declining."

The aviation industry operates in an environment where forcing functions and catastrophes can be deadly to the public and cannot be easily explained away. In the early 1990s, despite many safety improvement efforts, the previously declining accident rate had stopped declining. The airline industry formed a voluntary government/industry safety improvement collaboration known as CAST, the Commercial Aviation Safety Team.

CAST focused not only on errors but also became proactive by focusing on upstream threats that make those errors more likely. This relationship is like the effect of contextual details interacting with an unexpected forcing function to cause extreme failure. Their collaborative approach ensured that all participants involved in or affected by the threats were involved in developing mitigations for the threats. The operational environment is large with many facets. Even the least experienced participant, when well trained, can offer valuable information. This flow of information included what was not going well and whether the remedies regarding what was not going well-improved safety without producing unintended consequences.

CAST faced a challenge from many safety experts who thought the pre-CAST fatal accident rate was exemplary and could not be substantially improved. However, within ten years, the fatal accident rate decreased from the pre-CAST rate by more than 80% *while also improving productivity*. The collaboration minimized unintended consequences. This enormous safety improvement occurred without CAST generating any new regulations.

Despite numerous longstanding efforts by the healthcare industry to reduce errors and injuries caused by errors, the error and injury rates have stubbornly resisted significant, sustained improvement.

There are numerous ways to evaluate CAST's safety achievements and the difficulties experienced by healthcare. These methods too easily come from the experiences of the evaluator with risks of mistranslation (1). We offer a mathematical approach ap-

plied without modification by diverse scientific disciplines to various contexts – the color of noise.

"There are numerous ways to evaluate CAST's safety achievements and the difficulties experienced by healthcare. These methods too easily come from the experiences of the evaluator with risks of mistranslation (1). We offer a mathematical approach applied without modification by diverse scientific disciplines to various contexts – the color of noise."

Information, Noise, and Collaboration

Signals carry information. Noise interferes with information. This distinction is one of predictability versus unpredictability (2). However, noise as a stochastic variation may represent unrecognized influences in or on the system (3). Stochastic properties follow a probability, but the probability is on a probability distribution that can change. Stochastic variation, then, appears random yet also appears to follow or contain deterministic processes.

Appreciating that noise contains information can contribute to the use of noise for prediction, alter our view of the environment (4-6), and change how we think and reason (7-10). Increased predictability can focus on our vigilance, reduce our exposure to vulnerability, and mitigate some of the effects on the system that arise from threats (5, 11, 12).

Our view can then move beyond situations within a specific space and time in ways that can increase the flow of information within the system (13), bring into better distinction the boundaries of our capabilities, make visible early heralds of failure, and give better clarity to the presence of covert, compensated states (1). We generate and update information, make more effective inferences from imperfect information, and process the evolving consequences of simultaneous acting and *not* acting (14). We begin to think by acting (15-18). A collaborative approach then emerges as a robust flow of safety improvement information consisting of, among other things, information about errors and near misses.

Widespread nonuse or misuse of safety procedures, such as hand hygiene, handoff procedures, and checklists, indicates that the procedures may not be entirely suitable for the operational circumstances. The lack of operational suitability is often an indication that the procedures were not collaboratively developed; that is, the end-users of the procedures were not adequately involved in identifying the reasons for the nonuse or misuse and developing appropriate remedies. The stigma of errors and the threat of punishment incentivize health care professionals to hide and/or not report errors and near misses. Understood as environmental forcing functions, errors and near misses identify and mitigate potential threats that lead to errors and injuries.

The collaborative approach discussed in this article derives from commercial aviation. Collaboration improved aviation safety while also improving productivity without an increase in regulations. Involving all who touch the system – not only pilots but also maintenance personnel and, if appropriate, air traffic control personnel – helped ensure that those who touch the system would be aware of, and know-how to, engage any residual 'error traps' not adequately addressed. The tragic Boeing 737MAX accidents demonstrated that even after decades of development and improvement, the process for ensuring that airplane designs are adequately friendly and intuitive to the end-users – the pilots – has, and will always have, room for further improvement.

The difficulty lies in translating the knowledge and experience gained in new or dangerous contexts to routine operations with only the potential for serious harm. The risk lies in mistranslation by those inexperienced in dangerous contexts or those who lack a vocabulary that is familiar or readily accessible to spectators (1, 6). Missing is the salience and meaning spectators can use to expand their necessary cognitive, affective, and behavioral repertoires (19). Knowledge and experience reduce the effect of bravado, the influence of movies and television (12), the substitution of abstract for contextual (5, 20), or the understanding beyond the grasp of outsiders (1). The authors have organized a series of articles in *Neonatology Today* that combines the primary sciences, primary experience, and practical ways to overcome mistranslations while also bridging this gap.

This article describes the environment in a manner that applies to dangerous contexts, to environments with rare though severe disturbances, and to routine operations that are unlikely to experience such threats (21-23). Further, since everyone has the same brain structure, this material is given context within the neurosciences (6, 11, 19).

"In a world of stochastic variation, biological systems must maintain dynamic stability that is far from equilibrium (24, 25). Stochastic environmental variation as noise or a time series has the characteristics of a spectrum. When decomposed into constituent frequencies (by Fourier transforms), we can identify some frequencies with no temporal correlation."

The Environmental Color of Noise

In a world of stochastic variation, biological systems must maintain dynamic stability that is far from equilibrium (24, 25). Stochastic environmental variation as noise or a time series has the characteristics of a spectrum. When decomposed into constituent frequencies (by Fourier transforms), we can identify some frequencies with no temporal correlation. The values of a random signal at two instants in time are entirely independent of each other. This circumstance is "white" noise. In white noise, the variance is the same for all frequencies. There is no correlation variance, and time and space have constant variance (3, 26).

White noise is the variance incorporated into academic and scientific models (26). The randomness and independence of events in a white noise environment create a Gaussian distribution from which we can calculate statistics and probabilities (27). Independent, discrete-time intervals are amenable to applying classical logic and the formation of linear and deterministic processes (28). With independence, and discrete-time intervals comprising white

noise, we can create mathematically tractable models and more concise theories that possess greater conceptual clarity from the randomness (3, 29). While we may use white noise for mental representations of the environment, we must not mistake it for the actual world.

"White noise is not characteristic of the natural environment or the response of organisms to maintain homeostasis, the complex "coordinated physiological reactions which maintain most of the steady states in the body" (Walter B. Cannon (30)).

White noise is not characteristic of the natural environment or the response of organisms to maintain homeostasis, the complex "coordinated physiological reactions which maintain most of the steady states in the body" (Walter B. Cannon (30)). A white noise environment, with white noise responses and the concomitant Gaussian distributions, supports Cannon's classic "homeostatic" approach of the organism maintaining constant output. However, the world, particularly the biological world, is noisy and experiences stochastic demands and threats. This random variation affects the physiological and behavioral dynamics of organisms.

The healthcare industry and commercial aviation community are populated with good people working to do the right thing under sometimes challenging circumstances. When they attempt to maintain homeostatic stability in a dynamic environment, they may do something inappropriate. The problem is probably not solely caused by the person, especially if a high percentage of people similarly situated might also do the same inappropriate thing. Instead, a significant contributor to the problem is probably the applicable procedures and equipment the person uses.

What we observe as a stochastic variation arises from instability due to environmental fluctuations, countered by non-equilibrium dynamical systems. Environmental fluctuations are caused by various factors correlated on different time and space scales (3). Non-equilibrium dynamical systems arise from internal fluctuations due to multiple degrees of freedom (31). Stochastic feedback from multiple degrees of freedom drives the system away from extreme values and toward stability. However, multiple degrees of freedom do not produce the constant output of classic homeostasis (24, 31).

Every inappropriate action made by a participant provides an opportunity to learn about what procedures and equipment should be improved to reduce the likelihood of stochastic error. In aviation, reports about errors and near-misses are one of the primary sources of information about the existence and potential remedies to mitigate stochastic threats. Convincing pilots to report their errors and near misses necessitated a change from their old way of doing business, which was to hide their mistakes as much as possible. This change, in turn, necessitated three other changes:

- a change from believing a mistake was an indication of a bad human to recognizing that all humans make mistakes, even on their best day
- a change by the employers (airlines) away from using reports of inadvertent error as a basis for punishment toward using reports of the inadvertent error to learn how to make the system less likely to cause an error
- a change by the safety regulator away from using reports as a basis for punishment or enforcement toward using reports of the inadvertent error to improve the system safety

Collecting more data or data over a longer time series does not produce a better norm or better stochastic models. Increasing variance with time (or distance) creates 'redder' noise. Variance in red noise does not form a Gaussian curve. Instead, the variance increases with the time series, and we lose the norm in power distribution. More data only increases the measured variance, and in pink noise, the variance increases no matter how long the time series (32). "In comparisons of model predictions and real data, stochastic models often perform as poorly as deterministic ones, John M. Halley (32). We can better understand environmental stochastic noise and non-equilibrium dynamic stability by describing and understanding noise as a spectrum (3, 33).

Since noise is a spectrum within the environment, the errors created by noise form an environmental spectrum; treating errors as information (34) in aviation allowed the regulator – the Federal Aviation Administration – and the airlines to learn from inadvertent errors. Rather than punishing for error, error became an important step toward continuously improving safety because it enabled the free flow of information about aspects of the system that needed improvement. Punishing the people when the real problem is the procedures or the equipment undermines the labor-management relationship – because punishment develops an adversarial relationship between labor and management – and it incentivizes people to hide their mistakes rather than learn from them.

"Decomposing a time series by Fourier transforms and identifies white noise, described above, and distinguishes frequencies with long periods. Like the longer frequencies of red light, this is "red" noise. Because of the magnitude of measurements, frequencies are plotted against their power as a log:log plot."

Decomposing a time series by Fourier transforms and identifies white noise, described above, and distinguishes frequencies with long periods. Like the longer frequencies of red light, this is "red" noise. Because of the magnitude of measurements, frequencies are plotted against their power as a log:log plot. A log(frequency) to log(power) plot for colored (reddened) noise signals approximates straight lines. A specific line for $1/f$ or f^{-1} is called pink noise, midway between white noise (f^{0}) with constrained variance and "brown" noise (f^{2}) for randomness (named for Brownian motion).

Time dependence forms a power distribution describing a more significant influence on the system from uncommon low-frequency events. These red noise events are also poorly predictable. A special relationship occurs at the 'flicker' frequency, the $1/f$ oscillation, where increased power spectrum at low frequencies produces abrupt, rapid fluctuations and catastrophic failure. This concept is 'pink noise.'

Development of Reddened Noise:

This problem of more data clouding the conclusions develops when an event is influenced by what preceded the event. That is, the event is no longer independent of preceding events. Autocorrelation is when past observations or events have an impact on current ones. Autocorrelated events are more susceptible to feedback loops, allowing even minor or mundane noise signals to achieve resonance, becoming amplified and consequential.

"Red and pink noise develop from autocorrelation, the feedback when the past influences the present or a system interacts with other systems. Red and pink noise has zero mean, increasing variance, and are autocorrelated in time by feedback. As power distributions, the non-Gaussian nature of red and pink noise distributions impairs our ability to use classical logic, rigid models, and strict concepts."

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Spatial autocorrelation has a role in epidemiology as the degree of similarity between objects located near each other – everything is related to everything else, but near things are more related than distant things. Spatial autocorrelation identifies disease clustering as clustered, random, dispersed, and whether the disease is in a general or specific region. Spatial autocorrelation measures the degree of similarity between objects located near each other. If spatial autocorrelation confirms spatial dependency, then the disease rates can be adjusted in adjacent areas (35).

Neighbors are features within a neighborhood used to characterize spatial relationships among objects. This relationship could be absolute distance based on the distance separating them, relative distance with the nearest feature considered a neighbor or topology-based with neighbors considered based on their relations or attributes.

Red noise is dominated by low-frequency (or long-period) cycles producing an increased probability of long runs of above or below average conditions. Low-frequency events (reddened spectrum) have an inordinate influence on a system because prolonged decay continues dissipating energy and environmental disruption (3, 25).

Pink noise (also called fractal, flicker, 1/*f*, or *f -1* noise) is half the integral of white noise. Pink noise is the power function halfway between white noise's predictability and the randomness of brown noise. We can observe 'flickers' of power (abrupt increases in magnitude) (36, 37) at 'half' the integral of white noise processes. Flicker noise sums (calculus integration) *diverge toward zero or infinite frequencies*. Without a long-term mean or defined value at an instantaneous time, pink noise does not form a Gaussian curve. Because these divergences are logarithmic, extending time intervals in a time series may not capture the flicker (36). Rare events, acting as forcing functions, are more severe and sudden in the pink noise environment (32), forming a power distribution. Forcing functions are events to which the system must respond.

[The name flicker noise came from John B. Johnson's initial measurements of the white noise spectrum. He measured an unexplained flicker at low frequencies, halfway between white and brown noise (37).]

"The effect of noise on a population as variance comes from the relative time scales between environmental and population-level processes. This effect is from the relative magnitudes of environmental stochastic autocorrelation times and population dynamics."

Color	Structure	Variance	Distribution
White	No frequencies dominate Flattened spectrum Spectral density has equal amounts of all frequencies	Data *decreases* variance Forms Gaussian curve	Gaussian distribution - Elements fully independent - No autocorrelation
Red	Low frequencies dominate Long-period cycles	Data *increases* variance Forms power distribution	Power law distribution - Elements *not* independent - Mutual/ reciprocal relations
Pink	The midpoint of red noise Slope lies *exactly* midway between white noise and brown (random) noise	Data *continuously increases* variance Distinguishes pink noise from reddened spectra	Power law distribution - No well-defined long-term mean - No well-defined value at a single point

Table. Patterns and Characteristics of Noise (38)

Time Scales:

The effect of noise on a population as variance comes from the relative time scales between environmental and population-level processes. This effect is from the relative magnitudes of environmental stochastic autocorrelation times and population dynamics. Short environmental autocorrelation times act as white noise on populations. The contribution of environmental stochastic noise will dominate in large systems (39).

"Subsystems with short time scales may not be affected by noise frequencies with more prolonged periods. A more extensive system or one with a long time scale may have the capacity and experience to dampen long period disturbances that will damage smaller systems or those with short time scales (3)."

Subsystems with short time scales may not be affected by noise frequencies with more prolonged periods. A more extensive system or one with a long time scale may have the capacity and experience to dampen long period disturbances that will damage smaller systems or those with short time scales (3). We see this with the difference in experience between a novice and a veteran. The danger to the system occurs from a reset baseline as those new to a program enter an established, well-controlled system (40). Knowledge is lost, and expectations of readily achieving stability become stronger as those new to the field replace veterans.

To capture the experience of novice and veteran alike, CAST brought in pilots with a wide variety of backgrounds and experience – not just the manufacturer's chief test pilot – to "fly" the design in engineering simulators as the design was developed. This array of experience helped identify possible additional human factors issues beyond those that the human factors experts included in the original design.

Problem Characteristics:

Despite their stochastic characteristics, white noise environments follow the Gaussian distribution and are amenable to algorithms, rules, and protocols associated with known success. These are the well-structured problems described by Herbert Simon (41). The environmental stochastic variance of white noise can appear daunting to the uninitiated, believing they have experienced a reddened environment.

"Red noise environments with low frequency forcing events have a greater influence on the system than white noise—reddened events within the normal variation of activity act as forcing functions on populations."

Red noise environments with low frequency forcing events have a greater influence on the system than white noise—reddened events within the normal variation of activity act as forcing functions on populations. Red noise environments contain ill-structured problems requiring the use of heuristics (41) and bias-correcting error (34), decision-making driven by feedback (John Boyd's OODA Loop) (8), and practical, common-sense problem-solving approaches (10).

"In the pink noise environment, catastrophes occur when the environment becomes a major aspect of the problem. Catastrophic events arising from the change in entropy due to environmental stochastic noise differ only in magnitude and timescale (32). The external and internal environments share feedback, embedding the problem into the external environment."

In the pink noise environment, catastrophes occur when the environment becomes a major aspect of the problem. Catastrophic events arising from the change in entropy due to environmental stochastic noise differ only in magnitude and timescale (32). The external and internal environments share feedback, embedding the problem into the external environment. We see this with neonatal care during abrupt and prolonged disasters when the environment intrudes into the NICU, effectively embedding the NICU into the environment (21, 23). This moment-to-moment feedback can create a "loss of cosmology," which can collapse sensemaking (42), or the individual allows 'abstractionism' to supersede contextualization of the problem (20)

While some search for or develop plans for the stochastic ill-structured or the embedded problem, another approach is to use what famed airline pilot Capt. Chesley "Sully" Sullenberger used for real-time error management (personal communication before the Hudson River landing). He recalled hearing of an error described as a ball rolling down a ramp, where speed bumps captured the error. The steeper the ramp, the taller the speed bumps need to be. This relationship is essentially like increasing capture frequencies as the error (the ball) increases its speed. "Another part of the idea is that it often requires more than a one-speed bump to trap the error finally. The ball may miss some bumps or roll over them if it is going fast enough. (So, the taller the bump, the more likely it will trap the ball.) Having many speed bumps represents 'defense in depth,' a military concept that we talked about that day. A multilayered defense system is less likely to be penetrated than a single layer." The "error ball and ramp" model that Sullenberger describes is a dynamic organizational design to reduce system failure that recognizes the operator's real-time efforts decrease the chance of failure.

Forcing Functions:

The meaning of the types of environmental stochastic noise comes from the characteristics of their fluctuations that cause unpredictable events and the energy of their 'forcing functions.' Frequencies with the power to force a system or population to respond to the environment are forcing functions.

The forcing functions become ubiquitous in reddened noise environments, not entirely random except by timing. The forcing function emerges from known processes within normal variation, differing only as a matter of time scale and magnitude.

Fluctuations with long frequencies, slow in onset, and that carry greater power to affect the environment are *red noise,* as in long-wavelength red light.

Fluctuations with long frequencies that can cause abrupt catastrophic events are *pink noise* because they are *exactly* between white noise and red noise or between white noise. The hallmark of pink noise, 1/*f*, is the presence of rapid fluctuations and a power spectrum that increases at lower frequencies. Pink noise represents long-timescale fluctuations without a well-defined long-term mean. Accuracy does not improve by averaging more measurements over time (36).

Red and pink noise disturbances occur on any timescale with any order of magnitude. There is no special distinction between normal environmental variation and ecological 'catastrophes': it is the same thing seen at different timescales (32).

Forcing functions may be more important to healthcare systems than averages. The subtle or nuanced forcing function readily disregarded for several reasons may be more important. Resonance can amplify small events that can become meaningful events unless dampened by the system.

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While possibly counterintuitive, this also describes human behavior – our past experiences influence our current behavior, and we constantly interact with those around us. All human behaviors are autocorrelated. Any system with *human behavior is a red noise environment that will generate forcing functions into the system.*

Birds entering the plane's engine are forcing functions. Captain Sullenberger's water landing would apply more strictly to engineers, pilots, flight crews, and passengers if framed as a normative incident. If framed as a forcing function, the water landing applies to all of us because forcing functions are a part of living.

Capt. Sullenberger was trying to increase the angle of attack as much as possible just before the landing before the aircraft stalled to maximize the flare and thus minimize the airplane's downward velocity when it impacted the water. His effort was frustrated because the phugoid damper* prevented him from getting the last 3 1/2 degrees of nose-up pitch that would otherwise have been available before stall. Consequently, the sink rate was higher than it otherwise would have been, and the rear fuselage structure was breached to the extent that a flight attendant seated in the rear was injured, and water entered the airplane. Automation intended to improve safety and comfort hindered the most adaptable part of the system, the human pilot. *Sully was unaware of this until we [the NTSB] discovered it in our investigation* [emphasis added]. In other words, Sully solved a problem he did not know he had.

* "Phugoid" describes the aircraft pitching up and climbing, then pitching down and descending. The aircraft's speed changes between climbing and descending.

A convergent, deductive, analytic approach drives the search for facts and information which will guarantee our conclusions. The security offered by our actions and the structures we create will reinforce the normative frame, but the linearity impedes stochastic resonance (24). Rigid structure and linearity narrow and increasingly confine responses. As in Sullenberger's water landing, a pragmatic frame with stochastic resonance enhances our capability to solve problems linked to more profound, unidentifiable structures.

Safety:

Considered a response to reddened frequencies, we can discuss safety as information about long-period events and forcing functions or as the forcing function itself. We caution against a punitive approach to an error in reddened systems as we all become novices again at some level and situation. "For everyone, there is a first time," Kaldhen Sherpa, Sherpa Trekking Service.

Safety information

Safety information as long period frequencies reveal what the problems are, inform a determination of priorities regarding which problems should be addressed first, inform decisions regarding how best to remedy the problems, and provide quick and proactive feedback – i.e., "weak signals" that can help avoid having to wait for the next actual mishap to spot a problem – about whether the remedies are working. In a system populated by good people trying to do the right thing, the most valuable safety information is information about errors and near misses.

More specifically, good people trying to do the right thing make a mistake or have a close call. Information about errors and near misses reveals where there are error traps and weaknesses in the system and often suggests remedies for those traps and weaknesses.

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Did the person who made a mistake have all the necessary information at the moment, and if not, what additional information was needed, and how could it be made available? Was the process or equipment inappropriate for the situation? If so, how could that be addressed? Did the person understand the process or equipment? If not, should the remedy be in training, the design of the process or equipment, or both? Did the person know whether the process or equipment was working as intended? If not, how can that be remedied? Information about errors and near-misses helps to answer these and other questions that arise when undesired outcomes occur or almost occur.

Safety and Forcing Functions

Forcing functions that affect the working processes are productivity issues, those that affect the product or service are quality issues, and those that harm a person are safety issues. Viewed as the consequence, we inadvertently divide them among distinct review programs and can arrive at diverse solutions, missing the true incidence of the forcing function.

"Forcing function as a neutral term can drive investigation into the various reddened frequencies and stochastic interactions that make them so troublesome. Focus on error and safety as persuasion implies telling someone what they are not – mistaken and unsafe."

Forcing function as a neutral term can drive investigation into the various reddened frequencies and stochastic interactions that make them so troublesome. Focus on error and safety as persuasion implies telling someone what they are not – mistaken and unsafe. Focus on early identification and dampening a forcing function tells people what they are – vigilant and trusted (43).

The idea of forcing functions makes visible safety lapses and the breach of duty in liability. In acting as outside influences rather than interactive forcing functions, liability and safety can cause decision errors. C. Northcote Parkinson (44) is known for his eponymic Parkinson's Law "work expands to fill the time available for its completion." Identified another contribution to economic inefficiency during WWII – any criticism would likely be met with, "Don't you know there's a war on?" (45) (Stevenson 1993). For example, healthcare executives, resistant to a patient safety study out of concern for liability to the hospital, queried a committee about liability. One member asked, "What duty are we breaching?" The executives could not articulate any duty the study would breach. Queries about liability and safety will easily terminate or endanger extension of operations into ambiguity, adversity, or threat. The hospital did not conduct the study.

William Haddon argued for an ecological approach to injury prevention, much like treating injuries as ecological forcing functions. Haddon applied this ecological model to injuries (46) using the same human-as-host concept. He described the "infectious" agent as energy and the vector as a carrier of that energy. A host (human) is injured by an agent (a form of energy) carried by a vector (automobile, chemical release, fire, and the like). With the addition of the phases, pre-event, event, and post-event as distinct time elements (47), the science of epidemiology could now identify more effective interventions to prevent or reduce injuries.

Error as Residuals

Any response to the environment has a deterministic component that is predetermined and predictable. There is another stochastic component, therefore not predictable, that we can associate with forcing functions. The difference between the observed value and the expected value (for example, the sample mean or expected outcome) is the measure of error as a 'residual.' Residuals can be random or non-random.

A non-random pattern of residuals indicates that the deterministic component has not captured explanatory information. That is, the data is not explaining all that is possible. The better the model is, the fewer non-random residuals will appear. The deterministic component should not contribute to error. The random component is the stochastic portion from forcing functions.

Autocorrelation occurs when adjacent residuals are correlated. One residual can predict the next residual, revealing that predictive information has not been captured. This usually occurs with time series, called 'serial correlation,' as the degree of correlation of the same variables between two successive time intervals.

As autocorrelation of residuals, red noise becomes the stochastic component of error measures between the expected and observed. For example, error management too quickly becomes focused on subordinates and line staff (34). Identification of the forcing functions that contribute to error and then harm develops a full spectrum analysis (48) of noise internal to the system. Error management can expand to review information flow (13), leadership and management styles (49), and continuing education focus on competency rather than proficiency (50). A broader approach would be to compare forcing functions that changed the air transportation industry with efforts for patient safety.

Stochastic Feedback and Resonance

Healthy systems display highly irregular dynamics to generate non-equilibrium dynamic stability. This stability arises from internal fluctuations due to multiple degrees of freedom from stochastic feedback that interacts over time or space scales (31).

In the ideal system, noise is the enemy. Stochastic resonance occurs in noise-added systems such as reddened noise environments. Through unpredictable fluctuations, stochastic resonance can increase the reliability of a signal and the system's performance through system nonlinearities. We can think of stochastic resonance as "noise-enhanced signal processing." We can consider stochastic resonance to be "noise-induced" (51).

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Stochastic resonance is nonlinear and cannot be beneficial in a linear system. The benefits of stochastic resonance come from the greater degrees of freedom and more complex interactions between nonlinearities and randomness rather than a particular frequency (51).

Criminalization of Safety Breaches

The threat of punishment and litigation incentivized pilots, as it currently does healthcare professionals, to hide their errors and near misses and not report the errors and near misses of others. Consequently, the air industry did not, and healthcare does not learn from those errors and near misses to identify and mitigate potential threats that can injure or kill.

The airline industry, both employers and regulators, shifted away from using reports of inadvertent error as a basis for punishment. The industry moved toward using reports of inadvertent error to

learn how to make *the system* less likely to cause an error. Error, as we discuss, is not the error in the elements of malpractice, negligence, or a crime. This process must be continually clarified to avoid confusing inadvertent errors due to environmental noise with an error that may comprise a torte.

The Federal Aviation Administration supported an important step toward continuously improving safety by not punishing. The change in position enabled the free flow of information about aspects of the system that needed improvement. Whether doing something inappropriate should result in punishment, or is there a better way to produce the desired outcome next time. Punishing the people when the real problem is the procedures or the equipment undermines the labor-management relationship.

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The line worker and pilot can too easily become a target. They have less immediate support than ancillary staff or those higher in the echelon, and their actions are more easily connected directly to a failure. Criminal prosecution does not address system issues such as:

- Robustness of connection for the part that fell off
- Mechanics fatigued, distracted, impaired
- Training of mechanics adequate
- Work environment suitable
- Necessary tools available
- Parts inventory adequate
- Adequacy of airport Foreign Object Debris (FOD) procedures

Pilots have faced criminal prosecution for actions encountering a problem that they have never seen before, even in training:

- Turkish Airlines, Amsterdam (2009)
- Rio to Paris (2009)
- Asiana, San Francisco (2013)
- 737MAX (2018-9)

There have been exceptions to the assumption of a criminal act:

- Hydraulic failure, Sioux City, IA (1989)
- Landing in the Hudson River (2009)

Overzealous criminalization, however, may adversely affect safety improvement efforts. Following the TWA 800 (1996) crash, the US NTSB successfully gained primacy of safety investigation over criminal enforcement unless there was evidence of intent to harm. From an MOU between the NTSB and FBI, the presumption that an accident was caused by inadvertent error rather than criminal wrongdoing, then the NTSB will lead an investigation. The FBI leads the investigation if the accident is clearly a criminal act (e.g., 9/11). If the NTSB investigation uncovers criminal activity, the NTSB will ask the FBI to lead, and the NTSB will provide technical assistance as requested.

A Registered Nurse now faces a prison term after being convicted of criminally negligent homicide and impaired adult abuse after mistakenly administering the wrong medication (52). The criminal justice system seeks justice through an adversarial approach, one that "substitutes an abstract conceptual order for the current [experienced] perceptual order" (Karl Weick (20)).

Such an approach disintegrates contextual details critical for safety and reliability while modeling an abstract conceptual order that is impractical and endangers those who operate in dangerous contexts. Weick captures this in his discussion of the sinking of the 790-foot container ship, the *El Faro* – "A thread among many discussions of sensemaking is that the process boils down to managing interruptions and recoveries, discontinuity and continuity, differences and sameness across situations" (20).

Healthcare' routines' are replete with interruptions that healthcare professionals must recover from in a collaborative, supportive way. When we believe we have achieved continuity, a complicating element creates discontinuity. We do not have the option of starting afresh; we must change some things and keep others – but what to change or keep, we cannot know until much later. Across situations, we see the same thing, a headache attributed to COVID-19 is a stroke, acute gastroenteritis in the evening is a pediatric brain tumor, and abdominal pain while making jump shots playing basketball is appendicitis.

"Spectators such as lawyers and expert witnesses must reduce red forcing functions or pink catastrophic events into a white noise format – elements interchangeable in time and space. These elements create a right and wrong way, a defense versus a prosecution. Multiple interacting elements, some readily visible but irrelevant and some covert or occult, have temporal and spatial autocorrelations that may not be salient in the time scale of bedside treatment."

Spectators such as lawyers and expert witnesses must reduce red forcing functions or pink catastrophic events into a white noise format – elements interchangeable in time and space. These elements create a right and wrong way, a defense versus a prosecution. Multiple interacting elements, some readily visible but irrelevant and some covert or occult, have temporal and spatial autocorrelations that may not be salient in the time scale of bedside treatment. Through topological relations not visible at a distance, decisions made by executives and administrators can have immediate yet ambiguous influences in the workspace.

Protection of oneself by not acting is not uncommon. One author (DvS) served in a pediatric ICU covering a large rural area. Management of epiglottitis, by the standard of care and medical staff policies, required endotracheal intubation in the operating room

by a pediatric ENT surgeon with the participation of an anesthesiologist. The medical center with the PICU had the only pediatric ENT surgeons on staff. About 0200h during the Fall, an emergency physician at a rural ED requested transport for a child with epiglottitis. To provide airway management, including intubation, the author traveled by surface ambulance because high desert winds precluded helicopter transport. Later in the morning, the Chief of Staff (an ENT surgeon) and chairman of anesthesia counseled the author about staff privileges and whether any subsequent intubation would result in loss of staff privileges. A prolonged discussion included the admission that no medical center anesthesiologist or ENT surgeon would travel 45 minutes to a referring hospital in the middle of the night, and no local anesthesiologist or ENT surgeon would intubate a child with epiglottitis. Several years later, a surgical resident staffing a distant rural ED with no other physician available requested the transfer of a child with epiglottitis. None of the four receiving PICUs would accept the child without intubation by the surgical resident. The author sent the PICU fellow to treat and transport the child. The following morning, one of the receiving PICUs chastised the author for taking a child in their catchment area and pointing out the dangers of intubating a child with epiglottitis. The author discussed these cases with his colleague. They decide that any physician transporting a child who dies in transit from airway obstruction would be a hero and consoled for the emotional pain. However, the same physician acquiring and protecting the airway to ensure safe transportation would lose his career.

"They decide that any physician transporting a child who dies in transit from airway obstruction would be a hero and consoled for the emotional pain. However, the same physician acquiring and protecting the airway to ensure safe transportation would lose his career."

Criminalizing this environment drives critical information out of view, but it also becomes inaccessible for learning and knowledge creation. Insidious and more common, it drives actors to act by 'not acting' to create invisible errors that quickly become incorporated into organizational knowledge. Like safety, the injury from hiding experiences is today but only becomes visible tomorrow when the harm is irreversible. Like occult cancer, the criminalization of inadvertent errors can kill silently at a distance from its origin.

The Business Case:

When the US commercial aviation industry began its systematic collaboration with CAST (Commercial Aviation Safety Team), the primary objective was to improve safety. Moreover, given the widespread fear of flying, improving safety was so important that there was little or no initial concern about whether CAST would also improve the bottom line. Much to the pleasant surprise of CAST participants, CAST improved safety and productivity. This result was significant because, although safety improvement experts are reluctant to admit it, safety improvements that reduce productivity and hurt the bottom line are not generally sustainable. CAST has been sustainable and is still going strong after more than two decades because it improved productivity while improving safety. One of the major successes of CAST has been that it has not only improved safety, but it has also done so effectively and efficiently. Just as collaboration enables safety improvements, as noted above, the collaboration also enables simultaneous productivity improvements.

Because all the key industry participants are involved in the collaboration, concepts that undermine productivity for any participants are rarely approved by the collaborative process. Significantly, the bottom-line improvements that resulted from CAST were not related to costs that were avoided because the safety improvements helped prevent accidents and incidents – a result that would not be provable. On the contrary, the bottom-line improvements were immediate and measurable reductions in operations and maintenance costs. Precedents in the healthcare industry have demonstrated the capability of collaborative programs to improve safety and generate immediate and measurable improvements in the bottom line (53-57).

"On the contrary, the bottom-line improvements were immediate and measurable reductions in operations and maintenance costs. Precedents in the healthcare industry have demonstrated the capability of collaborative programs to improve safety and generate immediate and measurable improvements in the bottom line (53-57)."

Conclusion:

John H. Steele (2) identified three essential features for conceptual or numerical models of natural systems: (1) a high order of nonlinearity, (2) large variability in the forcing functions, and (3) a wide range of space and time scales. The choice of model and level of analysis has implications in:

- Education, training, and planning (50)
- Categorization and standards (58)
- Developing approaches for allostasis

Despite integrating across multiple levels of analysis, such as degree of nonlinearity, forcing functions, time scales, spatial autocorrelation, and a topological space, ultimate and proximate causes cannot be accomplished in a single model. Arguing across levels of analysis creates false debate (59).

"Never use malice if ignorance will fully explain the member's behavior," William J. Corr.

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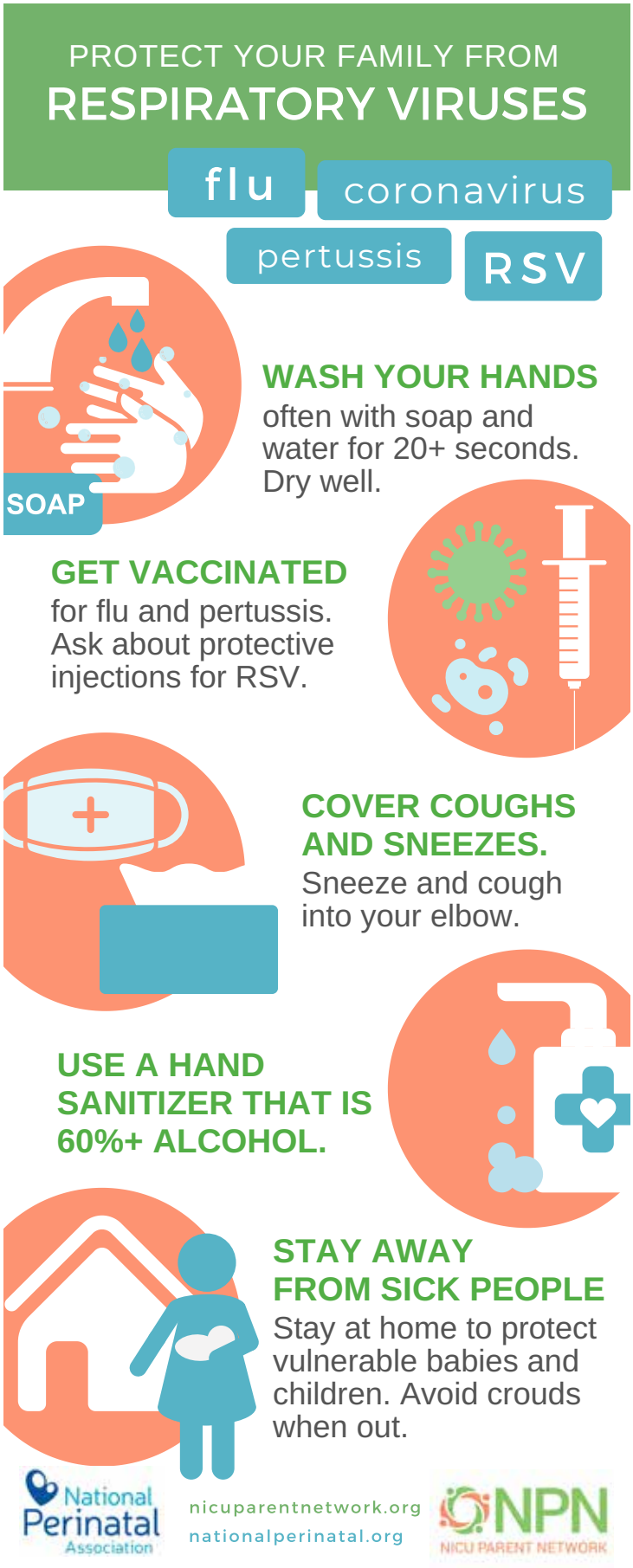

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Transform bathing to a positive experience

TurtleTub™

Benefits of Immersion Swaddle bathing:

- **Minimize temperature loss** [1-3]
- **Decreases crying** [1,3]
- **Reduces physical and behavioral stress** [2, 4-6]
- **Supports family centered care** [6,7,10]
- **Enhances ability to feed after bath** [6,10]
- **Evidence-Based Practice** [1-6, 8-10]

Swaddle bathing with the TurtleTub complements delayed bathing and minimizes adverse clinical outcomes associated with traditional bathing methods. After participating in hospital bathing, parents can continue to swaddle bathe at home. Preterm infants, full-term infants, and infants with NAS all benefit from immersion swaddle bathing. In addition, the TurtleTub is a strong parent pleaser, providing a marketing advantage for your hospital.

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Keeping Your Baby Safe

during the COVID-19 pandemic

How to protect your little one from germs and viruses

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

Here's what you can do...

Wash Your Hands

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

Limit Contact with Others

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

Provide Protective Immunity

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

Take Care of Yourself

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

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

WARNING

Never Put a Mask on Your Baby

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

If you are positive for COVID-19

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

We can help protect each other.

Learn more

www.nationalperinatal.org/COVID-19

National Perinatal Association

Fellows Column: Vocal Cord Paralysis After Transcatheter Closure of PDA in a Preterm Infant

Daniel Farishta, MD, Shabih Manzar, MD, Ramachandra Bhat, MD

"A preterm infant underwent transcatheter closure of patent ductus arteriosus (PDA). Based on angiographic findings, a 5.2 mm Amplatzer Piccolo Occluder device was chosen and delivered in an intraductal position (Figure 1, panel A)."

Short Clinical Vignette:

A preterm infant underwent transcatheter closure of patent ductus arteriosus (PDA). Based on angiographic findings, a 5.2 mm Amplatzer Piccolo Occluder device was chosen and delivered in an intraductal position (Figure 1, panel A). Postoperatively, the infant developed feeding difficulty. The modified barium swallow study showed silent aspiration of nectar liquid (Video, Figure 2). Nasolaryngoscopy performed by the Otolaryngologist revealed left true vocal fold (TVF) paralysis with limited adduction.

Discussion:

The plausible mechanism of left TFV paralysis noted after PDA closure is the impingement on the left recurrent laryngeal nerve (LRLN). LRLN runs in close proximity to PDA, looping back on it (Figure 1, panel B). We postulated that as the retention disc diameter of the Amplatzer Piccolo Occluder device used was larger than the preoperative PDA diameter, 5.2 mm versus 2.9 mm, it would have impinged the LRLN (device cross-section shown in the illustration). The other possibility would be the entrapment of the LRLN between the dilated left pulmonary artery and the device.

"We postulated that as the retention disc diameter of the Amplatzer Piccolo Occluder device used was larger than the preoperative PDA diameter, 5.2 mm versus 2.9 mm, it would have impinged the LRLN (device cross-section shown in the illustration). The other possibility would be the entrapment of the LRLN between the dilated left pulmonary artery and the device."

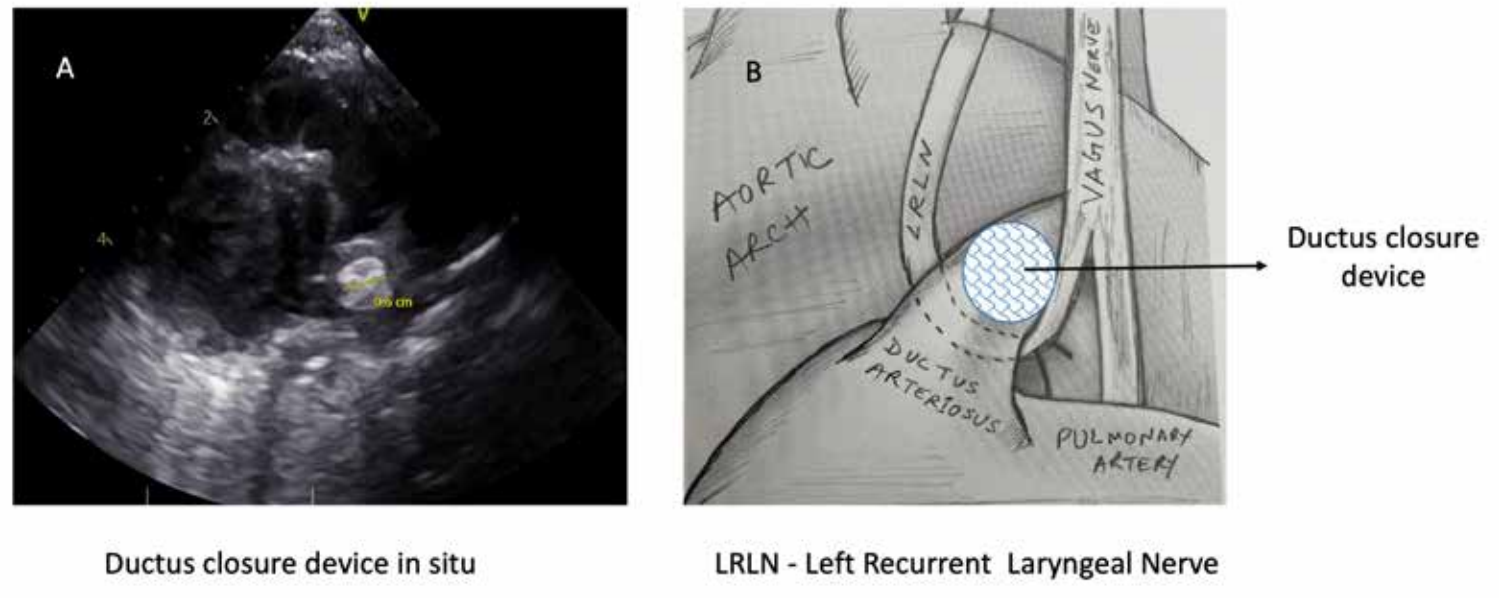

Figure 1:

Panel A- Echocardiogram showing Amplatzer Piccolo Occluder device in situ.

Panel B- Diagrammatic representation of Amplatzer Piccolo Occluder device compressing and impinging the LRLN (Figure adapted from Ryan et al. Neoreviews. 2020;21(5):e308-e322)

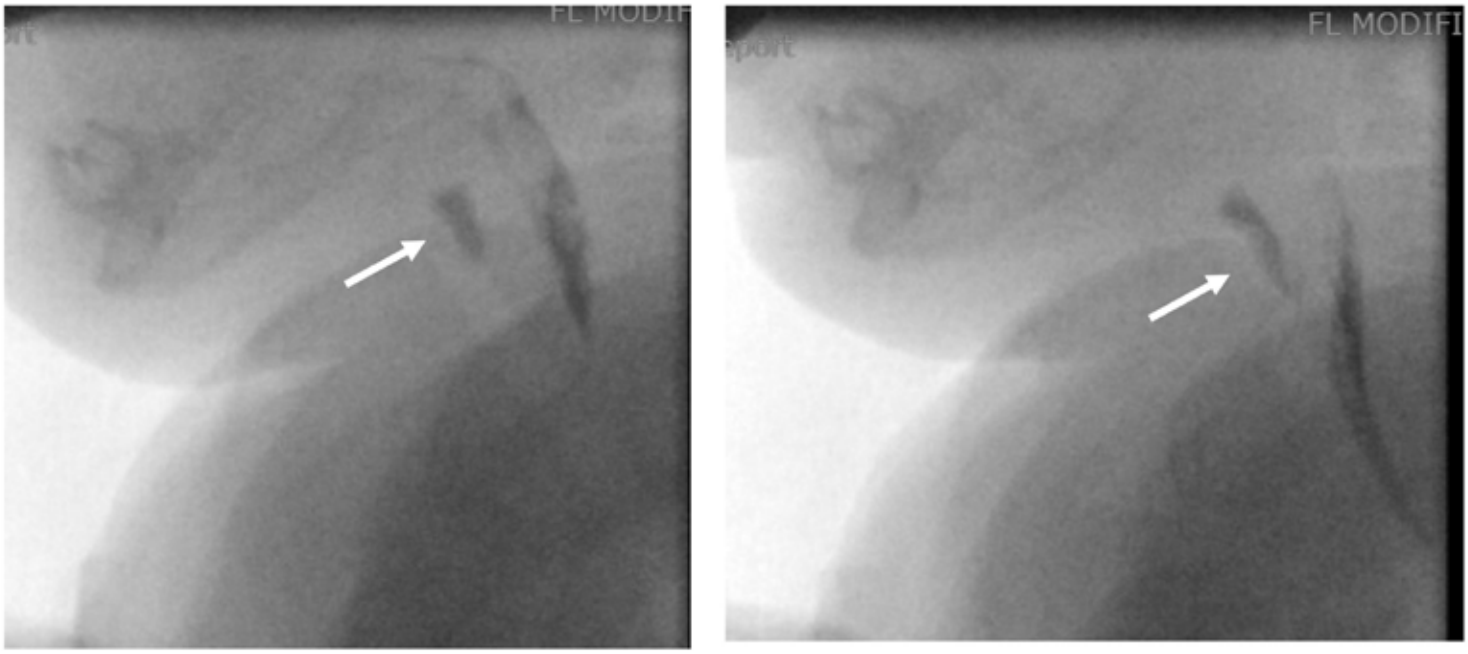

Figure 2:

Modified barium swallow study still images showing aspiration (white arrows) of nectar liquid

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Video:

Modified barium swallow study showing aspiration of nectar liquid.

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Brilliant! Dr. Bell bridges the journey from grief to growth. This is classic wisdom on healing from our heartbreaks and ultimately enjoying a fulfilling life.

– Christine Theard, M.D.

Post-Traumatic Thriving

The Art, Science, & Stories of Resilience

Randall Bell, Ph.D.

Factitious Microcephaly and the Timing of Fetal Neurological Injury

Barry Schifrin, MD, Maureen E. Sims, MD

Case resume:

The patient is a 27-year-old primigravida. She is 5'1 ½ inches tall and weighs 190 pounds at the outset of pregnancy. The prenatal course is uneventful, during which the patient will gain 34 pounds; diabetes and GBS screening are negative. Periodic ultrasound examinations are consistent with normal growth, head size, and amniotic fluid volume. At 40.0 weeks gestation, she arrives in the early evening at the hospital complaining of contractions for two days. The fetal monitor reveals frequent fetal movements and a stable baseline rate with recurrent contractions. Vital signs are normal. A pelvic exam reveals the cervix to be 1.5 cm dilated, 100% effaced, with the head at a -1//-2 station with bulging membranes

"Shortly after the monitor is reapplied in the morning, the fetus suffers a sudden drop in heart rate to the 70-80s with a very protracted return to baseline over about 10 minutes. Within 30 minutes, the patient has a large emesis, and the fetus shows another prolonged deceleration. "

Four hours after admission, the cervix is 2.5 cm dilated. Artificial rupture of the membranes (AROM) reveals straw-colored fluid. The patient is given Demerol 125 mg. / Phenergan 50 mg. IM for pain, and the fetal monitor is removed overnight for 7 hours. The first dose of Ampicillin 2 gm. IV is given, to be repeated at 1 gm. IV q4 hours until delivery.

Shortly after the monitor is reapplied in the morning, the fetus suffers a sudden drop in heart rate to the 70-80s with a very protracted return to baseline over about 10 minutes. Within 30 minutes, the patient has a large emesis, and the fetus shows another prolonged deceleration. Shortly after the deceleration, the monitor is removed. Without obtaining the patient's BP or securing the recovery of the FHR pattern, the patient is allowed up to the bathroom. A gush of blood from her vagina pools on the floor when she stands up. She then walks toward the bathroom and faints in her husband's arms. She is returned to bed, and the monitor is replaced for about 12 minutes revealing a slow recovery of the FHR from a prolonged deceleration. The mother's heart rate (MHR) rate is 140, and she is diaphoretic. Following the episode, there are 7 to 8 contractions in 12 minutes, a frequency, along with the bleeding that required consideration of placental abruption. With the cervix still 4 cm. dilated, the patient is taken to the operating room in anticipation of a cesarean section. She is provided oxygen with a rebreather mask and maintained on her right side. The external fetal monitor is replaced with a fetal scalp electrode (FSE), revealing an FHR of 110-118. Contractions are every 2 minutes, lasting 30-40 seconds, and mild-moderate intensity. The MHR is 124 and the BP 125/70. The FHR is stable at about 120, rising slowly to about 140 with obvious accelerations but absent variability and no decelerations.

In the inappropriate belief that the tracing had recovered, the cesarean section is abandoned to await progress in labor with plans to start oxytocin drip irrespective of the frequent contractions. Shortly thereafter, the patient is feeling the urge to push with contractions. Examination reveals the cervix has dilated rapidly to 9.5 cm with the head in the OP position. She is given analgesia to combat the strong urge to push. After 1.5 hours, the cervix is fully dilated. Believing the fetal tracing to be satisfactory apart from a "slight, uncomplicated fetal tachycardia," the patient is encouraged to start pushing with each contraction despite very frequent contractions. The station of the presenting part is +1, and the position is OA. There is no mention of molding or caput. After 1.5 hours of pushing, 2nd stage, with the head in the OA position and still at +1 station, the physician applies mid-forceps. The FHR reveals a profound deceleration during the forceps application to about 110 bpm. The baby delivers 2 minutes later. The indication for the procedure is the concerning FHR changes and prolonged 2nd stage of labor.

" The FHR reveals a profound deceleration during the forceps application to about 110 bpm. The baby delivers 2 minutes later. The indication for the procedure is the concerning FHR changes and prolonged 2nd stage of labor."

There is no pediatrician present at delivery. At birth, the male infant weighs 3085 gm. (25-50th percentile). Meconium is present. The Apgar scores are 2, 7,8, and 10 at 1,5,10, and 15 minutes. The initial heart rate is about 70 but greater than 100 by 1 minute of age. The infant is floppy. Resuscitation includes suction, stimulation, and positive pressure ventilation with bag-and mask x 5-6 min. He takes his first breath and cry at less than 1 min. He sustains respirations at about six minutes of age. The baby's head is found to be persistently turned to the right. The right corner of the mouth is also drooping, likely resulting from facial nerve palsy. There are prominent forceps marks and bruising across the right side of the face, including the eyelids and the cheek. The baby's length is 50 cm. The head circumference is 33 cm. The ponderal index is 2.47

Neither umbilical cord gases nor placental examination is obtained. The first pH at one hour reveals a pH of 7.24 with a base deficit of 5.4. At 8 hours of age, the baby is found to be jittery, secondary to hypoglycemia treated with 10% dextrose. Seizures begin at 15-16 hours and are treated with phenobarbital and Dilantin. CBC reveals a hematocrit of 42.4%, platelets of 250,000,

NRBCs 21. There are indicators of renal (creatinine) and hepatic (LDH) abnormalities and persistently elevated serum lactate. At 20 hours, the baby required intubation – attributed to respiratory depression secondary to the aggressive treatment with anticonvulsants; post-intubation arterial blood gases were normal with $PaCO_2$ of 35 mmHg. At 23 hours of age, he is transferred to a regional facility with seizures and facial asymmetry, including a right facial droop.

The following day a portable cranial ultrasound reveals effacement of the cerebral ventricles and an overall mild diffuse increase in parenchymal echogenicity consistent with cerebral edema, which is likely based on hypoxic-ischemic encephalopathy - follow up is recommended within 72 hours. There is no mention of microcephaly.

Laboratory values reveal abnormalities in the liver (LDH) and renal (creatinine) function.

On DOL 3, an EEG is markedly abnormal consistent with severe cerebral/cortical injury. A spinal tap reveals xanthochromic (blood-tinged) fluid. At DOL 5, a CAT scan of the head reveals effacement of the lateral ventricles with diffusely decreased attenuation throughout the cerebrum with increased attenuation differences in the cerebral hemispheres (a prolonged partial injury) and the brain stem cerebellum and inferior thalamus (an acute injury). These results give rise to one of two clinical scenarios: a) An acute sentinel event of total asphyxia with severe cerebrum, brainstem, cerebellum, and hypothalamus hypoxia associated with residual subacute, prolonged, partial cerebral hypoxia, or b) An acute sentinel event of total asphyxia with severe cerebrum, brainstem, cerebellum, and hypothalamus hypoxia followed by another episode of subacute, prolonged, partial cerebral hypoxia. The fetal monitor tracing is more compatible with the second sequence.

The child is microcephalic, suffers seizures, and is diagnosed with CP (spastic quadriplegia), severe developmental delay, and cortical visual impairment on follow-up. He dies at 14 years of age. Follow-up reveals the baby has seizures, cerebral palsy, spastic quadriplegia, microcephaly, and severe developmental delay. The baby also has a cortical visual impairment, all attributed to an anoxic/ischemic event at birth.

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Causation:

The initial tracing is reactive with normal variability, cyclical activity, and absent decelerations. This tracing bespeaks normal neurological responsiveness and absent hypoxia in the fetus. Despite the significant uterine activity, monitoring is intermittent. When reattached after a 7-hour hiatus, the fetus shows decelerations. In getting up to go to the bathroom, the patient experiences faintness and vaginal bleeding. Upon return to bed, it is evident that the fetus has suffered another prolonged deceleration in association with a dramatic increase in uterine activity and a marked abnormal recovery consistent with an acute neurological injury. During the 2nd stage, pushing is associated with indicators of additional injury. With the application of mid-forceps, there is a profound fetal deceleration from a baseline of 180 to about 110 bpm just prior to delivery. The newborn shows trauma from the forceps, including bruising and facial nerve paresis. To these developments, the neonatal course, including hypoglycemia and seizures with evidence of acute injury to the liver, the kidneys, and the brain, points with singular specificity to hypoxic-ischemic and potentially traumatic injuries arising during the intrapartum period.

This is consistent with multi-organ injury with dysfunction (failure) in severe global fetal hypoxia. Finally, there is no obstetrical, neonatal, neuroradiological, or clinical evidence that the baby had an abnormal brain or had sustained any neurological injury prior to admission to labor and delivery.

Allegations:

The injury to the fetus derives from significant deviations from the standard of care, including the early rupture of membranes, likely at the high station, the failure to appreciate the poor feasibility of safe vaginal delivery, the failure to properly maintain the fetal monitor tracing in the face of abnormalities of both heart rate pattern and uterine contractions, the failure to properly recognize, monitor and respond to excessive uterine contractions and abnormalities in the fetal heart rate pattern, and ultimately the failure to recognize proper indications and contraindications for operative delivery.

Proper care would have timely recognized the excessive uterine activity and maintained continuous observation providing early detection of decelerations in the heart rate. The frequent decelerations during that time and the numerous risk factors reducing the feasibility of safe vaginal delivery in the foreseeable future required a timely, atraumatic cesarean section.

Indeed, there is no comment in the medical record about excessive uterine activity and no action to minimize the frequency of contractions. Despite the bleeding and excessive uterine activity unrelated to oxytocin, no provider considered the possibility of placental abruption.

The importance of recognition and prevention of excessive uterine activity, also known as tachysystole or uterine hyperstimulation, has been well-recognized for many decades. It does not reliably make labor go faster. (1) It is associated with neonatal HIE, while prolonged pushing increases the risk of fetal hypoxia and seizures. (2) (3)

There is no plausible benefit to permitting excessive uterine activity to the point of fetal distress. When excessive uterine activity is found, it must be dealt with as a preventive measure, irrespective of abnormal fetal response. When it is spontaneous, there must be

consideration of the potential for placental abruption, especially in the presence of bleeding, fainting, and vomiting. In the presence of decelerations and spontaneous hyperstimulation, intervention is required.

"Early rupture of the membranes increases the risk of decelerations during labor and molding of the fetal head, and when performed with an unengaged presenting part, it adds the risk of prolapse of the umbilical cord without commensurate benefit in terms of enhancing the progress of labor. (4, 5)"

Early rupture of the membranes increases the risk of decelerations during labor and molding of the fetal head, and when performed with an unengaged presenting part, it adds the risk of prolapse of the umbilical cord without commensurate benefit in terms of enhancing the progress of labor. (4, 5) Not rupturing the membranes at the high station as required by the standard of care would have diminished the likelihood of decelerations, which would have enhanced fetal reserve and potentially avoided injury.

We believe that in many cases, the tracing permits the affirmative diagnosis of fetal injury, sometimes, as in this case, many hours prior to delivery. (6, 7), Unfortunately, this insight into the timing of the injury is often not considered in the evaluation of the newborn for therapeutic hypothermia. (8) Therapeutic hypothermia requires initiation within 6 hours of birth on the premise that the injury occurred around the time of delivery.

Defense allegations:

These entirely consistent opinions from the plaintiff's obstetrical, neonatology, and pediatric neuroradiology experts were met with disparate rebuttals from 2 defense experts.

One expert acknowledged the vasovagal episode while using the bathroom with resulting fetal bradycardia as the cause of injury but believed that the injury was not preventable. The other expert believes that the injury occurred antepartum.

Neither commented on the excessive uterine activity and intermittent decelerations. Nor did they opine on the appropriateness of sending the patient to the bathroom under the circumstances. Neither believed the tracing required intervention despite the abnormal features. They opined that the conduct and presumably the timing of the delivery was appropriate. One conceded that "A case could be made for assessing the patient at least a half-hour earlier concerning the delivery

They both opined that the meconium staining of the 40-week fetus was likely to present well before delivery, reflecting an earlier insult. At term, the passage of meconium is more likely related to gestational age than to some prenatal insult. As mentioned, there is no basis for an antenatal injury.

Both accept that the fetal head is microcephalic at birth based on the single value of 33 cm. at birth. That head circumference falls between the 8%ile and the 12%ile. Neither opinion took into account the impact of labor and operative vaginal delivery on the single assessment of the fetal head circumference. The newborn is "obviously not IUGR." but suggests a" significant change between the 38-week ultrasound and the delivery measurements. It would be reasonable to assume that some other process affects the head or brain development, with the insult occurring well before labor, most probably days to weeks before." This allegation in an otherwise asymptomatic mother and an acute neurological injury in her fetus seems quite improbable: there is no complaint of decreased fetal movement, and the fetal heart rate pattern on admission is quite reassuring. An arrest of fetal head size at 38 weeks with the head in the 50th percentile cannot possibly result in microcephaly two weeks later. The growth curve of the fetal biparietal diameter at that point is almost flat.

It should be noted that ultrasound examinations were performed: at 18, 24, and 38.2 weeks gestation. In each case, the HC measurements are consistent with gestational age. While the medical record provides no comments on molding and caput, there are obvious forceps marks and bruising along the face's right side, including the eyelids and the cheek.

The use of a single HC measurement suggests a diagnosis of congenital microcephaly that cannot and does not reasonably justify such a diagnosis, given the numerous observations strongly inviting the inference that the baby's head circumference has been artificially reduced by the number of days of uterine activity, the excessive uterine activity, the prolonged labor, and ruptured membranes, the non-productive pushing and the forceps delivery.

"The use of a single HC measurement suggests a diagnosis of congenital microcephaly that cannot and does not reasonably justify such a diagnosis, given the numerous observations strongly inviting the inference that the baby's head circumference has been artificially reduced by the number of days of uterine activity, the excessive uterine activity, the prolonged labor, and ruptured membranes, the non-productive pushing and the forceps delivery."

In 1983, Sorbe and Dahlgren studied the molding of the fetal head of 319 vaginal deliveries using a photographic method. (9) They documented the size and form of these infants' heads both immediately after delivery and three days later (a measurement lacking in this case), during which certain diameters of the head returned to a larger size. They found that infants born to primiparous women showed significantly higher degrees of head molding than those born by multiparous women. Oxytocin stimulation during labor prolonged labor or at least prolonged contractions and instrumental deliveries resulted in increased fetal head molding.

The importance of fetal presentation at birth (not stated here), the duration of labor, the mother's age, and the infant's birth weight were also analyzed concerning the molding of the fetal skull during labor. Similarly, studies show that the dimensions of the lateral ventricles are quite diminished immediately after vaginal delivery. (10)

The case was adjudicated.

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

KEEPING MOTHERS + INFANTS TOGETHER

Means balancing the risks of...

- HORIZONTAL INFECTION
- SEPARATION AND TRAUMA

EVIDENCE

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

PARTNERSHIP

What is the best for this unique dyad?

SHARED DECISION-MAKING

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

TRAUMA-INFORMED

Both parents and providers are confronting significant...

- FEAR
- GRIEF
- UNCERTAINTY

LONGITUDINAL DATA

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

- MENTAL HEALTH
- POSTPARTUM CARE DELIVERY

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

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Gravens By Design: Transformational Change: Making it Happen in the NICU, 2022 Conference Summary

Robert White, MD

"The Gravens Conference returned to an in-person format in 2022, with an online component. We anticipate this hybrid offering will be the standard model for all future meetings since it permits many people to attend who would not otherwise be able to do so and preserves the many benefits of direct interaction among our participants."

The Gravens Conference returned to an in-person format in 2022, with an online component. We anticipate this hybrid offering will be the standard model for all future meetings since it permits many people to attend who would not otherwise be able to do so and preserves the many benefits of direct interaction among our participants.

Day 1 – Transformational Change: Making it Happen in the NICU

Our first day began with understanding the importance of the care we provide, as described by families and those who research their needs and desires in the NICU. Led by Dr. Annie Janvier, a parent and physician team from CHU Sainte-Justine in Montreal presented extensive research on the discrepancy between the perspectives of the medical members of the follow-up team, who tend to focus on describing the presence of deficits, compared to that of parents who are cognizant of their child's challenges but much more likely to focus on their positive attributes.

Dr. Livio Provenzi from Italy introduced us to the fascinating effect of early life experiences on the epigenetic expression of a premature infant's genome, which has lifelong implications. The environment of care in the NICU can alter the trajectory of many health factors far beyond the neonatal period, so neonatal neuroprotection demands attention to not just the care we provide but the environment in which it is provided – and to a large extent, we are, or control, that environment.

Dr. Daphna Yasova Barbeau from Gainesville, FL, reviewed the current understanding of infant sleep stages and their maturation in the newborn period and described the impacts of the environment on sleep in NICU babies. The research now is more nuanced than our early efforts to protect sleep simply by preventing any external stimulation for sleeping infants, who can tolerate and benefit from nurturing stimuli while asleep.

Dr. Terrie Inder from Boston described a comprehensive program for the developmental support of infants in the convalescent stage of NICU care. Their team provides continuity of care for babies and supports families up to and beyond discharge in a setting that utilizes multiple rooms with three patient beds in each room to provide a more open and social setting than the single-family rooms used for their more critical, extremely premature infants.

Dr. Bobbi Pineda from Los Angeles described the Supporting and Enhancing NICU Sensory Experiences (SENSE), a method for teaching and facilitating parental delivery of developmentally-appropriate care according to the infant's age and clinical status. More than 100 NICUs have now adopted it, and evidence is accumulating of its value to integrate families into the developmental care of their babies.

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Dr. Jochen Profit from Stanford described his research showing that self-care teamwork was important in promoting teamwork and resilience, preventing burnout, and changing the culture of care in the NICU.

Day 1 closed with Dr. Paige Church and her parent and physician team from Toronto, who showed how NICU family and developmental care practices could be improved through quality initiatives.

Day 2 – Developmental Care Track

Day 2 – NICU Design Track

A featured segment of the 2021 Gravens Conference was a virtual workshop entitled "ReImagining the NICU." Later in 2021, the working group met again virtually to refine concepts of how the NICU of the Future might look, building on ideas regarding the design of the NICU itself into more flexible spaces to accommodate emerging patient needs as an infant's status improved, potential technology innovations that could enhance the NICU experience for babies, parents, and staff alike, and possible ways in which the transition to the home could be accomplished, both through operational improvements and through re-thinking the places that might happen outside of a traditional NICU. These concepts were then brought to the 2022 Gravens conference as a general presentation and brainstorming session on day two, followed by a

more intensive working session on day three. The many ideas generated will be considered in future editions of the Recommended Standards for Newborn ICU Design and documents that capture best potential practices for NICUs of the future.

Dr. Mobolaji Famuyide and her team from Jackson, MS, and Dr. Beau Batton and his team from Springfield, IL then presented their new NICUs, followed by Judy Smith from Phoenix with a presentation on answers to common questions when planning a State of the Art NICU, Bob White from South Bend, IN with a 5-year post-occupancy survey of staff in their NICU, and a "Crowdsourcing" session where others in the audience with expertise addressed questions from attendees.

Day 3

The keynote speaker for day 3 was Natalie Johnson, a health and well-being consultant and Chief Visionary of ViDL Solutions. Her talk, entitled "Stress is Your Superpower," introduced us to the cognitive reframing of challenges as a technique for improving resilience and reducing burnout. This talk was followed by a workshop that explored this and related techniques to enhance resilience; other concurrent workshops also allowed attendees to learn more about topics presented in the plenary sessions on days 1 and 2. The afternoon sessions on day three were devoted to abstract presentations on topics that included developmental care, family support, feeding and lactation, and discharge preparation.

"The next Gravens Conference will be held in Clearwater Beach, FL, on March 8-11, 2023; we plan to meet in person with a virtual option also available. More information will be published in Neonatology Today in the upcoming months."

Day 4

The next Gravens Conference will be held in Clearwater Beach, FL, on March 8-11, 2023; we plan to meet in person with a virtual option also available. More information will be published in Neonatology Today in the upcoming months.

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INFANT AND FAMILY-CENTERED DEVELOPMENTAL CARE (IFCDC)

STANDARDS AND SAMPLE RECOMMENDATIONS FOR INFANTS IN THE INTENSIVE CARE UNIT

SYSTEMS THINKING IN COMPLEX ADAPTIVE SYSTEMS

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

POSITIONING & TOUCH FOR THE NEWBORN

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

SLEEP AND AROUSAL INTERVENTIONS FOR THE NEWBORN

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

SKIN-TO-SKIN CONTACT WITH INTIMATE FAMILY MEMBERS

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

REDUCING AND MANAGING PAIN AND STRESS IN NEWBORNS AND FAMILIES

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

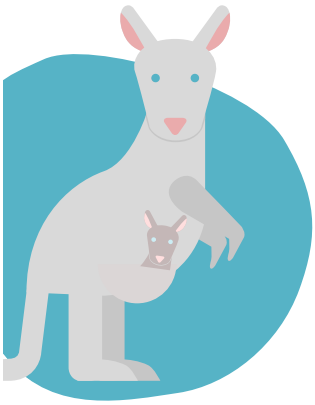
MANAGEMENT OF FEEDING, EATING AND NUTRITION DELIVERY

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

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

SUPPORTING KANGAROO CARE

SKIN-TO-SKIN CARE DURING COVID-19



GET INFORMED ABOUT THE RISKS + BENEFITS

work with your medical team to create a plan

GET CLEAN

WASH YOUR HANDS, ARMS, and CHEST

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

PUT ON FRESH CLOTHES

change into a clean gown or shirt.

IF COVID-19 + WEAR A MASK

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

National Perinatal Association

nicuparentnetwork.org

NPN NICU PARENT NETWORK

nationalperinatal.org/skin-to-skin

COVID-19

STOP THE SPREAD AT HOME

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

HYGIENE TIPS

MOUTH
- Wear a face mask or face shield.
- If in car, wear mask & put windows down.
- NO cloth face masks for children younger than 2yrs.
- Avoid kissing

EYES
Wear protective eye gear (glasses)

HANDS
ALWAYS wash your hands

CLOTHING
- Wear a jacket when dealing with infected.
- DO NOT share clothing, sheets, or pillows.

BATHROOM

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

PROTECT

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

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

SELF ISOLATION

- Sick should be separate from household.
- Room with window preferred
- Aerate room 3x day.
- Create a room divider with sheet.
- Keep water and sanitation liquids near
- Keep garbage bag in room.
- Don't cuddle with pets.

6 FT

Practice social distancing

KITCHEN

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

TRACK COVID-19 NEAR YOU BY VISITING COVIDNEARYOU.ORG

#STOPTHESPREAD

MIORA

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COVID-19

DETENER LA PROPAGACIÓN EN CASA

Qué hacer cuando usted o un ser querido está infectado.

CONSEJOS DE HIGIENE

BOCA
- Use una mascarilla o careta
- Si está en el automóvil, use una máscara y baje las ventanas
- NO mascarillas de tela para niños menores de 2 años.
- Evitar besos

OJOS
Use equipo de protección para los ojos (lentes)

MANOS
SIEMPRE lávate las manos

ROPA
- Use una chaqueta cuando se trata de infectados.
- NO comparta ropa, sábanas o almohadas.

BAÑO

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

PROTEGER

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

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

AISLAMIENTO

- Los enfermos deben estar separados del hogar.
- Habitación con ventana preferida
- Airear la habitación 3x al día
- Crea un separador de ambientes con sábana.
- Mantener agua y líquidos de saneamiento cerca
- Mantenga una bolsa de basura en la habitación.

6 FT

Practica el distanciamiento social

COCINA

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

SIGUIR COVID-19 VISTAR COVIDNEARYOU.ORG

#STOPTHESPREAD

MIORA

Visitar Miora.org

Traído por Miora en asociación con United2Care

Ways to Manage Covid 19 @ Home

Household

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

Stop the Spread at HOME

MIORA

Sick

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

Maneras de manajer COVID-19 en casa

Hogar

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

Detén la propagacion en casa

MIORA

Enfermo

1. Aíslese permanecindo en una habitación separada con baño separado. No vayas a espacios compartidos
2. Si no se puede aislarse crea un separador de ambiente con una sabana.
3. Ventile la habitacion con aire fresco por lo menos 3 veces al día.
4. Mantenga agua y productos de saneamiento en la habitacion.
5. Mantenga una bolsa de basura en la habitación.
6. Proteja a las mascotas, no las abrace.
7. Notifique a todos los contactos de los últimos 10 días.
8. No espere! Si se siente peor llame a su medico.

WEAR A MASK

PROTECT PARENTS + BABIES

COVID-19

When we all wear masks...

We protect parents and babies.

Project Sweet Peas + National Perinatal Association

USA UNA MASCARILLA

PROTEGER A LOS PADRES Y BEBÉS

COVID-19

Cuando todos usamos mascarillas ...

Protegemos a los padres y los bebés.

Project Sweet Peas + National Perinatal Association

Peer Reviewed

Health Equity Column: Lifting Up Black Maternal Health Week

Jenné Johns, MPH, Jaye Wilson, LPN

April marks two federally recognized priorities in the United States: National Minority Health Month and Black Maternal Health Week. As we move as a nation to solve some of the most pressing and challenging inequities faced by Black, Brown, and Minoritized communities, we are reminded this month that we must continue to lift up solutions led and created by those populations most impacted by these disparities. We must also acknowledge the continued growing disparities in Black maternal mortality rates and the widening disparities in the rates of premature births in one of the wealthiest and most technologically savvy nations around the globe. While the White House released its second Annual Proclamation in support of Black Maternal Health Week, we need more…more advocates, more funding, and more solutions that we know work to keep Black Moms, Babies, and Preemie babies alive, healthy, and thriving.

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In this month's Health Equity Column, I have interviewed Jaye Wilson, LPN, Founder, President, and CEO of Melinated Moms, a powerful advocacy organization for women of the melinated spectrum. Jaye offers her personal and professional experiences leading local and national advocacy solutions to support, empower, and activate Black and Brown women with lived experiences during their birthing journey. As you read this column, I encourage you to reflect on how your institution is partnering with or supporting Black women-led and Black women serving organizations to save Black Moms, Black Babies, and Black Preemie, Babies.

What is your definition of health equity?

My definition of health equity is providing the right tools that are necessary for a person to thrive in the most healthy way. So that's looking at their health from different angles, such as physical health, by making sure they have medical providers or clinician that is following any diagnosis or any health-related ailment. With mental health, you know, making sure that they're mindful and they have someone that is connected to them and helping them to balance their emotional health. There's spiritual, so just keeping them grounded and whatever that means for them, you know, so it's not specifically religious base, but you know having a connection with a higher power that gives people purpose. There's environmental, you know, looking around them to make sure that they're in a safe environment, and they're able to thrive. All of these different angles really uplift why health equity is important because what I may need to be holistically healthy may be much different and look different than what your needs are. Creating an equitable space to meet your needs and meet my needs, that's the ultimate goal

"All of these different angles really uplift why health equity is important because what I may need to be holistically healthy may be much different and look different than what your needs are. Creating an equitable space to meet your needs and meet my needs, that's the ultimate goal"

What are your organizational priorities for addressing health and racial equity in perinatal and neonatal care?

Melinated Moms is a community center, women empowerment organization, and we primarily represent moms and women across the melinated spectrum because a large group of our members, our moms, more than 90%, understand how pivotal it is to have representation for moms and their different birthing experiences. For me, I'm a four-time survivor of preeclampsia, and 2 of my children passed away before they were able to come to term due to my preeclampsia. So I understand that avenue of needing to share that with someone, needing to have resources around how to navigate what that journey looked like, you know, going through loss. But then also going through subsequent pregnancies that were successful, but still just as hard. So you know, we created this platform so that moms can see themselves and other people. Seeing how much, Once Upon A Preemie Academy has really bridged the gaps on what it looks like for black maternal health and representation and health equity, we want to be a part of that. So I felt like this was the best partnership ever. I've been so so excited to work with her for so many years. I feel like we're aligned in that way, and we're doing a lot of the same work. I'm really good at engaging the community and finding women who have these unique but common commonalities. I'm also really good at helping them to bring those things out without feeling judged or filling alone. When we're going through these issues that impact our journey into motherhood, it often feels like an isolating moment. But when you find like-minded people who are willing to talk, willing to share resources, and also willing to uplift you while you're go-

ing through it, that's the best thing.

What personal and professional experiences led you to focus on health equity in perinatal and neonatal care?

Obviously, I'm a mom so going through my pregnancy journey, I had no idea that this was a statistic. I just thought this was something that happened to me. Clinically, though, I'm also a nurse. So I've been a nurse for 16 years now. I've always worked in community health. So I've worked for a community health center where I managed care for marginalized populations. I saw how even working in that place, which was awesome. I loved working there. Motherhood was still very, very much marginalized in itself. So the previous place I worked for was an LGBT Community Health Center, and we had some patients who were same-sex couples who wanted to have children and we did so many things to help them get to that place of pregnancy, but once they will become pregnant, we will refer them out. I always wondered if they revere us as this great place for care, comfort, and a non-judgmental space? Why are we not caring for them in the most vulnerable times of their lives? Why are we then sending them back into these stigmatized spaces that don't value who they are, and don't value their lifestyle, or don't embrace the other parts of who they are that drop them to this point? So for me, that's where my professional background met my personal goals and commitment for being that platform. So you know, as I said, we cater to all moms and women across that melinated spectrum. So that's race, ethnicity, gender, identity, and expression. That's culture, that's language. We see how all of those things mirror one another in terms of creating a supportive network. So I've seen firsthand you know how pivotal it is to have the right types of support. Building Melinated Moms, we have been able to do that and expand our community not just nationally but internationally. So we've seen ourselves, and other moms have seen themselves in our work because of that.

" So I've seen firsthand you know how pivotal it is to have the right types of support. Building Melinated Moms, we have been able to do that and expand our community not just nationally but internationally. So we've seen ourselves, and other moms have seen themselves in our work because of that."

What is your call to action for the industry as we seek to eliminate health and racial inequities in perinatal and neonatal care?

Yes, my call to action is bringing parents to the table to create the change that they need and deserve to see for themselves and for their children. We see so many statistics about black and brown children being disproportionately born too soon or being born very early, or with low birth weight. So our children are at the highest risk for, you know, neonatal death, health ailments, and a lot of emotional turmoil. I've also seen, even from my professional space, I used to do pediatric home care, where I will care for special needs pediatric children, whom a lot of them were preemie patients right born at 22 weeks, 24 weeks, 26 weeks. And these parents, a lot of them black and brown, didn't have these supports in their lives. They didn't have people who would listen to them or who wanted to even engage with them. They just heard, well, this is what you need to do, figure it out. So I invite anyone who has ears to really be a part of that listening space, like listening to what their needs are, but then also creating that advocacy action plan with them instead of for them. It's very apparent whenever you're creating a solution for a specific community that if you do not include that community, it will almost always meet resistance, even if it's something that will work. You always have to have the community members at the table. That makes it a solution-based effort. So I invite anyone to be a part of that to create the solutions with the community members who are experiencing this.

" You always have to have the community members at the table. That makes it a solution-based effort. So I invite anyone to be a part of that to create the solutions with the community members who are experiencing this."

Final Remarks and Melinated Moms work with Once Upon A Preemie for Black Maternal Health Week

I wrote a book called *Find Your Roar*, which turned into advocacy training, and we are so excited that Once Upon A Preemie has invited us to teach our course to other premature parents of color. We are also combining our efforts for Black Maternal Health Week as a space to talk about the stigmas that have impacted childbirth and communities of color. The stigma around black premature health and black preemie parents is an area we really are excited to dive into with Jenne and with Once Upon A Preemie Academy. We want to continue to support the work that she's doing while we're also activating more advocates to be a part of these conversations. So April is going to be a busy month for all of us, but I'm really excited for this partnership.

"The stigma around black premature health and black preemie parents is an area we really are excited to dive into with Jenne and with Once Upon A Preemie Academy. We want to continue to support the work that she's doing while we're also activating more advocates to be a part of these conversations."

Disclosure: *The authors have no disclosures.*

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About the Author: Jenné Johns, MPH:

Title: President and Founder

Organization: President, Once Upon A Preemie www.onceuponapreemie.com and Founder, Once Upon A Preemie Academy www.onceuponapreemieacademy.com

Jenné Johns, MPH is President of Once Upon A Preemie, Founder of Once Upon A Preemie Academy, mother of a micropreemie, author, speaker, advocate, and national senior health equity leader. Once Upon A Preemie is a non-profit organization with a two-part mission: 1.) to donate Once Upon A Preemie books to NICU families in under resourced communities, and 2.) lead virtual health and racial ethnic training programs and solutions to the neonatal and perinatal community through the Once Upon A Preemie Academy. Jenné provides speaking, strategic planning and consultation services for fortune 500 companies focused on preemie parent needs from a cultural lens and reading as a tool for growth, development, and bonding. Jenné is also a national senior health equity thought leader and has led solutions-oriented health equity and quality improvement portfolios for the nations' largest health insurance and managed care companies.

About the Author: Jatesha "Jaye" Madden-Wilson, LPN

Title: Founding President, CEO of Melinated Moms

Organization: Melinated Moms

Bio: Jatesha "Jaye" Madden-Wilson, LPN, is a multifaceted social entrepreneur. She is a Community Health Nurse (LPN), dynamic public speaker, published author, thought leader, and the Founding President and CEO of Melinated Moms. In her professional career, Jaye applied the power of advocacy through lobbying on the state and federal levels as a community health advocate for marginalized communities. Gaining a strong understanding of the importance of advocacy, Jaye applied these principles to grow the community of Melinated Moms. Of all of her titles and accolades, the proudest title she holds is mother. She is the mother of two brilliant girls who motivate her to continue to change the world every day. That desire continues to serve as the organization's foundation and legacy.

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

In Loving Memory

August 9, 1996 - April 3, 2010

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

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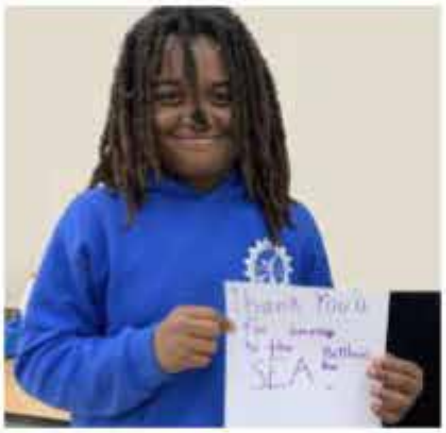

1 session	$15
1 week	$30
1 month	$120
1 semester	$540
1 year	$1,080
Middle School	$3,240

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Let's Talk About Light and Health – A new kind of lullaby: Robust light/dark pattern for babies

Sofia Axelrod, PhD, Randy Reid, MBA, Allison Thayer, MS

" This interview is part of our Let's Talk About Light and Health series, and the name of this session is A New Kind of Lullaby: Robust Light/Dark Pattern for Babies."

Video link:

https://www.youtube.com/watch?v=rYO7CH30Vsk&t=0s

Randy Reid: This interview is part of our *Let's Talk About Light and Health* series, and the name of this session is *A New Kind of Lullaby: Robust Light/Dark Pattern for Babies*. Dr. Axelrod, welcome.

Dr. Axelrod: Thank you for having me. I am very excited to be here.

Randy Reid: Well, we're very excited to have you, and the first thing I have to do is: tell our audience a little bit about the Nobel Prize you won in 2017.

Dr. Axelrod: It wasn't actually me who won the prize, it was my mentor Michael Young, and he basically discovered a long time ago in these little fruit flies that we have genes in our bodies that control when we sleep, when we eat, anything that really happens in our physiology. It turns out that humans have the same exact genes. And that's what he won the Nobel Prize for.

Randy Reid: Tell the audience a little about your background.

Dr. Axelrod: I studied biology, and I've always been fascinated by how our bodies work, and as I studied, I realized I wanted to dig deeper and understand the genetics and molecular biology and the cell biology of what really happens in our bodies. I later realized that people now even study behavior with these tools of genetics. So I joined Mike's [Young] lab to basically use these molecular tools to dissect something as complex as sleep. I figured we might as well use something as simple as a fruit fly to do this because we believe all animals sleep, including fruit flies, so you might as well understand it in them and then translate it potentially to something as big and complex as a human. I was working in the lab and making progress on my project around the fundamentals of why we sleep and how we sleep, which is actually not clear. We do it every night, but we don't necessarily understand from a scientific perspective what happens in the body and how it's really regulated. That's what I was studying in the lab at the time that I became pregnant. I should say that I have actually been a life-long insomniac and when I joined this laboratory at Rockefeller, and I was learning all about sleep and circadian rhythms, I understood what I had to do to help myself sleep better, so that was one way of taking the knowledge from the lab and applying it in the real world.

Randy Reid: Let's expand about that because I saw on your biography that you are a lifelong insomniac, and you had a baby, and you thought you'd never sleep again. What did you discover and tell our audience how that led to some of the workshops that you did and eventually the book you published?

" One of the things we know from research is that light really matters when it comes to circadian rhythms. Light is the thing that tells our body what time it is. By manipulating light in our environment, either by going outside or using specific types of lighting, we can affect our circadian clock."

Dr. Axelrod: One of the things we know from research is that light really matters when it comes to circadian rhythms. Light is the thing that tells our body what time it is. By manipulating light in our environment, either by going outside or using specific types of lighting, we can affect our circadian clock. In the lab, we use that every day because we have our lab animals, but the same thing happens in humans. When we don't want the study subject (whether it's a fly, mouse, or human) to experience the effects of light, but we still need to see, we use red light because red light does not affect our circadian clock. I was standing in our dark room with the red flashlight because I was handling my experimental flies, and I was quite pregnant. And I thought: 'Why don't we use red light to help babies sleep?' All life responds the same way to light, whether it's a fly or babies. Often night lights for babies are blue. And blue lights actually activate our circadian system and tell us to be awake, so it's like the opposite of what we want if you want your baby to sleep and if you want yourself to sleep. So I got a bunch of red light bulbs and installed them. I also thought it helped me wind down at night, which makes sense because it naturally increases your melatonin release. And when I had my first daughter, I used the red light at night for any night wakings and whenever I had to placate her or change her diaper. I

only used red light. I used a lot of light during the day and at night, only red light, to entrain her circadian rhythm, and it worked really well because it's our biology.

Dr. Axelrod: Then I thought, 'Okay, what else do I know? What else can I use from my knowledge as a sleep scientist to apply to her sleep?' there are a couple other things that are very clear to us as scientists that have not made it out to the real world. One, for example, is that there is this notion that sleep begets sleep. That a baby needs to sleep a lot during the day to sleep well at night. And that goes against everything we know about sleep science of sleep needs. We have a total daily sleep need that is daytime sleep plus nighttime sleep. If I put you down for a 5-hour nap during the day, you're not going to be tired at night. The same is true for babies. It's just more confusing because they get tired more quickly, so they do need to nap. But make sure to keep that in balance so you can maximize nighttime sleep. So I researched that, and I figured out how much at every age a baby should be sleeping to sleep better at night. That was basically the second big idea that made it into my method. Generally, just about circadian rhythms, the idea that we have an inner clock that is either reinforced by things that we do, like getting up at a certain, like eating at a time or is weakened like if we do erratic wake times, erratic feeding times.

" Generally, just about circadian rhythms, the idea that we have an inner clock that is either reinforced by things that we do, like getting up at a certain, like eating at a time or is weakened like if we do erratic wake times, erratic feeding times."

Dr. Axelrod: There is this notion in parenting that you should let the baby decide when to eat, when to sleep, [and] when to do whatever the baby wants because it seems too intuitive to do this "baby-led parenting," as it's called. But it doesn't make sense from a circadian perspective, and there's data that shows that you can help babies sleep through the night and be generally happier by helping them get on a schedule.

Those are the three things that I synthesized from my knowledge as a sleep scientist and chronobiologist. Control light exposure, watch the sleep need and keep the circadian rhythms going.

Dr. Axelrod: The other thing that is really divisive in the parenting community is "sleep training." A lot of people think that sleep training will harm your baby and that if you let a baby cry.

Randy Reid: What is sleep training?

Dr. Axelrod: All these things that I just mentioned will naturally help the baby sleep more at night. But there is one more thing that I have to talk about, and that is the ability to fall asleep at all. Which is not something that we are actually born with. It's a skill that we learn. We need to learn to be able to put ourselves to sleep. That's something that babies struggle with, and that's why they cry. We need to teach them to fall asleep, ideally on their own, if we want to sleep ourselves. If we teach them to need you to fall asleep if you teach them to need a nursing mother to fall asleep, or anything else really. Some people call that "sleep crutches." If a baby needs to sleep on top of you, if a baby needs to be carried around, if a baby needs to sleep with you, then the baby learns that this is what is required to fall asleep. That becomes their mode of sleeping. I'm, for example, a person who is a bad sleeper, a light sleeper; I just can't sleep if someone is touching me or crawling on me. For me, it was paramount for me to solve that. Other people, like my husband, he doesn't care.

Dr. Axelrod: If it's important for you that you have a good sleep at night, then you need to teach your baby to fall asleep on their own. You do that with the things I mentioned earlier: control the light, entrain their rhythms, and watch the naps. But there's one more thing, and that's sleep training. It's a very controversial idea. I don't even want to call it "sleep training" anymore. You can call it whatever you want, "teaching them to sleep through the night." You need to teach them to fall asleep on their own. It's also called "self-soothing." It's the ability to lay down and calm down and close your eyes and believe that you can make it fine on your own to fall asleep. The most effective way that has been studied rigorously to accomplish that is called "sleep training." The idea is super simple. It means when it's the baby's bedtime, and baby needs to sleep, and baby is fussing or crying, but you are sure that they're fussing and crying because they're tired and need to sleep.

"Actually, there are positive consequences. It has been shown that parents are happier and sleep better. Children grow up to be well-adjusted kids who have no mental health problems or anything like that and do well at school."

Dr. Axelrod: Instead of somehow intervening and trying to make the baby not cry in that situation, you just let them be. You let them be for how long; it kind of doesn't matter. There are studies that say waiting just 90 seconds is enough. That's what I recommend in my book because I know how hard it is for a parent to hear their baby cry. Just by waiting 90 seconds each time, though, because you want to teach them that this is what's going to happen now. You're tired, you need to calm down, and you can do it. You don't need mom or dad. You don't need anyone; you can do it by yourself. So just waiting 90 seconds, the baby learns, "It feels uncomfortable, but I can do it." Research shows that this is highly effective in teaching your baby to sleep through the night. There are no negative side effects; there are no long-term consequences**.** Actually, there are positive consequences. It has been shown that parents are happier and sleep better. Children grow up to be well-adjusted kids who have no mental health problems or anything like that and do well at school.

Randy Reid: What if they continue crying after 90 seconds, it goes to two or three minutes; then do you go in?

Dr. Axelrod: Exactly, so my method, I call it actually "gentle sleep training. "On its surface, it's gentle to the baby, but really it's gentle

on the parent because I was the parent that was sitting at the edge of my bed counting the seconds until my own method told me I can finally go and help that baby. We're biologically programmed to do that, so to not do that feels horrible. So I go in after 90 seconds, and I pat the baby, and there are these ideas that are just shushing and patting them comforts them, and then you do this for a few minutes, and then you leave again. The cycle the first time you do it might take a long time, like up to 45 minutes. Relatively speaking, 45 minutes is not a long time, but 45 minutes of crying is hard. So I tell the parents I work with to be ready for that; this will be excruciating, but just trust the process and the data that show that this will work. Typically after one to two nights, this is just over, and everybody gets the sleep they need, so I really encourage people to find the inner strength to bear with it and to do it.

Dr. Axelrod: There're all kinds of tricks around how to make it easier. It certainly helps to do this earlier than later because if a baby is already a year old, they remember, and they're not going to be happy about the sudden change that occurs in their sleep routine. If they're used to being nursed to sleep, they'll be like, 'where is my boob,' if they're used to co-sleeping, they'll be like, 'why am I supposed to sleep on my own?' For a three-month-old baby, it's a much easier proposition. So doing it earlier rather than later is easier. Using your partner who, if you're nursing, is not nursing, is easier because the baby smells actually the milk on the mother, and if they're used to being nursed to sleep, they'll be like, 'what, you're trying to placate me without nursing me? That doesn't make any sense." So there're all kinds of things to make this easier. Also, "evicting," I call it, harshly evicting the baby from your bedroom helps with this short delay because if the baby is right there crying, it's very hard to not tend to them so just creating a little bit of distance helps. So there's a bunch of things we can do.

Randy Reid: What about sound machines? I haven't heard you mention that. Is that a crutch, or is that okay?

Dr. Axelrod: I consider "crutches" anything that impairs my ability to get sleep; therefore, a white noise machine is totally fine. In fact, there is pretty good evidence that they also help the baby sleep. Which is interesting, right? Why would noise help someone sleep? But we actually think it's because of the noises the babies experience when they're still inside of the mother's body. It's actually quite loud in there, and it seems like white noise might remind them of this cozy environment. Which is the same reason, by the way, why swaddles are so effective. Young babies/newborns have these reflexes where they keep waking themselves up, and just by doing this, you're kind of making them more tired, and they don't wake themselves up when they have this moral reflex.

Randy Reid: What about the 'Snoo?'

Dr. Axelrod: The 'Snoo' is based on a pediatrician's method of how to put babies to sleep. His name is Richard Ferber, and his method has become so popular. And his book was and still is, of course, is one of the bibles of baby sleep, and he actually came up with the idea of "Ferberizing" a baby, which is to soothe them to sleep. And that you can help a baby sleep by shushing, by swaddling, and there's like a couple of s's, and the Snoo does them all. The Snoo swaddles the baby, the Snoo will shush the baby, and the Snoo will rock the baby because movement is another one that puts the baby to sleep. Again probably because they were rocked in our bellies when we were pregnant, and the Snoo does all these things; and in an automated fashion. I think it makes total sense. It's a very expensive thing, but then again, your sleep is also very valuable. So this can really help a lot of people in the first couple of months, which some people even call the fourth trimester because the babies are really small and, like I said, can't put themselves to sleep yet. It wasn't out yet when I had my kids, but if it had been, I probably would have gotten it because, you know, you're just a zombie, and this tool seems to be working quite well for a few months. It helps basically with the fourth thing that I described, but I think it's important to still do the other things [we discussed earlier]. Otherwise, you have a baby that will wake up at night, and you have your Snoo to take care of that, but once they grow out of the Snoo, which happens very quickly because it's just really a bassinet for the first couple of months, then your baby will not have a good sleep cycle, and then you have to deal with that so it can be a problem if the parents don't really do any of the other things that are important to teach a baby's body to be tired at the right time.

"It helps basically with the fourth thing that I described, but I think it's important to still do the other things [we discussed earlier]. Otherwise, you have a baby that will wake up at night, and you have your Snoo to take care of that, but once they grow out of the Snoo, which happens very quickly because it's just really a bassinet for the first couple of months, then your baby will not have a good sleep cycle, and then you have to deal with that so it can be a problem if the parents don't really do any of the other things that are important to teach a baby's body to be tired at the right time."

Randy Reid: Do you have an app that you've created?

Dr. Axelrod: Yes, so I really want to help parents in a way that addresses all their needs. Not everybody will be able to absorb my book in a way that helps them solve their baby's problems, so I thought, 'okay, let's forget about all that. Let's just make an app.' You don't have to ever have heard about my lofty ideas, you just put in your baby's age and a few other parameters that I've identified are relevant for baby sleep, and the app will simply tell you what to do. It will tell you exactly when to put the baby down; it will tell when to wake the baby up, what to do with the light, and how to sleep at night. Just do what the app tells you, and your baby will sleep. So that's what I did. It's called "Kulala," and people really like it, I think.

Randy Reid: What does that [Kulala] mean?

Dr. Axelrod: Kulala means 'sleep' in Swahili. I don't have any relation to it, but I thought it also sounded really cute, like a lullaby.

Dr. Axelrod: Also, in terms of the light, I actually wanted to point out that aboriginal communities in Africa don't have a lot of the sleep problems we have because they have a much stronger light/dark cycle. They don't have this constant dimness that we have during the day and the enhanced brightness that we have at night, so there is something there.

Randy Reid: What is the name of your book?

Dr. Axelrod: My book is called 'How Babies Sleep,' and it's actually been translated now into 11 languages. Here's a Japanese version. I've just been to Italy for a sleep conference last week, and I went to a bookstore in Florence, and they had my book, so that was a big rush. It's helping parents worldwide, and it's just incredible.

Randy Reid: Can we buy that on Amazon? We don't have to go to Italy, correct?

Dr. Axelrod: You don't have to go to Italy; yes, you can buy it anywhere that books are sold.

Randy Reid: You also have a light that you sell, is that correct?

Dr. Axelrod: Yes, that's right. I used these red light bulbs when I had my kids, but they're not really something that parents are going to use unless they're really dedicated, you know, going to a hardware store; it's just not an attractive, easy-to-use product for a parent. So I wanted to make something, mostly for myself, but of course for everyone else too; to have a nice lamp that only does the one thing, which is to provide the light that does not suppress a baby's melatonin because we want that sleep hormone to be high at night. So we made this beautiful all wood lamp. It only emits light in the right wavelength, which is above 650 nanometers. It's the perfect thing to compliment my method, so you have the book to learn all about it, you have the app to know when to turn the light on, and then you have the light to turn on when you have to placate baby at night when they're crying or when you are nursing or when you're changing a diaper.

Randy Reid: Where can our audience buy that lamp?

Dr. Axelrod: We have a website called "kulalaland.com," and that's where you can learn about what we're doing and you can buy my lamp. You can actually buy what we call our "Kulala Sleep System," which is the lamp, the book, and six months of the app subscription, so you have it all together in one package like a starter package. If you're pregnant or if you're a sleep-deprived parent, to get you out of that or as a baby shower gift.

Randy Reid: Regarding the lamp, is it LED technology in there?

Dr. Axelrod: Yes, LED technology has revolutionized lighting, and this is our chance now to really create lighting products that correspond to our physiology because our eyes are highly sensitive to very specific wavelengths, and lighting like incandescent lighting just can't achieve the precision that LED lighting can. So this lamp is engineered to really only have wavelengths above 650 nanometers, so it's completely safe. It does not activate the ipRGCs, which are the cells in our eyes that respond to blue light. So you can be 100% sure that this is inert for our circadian system. I use it every night, actually.

Randy Reid: Beyond sleeping better, are there any other impacts of light on babies' health?

Dr. Axelrod: Yes, of course, so sleep is really just one of what we call 'outputs' of the circadian clock. It's an important one, but it's only one. In fact, the more we learn about it, we realize that everything that happens in our body is on the clock. Whether it's body temperature, whether it's hormones, whether it's bowel movements, but also things like mood and even for babies growth. **There's data that shows that NICU babies (so, babies that are born prematurely) grow faster with circadian lighting. By making the differences between daytime and nighttime in terms of light very strong, you can make a baby grow faster, so the effects go beyond sleep. Sleep is very important mostly for the parent. The baby doesn't care whether they sleep during the day or at night, but the parent cares a lot. But having a strong circadian rhythm and light is part of that, and sleep is part of that will help the baby grow and be healthier and happier.**

"There's data that shows that NICU babies (so, babies that are born prematurely) grow faster with circadian lighting. By making the differences between daytime and nighttime in terms of light very strong, you can make a baby grow faster, so the effects go beyond sleep. Sleep is very important mostly for the parent. The baby doesn't care whether they sleep during the day or at night, but the parent cares a lot. But having a strong circadian rhythm and light is part of that, and sleep is part of that will help the baby grow and be healthier and happier."

Randy Reid: If a baby is raised without any concern for circadian entrainment whatsoever and is getting fluorescent light at night and they're just growing up that way, are there long-term damages, or can that be fixed at a later age?

Dr. Axelrod: I don't know, because that's research that's I don't even know if anybody's doing a longitudinal study like that. That's actually something I would be very interested in studying, but one thing is very. The function of the circadian rhythm is basically for us to know what's going to happen next, so if you have a strong circadian rhythm, your body just knows 'I'm going to get food, I'm going to have lunch,' and it starts preparing your digestive system and starts secreting enzymes. Or your body knows, 'I'm tired and cranky, and I'm gonna get sleep, so I'm gonna fall asleep now.' If you don't have that because of erratic behavior or erratic lighting and all of that is collapsed, your body constantly doesn't know what's happening, and your body is not as well organized. That will have detrimental effects on your health, and there is research that shows that, for example, constantly phase-shifting people, business travelers, or shift workers have serious health problems. You would imagine that starting like that early in life when your organization is even more dependent on a structure would have

negative outcomes.

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Dr. Axelrod: I've become totally obsessed with light and chronobiology, and I used to be a scientist who didn't care about applications at all. I just wanted to know how stuff works, but this is such a simple and powerful tool that we can use to make ourselves sleep better, feel better, and be healthier. I think it's really important that people understand that and that companies create products to help achieve that. I'm sitting inside here, and it's really dim. The lighting inside is ten thousand or a thousand times dimmer than outside, and that's why we get sick. And at night, we stare at our screens, and it's much brighter than it should be. So, you know, it's so easy. It's just a light, and it will really help us live better. I think it's exciting that people are working on this and that people are researching it. We have a bright future ahead of us if we use what basically nature has provided us with.

Randy Reid: Well, Dr. Axelrod, thank you so much for speaking to our audience today, and please stay tuned now for a few questions. Thank you.

Randy Reid: Dr. Axelrod, thank you very much for that; we will now open the floor for questions. I'd now like to introduce our producer of Let's Talk About Light and Health, and that is Allison Thayer, and Allison will moderate the questions.

Allison Thayer: Thank you, Dr. Axelrod, for that interview too. That was really interesting. We want to open up the floor to parents, anybody who's going through this, and we'd love to hear from you.

Allison Thayer: If you don't mind, though, I actually have a question myself. You talked a bit about entrainment of sleep, which is generally getting your body to be awake during the day and to sleep at night. From other talks, we've learned that bright light during the day and then that dimmer light at night or that red light that doesn't suppress your melatonin is really important to have at night so that we don't disturb our circadian clocks. But then, for babies, I'm wondering about napping during the day. Can you talk a bit more about a lighting schedule for babies that is during the day? How does that fit in with a nap schedule, and do babies have the same effect that we have from light during the day?

Dr. Axelrod: It's confusing to parents because they don't have the same sleep/wake pattern like we do that would nicely fit together with our circadian rhythms and everything. I just talked about in terms of lots of light during the day, no light at night, and sleep at night, but babies do sleep during the day, so what does that mean? That goes back to the other kind of system I described, which is the sleep pressure. Babies' sleep pressure rises a lot quicker than ours, so yes, they do need to sleep during the day. That's somewhat decoupled from the circadian rhythms, ergo, that means for the lighting my recommended (nobody has studied this specifically, but) if we go back to what circadian rhythms are doing and how light entrains our circadian clock, you would not want to necessarily (especially for newborns) put them in complete darkness for naps. Especially in the very early days, it's really important to establish these very robust patterns and make the day as different from the night as possible in terms of light. For example, where the baby is sleeping, I would always put them at night in the exact same spot, complete darkness, very quiet. But during the day, I wouldn't actually do all these things. I wouldn't keep it too quiet; I wouldn't make it too dark. So the baby of course, can [still] nap, and we want to encourage that, but also that the body and the baby from day one understand on a physiological level that daytime sleep is different from nighttime sleep. Otherwise, if you provide the perfect sleep environment during the day, you will end up with a baby that potentially sleeps too much during the day, and that shortens nighttime sleep. That's the people who come to me and say, "my baby sleeps six hours during the day and doesn't want to sleep at night; why?" So you can, you can lay that foundation in the early days.

Randy Reid: How important is it for the baby that the mom is getting proper light/dark cycles during pregnancy?

Dr. Axelrod: That's a great question. The research on this is developing, but all data that I know of indicates that it's the mother's circadian rhythm that, even during pregnancy, already informs the fetal circadian rhythm. There are also peculiarities about a pregnant woman's circadian rhythm. They shift earlier in early pregnancy, which is interesting, but overall the recommendation would be, yes, you should try to already before you give birth to try to entrain yourself. It's quite likely that will entrain the unborn baby, and then when they're born, they already have a more robust circadian rhythm.

Allison Thayer: That fits in with the next question from Robert: What do we know about the sleep architecture of babies throughout the course of the day? Is nighttime sleep different than daytime sleep? We kind of answered that a little bit, but do you have anything else to comment on that?

Dr. Axelrod: I don't know that there is a lot known about that, but I think in terms of our sleep (which ultimately is my goal of maximizing), I operate under the assumption that there is not a big difference in terms of sleep quality. Babies need a lot of sleep, and there are interesting studies coming out around, like how sleep is fundamentally different in young babies from older children. We think in young children, sleep has developmental functions that sleep for us [adults] doesn't have because we're fully developed, but that being said, there is a lot of flexibility on our part in terms of what we decide when a baby should be sleeping. You have more

power than you think in deciding when a baby should be sleeping, and you can kind of align it, not completely, of course, but you can shift the baby's sleep to align with your schedule and light, and sleep pressure are the two knobs we can turn.

Dennis Spaulding: We have already spoken about this a little bit, but I was curious about babies, and my son was a problem sleeper, or maybe it was myself with his training. Do babies need a certain time during the day, either after the nap or something like that, where they would really benefit from bright light, so to speak, to entrain them?

Dr. Axelrod: Great question. Nobody knows that, but the fact that babies are so sensitive to light, and we don't know really why (some people say because their eyes are more clear), and it's very clear that bright light at night wipes out their melatonin. So nobody tested that you can also help with sleep at night and with your circadian rhythms by providing more light during the day, but everything we know about circadian rhythms would suggest that, yes, you would want to expose baby to plenty of light during the day. Go for a walk and things like that. Also, for naps, don't make it too dark, especially for newborns. They will sleep wherever. I can't tell you a specific regimen in terms of how much light, but I would recommend as much as possible. Some people live in apartments or houses that don't have a lot of natural light. That's something I would pay attention to. There is no solution right now for lighting that would generate outdoor lighting conditions indoors, apart from these seasonal affective disorder lamps. Nobody has tested how babies react to that, but you want to generally increase the amount of light a baby has during the day based on your general understanding of circadian rhythms.

Allison Thayer: To clarify, do you want red light during the day, or do you want a different type of light

"No red light during the day. For all the reasons I just explained. I call it night-mode and day-mode, and the red light is in night mode. So, either in complete darkness or if you have to see because you need to placate your baby or you need to change a diaper, red light is safe."

Dr. Axelrod: No red light during the day. For all the reasons I just explained. I call it night-mode and day-mode, and the red light is in night mode. So, either in complete darkness or if you have to see because you need to placate your baby or you need to change a diaper, red light is safe.

Dr. Axelrod: But during the day, older kids do need certain conditions to be able to nap, so you can't just put a two-year-old in a bright, loud room. For sure, we have to help older kids to sleep better, but I would leave the red light out of it. Typically anyway, during the day, usually no amount of blackout shades can, you know, create the complete darkness that we have at night, so the red light is kind of useless for that. Anyway, we wouldn't want to use the red light in that way. We wouldn't want the complete darkness and red light during the day because we don't actually want melatonin to go up during the day

So the next question we have from Mark: "Do babies have weekends that follow their parents' shift from weekday working to weekend socializing, and what would a babysitter do? Do we keep the baby on the workday schedule?"

"So if you had a really good schedule during the week and your child's and your own body now really know 'at this-and-this time I'm tired, I'm going to sleep.' Everything is aligned, and the sleep hormone is working to your advantage, and then it just all erodes over the weekend, then all that just goes away a little bit, and then your body doesn't know anymore what's going on."

Dr. Axelrod: Great question. Very important to not do that. It's super important to not change anything. Nobody wants to hear that, right. On the weekend, you just want to sleep in. That's something I actually ended up fixing about my own sleep when I joined Mike's [Young] lab, and then for my kids even more so, you don't want to do that [change your schedule on the weekend]. You want to be really on the clock and on the weekend, not shift (which would basically introduce jet lag or social jet lag into everybody's body's schedule). The problem with that is it overall just weakens the circadian rhythm. So if you had a really good schedule during the week and your child's and your own body now really know 'at this-and-this time I'm tired, I'm going to sleep.' Everything is aligned, and the sleep hormone is working to your advantage, and then it just all erodes over the weekend, then all that just goes away a little bit, and then your body doesn't know anymore what's going on. And your baby's body doesn't know anymore what's going on. What does that mean? They'll be sort of sleepy and cranky because their sleep needs and their sleep pressure is not aligned anymore with circadian rhythms, and so as annoying as that is, I totally advocate for not changing anything ever. Caregivers, get them all on the same page, tell them what's going on, tell them that you have that schedule and why you have that schedule. Don't let the grandma let the baby sleep all day. A struggle I had personally is, for example, in the daycare where sometimes they just nap for hours and hours and then those nights after daycare, suddenly bedtime ends up being much much later, and parents are like 'why is that and what can I do about that?' The only thing is to shorten that [naps], and overall you don't want the weekends to look different from weekdays. You want everything always to be the same, as hard as that is. That is kind of an organizing principle that if you follow that, everything else becomes easier. That's why I would advocate for that.

Randy Reid: How long before bedtime should we limit screen exposure for toddlers?

Dr. Axelrod: That's another big one. Even earlier [when a child is

younger], like when you're feeding a baby, that can take a long time, and what does a mom do when she's, for example, nursing a baby? She's on her phone, and I think that's totally valid, and I don't want to take that away from anyone. The good news is, we have tools to make the screens dimmer, and we have these filters now that are now built into IOS and also Androids that make the screen filter out the blue light. On top of that, you can find additional apps that make it even red. I'm very strict about this, so I actually have an app that makes the screen red. So you don't need to limit screen time, but if that's something that you need as a last resort because the kids are going crazy and you want them to watch their show for half an hour, that's fine. Just make sure if it's on the iPad to make it dim and yellow or even red. If it's a TV, it's much harder. I actually have on the TVs in our apartment different modes that I manually installed that are very dark. You can actually, if you're so inclined, filter out the colors, but it's not easy. So if you can't, if you don't have these tools to filter out the blue light, then I would stop doing any screen time one hour before bedtime. Not much longer, actually, because this is quite dynamic.

Randy Reid: Is it fair to say that a baby's day is shorter and they should have more cycles in 24 hours than adults?

> ***" One of them is circadian rhythms, and the other is sleep pressure. For adults, these two things just come together; and our sleep pressure is very high and needs to be filled once a day, and our circadian rhythms are 24 hours, so it fits together. For babies, they just need to do that more often because their sleep pressure rises much quicker, but their circadian rhythm is still 24 hours."***

Dr. Axelrod: That's an interesting question. It might seem like that if we use sleep as kind of an indicator of circadian rhythms or how many times we sleep, right. You could say if we sleep one time in 24 hours, then our circadian rhythm is 24 hours, but a baby sleeps five times. Maybe its circadian rhythm is only five hours, but that's not the case. So that speaks to these two processes that really determine sleep timing. One of them is circadian rhythms, and the other is sleep pressure. For adults, these two things just come together; and our sleep pressure is very high and needs to be filled once a day, and our circadian rhythms are 24 hours, so it fits together. For babies, they just need to do that more often because their sleep pressure rises much quicker, but their circadian rhythm is still 24 hours. I would say that baby's circadian rhythm is just like ours. It's weaker, and it needs more entrainment, which is why all these things are extra important. In adults, our daily sleep, which happens only once, is actually another thing that entrains our circadian rhythm in a way. You can think of anything we do or don't do as either strengthening or weakening our circadian rhythm, so light is just one of them. Food is another one but sleep itself or when we are active, when we're moving, when we're not moving is another one. The erratic nature of babies' sleep-wake patterns also weakens the circadian rhythm, but their circadian rhythm itself is still 24 hours, so we have to work with other aspects of the circadian rhythm to increase the amplitude because sleeps will not do that. The sleeps [naps] are much more often than every 24 hours.

Allison Thayer: That makes a lot of sense, and Trisha's question kind of fits in with that. Trisha, would you like to ask yours?

Trisha Odenthal: Hello, I have a niece and a friend's children. What's the nap time length for three months, one year, two years, and three years? When do they abandon naps? How long should they be?

> ***" Parents/grandparents are very worried about waking a sleeping baby, and I give you permission to do that. It's okay, and the baby will be fine, and they will sleep better at night because we have this total sleep need. "***

Dr. Axelrod: That's another huge source of confusion for parents, grandparents, and caregivers on top of everything else we just discussed. Sleep needs in babies changes so quickly that it's hard to stay on top of it, and a baby that slept last week might not sleep well this week anymore. And what I've found, and there's solid evidence for that, is that it's usually because their sleep need is going down. It's going only one way. Babies are different, sure, but all babies sleep more when they're younger than when they're older, right? We [adults] sleep between, whatever six and eight hours, and babies sleep 20 hours when they're born and already only 12 hours (in 24 hours) when they're one year old. So there're huge changes happening, and it's really hard to understand what's going on. Now, the good news is that people have tracked baby sleep, and we know pretty precisely how much babies sleep at any age group. One can just map that out, and then the thing is, yes, there is your variability between babies. So I can tell you the average for each age, and then your baby's sleep might be a little higher, a little lower, but what's clear is that if your baby or if your grandchild used to sleep and doesn't sleep anymore, that means that the trajectory went down. That the sleep need did decrease, and it is useful to know that and to know what the average is and just default to that. In my book, I have all the charts, and I also have an app that I recommend. It has all these schedules, so you just put in your grandchild's age, and if it's a young baby, the weight is also important. Then it basically gives you the right schedule for any age group and also for when the parent wants to get up in the morning. That's when I said you can kind of shift that around. You don't have to just resign to getting up at 5am if you don't want to. If your baby is someone who needs more sleep than others, that's fine, but if they used to sleep and don't sleep anymore, then I would recommend looking at that schedule and just reducing the nap time to whatever the average is. Because thousands of babies sleep like this. Parents/grandparents are very worried about waking a sleeping baby, and I give you permission to do that. It's okay, and the baby will be fine, and they will sleep better at night because we have this total sleep need.

Dawn Brown: Does the time that you feed the baby impact or help

the circadian treatment as well and also what you're feeding the baby or toddler? Does that impact circadian treatment?

Dr. Axelrod: Yes, and yes. However, again, it's confusing because in the very beginning, the baby is so erratic, and you're also told (depending on the weight of your baby) [that] you have to feed on a certain schedule. Many pediatricians will make you feed the baby, for example, every two hours during the day, and you can't do anything about that because the baby just needs to grow. The main imperative of everything is just to regain birth weight and to establish a growth pattern, and so you can't and really impose any schedule on that, and you shouldn't. That's where, for example, the robust light/dark patterns are kind of the circadian entrainment you can offer the baby when the feeding and the sleep cannot. Later then, as soon as they regain their birth weight, then you let them sleep at night. That's when you start noticing [that] 'my baby starts falling asleep after this many hours, and that's when you can start kind of working towards a schedule. And the same with feeding. I think parents don't realize that after when they have regained their birth weight (and with a pediatrician's clearance) you don't have to stay on this extremely tight feeding schedule. I would ask your pediatrician how far should your baby be able to go without food and stick to that because if you end up nursing or feeding them more frequently than that, then that becomes something the baby just gets used to, just like the sleep. So yes, absolutely, feeding times can be used to entrain circadian rhythms, but I would figure out with the pediatrician for very young babies what that should be. For babies that have regained the birth weight typically, you can go three to four hours without feeding, so getting out of this constant feeding pattern that you know parents have with very young babies is very important.

"So yes, absolutely, feeding times can be used to entrain circadian rhythms, but I would figure out with the pediatrician for very young babies what that should be. For babies that have regained the birth weight typically, you can go three to four hours without feeding, so getting out of this constant feeding pattern that you know parents have with very young babies is very important. "

Dr. Axelrod: The other thing was about the food composition. That's super interesting for nursing mothers. It has been actually shown that the milk composition changes in the circadian fashion over the course of day and night, and that pertains to the nutrient composition of breast milk. It's a lot more fatty at night, and lactation consultants recommend, for example, if you pump to give the pumped milk at the same time when you pumped it because the theory goes that it helps the baby sleep better at night when they get the night milk because it's much fattier and also it is actually enhanced in hormones from the mom that help the baby sleep better at night. So yes, in terms of breast milk for sure. In terms of formula, no, because there's no variability in that.

Allison Thayer: I have one more question to wrap up. How broadly do pediatricians embrace your philosophy?

Dr. Axelrod: I honestly think that's why I even got into this whole thing because a baby's sleep is not a medical problem, right? A baby that doesn't sleep is kind of nobody's problem except for the overwhelmed parents. You go to your pediatrician, and as long as the baby grows, their job is done. That's really the only thing that matters for a young baby that they grow. They might throw you some advice, and of course, there are probably pediatricians who are much more into helping with that than others. Ultimately, there is really nobody there that will specifically help with a baby's sleep because it's just not a medical problem. It doesn't matter for babies' growth really whether they sleep during the day and then not at night. Whether they're sleep-depriving the parent or whether they're perfect sleepers and sleeping, that will not matter for their growth, and therefore, pediatricians don't necessarily have the training, or it's just also not in their wheelhouse really. So that's where someone like me who comes in to fill that gap. And yes, of course, I'm talking to pediatricians like my pediatrician and other people to get that word out there because I really think that when you become a mother, you just need to sleep. And again, who exactly will help you with that? It's not the pediatrician. It's not the GP [general practitioner] or the OB/GYN [obstetrics gynecologist], you're just kind of thrown into the deep end, and it's hard. I think this should become something that is more integrated into the healthcare system. I think that would be very important.

Allison Thayer: Do you know of any support groups, or have you been a part of anything that you've been able to talk to people more on like a mom level about this?

Dr. Axelrod: We have been very active in our own outreach. We have a Facebook group that is called "Science-Based Baby Sleep Support" again because there are just so many opinions out there, and I think it's important to talk about things in an emotional way because this is all very emotional, but always from the perspective of "what can we support with data" versus what is just more a philosophical question that nobody can really answer. There are all these trigger things: co-sleeping, sleep training, all these things people are very emotional about. We can discuss these things in an empathetic way but from the perspective of science.

Randy Reid: I think we're ready to wrap up now, and Dr. Axelrod, I want to thank you. I think your talk was just great, and I sure learned a lot, and I know our audience did as well. Allison, our producer, we want to thank you and the Light and Health Research Center from Mount Sinai for making this happen. And last, we want to thank our audience. We had great participation today, and we really do appreciate these questions.

" Please do remember on the 25th of April, our next talk is Hold the coffee: Perking up the office with light, and that will be at noon eastern. Sign up at lightnhealth.eventbrite.com. Thank you all."

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talk is Hold the coffee: Perking up the office with light, and that will be at noon eastern. Sign up at lightnhealth.eventbrite.com. Thank you all.

Disclosure: *Mr. Reid is Executive Director of the National Lighting Bureau, the editor of the EdisonReport and the editor of designing lighting (dl) magazine.*

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As the founder of Solaria Systems, Inc., Dr. Axelrod and her team build lighting, software, and data technologies to help families, workers, and patients sleep and feel better and live longer

and healthier lives. She has also applied her expert knowledge to baby's sleep, writing the book- How Babies Sleep. Using insights plucked from the front lines of scientific research, Dr.

Axelrod's ultimate goal is to elucidate the basis of sleep and fundamentally improve it in our notoriously sleep-deprived society.

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Icahn School of Medicine at Mount Sinai
Light and Health Research Center

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A new kind of lullaby:
Robust light/dark pattern for babies

GUEST SPEAKER

Sofia Axelrod, PhD
Sleep Research Associate
Young Laboratory of Genetics at The Rockefeller University

As the founder of Solaria Systems, Inc., Dr. Axelrod and her team build lighting, software, and data technologies to help families, workers, and patients sleep and feel better, and live longer and healthier lives. She has also applied her expert knowledge to baby's sleep, writing the book- *How Babies Sleep*. Using insights plucked from the front lines of scientific research, Dr. Axelrod's ultimate goal is to elucidate the basis of sleep and fundamentally improve it in our notoriously sleep-deprived society.

EPISODE HIGHLIGHTS

Sleep is important, especially for babies in their early years to help promote general health, good mood, and growth. There are two processes for sleep cycles:

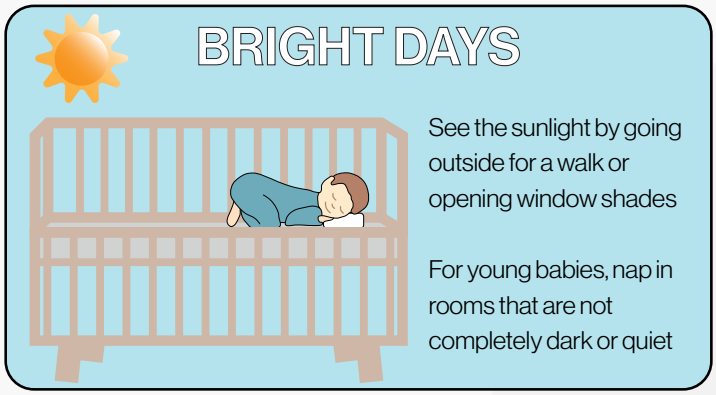
- **Circadian rhythms** cycle approximately every 24 hours for adults and babies. A baby will share a mother's circadian rhythms while in the womb. After birth, these cues from the mother are taken away so a baby needs to establish their own circadian rhythms.

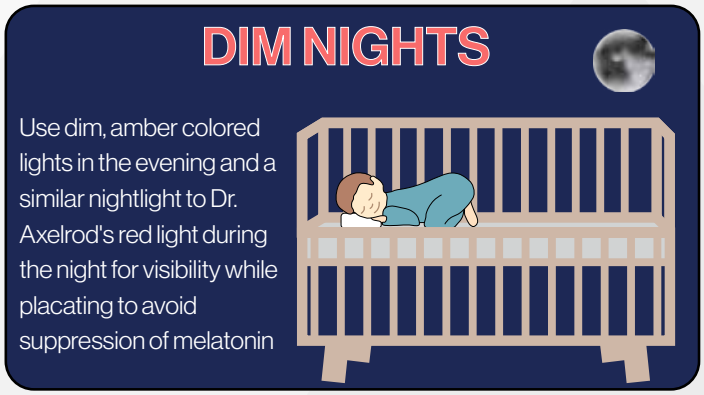
- **Sleep pressure** builds up during waking hours. In growing babies, sleep pressure builds up a lot faster than adults, which is why they need to nap all the time.

For how imperative sleep is, it's not always easy to come by, especially for newborns and their parents. Learn more about Dr. Axelrod's three-step process to help babies (and you!) sleep better:

1. Controlled light exposure to establish circadian rhythms

Make the day as different as possible from nights (for both sleep and play) to establish the difference between daytime and nighttime. Here are some tips:





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The Village Son

A Life's Journey

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

Houchang D. Modanlou

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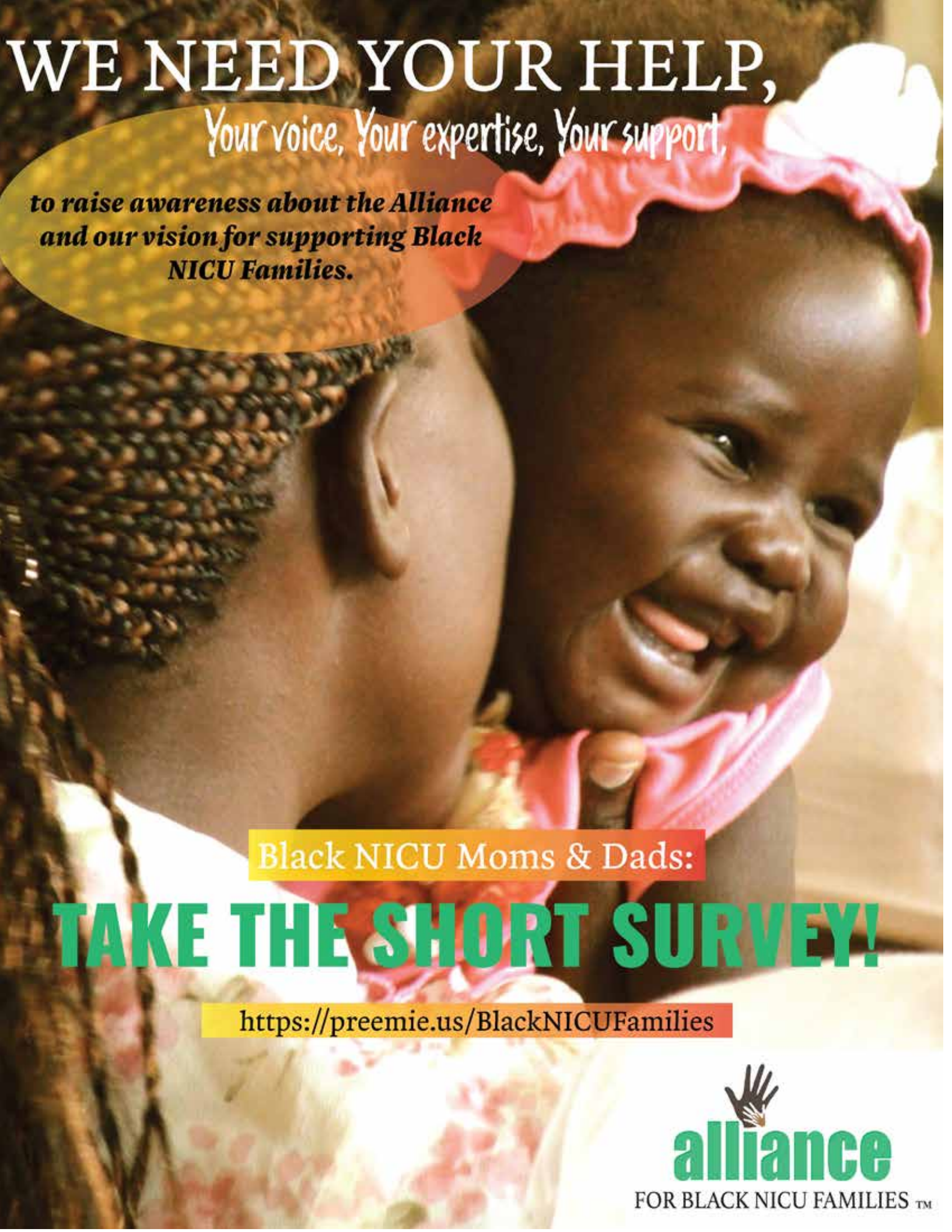
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Your voice, Your expertise, Your support,
to raise awareness about the Alliance and our vision for supporting Black NICU Families.
Black NICU Moms & Dads:
TAKE THE SHORT SURVEY!
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FOR BLACK NICU FAMILIES ™

Using a Community Approach to Address Sudden Unexplained Infant Death

Alison Jacobson

first candle

Saving babies. Supporting families.

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

"The introduction in 1994 of the Safe Sleep Guidelines developed by the American Academy of Pediatrics (AAP) led to a 50% reduction in SIDS rates, which remain level while SUID rates have increased, with rates twice as high among Black and Native American infants than white."

Approximately 3,500 infants in the U.S. die annually within the first year of life from Sudden Unexplained Infant Death (SUID) and Sudden Infant Death Syndrome (SIDS), making it the leading cause of infant mortality. The introduction in 1994 of the Safe Sleep Guidelines developed by the American Academy of Pediatrics (AAP) led to a 50% reduction in SIDS rates, which remain level while SUID rates have increased, with rates twice as high among Black and Native American infants than white.

In the years since our involvement in the Safe Sleep campaign launch, we have come to learn anecdotally that compliance with the guidelines is not a given, even when the evidence indicates this reduces sleep-related infant mortality. In 2020 and 2021, First Candle commissioned online focus groups in Michigan, Connecticut, and Georgia to understand this issue better to explore what parents, extended family members, and caregivers thought about the guidelines and their feelings about following them. (1)

We learned that context and trust matter – who is giving the advice and how it is being given -- and that families often feel there is a gap between the health care universe and the realities of daily life they face.

We came to realize that education would be far more effective if it reflected the realities of lived experiences, helped by communication that is clear, positive, sensitive to literacy levels and language needs, and included outreach that involves local communities.

" Straight Talk will continue its train-the-trainer work to help health care providers counsel families on safer sleep practices in constructive and culturally sensitive ways, and the Let's Talk Community Chat will offer families the chance to receive education and support around safer sleep and breastfeeding every month at a convenient and accessible location."

With that in mind, we decided to expand our Straight Talk for Infant Safe Sleep training program and also introduce the Let's Talk Community Chat initiative, which launches this month. (2) Straight Talk will continue its train-the-trainer work to help health care providers counsel families on safer sleep practices in constructive and culturally sensitive ways, and the Let's Talk Community Chat will offer families the chance to receive education and support

around safer sleep and breastfeeding every month at a convenient and accessible location.

These community events will bring together new parents with doulas, lactation consultants, fathers, and grandparents from the community who have gone through Straight Talk and become trained facilitators. This program addresses the issue that not all families may have the opportunity to talk in-depth with health care providers about safer sleep best practices or receive support around breastfeeding or get to well-baby visits. It also recognizes that the information they may have received could have come across as a directive rather than a conversation.

Safer sleep messaging is not a one-size-fits-all scenario and should meet families where they are "at" so they are receptive to it. We also know that fathers want to speak with other fathers or male figures, which holds true for grandparents.

The goal is to provide everyone in the family – parents, siblings, relatives, and other caregivers – clear information about safer sleep practices, the reasoning behind the AAP Safe Sleep guidelines and talk with them about the challenges, obstacles, and choices they make about where and how their baby sleeps. Supplies such as diapers, sleep sacks, and other items will also be offered, and connections to agencies and other resources families may need.

"The first Let's Talk Community Chat is being held in Harlem in New York City, with subsequent sessions held once a month. This session is in partnership with Hope Center Harlem and the Northern Manhattan Perinatal Partnership and with support from the Ryan Wolfe Kossar Foundation."

The first Let's Talk Community Chat is being held in Harlem in New York City, with subsequent sessions held once a month. This session is in partnership with Hope Center Harlem and the Northern Manhattan Perinatal Partnership and with support from the Ryan Wolfe Kossar Foundation. The program will also be introduced in Brooklyn, Queens, and the Bronx, New York.

By expanding our reach to include families and healthcare providers, we can deepen our understanding of what works and does not work in advancing infant safer sleep and breastfeeding and help both professionals and consumers approach each other in partnership and community.

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***Disclosure**: The author is the Director of Education and Bereavement Services for First Candle, a 501c (3) non-profit organization.*

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About First Candle

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

Neonatology Today's Digital Presence

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 CrossRef and will assign DOI to all published material.

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

1. 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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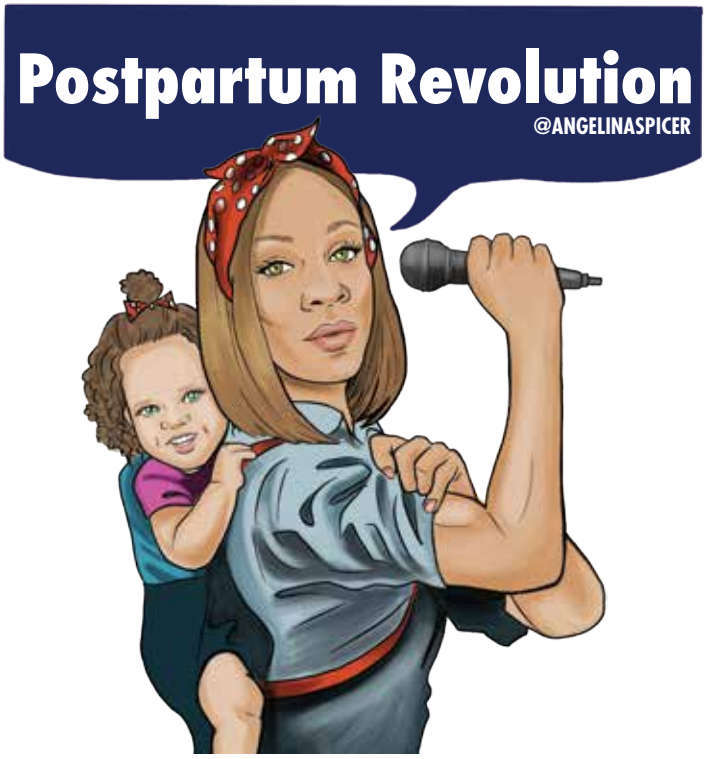

Better Regulation of Breast Milk Banking Will Protect Vulnerable Infants

Mitchell Goldstein, MD, MBA, CML

"Our decades of clinical data and outcomes demonstrate that for fragile premature infants, human milk is far more than nutrition; it is, quite simply, medicine."

In my capacity as a practicing neonatologist at Loma Linda University School of Medicine, I urge the U.S. Food and Drug Administration (FDA) to take immediate action regarding The Donor Milk Safety Act, legislation currently before Congress calling for breast milk and products made from human breast milk that is collected, processed, and distributed via milk banks to be treated and classified as an "exempt infant formula," rather than their current designation as simple food. Our decades of clinical data and outcomes demonstrate that for fragile premature infants, human milk is far more than nutrition; it is, quite simply, medicine.

Based on current evidence, this move is essential to ensuring that vulnerable infants in hospital neonatal intensive care units (NICUs) continue to receive lifesaving breast milk products free of any substances that might cause these infants serious harm. We already have enough experience with the harm caused by the FDA dragging its feet in these matters. Abbott Laboratories faces multiple lawsuits over contamination of its Similac, Alimentum, and Elecare formula with Cronobacter, Salmonella, and other bacteria. The FDA failed to follow up on violations uncovered in September 2021 and earlier at the manufacturing plant where the tainted formula was made. Several infants became ill, and some died due to ingesting contaminated formula. Will the FDA again wait for vulnerable infants to die before taking necessary action with breast milk products?

There is no question that feeding infants in the NICU breast milk and products made from breast milk instead of cow milk results in considerable health benefits, including decreased hospital stays and feeding intolerance; reduced risk of severe, life-altering complications; healthier weight gain; and better long-term outcomes. (1-8)

Because of improved outcomes such as these, the demand for breast milk has increased dramatically in recent years. Milk banks have rapidly emerged to fill this demand. The largest milk bank network in the United States saw its collections increase by 1400% since 2000, and its distribution grew by 22% in 2021 alone. This evolution of human milk banking has undoubtedly saved countless lives and reduced the cost of care for vulnerable preemies, (9-10) but it must be accompanied by requisite regulatory oversight to ensure safety. Unfortunately, federal regulation of milk banks has not kept up with their growth. This places infants in the NICU at considerable risk, entirely avoidable with proper regulatory standards.

Breast milk is both human tissue and biologic fluid, much like blood and plasma. The possibility exists that disease-causing germs or other toxic substances can be passed on to vulnerable infants via breast milk products unless the strictest measures that ensure this will not occur are put into place. A steady stream of new organizations that collect breast milk and distribute products made from breast milk are entering the market. Still, currently, they are required by the FDA to register only as a food manufacturer. Just a handful of states require milk banks to obtain a tissue bank license. Most banks operate based on their own set of screening, production, safety, and quality guidelines that are neither publicly nor independently audited or enforced.

In other words, the safety standards of most milk banks are primarily based on the known risks associated with the manufacture, processing, and distribution of food. These do not fully address the known risks associated with collecting, processing, and distributing human tissue and biologic fluid. Milk banks are not required to routinely test their breast milk products for viruses, bacteria, drugs, and other contaminants. As a result, vulnerable infants are at risk of being exposed via donor breast milk products to disease-causing bacteria and viruses as well as traces of medications or drugs, including nicotine, marijuana, homeopathic remedies, over-the-counter remedies, or prescription drugs such as opioid painkillers or antidepressants. These hazards are real. For instance, nicotine exposure in infants can result in damage to the liver and pancreas as well as disruption of sleep cycles. (11,12) Those milk banks that test their breast milk products have found nicotine and its byproducts to be the most common contaminant.

"There is also the risk that donated breast milk may be adulterated with milk from other sources, including cow or soy milk. As human milk banking operations are allowed to flourish without proper regulatory oversight, the risk to vulnerable infants continues to mount."

There is also the risk that donated breast milk may be adulterated with milk from other sources, including cow or soy milk. As human milk banking operations are allowed to flourish without proper regulatory oversight, the risk to vulnerable infants continues to mount.

We do not even know if infants have been harmed by these lax regulations because there are no strict rules on reporting adverse events or how to proceed should they occur. We certainly know from anecdotal reports that harm is possible, however. In 2019, three premature infants died after their donor milk product was contaminated with bacteria traced to the equipment used to measure and mix the milk at Geisinger Medical Center in Danville, Pennsylvania. (13) It is clear that the FDA needs to make nutrition destined for vulnerable infants a higher priority.

"Contrast the current milk banking standards with the collection and distribution of other human tissue, including blood, organs, and semen, for which strict federal regulations ensure that these lifesaving and life-giving products do not inadvertently cause harm. It is astonishing that, after we saw a multitude of patients exposed to the human immunodeficiency virus (HIV) in the 1980s from blood and tissue products, we seem to be making the same mistake once again with breast milk products. "

Contrast the current milk banking standards with the collection and distribution of other human tissue, including blood, organs, and semen, for which strict federal regulations ensure that these lifesaving and life-giving products do not inadvertently cause harm. It is astonishing that, after we saw a multitude of patients exposed to the human immunodeficiency virus (HIV) in the 1980s from blood and tissue products, we seem to be making the same mistake once again with breast milk products. Breast milk must be handled in the same way as other products derived from human tissue. While it may be convenient to think of donated human milk as any other food product, my experiences suggest that this is not a reasonable course. After caring for the first child with documented AIDS contracted vertically from her mother through breastfeeding, I clearly understand the risk. Seeing her die because of a disease that can now be prevented is sobering. Although there have been myriad improvements in HIV treatment, this infection is lifelong and still causes significant morbidity and mortality. Indeed, the American Academy of Pediatrics recommends that "federal or state guidelines are needed regarding the preparation, handling, and transfer of human milk as well as the operation of donor human milk banks." (14)

The only way to prevent harm is via comprehensive regulation by the FDA. The proposed bill will go a long way toward protecting vulnerable infants. By regulating breast milk products collected and processed via milk banks as an "exempt infant formula," this bill will empower the FDA to treat donor breast milk products fed to vulnerable infants in the NICU as the medicine that it is. This regulation means the FDA will determine and enforce safety and manufacturing process standards for human milk banks as well as conduct audits and inspections to ensure these standards are met. It will also update the standards as necessary to address novel risks such as those posed by SARS-CoV-2, the virus that causes COVID-19. There is no time for the FDA to wait for this bill to wend its way through Congress. The time to act is now before a preventable catastrophe occurs.

"They assume that all nutrition, medication, and interventions administered are evidence-based and meet the highest possible safety standards. It is unethical to feed their infants using a product that, while known to offer the best possible nutrition, may contain harmful substances because we have failed to regulate its manufacture appropriately."

Parents of infants in the NICU trust us to provide the best possible care for their vulnerable children. They assume that all nutrition, medication, and interventions administered are evidence-based and meet the highest possible safety standards. It is unethical to feed their infants using a product that, while known to offer the best possible nutrition, may contain harmful substances because we have failed to regulate its manufacture appropriately.

As a neonatologist who has dedicated his career to protecting vulnerable infants, I urge the FDA to take action today.

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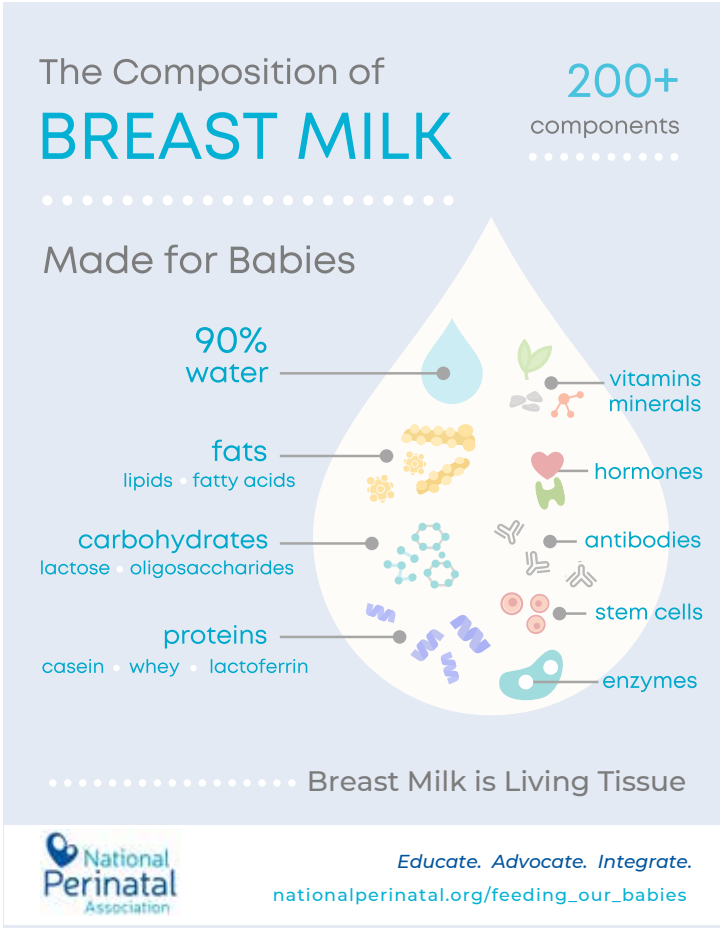


COPING WITH COVID-19

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

Provide culturally-informed and respectful care.

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

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

myNICUnetwork.org

and

National Perinatal Association
NICU Parent Network

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

TOP 10

RECOMMENDATIONS FOR THE PSYCHOSOCIAL SUPPORT OF NICU PARENTS

SUPPORT 4 NICU PARENTS

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

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

1 PROMOTE PARTICIPATION

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

Welcome!

2 LEAD IN DEVELOPMENTAL CARE

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

3 FACILITATE PEER SUPPORT

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

4 ADDRESS MENTAL HEALTH

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

5 SCREEN EARLY AND OFTEN

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

6 OFFER PALLIATIVE & BEREAVEMENT CARE

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

7 PLAN FOR THE TRANSITION HOME

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

8 FOLLOW UP

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

9 SUPPORT NICU CARE GIVERS

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

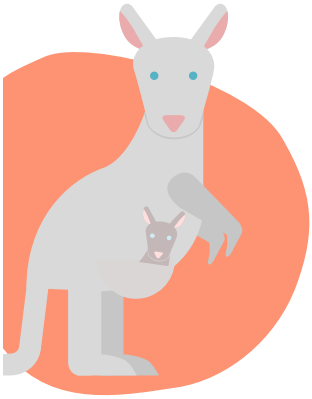
10 HELP US HEAL

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

SUPPORT4NICUPARENTS.ORG

SUPPORTING KANGAROO CARE

SKIN-TO-SKIN CARE DURING COVID-19



GET INFORMED ABOUT THE RISKS + BENEFITS

work with your medical team to create a plan

GET CLEAN

WASH YOUR HANDS, ARMS, and CHEST

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

PUT ON FRESH CLOTHES

change into a clean gown or shirt.

IF COVID-19 + WEAR A MASK

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

National Perinatal Association

nicuparentnetwork.org

NPN NICU PARENT NETWORK

nationalperinatal.org/skin-to-skin

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Raising Global Awareness of RSV

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

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

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

RSV GOLD

A Global Mortality Database for Children with RSV Infection

The RSV awareness video was produced in collaboration with the Bill & Melinda Gates Foundation

Gas Trapping and Hyperinflation

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.

"Gas trapping invariably leads to hyperinflation, which may lead to interstitial lung disease, pneumothorax, and cardiopulmonary compromise."

When the treatment is worse than the disease, prevention is key

"All micro-preemies are gas trapping or are about to." A colleague made this statement during a discussion on malignant hyperinflation, often seen in this patient group. Gas trapping invariably leads to hyperinflation, which may lead to interstitial lung disease, pneumothorax, and cardiopulmonary compromise.

Technological advances notwithstanding, this phenomenon has plagued clinicians ever since we started ventilating premature babies almost 60 years ago. For over 25 years, "conventional" ventilation (CV) was the sole option in the NICU. The inherently high resistance of small conducting airways (Ra/w) combined with decreased compliance of developing lungs necessitates using high ventilating pressures and rates to provide sufficient minute volume to clear CO_2. Since airway diameter decreases during the expiration, their resistance increases further such that there may be insufficient time for delivered tidal volume to escape, et voila, gas trapping occurs.

This was not a big problem when we treated "larger" 30+ week post-gestational age (PGA) infants, where poor compliance and oxidative stress rather than airway resistance were our primary concerns. While surfactant markedly decreased FiO_2 needs (and presumably oxidative stress), the problems inherent with high Ra/w increased as the PGA and size of our patients decreased. Older ventilators did not indicate impending problems nor modes to mitigate them; rather, the first indication of gas trapping was usually seen on a chest film (CXR).

The advent of synchronisation, assist/control (A/C) and pressure support (P/S) modes, flow graphics, and volume-targeted ventilation gave us some tools to recognise gas trapping. The Drager Babylog® 8000+ displayed a calculated value, an indicator of overdistention called "C20/C". This compared volume delivered during the last 20% of the inspiratory cycle to that of the first 80% (1), essentially a numeric representation of "beaking" (see figure 1) on a pressure/volume curve. Since less inspiratory time (Ti) is required to deliver less volume at a given respiratory rate, this will increase available expiratory time (Te) and may decrease gas trapping if present.

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The use of high-frequency ventilation (HFV) in the NICU has increased and is gaining acceptance as a first intention mode rather than a "rescue" strategy and is no longer considered experimental. Under the HFV label, it is important to distinguish between high-frequency *oscillation (HFO)* and high-frequency *jet* ventilation (HFJV); the two are very different.

In HFO, very high rates are used to deliver very small, sub-anatomical dead space tidal volumes (VtHF). Airway patency and maintenance of functional residual capacity (and by function oxygenation) are achieved with mean airway pressure (MAP), while ventilation is primarily a function of oscillating amplitude, which directly influences VtHF. In the absence of volume targeting (VG), oscillatory rate (f) has an inverse relationship to VtHF; thus, at a fixed amplitude, decreasing f increases VtHF, and increasing f decreases VtHF. This is because as f decreases, the driving device (diaphragm or piston) is in the inspiratory phase longer, giving more volume and vice versa.

If VG is used in conjunction with HFO, then f has a direct and linear relationship to ventilation, **providing increased f is not contributing to gas trapping**. Using VG also may allow for maintenance of minute volume using higher VtHF and lower f while using less amplitude. Gas trapping can occur with HFO under

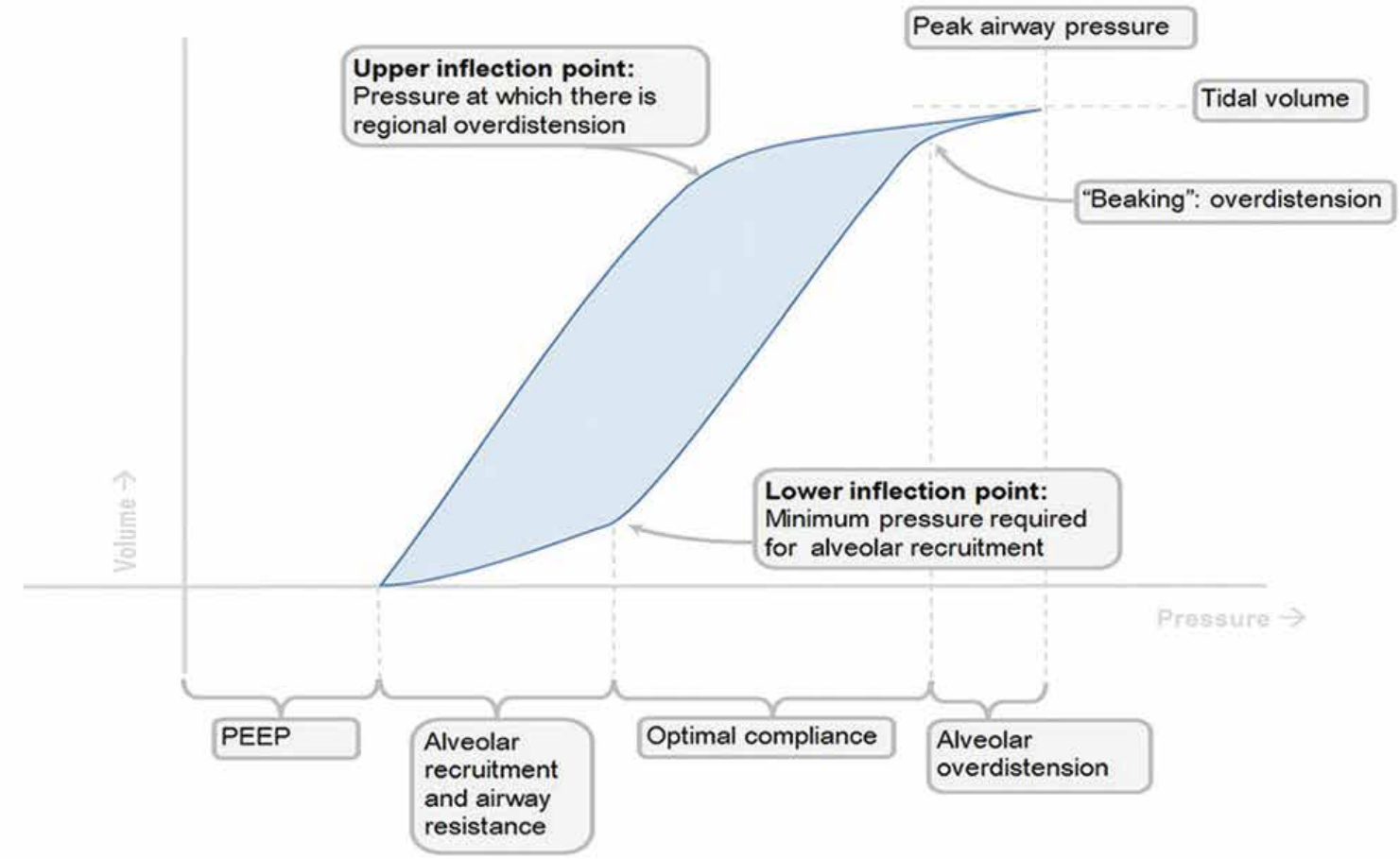

Figure 1: pressure-volume curve showing beaking (2)

two circumstances: one, as mentioned, is high *f* not providing sufficient time for exhalation, and the other is if MAP is not high enough to maintain airway patency. The latter is exacerbated by high amplitude since in a 1:2 I:E ratio, approximately 1/3 of it is below set MAP. As the lowest point of the amplitude, waveform gets lower, the risk of airways losing patency increases, possibly to the point of collapse. This phenomenon is known as a pinch point and prevents gas distal to the obstruction from escaping.

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Some HFO capable ventilators allow I:E ratio to be adjusted as high as 1:3. This may decrease the potential for gas trapping, but the increase in amplitude necessitated by a shorter inspiratory phase may offset any gains made. Using lower frequencies (if tolerated and VtHF does not need to be increased too much) is a better bet, but active expiration necessitated by the mode makes gas trapping likely.

Several characteristics of HFJV make it the mode least likely to create or exacerbate gas trapping. While the principles of ventilation and oxygenation are similar (VtHF being the primary determinant of ventilation and PEEP the primary determinant of oxygenation), HFJV's passive expiration eliminates the possibility of airway instability and pinch points as ventilating pressure increases; increased PIP in HFJV is always felt above-set PEEP since there is no oscillating waveform. It is vital to provide enough PEEP to maintain airway patency and FRC. The fact that Ti is very short (0.02 – 0.034 seconds) and is set rather than a fixed percentage of the total ventilating cycle means I:E ratios (and absolute Te) are greater with HFJV, as high as 1:12.

During inspiration, the HFJV breath is delivered as a high-velocity spike of gas that travels more or less down the centre of the airways. In doing so, incoming gas displaces the gas in its path, forcing it to the sides of the airway, where it exists in a spiral fashion. While the bulk of gas exits during the expiratory phase, some does so concomitantly with inspiration.

This is not to say that gas trapping does not occur during HFJV; rather, that is less likely. One of the features of the Bunnell LifePulse® is the ability of the machine to very accurately measure distal endotracheal tube pressure; peak inspiratory pressure, PEEP, and MAP are displayed. We have traditionally been taught that if the measured PEEP displayed on the machine was higher than the set PEEP, it was a clear indication of gas trapping. This is true; however, since the value displayed indicates what is happen-

ing in the lungs as a whole, regional gas trapping may be present without the jet giving us any obvious indication thereof. Since a brief pressure deflection occurs initially with the jet breath, it is safer to suspect gas trapping as measured PEEP approaches set PEEP and indeed with all micro-prems. Ensuring I:E ratios of 1:4 or greater have been a guide to avoiding gas trapping, but as our patients have become ever smaller, that is likely no longer the case; as high an I:E ratio as possible with these babies, preferably 1:12 provided by a rate of 240 is recommended.

Being warned and aware of gas trapping doesn't mean we can do anything about it; clear signs are often present in tiny babies, even at a jet rate of 240. If PEEP is not high enough to keep airways open, gas trapping initially shows up as increasing lung volumes. That this almost invariably leads clinicians to decrease PEEP is not helpful. The trouble is apparent hyperinflation from low PEEP is indistinguishable from too much PEEP and treating one when the problem is the other worsens the situation. If PEEP is already low, the culprit is likely gas trapping, and increased PEEP is more likely to help.

Once the lungs are recruited, and adequate FRC is established, it is important to decrease PEEP/MAP to the lowest point to provide stasis. Any de-recruitment should be corrected expeditiously as gas trapping can rapidly result in gross hyperinflation, air leak, and an escalation of support and FiO_2.

"Once hyperinflation is established, it can be very difficult to manage. Increasing PEEP/MAP to stent airways open and (hopefully) decrease gas trapping can be a tough sell when a CXR shows 10+ ribs of inflation, especially since doing so may not immediately improve. Conversely, the "old school" practice of drastically reducing PEEP/MAP to facilitate collapse can be disastrous, mainly if gas trapping is the culprit."

Once hyperinflation is established, it can be very difficult to manage. Increasing PEEP/MAP to stent airways open and (hopefully) decrease gas trapping can be a tough sell when a CXR shows 10+ ribs of inflation, especially since doing so may not immediately improve. Conversely, the "old school" practice of drastically reducing PEEP/MAP to facilitate collapse can be disastrous, mainly if gas trapping is the culprit. As the lungs collapse and become atelectatic several things happen. Gas exchange is reduced in areas of relatively good function resulting in higher FiO_2, which increases oxidative stress. Pulmonary vascular resistance is markedly elevated in areas of atelectasis, further taxing the heart, and an inflammatory response is elicited locally. The pulmonary structure is also damaged since alveoli are interdependent for structural integrity (3). Given the precarious clinical state these babies are often in, this may represent trading the proverbial frying pan for the fire.

Given the consequences of treating hyperinflation, it behooves us to determine the necessity of doing so. If the baby is stable (FiO2 and blood pressure acceptable), hyperinflation may be physiologically insignificant, and some babies are more stable left alone. Indeed, if a baby significantly deteriorates while one is trying to "fix" them, the treatment may be worse than the disease.

"As our patients become increasingly small, gas trapping and hyperinflation will become more prevalent. The adage "an ounce of prevention is worth a pound of cure" could not be more apt here, and choosing ventilation strategies that do not contribute to hyperinflation is far better than treating it once established. In that regard, HFJV represents our best option."

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3. https://www.physio-pedia.com/Atelectasis

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

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OPIOIDS and NAS

When reporting on mothers, babies, and substance use

LANGUAGE MATTERS

I am not an addict.

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

I was exposed to opioids.

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

NAS is a temporary and treatable condition.

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

My mother may have a SUD.

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

My potential is limitless.

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

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

National Perinatal Association

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

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

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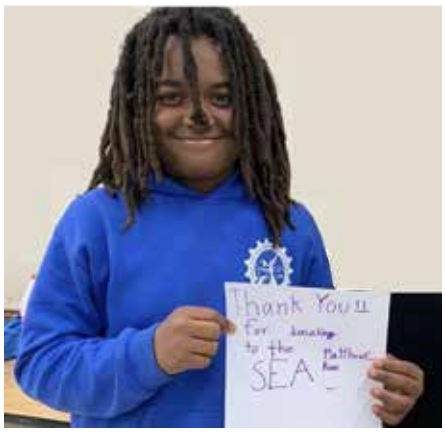
The average cost for the program to provide a mentor/ tutor for one child is listed below.



1 session	$15
1 week	$30
1 month	$120
1 semester	$540
1 year	$1,080
Middle School	$3,240

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Acknowledging and Supporting NICU Moms this Mother's Day

Leah Sodowick, B.A., Pamela A. Geller, Ph.D., Chavis A. Patterson, Ph.D.

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

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

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Educate. Advocate. Integrate.

"Mother's Day can be challenging and emotionally fraught for some, including mothers with an infant hospitalized in a neonatal intensive care unit (NICU). With the help of NICU staff and providers, mothers can anticipate and cope with the challenges and emotions that they may experience this Mother's Day, on May 8th."

Each year on the second Sunday in May, people across the United States and around the globe honor and celebrate mothers (Our use of the term "mothers" includes anyone who identifies as a mother, grandmother, gestational parent, or caregiver.) on Mother's Day. This holiday is full of joy, celebration, pride, and gratitude for many. There may be hugs, handmade and store-bought cards, photos posted and shared on social media, breakfast in bed, family gatherings, flower bouquets, and tokens of appreciation. Mother's Day can be challenging and emotionally fraught for some, including mothers with an infant hospitalized in a neonatal intensive care unit (NICU). With the help of NICU staff and providers, mothers can anticipate and cope with the challenges and emotions that they may experience this Mother's Day, on May 8th. This article will discuss the emotions and challenges NICU mothers may experience on the holiday and suggest ways to acknowledge, support, and celebrate NICU mothers and caregivers.

Parents in the NICU may grieve the loss of anticipated postpartum plans and experiences, such as caring for and bonding with their baby at home. Mothers in the NICU may also grieve the loss of expected holiday events and experiences (1). Grief is one of the many normal and common reactions NICU parents may have. On Mother's Day and the days surrounding this holiday, mothers in the NICU may feel disappointed, disheartened, and sorrowful if their expectations, visions, and anticipations for Mother's Day do not match their current reality—one that is often characterized by long hours at their baby's bedside and concern and worry about their baby's health and survival. Current realities may also involve difficult decision-making about treatment options and end-of-life care. NICU parents may be juggling multiple responsibilities, such as caring for older children and work. Parents may also experience physical separation from their baby when the gestational parent is recovering from childbirth, the baby is in an isolette, the baby is undergoing a surgical procedure, or when parents leave the hospital to go home or to their temporary residence. Furthermore, by spending time in the NICU, mothers may miss traditional family gatherings and their usual Mother's Day celebrations (1). Not being present for these events may exacerbate feelings of isolation as many families begin to reunite after separations due to COVID-19 restrictions.

Some mothers in the NICU may have difficulty or delays in forming their maternal identity due to limited opportunities for caregiving and interacting with their infant, shared caregiving responsibilities with NICU staff providers, disrupted mother-infant bonding, perceived lack of control, and increased psychological distress (2–5). Difficulty or delays in forming maternal and parental identity are part of an array of normal reactions and experiences that a parent may have. In a qualitative examination of NICU mothers' perceptions of the development of their maternal role in the context of NICU, the thematic analysis revealed that some respondents characterized themselves as mothers only while they were in the NICU; they reported not feeling like mothers when they left the hospital because they were not with their babies or serving as a primary caretaker (3). Researchers have found that mothers' perceived loss of parental role was one of the most stressful aspects of their infant's NICU hospitalization (6,7)predictors, and child outcomes associated with NICU-related stress for mothers of infants born very preterm (VPT. For mothers in the NICU who have not yet fully developed their maternal identity or perceive a loss of their parental role, Mother's Day may feel conflicting and isolating. Of note, mothers in the NICU who have experienced neonatal losses or are anticipating and planning for neonatal loss may experience an intensification of grief and have particularly difficult emotional experiences on Mother's Day.

We encourage NICU staff and providers to thoughtfully acknowledge and celebrate mothers and caregivers in the NICU this Mother's Day. Listed below are some suggestions:

Acknowledge Mother's Day

Staff and providers can communicate their acknowledgment of Mother's Day, even when it may not be a "happy" Mother's Day for mothers and other caregivers in the NICU. If this is the case, instead of wishing mothers a "happy" Mother's Day, one can

express, “I am thinking about you today on Mother’s Day.”

Validate and reflect emotions

NICU staff and providers can help mothers and caregivers cope with emotions that may arise during this holiday by validating and reflecting on mothers’ expressed feelings. Offering opportunities for parents to share their feelings by asking open-ended questions about how they are feeling and allowing time to listen to the responses can be very empowering for parents. Responding with statements that validate their experience also can be very helpful. For example, one could respond to a mother who expresses grief about the loss of expected Mother’s Day experiences by stating, “it makes sense why you would feel especially sad and disappointed today.”

Provide opportunities for caretaking

If possible, NICU staff and providers can find ways for parents to interact with their babies more on Mother’s Day. For example, mothers could be encouraged to take on a meaningful hands-on caretaking task, like feeding or bathing their baby or changing a diaper. Mothers also can be encouraged to engage in skin-to-skin care.

Encourage mothers to communicate with their babies

On Mother’s Day, NICU mothers can communicate and bond with their babies by reading them a book, story, or poem. Mothers could write and share a personal letter to their babies about their love, their family, and what it means to be their mother. Mothers may also wish to sing to their babies.

Praise mothers’ efforts to care for their babies

On Mother’s Day (and regularly), NICU staff and providers are encouraged to acknowledge and praise mothers’ efforts to care for their babies in the NICU. A simple phrase like “you are doing a great job” can be meaningful and impactful to mothers who may be lacking confidence and feeling uncertain about their maternal role.

Encourage mothers to attend parent support groups

NICU staff and providers can encourage mothers to attend parent support groups on Mother’s Day. Peer sharing of positive and negative maternal experiences in NICU support groups can strengthen social relationships and networks, provide therapeutic benefits, foster feelings of safety and comfort, and encourage parent advocacy (3,9). On Mother’s Day, NICU parent support groups can feature topics related to Mother’s Day. Mother’s Day themed activities, such as scrapbooking, crafting, and even expressive writing or journaling that allow for both positive and adverse feelings can also be incorporated.

Create cards or keepsake gifts for mothers

There are several ways Mother’s Day can be celebrated in the NICU. One way to celebrate the holiday is for NICU staff to take a photo of each baby or each mother with their baby and put it inside of a card that can be placed by the baby’s bedside. Staff may also wish to create small keepsake gifts for mothers. At Denver Health Medical Center, NICU nurses make keychains to give to each mother (8). Each keychain contains a photo of the mom with their baby.

Provide scent cloths for mothers

Small pieces of soft fabric with the baby’s and the mother’s familiar scent can bring comfort to mothers and babies and help facilitate bonding. The cloth can be placed in the baby’s bed and/or worn

Figure 1:Heart-Shaped Scent Cloth

against the mother's skin to absorb scent and then exchanged. The scent cloths can even be shaped like hearts (see figure 1).

Enlist volunteer assistance from past NICU graduate families

Staff and providers can consider enlisting volunteer assistance from past graduate families of the NICU to help support and celebrate mothers in the NICU on Mother's Day (1). Former NICU mothers and caregivers with first-hand lived experience and expertise could write cards with encouraging and supportive messages to current NICU mothers and assist with running parent activity groups.

It is important to remember that each mother in the NICU will experience Mother's Day differently, and some families may not be open to celebrating or participating in Mother's Day activities.

As a final note, we would like to acknowledge NICU staff, providers, and readers this Mother's Day. We recognize those who are mothers, grandmothers, and caregivers. We recognize those who have or have had infants hospitalized in the NICU. We recognize those who have lost children and those who have lost mothers. We recognize those with strained relationships with their mothers, those with strained relationships with their children, those who have chosen not to be mothers, and those who are yearning to be mothers. We honor you all and wish you a peaceful Mother's Day.

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

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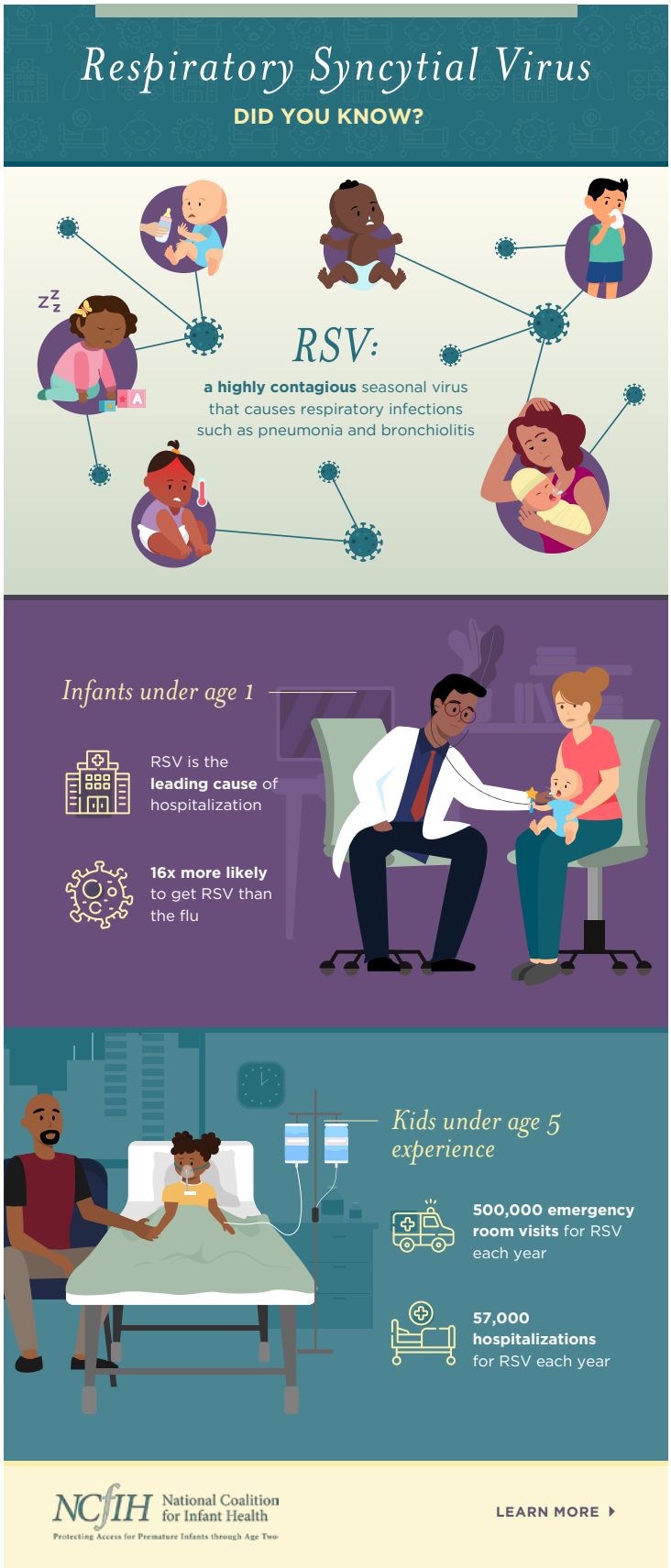
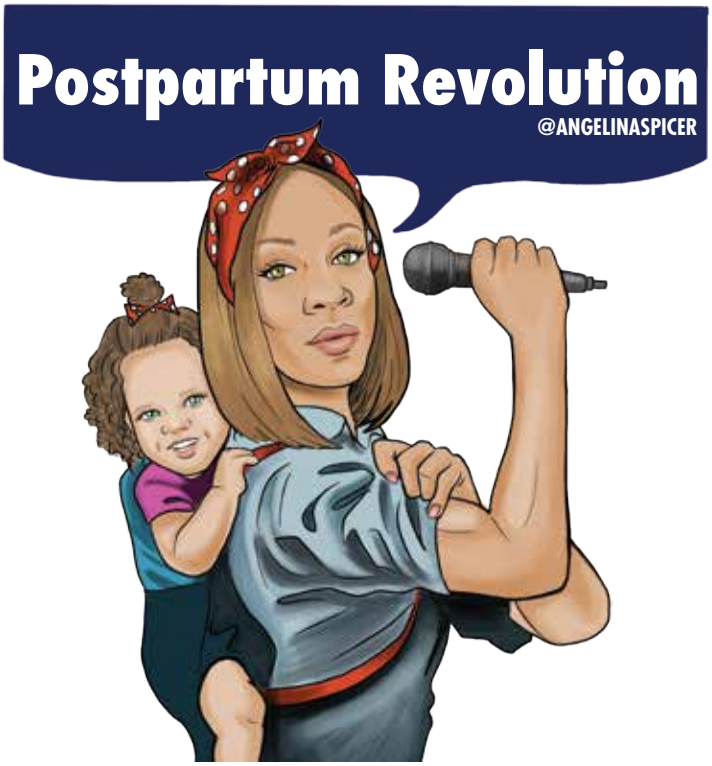


The Gap Baby: An RSV Story



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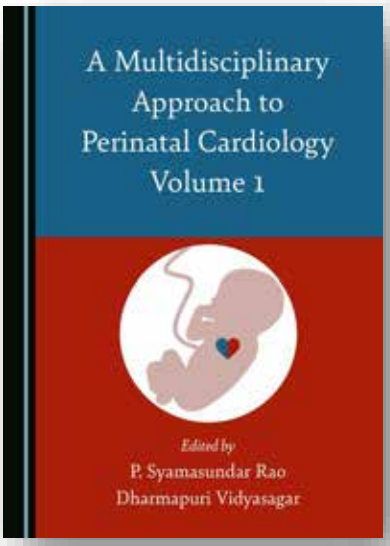
A Multidisciplinary Approach to Perinatal Cardiology *Volume 1*

Edited by P. Syamasundar Rao and Dharmapuri Vidyasagar



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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.

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

Amanda Brown, CNM, MSN, MPH
University of North Carolina-Chapel Hill Hospitals, Chapel Hill, NC.

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

Sue L. Hall, MD, MSW, FAAP
Neonatologist, Ventura, CA.

Claire Hartman, RN, IBCLC
Labor & Delivery, University of North Carolina Hospital, Chapel Hill, NC.

MaryLou Martin, MSN, RNC-NIC, CKC
Women's and Children's Services Nurse Educator, McLeod Regional Medical Center, McLeod, SC.

Cheryl Milford, EdS.
Former NICU and Developmental psychologist, in memoriam.

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

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

Parent/Patient Contributers:

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

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

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

Tracy Pella, MA
Co-Founder and President, Connected Forever, Tecumseh, NE.

Erin Thatcher, BA
Founder and Executive Director, The PPROM Foundation, Denver, CO.

CANCELLATIONS AND REFUNDS

- For Individual Subscribers:
  - If you elect to take only one course, there will be no cancellations or refunds after you have started the course.
  - If you elect to take more than one course and pay in advance, there will be no cancellations or refunds after payment has been made unless a written request is sent to help@myperinatalnetwork.com and individually approved.
- For Institutional Subscribers:
  - After we are in possession of a signed contract by an authorized agent of the hospital and the program fees have been paid, a 50% refund of the amount paid will be given if we are in receipt of a written request to cancel at least 14 (fourteen) days prior to the scheduled start date for your hospital's online program.
  - Refunds will not be given for staff members who neglect to start the program. Also, no refunds for those who start the program, but do not complete all 6 courses within the time frame allotted.

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

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

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

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

KEEPING MOTHERS + INFANTS TOGETHER

Means balancing the risks of...

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

EVIDENCE

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

PARTNERSHIP

What is the best for this unique dyad?

SHARED DECISION-MAKING

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

TRAUMA-INFORMED

Both parents and providers are confronting significant...

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

LONGITUDINAL DATA

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

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

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

Partnering for patient-centered care when it matters most.

nann.org nationalperinatal.org

National Association of Neonatal Nurses

National Perinatal Association

FREE ONLINE EDUCATION

Coping with COVID-19

A viral pandemic

A racial pandemic within a viral pandemic

Will mental illness be the next inevitable pandemic?

WWW.MYNICUNETWORK.ORG

and

National Perinatal Association
NICU Parent Network

Biden Administration Continues Focus on Maternal Health

Gavin Clingham, JD, Alliance for Patient Access, Director of Public Policies

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

March was an important month for President Biden's Administration to put its money where its mouth is when it comes to focusing on the enormous challenge of improving maternal health outcomes.

> *"March was an important month for President Biden's Administration to put its money where its mouth is when it comes to focusing on the enormous challenge of improving maternal health outcomes."*

On March 15th, President Biden signed the Fiscal Year 2022 appropriations bill into law, nearly five months late. This act released funding to the federal agencies, including focusing on maternal health. However, updating the budget allowed the President to ensure his maternal health priorities were reflected and programming could be implemented.

In that budget, maternal health programs that received funding increases include Maternal and Child Health Block Grants up 35 million to $748 million; State Maternal Health Innovation Grants up to $6 million to $29 million; an increase for the Maternal Mental Health Hotline; and an increase for screening and treatment for Maternal Depression and Related Disorders.

Then on March 28th, the President released his proposed budget for the fiscal year 2023. In addition to supporting existing maternal health programs, the budget calls explicitly for $470 million to increase maternal health programs in rural communities and address maternal mortality and morbidity rates in communities of color. Included would be an increase in funding for the Maternal, Infant, and Early Childhood Home Visiting Program, which works with over 70,000 families at risk for maternal and child health problems and has been proven to improve maternal and fetal health outcomes.

> *"In that budget, maternal health programs that received funding increases include Maternal and Child Health Block Grants up 35 million to $748 million; State Maternal Health Innovation Grants up to $6 million to $29 million; an increase for the Maternal Mental Health Hotline; and an increase for screening and treatment for Maternal Depression and Related Disorders."*

Finally, the Administration announced Black Maternal Health Week from April 11 - 17. The declaration explicitly recognizes that pregnancy, childbirth, and postpartum complications can lead to devastating health outcomes, including hundreds of deaths each year. It goes on to note that the maternal health crisis is particularly devastating for Black women, who are more than three times

> *"Finally, the Administration announced Black Maternal Health Week from April 11 - 17. The declaration explicitly recognizes that pregnancy, childbirth, and postpartum complications can lead to devastating health outcomes, including hundreds of deaths each year."*

as likely to die from pregnancy-related complications as white women, regardless of their income or education. President Biden committed to building on past work by further expanding access to maternal care, lowering health care costs, and making new investments to drive down mortality and improve maternal health.

Congress is in the process of reviewing the Fiscal Year 2023 budget request. They will carefully review each program request, determine the most appropriate funding level, and eventually pass the bills to be sent to the President. Congress will hear from Administration officials who will try to justify each request and explain why the funding is critical. Advocates and the public also provide comments on the proposals as they are being considered. More will be learned about the outcomes in the coming months as Congress works to complete the process by September 30th, the end of the current fiscal year.

"The Biden Administration included these programs as part of a larger social policy agenda that focuses on families through proposals such as paid family leave, increases in education and daycare programs, and a focus on maternal health."

The Biden Administration included these programs as part of a larger social policy agenda that focuses on families through proposals such as paid family leave, increases in education and daycare programs, and a focus on maternal health. They must now work with Congress to enact these policies, but focusing on these needs is a good start for families facing these challenges.

Disclosures: Gavin Clingham is the Alliance for Patient Access, Director of Public Policies.

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Keeping Your Baby Safe

during the COVID-19 pandemic

How to protect your little one from germs and viruses

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

Here's what you can do...

Wash Your Hands

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

Limit Contact with Others

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

Provide Protective Immunity

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

Take Care of Yourself

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

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

WARNING

Never Put a Mask on Your Baby

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

If you are positive for COVID-19

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

We can help protect each other.

Learn more

www.nationalperinatal.org/COVID-19

National Perinatal Association

The Gap Baby: An RSV Story

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

The National Coalition for Infant Health advocates for:

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

www.infanthealth.org

I CAN Digitally Involved (I CANDI): 2022 iCAN Summit presented by Jumo Health

Amy Ohmer

iCAN
International Children's Advisory Network

"Kicking off April with an exciting invitation to everyone within our pediatric healthcare and research community - You are invited to join the International Children's Advisory Network, Inc. (iCAN) at the 2022 iCAN Summit presented by Jumo Health."

Kicking off April with an exciting invitation to everyone within our pediatric healthcare and research community - You are invited to join the International Children's Advisory Network, Inc. *(iCAN)* at the 2022 iCAN Summit presented by Jumo Health. (1) This exciting week-long event offers interactive and engaging sessions through the support and expertise of our youth members from around the world and our many adult community partners (scientists, doctors, researchers, pharma, parents, and many other stakeholders). The summit will be held in person in Lyon, France, from July 11th to July 15th, 2022, at the University of Lyon. To learn more about the summit, including how to register, reserve a discounted hotel room, or make a charitable contribution, please head to our website at www.icanresearch.org/2022-summit. (1) iCAN is proud to be a patient-engagement resource to many organizations worldwide with a dedicated focus on pediatric medicine, clinical research, medicine development, and medical device innovation. Do not forget to download the complimentary app designed by youth members of iCAN's KIDS France chapter to stay on top of the latest summit planning.

Welcome to Deb Discenza and Jennifer Degl, iCAN's new co-chairs of the revamped iCAN Parent Chapter. All parents (and family members) are welcome to join iCAN to participate as advisors for the littlest patients (0-7 years old). Joining is free and can be done through either visiting www.icanresearch.org or by sending an email to iCANparent@icanresearch.org. To learn more, check out this page at https://www.icanresearch.org/parents-families. (2) Do not forget the newly launched iCAN Young Adult Professionals group too. (3) This special group is for our older, graduated members aged 18 to 25. At iCAN, we understand the power of sharing experiences to help support a better community.

Needed - Youth Voices: iCAN has a fun and super cool opportunity for children and young people *(must live in the US and be 12-18 years old, have been diagnosed with Type 1 Diabetes)* to help advise on a new project for a genetically modified compound in partnership with the International Children's Advisory Network.

Why is the opportunity available?

- **Researchers want to understand the youth perspective**

2022 SUMMIT

iCAN
International Children's Advisory Network

SAVE THE DATE

July 13th through July 17th, 2022

To be held in-person at the University of Lyon, Franc

Hosted by iCAN KIDS France

Registration Opens May 15th, 2022

PROVIDING CHILDREN AND FAMILIES A VOICE IN MEDICINE, RESEARCH AND INNOVATION
around the world

Sign up for for updates at
www.iCANResearch.org

and not just "guess."

- **Researchers want to understand better how to communicate about this unique compound.**

What will iCAN Youth Members Do?

- **This is a fun volunteer opportunity for kids to learn more about the "behind the scenes" of science, medicine, and research and to experience the wonderful feeling of sharing knowledge about living with T1D to help improve the experience for other kids around the world. The kids are truly the experts!**
- **The youth advisors will learn about the compound and share their ideas and thoughts about what is presented to them.**
- **There is nothing required further once this hour is over.**

Who can participate and when?

- **Six youths ages 12-18 years old will participate in a one-hour focus group on Saturday, April 30th, 2022, at 10:00 a.m. EST.**
- **To participate, please send an email to Amy Ohmer at info@icanresearch.org today.**

At iCAN, we want to help you with learnings from our youth members. To do this, we have a special monthly event called "iCAN Ask the Experts" (ATE). This event focuses on youth member small group discussion on relevant topics within pediatric healthcare and research. After each session, iCAN provides a written summary of topics and a video recording of the session to ensure that information is shared to help improve the patient experience. To participate in our ATE sessions, please email us at info@icanresearch.org.

iCAN is working with the Duke Clinical Research Institute (DCRI) to support a new anthology created by iCAN Youth Members to share their creative work of participating in clinical research trials. Using the prompt: *"If you could go back in time to tell yourself what you know now about research, what would you say?"* iCAN Youth Members will be submitting ideas using short stories, poems, illustrations, electronic art, and original photographs to be included in a book to be shared at the 2022 iCAN Summit. Everyone is welcome to participate, and the deadline is May 1st for all submitted materials. To see all of the projects and opportunities available for kids to participate in, visit this link at https://www.icanresearch.

Calling All Young Creatives: Anthology FAQ

What is an anthology?

An anthology is a collection of writings and art work centered on a common theme.

Why is this anthology being produced?

The Duke Clinical Research Institute and iCAN are co-creating the anthology to illustrate the importance of pediatric clinical research. We hope that the anthology will serve as a useful education tool for families that have children in clinical research, as well as the children who are participating. We will share electronic versions of the anthology freely online with pediatric participants and families as they begin their clinical research experience.

What type of content should be contributed?

A variety of content will be considered for acceptance in the anthology. Please feel encouraged to submit personal essays (10,000 maximum word limit), short stories, poems, illustrations, electronic art, and photographs.

What topics should be focused on in contributed content?

We hope to receive a wide variety of content that details the pediatric clinical research experience. Please feel encouraged to think creatively and inclusively.

Can anyone from iCAN participate?

Yes! We encourage any iCAN participants to contribute their work. We want to hear from everyone and ensure the anthology covers a wide array of experiences and points of views.

How will content be selected for inclusion in the anthology?

Content will be selected for inclusion in the anthology based on creativity, usefulness to pediatric clinical research participants and families, and diversity of experiences.

Who will select the content to be included in the anthology?

A selection committee will review the submitted content. The committee will include creative writers, physicians, parents, and iCAN Youth Council members to ensure diverse perspectives are represented.

Will there be a prize for selected authors?

Yes! If your submission is selected, you will receive a published, hard copy of the anthology and a gift card. Everyone will receive an electronic version of the anthology.

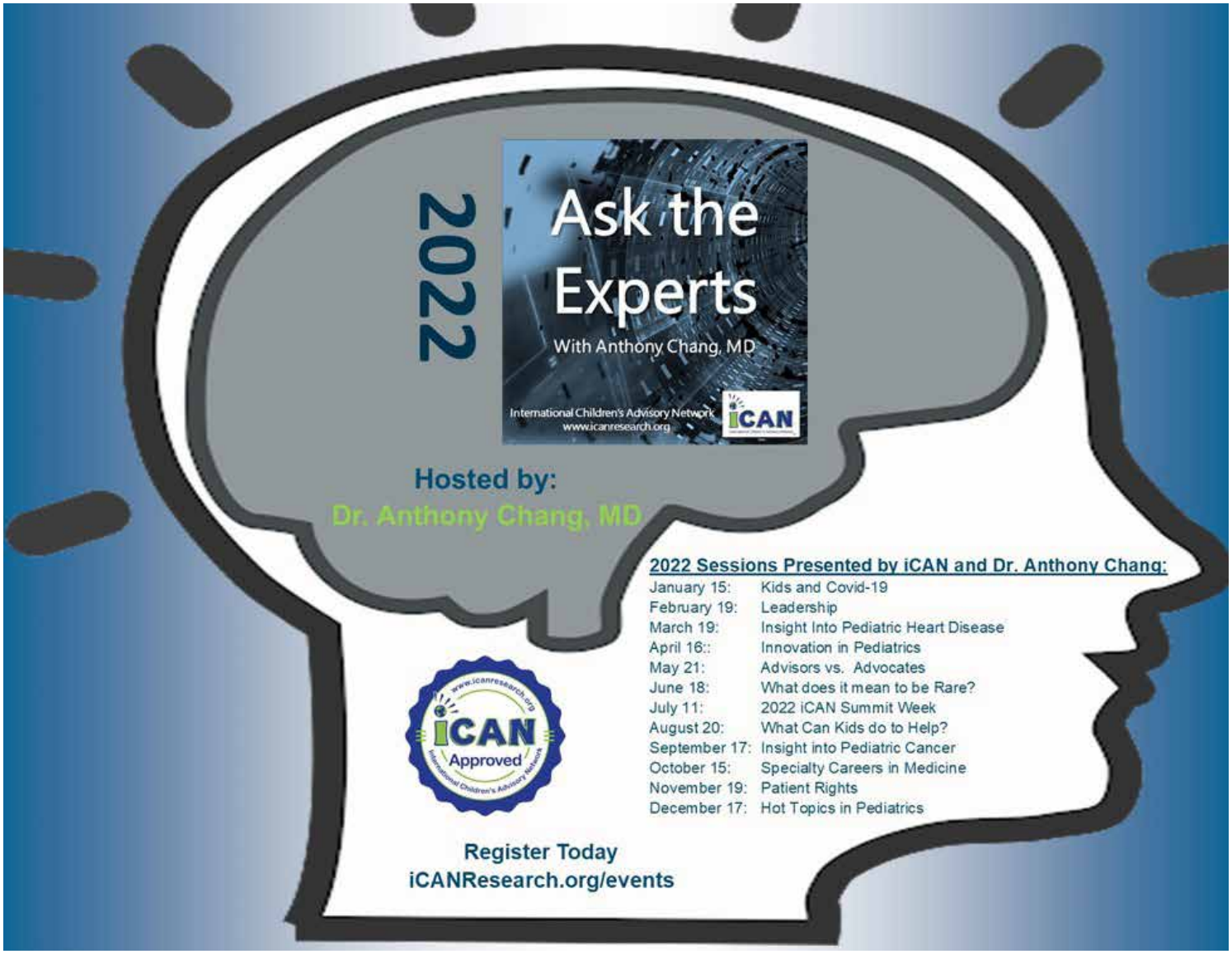
If my content is not selected, will it still be shared somehow?

Yes! Even if content is not selected for inclusion in the anthology, we will consider sharing on our website and social media presences if consent is granted.

What is the deadline for submitting content?

All content should be submitted to Amy Ohmer (amyohmer@icanresearch.org) by May 1, 2022.

Duke Clinical Research Institute

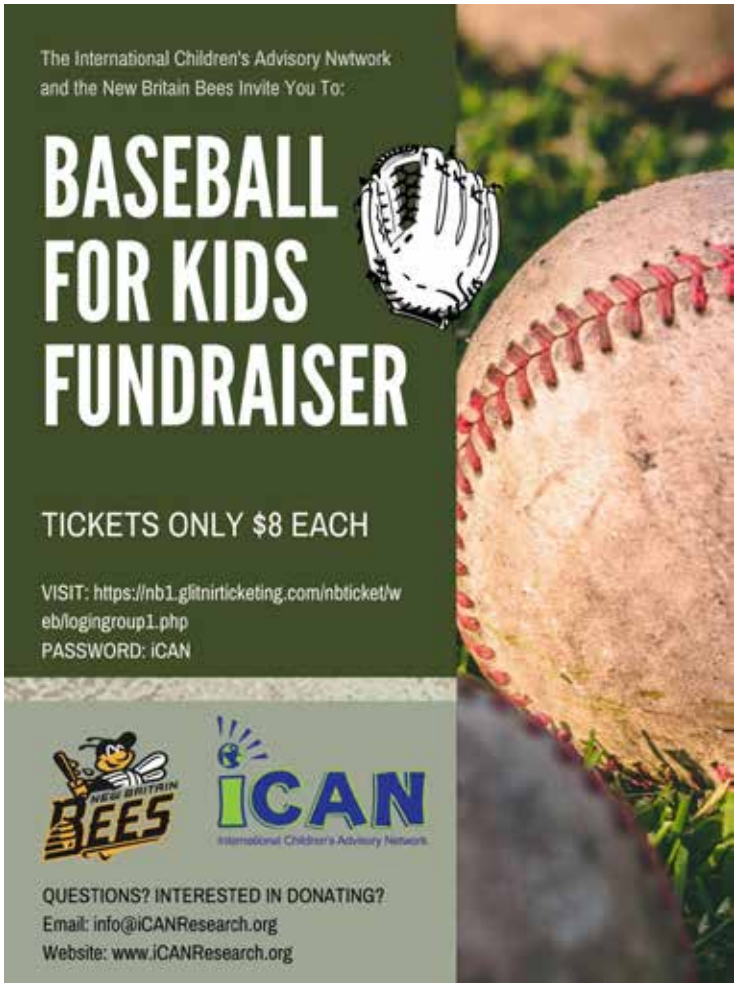


org/open-projects. (4)

The 'I CAN' Book is now available for purchase at www.icanresearch.org for $25.00 USD using our special PayPal link on the home page under donations. After payment, please contact us at info@icanresearch.org with your name and mailing address to receive your copy - this beautiful hard-bound book is created by iCAN Youth Members from around the world and filled with positive statements about overcoming challenges to be the best you can be. This beautiful book is fully illustrated by our KIDS Bari chapter and is a treasure you and your family will treasure for years to come.

SAVE THE DATE:

- iCAN's unique youth series, **'Ask the Experts,'** has a new session on Leadership planned for **April 16th, 2022, at 10:00 a.m.EST**. To join this fun and free event, please register at www.icanresearch.org/events.(5) All are welcome to attend, and kids of all ages are invited to join. Additional sessions are open for registration, and we welcome all doctors, researchers, and community leaders to join us.
- Calling ALL KIDS - Submit your materials to participate in the **DCRI Anthology** by May 1st, 2022, by sending a .jpeg of your art, short stories, and other creative pieces to info@icanresearch.org.
- The **iCAN Summit Poster Session** submissions deadline is June 1st, 2022. If you have research to be shared and would like to showcase your work at the 2022 iCAN Summit presented by Jumo Health from July 11th to July 15th, 2022, please send your submissions for the poster session to info@icanresearch.org no later than 6/1/2022.
- **Join iCAN on June 4th, 2022, at the New Britain Bees Baseball Game** by registering at www.icanresearch.org/events. (5) This is a fundraiser event, and you do not need to be there to participate. Donate by purchasing tickets, and iCAN will give the tickets to a local child that may not have been able to attend a game. For every $8.00 ticket, iCAN earns $5.00. All are welcome, and we hope to make this a very successful event. Thank you to Dr. Sharon Smith for helping us to support this effort. If you would like to donate or support iCAN, please contact Amy Ohmer at amyohmer@icanresearch.org.



- iCAN will be hosting the **iCAN Summit from June 11th to June 15th, 2022,** in Lyon, France. To learn more about joining, please watch our 2022 Summit video to understand what iCAN is all about. (6) **Registration opens on March 15th, 2022, at www.icanresearch.org.** The summit will emphasize rare diseases this year, with experts joining worldwide. Kids will be able to participate in a focus group, one-on-one discussions, share insight into their medical conditions, and as a week-long project, work on the development of Serious Games, an interactive approach to supporting pediatric patients. We hope to see our community as this summit marks the first travel experience for our pediatric medical community in over two years. Questions? Donations or sponsorship support is still needed! Email us at info@icanresearch.org, and we can help meet your learning needs.

Get ready for the iCAN 2022 Summit in Lyon, France! (6)

- **Join iCAN and the American Academy of Pediatrics National Conference and Exhibition from October 7th - 11th, 2022,** at the Anaheim Convention Center, Anaheim, California. We cannot wait to see you at booth #2034! Look for the iCAN colors and stop by and say hello!

References:

1. http://www.icanresearch.org/2022-summit
2. https://www.icanresearch.org/parents-families
3. https://www.icanresearch.org/ican-young-adult-professionals
4. https://www.icanresearch.org/open-projects
5. http://www.icanresearch.org/events
6. https://youtu.be/EFzxk0zTw3Y

Disclosure: *The author has no conflicts of interests to disclose.*

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Call for Posters

iCAN 2022 Summit

July 11-15th, 2022

SUBMISSION DEADLINE: June 1st, 2022

The 2022 iCAN Hybrid (Virtual and In-Person) Poster Session is Hosted by:

The International Children's Advisory Network, Inc. (iCAN)

and the collective group of Kids and families Impacting Disease through Science (KIDS) Youth Chapters

Seeking posters on current topics including but not limited to:

iCAN CHAPTER POSTER UPDATES - ALL iCAN Chapter MUST submit a poster of the team by 6/1/22.

In addition, the iCAN Community may share posters on the following topics:

Rare and Orphan Disease
Ethics and Drug Development
Careers in Medicine, Advocacy, Research
Institutional Review Board
Assent and Consent Processes
Research with Family and Youth Perspectives
Current Social Issues
Pediatric technology and innovation
Inclusion and Diversity
Research and Evidence Based Practice
Health Equity Research
Sports Medicine Research
Professional Boundaries
Personalized Medication
Youth Engagement in Science, Medicine, Research

Submission guidelines:

1. Posters must reflect patient and family voice in research or be educational in nature regarding medical research.
2. For posters reporting research activities, research must be started at the same time of submission.
3. Authors whose posters are accepted are responsible for submitting poster content in **.jpeg format** to **info@icanresearch** no later than June 1st, 2022.
4. All posters will be reviewed by iCAN Summit facilitators for approval.

Poster Information to be submitted:

I. **Author Biography (Brief):** For each author, list full name, academic and professional credentials, position title, affiliation, mailing address, telephone, and email address. Please designate one contact person. All correspondence regarding poster submission will be sent to the contact person. Author information will be listed in the conference program as submitted on the cover sheet.

II. **Poster:** Overview of a project, process, and outcomes. **Posters** should be no longer than one page. The abstract must include all of the following: the purpose of the presentation, originality, innovation and/or timeliness of the topic, application of the information to youth and family health advocates. Information presented should be relevant to attendees from various organizations and locations, and for individuals ages 8 and older.

Deadline for submissions is June 1st, 2022. Please send all poster information to info@icanresearch.org.

Respiratory Syncytial Virus is a

Really Serious Virus

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

Coughing that gets worse and worse

Breathing that causes their ribcage to "cave-in"

Rapid breathing and wheezing

Bluish skin, lips, or fingertips

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

Call your doctor and meet them at the hospital.

If you baby isn't breathing call 911.

Thick yellow, green, or grey mucus

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

Fever that is higher than 101° Fahrenheit

101°

which is especially dangerous for babies younger that 3 months

National Perinatal Association

www.nationalperinatal.org/rsv

PROTECT YOUR FAMILY FROM RESPIRATORY VIRUSES

flu coronavirus pertussis RSV

WASH YOUR HANDS
often with soap and warm water.

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

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

USE AN ALCOHOL-BASED HAND SANITIZER.

STAY AWAY FROM SICK PEOPLE
Avoid crowds. Protect vulnerable babies and children.

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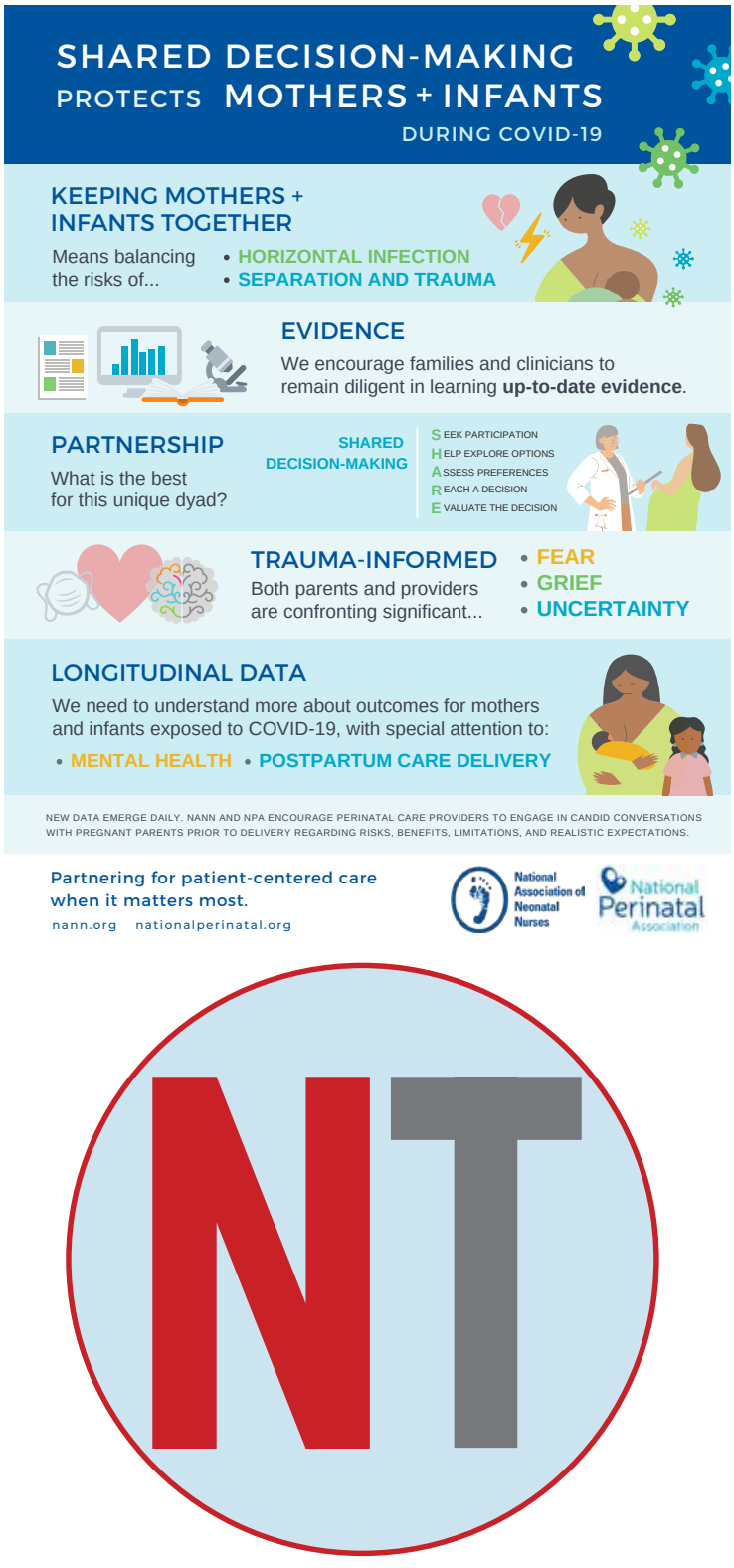

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FREE RESOURCES FOR YOUR NICU

Coping During COVID-19

Targeted interventions to improve the mental health of parents, infants, families, and providers

BONDING WITH YOUR BABY

HELPING CHILDREN AND FAMILIES COPE

CAREGIVERS NEED CARE TOO

National Network of NICU Psychologists

nationalperinatal.org/psychologists

Respiratory Syncytial Virus:

How you can advocate for babies this RSV season

Track national data and trends at the CDC's website www.cdc.gov/rsv

Identify babies at greatest risk

including those with CLD, BPD, CF, and heart conditions

Teach families how to protect

their babies from respiratory infections

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

Use your best clinical judgement

when prescribing RSV prophylaxis

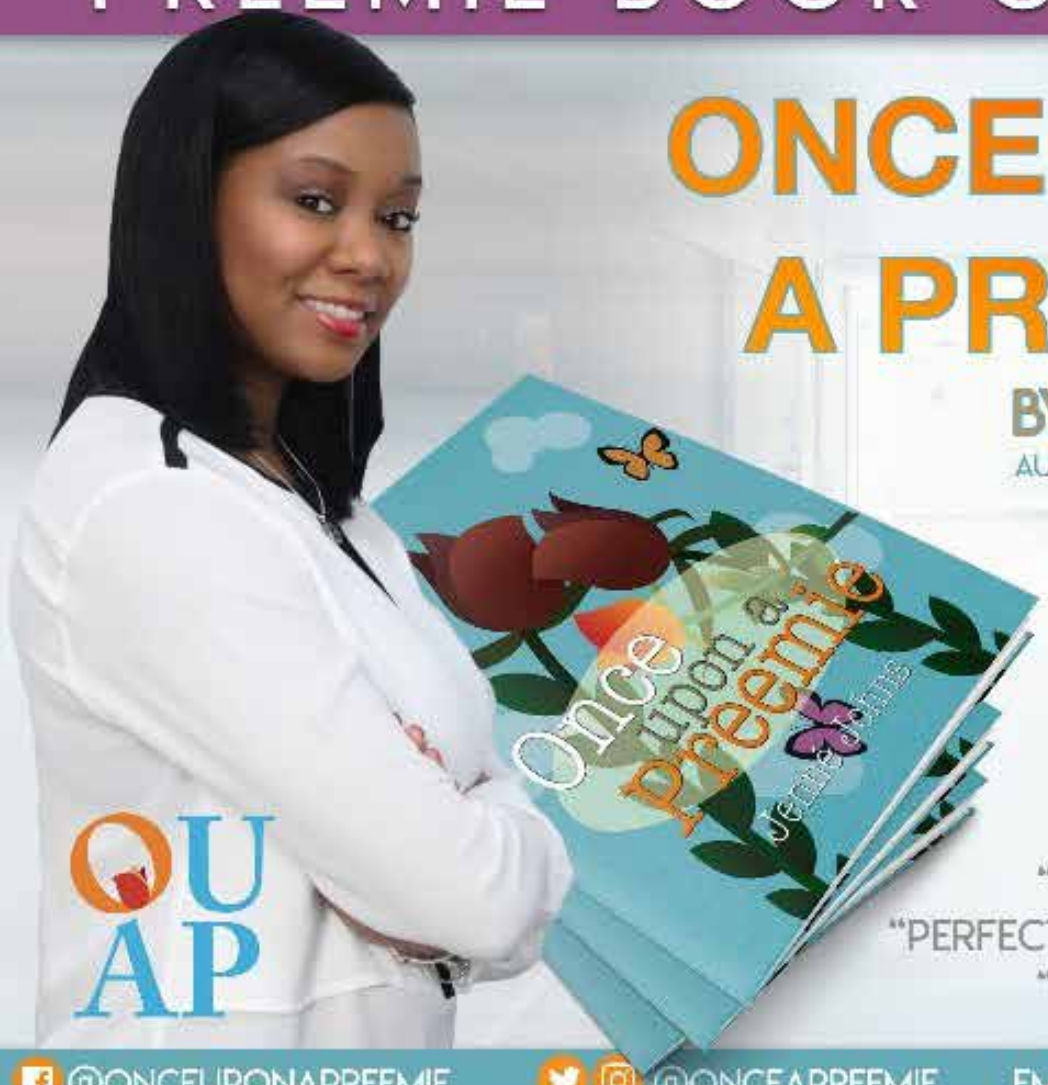
Tell insurers what families need

and provide the supporting evidence

National Perinatal Association

*See the NPA's evidence-based guidelines at www.nationalperinatal.org/rsv

PREEMIE BOOK ON SALE



ONCE UPON A PREEMIE

BY JENNÉ JOHNS

AUTHOR | SPEAKER | ADVOCATE

QUAP

"ONE OF A KIND"
"PERFECT FOR PREEMIE FAMILIES"
"ENCOURAGING"

@ONCEUPONAPREEMIE @ONCEAPREEMIE EMAIL: HI@ONCEUPONAPREEMIE

ONCE UPON A PREEMIE IS A BEAUTIFUL NEW WAY TO LOOK AT THE LIFE OF A PREEMIE BABY. IT EXPLORES THE PARENT AND CHILD NEONATAL INTENSIVE CARE UNIT (NICU) JOURNEY IN A UNIQUE AND UPLIFTING WAY.

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Preemie Family

The Joyner Report

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WDAS 105.3 FM

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wgts 91.9 Washington, D.C.

MAJIC 102.3 92.7 The Real Sound of the DMV

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Still a **Preemie?**

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

But that's not every preemie's story.

Born between 34 and 36 weeks' gestation?

STILL A PREEMIE

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

Jaundice | Feeding issues | Respiratory problems

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

Born preterm at a "normal" weight?

STILL A PREEMIE

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

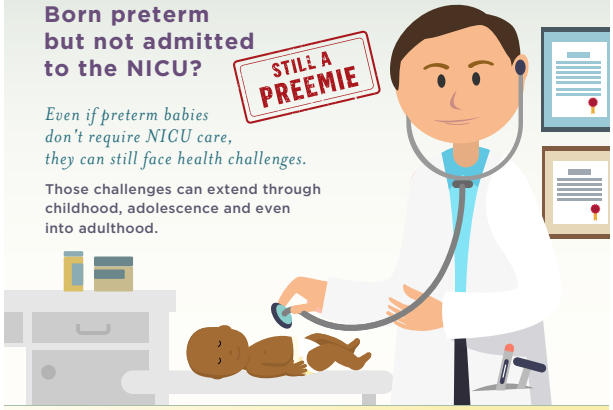
But because some health plans determine coverage based on a preemie's weight, **families of babies that weigh more may face access barriers and unmanageable medical bills.**

Born preterm but not admitted to the NICU?

STILL A PREEMIE

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

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



Some Preemies

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

All Preemies

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

NCfIH National Coalition for Infant Health

Protecting Access for Premature Infants through Age Two

www.infanthealth.org

OPIOIDS and NAS

When reporting on mothers, babies, and substance use

LANGUAGE MATTERS

I am not an addict.

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

I was exposed to opioids.

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

NAS is a temporary and treatable condition.

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

My mother may have a SUD.

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

My potential is limitless.

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

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

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You can help reduce the risk of Sudden Infant Death Syndrome (SIDS), the leading cause of death among infants between 1 month and 1 year of age. Take our **free continuing education (CE) activity** to stay up to date on the latest safe infant sleep recommendations. Approved for 1.5 contact hours.

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

NIH *Eunice Kennedy Shriver* National Institute of Child Health and Human Development

SAFE TO SLEEP®

Compiled and Reviewed by David Vasconcellos, MS IV

CDC: STDs, Including Congenital Syphilis, Increased During COVID-19 Pandemic

April 12, 2022

Steve Schering, Staff Writer

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

Despite shutdowns and stay-at-home orders during the pandemic, reported cases of sexually transmitted diseases (STDs) in the United States, including congenital syphilis, increased in 2020.

While reported cases of STDs initially decreased during the early months of the pandemic, most resurged by the end of the year, according to a new report from the Centers for Disease Control and Prevention (CDC).

Ultimately, reported cases of gonorrhea, syphilis and congenital syphilis surpassed 2019 levels, while chlamydia cases declined 13% from 2019 numbers. In total, 2.4 million cases of chlamydia, gonorrhea and syphilis were reported in 2020 compared to 2.5 million in 2019.

"While there were moments in 2020 when it felt like the world was standing still, STDs were not," said Jonathan Mermin, M.D., M.P.H., director of CDC's National Center for HIV, Viral Hepatitis, STD and TB Prevention. "At the end of 2020, primary and secondary (P&S) syphilis cases increased 7%, gonorrhea cases increased 10% and syphilis cases among newborns, or congenital syphilis, experienced the largest increase at 15%."

Early data indicate P&S syphilis and congenital syphilis cases continued to increase in 2021 as well.

According to Dr. Mermin, reported cases of congenital syphilis in the United States increased 235% between 2016 and 2020, a trend he called "worrisome."

"The consequences of congenital syphilis are the most severe," Dr. Mermin said. "They include lifelong physical and mental health problems, miscarriage or stillbirth. Unfortunately, we already know some STDs continued to increase in 2021 as well."

In 2020, 1.6 million cases of chlamydia were reported, down 1.6% from 2016. Gonorrhea cases (677,769) increased 45% from 2016 levels, while syphilis cases (133,945) also increased, up 52% from 2016 numbers.

Dr. Mermin said he believes the decline in cases of chlamydia, which often is asymptomatic, may be a reflection of reduced STD screening and under-diagnosing of the disease rather than a reduction in new infections.

The data also show significant disparities in rates of reported STDs. In 2020, more than half (53%) of reported cases of STDs were among adolescents and young adults ages 15 to 24 years. Disparities continued to persist in rates of reported STDs among some racial minority or Hispanic groups when compared with rates among non-Hispanic White people.

In 2020, 32% of all cases of chlamydia, gonorrhea and P&S syphilis were among non-Hispanic Black people, while they made up approximately 12% of the U.S. population.

The disparities are unlikely explained by differences in sexual behavior, health officials said, and rather reflect differential access to quality sexual health care.

Health officials warn the overall STD numbers may be underreported as frequency of in-person health care services likely declined in early 2020, which likely resulted in less-frequent STD screening. Public health staff also likely were diverted from STD work to help respond to the COVID-19 pandemic.

"Social and economic factors, such as poverty and health insurance status, create barriers, increase health risks and often result in worse health outcomes for some people," Leandro Mena, M.D., M.P.H., director of the CDC's Division of STD Prevention, said in a press release. "If we are to make lasting progress against STDs in this country, we have to understand the systems that create inequities and work with partners to change them. No one can be left behind."

Resources

- *Sexually Transmitted Disease Surveillance 2020*
- *Sexually Transmitted Infections National Strategic Plan*
- *STD prevention resources from the CDC*

- *National HIV/AIDS Strategy*

Contact information for AAP headquarters

American Academy of Pediatrics

345 Park Blvd, Itasca, IL 60143

New AAP main number: 630-626-6000

NT

FDA: Monitor Thyroid in Newborns, Young Children Who Receive Iodine-Containing Contrast Media

April 1, 2022

from the Food and Drug Administration

The Food and Drug Administration (FDA) is advising health care professionals to evaluate thyroid function in pediatric patients 3 years and younger within three weeks of receiving iodine-containing contrast media.

The FDA first alerted the public about cases of hypothyroidism in infants receiving iodine-containing contrast media in 2015. Since then, several studies evaluating this risk have been published.

Those at increased risk of hypothyroidism or a temporary decrease in thyroid hormone levels after receiving iodine-containing contrast media include neonates, particularly those born prematurely or with very low birth weight, and children younger than 3 years who have cardiac conditions or have had other problems requiring care in neonatal or pediatric intensive care units. Pediatric patients with cardiac conditions may be at greatest risk since they often require high doses of contrast during invasive cardiac procedures.

Although these forms of thyroid dysfunction after receiving iodine-containing contrast are uncommon and usually temporary, the conditions should be identified and, when needed, treated early. Hypothyroidism during early life may be harmful for motor, hearing and cognitive development and may require levothyroxine (T4) replacement therapy.

The FDA made this recommendation based on review of 11 published studies that assessed thyroid function in cohorts ranging from 10 to 2,320 children from birth through 3 years who were exposed to iodine-containing contrast media. In these studies, most cases of decreased thyroid hormone levels were temporary and did not require treatment. The reported rate of decreased thyroid hormone levels ranged from 1% to 15% and tended to be higher in newborns, particularly those who were born preterm. The time from iodine-containing contrast media exposure to diagnosis ranged from 8.5 to 138 days, with most occurring within three weeks in some of the publications.

The FDA has approved a new warning to the prescribing information for the entire class of iodinated contrast media injections to describe the risk of hypothyroidism or a temporary decrease in thyroid hormone levels and recommendations for monitoring. The FDA is urging health care professionals to report side effects involv-

ing iodine-containing contrast media to the FDA MedWatch program.

The FDA's Office of Pediatric Therapeutics (OPT), Division of Pediatric and Maternal Health (DPMH) and Division of Imaging and Radiation Medicine (DIRM) contributed to this article. OPT resides in the Office of Clinical Policy and Programs in the Office of the Commissioner. DPMH resides in the Office of Rare Diseases, Pediatrics, Urologic and Reproductive Medicine. DIRM resides in the Office of Specialty Medicine. Both DPMH and DIRM reside within the Office of New Drugs in the Center for Drug Evaluation and Research.

Resource

FDA Drug Safety Communication on thyroid monitoring in babies and young children who receive injections of iodine-containing contrast media for medical imaging

Contact information for AAP headquarters

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JIA Disease Activity, Disability Linked to Social Factors

April 07, 2022

For children with polyarticular juvenile idiopathic arthritis (pJIA), functional disability lasts longer and disease activity is increased among those who belong to a racial/ethnic minority or if they come from homes with low household income or low family education, according to a study published online in *Pediatric Rheumatology.* The findings also initially revealed a higher likelihood of functional disability among those living in a poorer community, but that association lost statistical significance after adjustment for confounders.

"We chose community poverty level as the primary predictor for outcomes in pJIA because the socioeconomic context of communities and neighborhoods affects the characteristics of the social, service, and physical environments to which all residents are exposed regardless of their own socioeconomic position and may have a greater negative impact on those with fewer individual resources," the authors write. "While community poverty level was not associated with an increase in odds of moderate-to-severe disease activity, those with high community poverty level did have higher disease activity scores (0.33 points greater on average than those with low community poverty level, in adjusted analysis)."

Nayimisha Balmuri, MD, an assistant professor of pediatrics at Johns Hopkins Medicine and study co-author, told *Medscape Medical News* that anecdotal experience from everyday practice has shown that «patients with myriad social determinants of health stacked against them present sicker, take longer to present, and require far more aggressive therapies and follow-up,» which wreaks havoc in terms of disease activity. «It›s really difficult, then, to play catch-up to other cohorts of patients,» Balmuri added.

Disparities in Outcomes Persist

A key clinical take-home message from these findings is that the differences in clinical outcomes are relevant throughout the entire year of therapy, Balmuri said. "Patients get better; however, they don't get better the same," she said, and this is because of a variety of reasons. "Getting in the door is one of [those reasons], but then continuing to follow-up care is another." For general practitioners, it's especially important to refer patients who complain of joint pains to a specialist and to then follow up to be sure they're improving and they're getting the care they need.

For pediatric rheumatologists and subspecialists, "it's important for us to realize that the disparity doesn't end when patients come into your door to begin with," Balmuri said. "It continues over the short term and far past that into adulthood."

Candace Feldman, MD, MPH, ScD, an assistant professor of medicine in the Division of Rheumatology, Inflammation, and Immunity at Brigham and Women's Hospital, Boston, Massachusetts, told *Medscape Medical News* that the research «provides an important foundation to the study of the impact of social determinants of health on disease activity and disability among children with JIA. Individuals with rheumatic conditions should be screened for social determinants of health–related needs, and infrastructure should exist within the rheumatology clinic to help address the needs uncovered.» Feldman was not involved in the study.

In addition to the results' clinical significance, Feldman also noted the policy implications of these findings. "Physicians should advocate for efforts to dismantle structural racism, to address income inequality, and to mitigate the effects of climate change, which also disproportionately affect historically marginalized populations," Feldman said. Although this study focused predominantly on poverty, she noted that financial insecurity, food insecurity, homelessness, or housing instability were other social determinants of health to consider in future research.

Balmuri and William Daniel Soulsby, MD, a clinical fellow in pediatric rheumatology at the University of California, San Francisco, who is the study's lead author, said they focused on poverty in this study not only because it's so understudied in patients with pJIA but also because research in adults with lupus has found that leaving poverty was associated with a reversal of accrued disease damage.

Interactions of Social Determinants

The authors analyzed retrospective data from 1684 pediatric patients in the Childhood Arthritis and Rheumatology Research Alliance (CARRA) registry covering the period April 2015 to February 2020. All

study participants had been diagnosed with pJIA. Symptom onset occurred before age 16, and at least five joints were involved. The authors excluded patients who had been diagnosed with other systemic inflammatory or autoimmune diseases.

The authors defined exposure to a high level of community poverty as living in a ZIP code where at least 20% of residents lived at or below the federal poverty level. The authors also collected data on household income, although these data were missing for more than a quarter of participants (27%) and were therefore included only in sensitivity analyses. They used the clinical Juvenile Arthritis Disease Activity Score–10 (cJADAS-10) and the Child Health Assessment Questionnaire (CHAQ) to assess disease activity and disability at baseline and 6 and 12 months later. A cutoff of 2.5 on the cJADAS-10 distinguished mild disease activity from moderate to high disease activity, and a CHAQ score of 0.25 was the cutoff for having functional disability.

Among those who reported household income, just over half the cohort had an income of at least $50,000. The study population was 74% White, and more non-White patients lived in high-poverty communities (36.4%) than did White patients (21.3%). Patients whose families had no more than a high school education (23.1% vs 13.7%) and those with public insurance (43.0% vs 21.5%) were also overrepresented in poorer communities.

The median cJADAS-10 scores declined overall during patients' first year of therapy. However, those with public insurance, a lower family education level, or residency in poorer communities made up the greatest proportion of patients who continued to have moderate to severe disease activity a year after diagnosis.

The unadjusted calculations showed that children living in high community poverty had 1.8 times' greater odds of functional disability (odds ratio [OR], 1.82; $P < .001$). However, after adjustment for age, sex, race/ethnicity, insurance status, family education, rheumatoid factor, and cyclic citrullinated peptide antibody, the association lost statistical significance ($P = .3$). Community poverty level was not associated with disease activity before or after adjustment.

"Race was adjusted for as a confounder; however, the association between race/ethnicity and social determinants of health is likely more complex," Feldman said. "Interactions, for example, between individual race and area-level poverty could be investigated."

Odds of persistent function disability were 1.5 times' greater for children with public insurance (adjusted OR [aOR], 1.56; $P = .023$) and 1.9 times› greater for those whose families had a lower education level (aOR, 1.89; $P = .013$). Children whose race/ethnicity was indicated as being other than White had more than double the odds of higher disease activity (aOR, 2.48; $P = .002$) and were nearly twice as likely to have persistent functional disability (aOR, 1.91; $P = .031$).

Future Directions

Soulsby was struck by the difference in statistical significance between individual-level poverty, as measured by household income, and community-level poverty. "It's interesting because it may suggest that both of these forms of poverty are different and have different impacts on disease," he said. Balmuri elaborated on the nuances and interactions that exist with social determinants of health and how objective outcomes, such as disease activity as measured by clinical tools, can differ from subjective outcomes, such as patients' reports of pain, daily disability, and social experiences.

"The human condition is far more complicated, unfortunately, than any dataset could have on their own collected," Balmuri said. She said she plans to expand her pJIA research into other social determinants of health. "It's first about getting people's eyes and minds open to something we see every day that, for some reason, sometimes people are blinded to, [using] the data that we do have, and then our hope is to build upon that."

Feldman noted that ZIP codes, which were used as a proxy for community poverty, may not provide the best perspective regarding a patient's neighborhood, because significant variation may exist within a single ZIP code, which is something the authors noted as well. The investigators were limited in the data available from the registry, and Balmuri and Soulsby suggested that 9-digit ZIP codes or census tracts might better capture neighborhood deprivation.

The research was funded by the Arthritis Foundation and the National Institute of Arthritis and Musculoskeletal and Skin Diseases. Feldman has received research support from Pfizer and the Bristol-Myers Squibb Foundation. Soulsby and Balmuri have disclosed no relevant financial relationships.

Pediatr Rheumatol. Published online March 7, 2022. Full text

For more news, follow Medscape on Facebook, Twitter, Instagram, and YouTube.

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Occupational Disinfectant Use During Pregnancy Tied to Eczema, Asthma in Offspring

Publish date: April 4, 2022

By Linda Carroll

NEW YORK (Reuters) – Pregnant women with frequent occupational exposure to disinfectant are at significantly increased

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Consultation

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

risk of having children with eczema and asthma, new findings from Japan show.

While the study, published in Occupational and Environmental Medicine, doesn't pinpoint a mechanism to explain the heightened risk, there are some theories, said lead author Reiji Kojima, MD, of the University of Yamanashi, Japan.

"The microbiome is said to be involved in the development of allergic diseases in children and it is possible that the microbiome is altered by disinfectant use," he told Reuters Health by email, cautioning, "it is also possible that people in disinfectant-using occupations are exposed to other chemicals, which may have contributed to the present results. Other possibilities are that people in disinfectant-using occupations have better access to health care and tend to report more allergic diseases in children. Further research is needed to elucidate the mechanisms."

To take a closer look at the possibility that disinfectant use during pregnancy might impact risk of allergies in children, Dr. Kojima and colleagues turned to data from the nationwide Japan Environment and Children's Study (JECS), which recruited more than 100,000 pregnant women who lived in one of 15 areas between 2011 and 2014.

Compared with moms who never used disinfectants, those with exposure one to six times a week had 18% greater odds of having children with asthma after adjustment for confounders (95% confidence interval, 5% to 33%), while daily exposure was tied to a 26% increase in odds (95% CI, 5% to 52%).

Similarly, after adjustment, exposure to disinfectants one to six times a week was associated with 16% greater odds of eczema in offspring (95% CI, 1.02-1.31); with daily exposure, the increase in odds was 29% (95% CI, 6% to 57%).

Among factors that the team adjusted for were maternal and parental allergies, maternal age at pregnancy, maternal exposure to indoor smoke during pregnancy, maternal alcohol consumption during pregnancy, mode of delivery, annual household income, birth weight, gestational age at delivery, gender of the child, exclusive breastfeeding, and daycare attendance at 1 year, maternal occupation, and maternal return to work.

"The study found that 'occupational' disinfectant use during pregnancy increased the risk of developing asthma and atopic dermatitis in children," Dr. Kojima said. "However, this result still needs to be validated with regard to the impact of disinfectant use in general. There is a clear benefit of disinfectant use in the prevention of coronavirus infections. Disinfectants should still be used."

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Pfizer Announces Positive Findings from COVID Vaccine Booster for Ages 5-11

April 14, 2022

Melissa Jenco, News Content Editor

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

A Pfizer-BioNTech COVID-19 vaccine booster in children ages 5-11 years significantly increased neutralizing antibody titers against the omicron variant with no new safety concerns, according to new data from the manufacturers.

"These data reinforce the potential function of a third dose of the vaccine in maintaining high levels of protection against the virus in this age group," the companies said in a news release.

The data have not been formally peer reviewed or published in a journal. They are based on clinical trials with 140 children who received a 10-microgram booster six months after their two-dose primary series. The dose is one-third of the adolescent and adult dose.

In the trials, there was a six-fold increase in SARS-CoV-2 wild-type strain-neutralizing geometric mean titers one month after a booster compared to one month after the second dose. An analysis with 30 of the children showed a 36-fold increase in neutralizing antibody titers against the omicron variant compared to the level after the second dose.

The third doses were well-tolerated and did not generate new safety concerns, according to the manufacturers.

Pfizer and BioNTech plan to request emergency use authorization from the Food and Drug Administration in the next few days. The Centers for Disease Control and Prevention's (CDC's) Advisory Committee on Immunization Practices is scheduled to meet April 20 to discuss boosters, although it hasn't announced which brand or age group it will discuss.

Children ages 5-11 years became eligible for COVID-19 vaccines in early November 2021. About 28% of this age group has been fully vaccinated, according to CDC data.

Resources

- AAP COVID vaccination resources

- CDC clinical considerations for administering COVID-19 vaccines
- Information from HealthyChildren.org on preparing children for a COVID-19 vaccine

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NT

Treating Chronic Hypertension in Early Pregnancy Benefits Parents, Babies

Saturday, April 2, 2022

Study shows pregnant adults less likely to experience preterm births or other serious problems with treatment.

Adults treated with medication for high blood pressure present before or during the first 20 weeks of pregnancy, defined as chronic hypertension in pregnancy, had fewer adverse pregnancy outcomes compared to adults who did not receive antihypertensive treatment, according to a study supported by the National Institutes of Health.

The study, which involved more than 2,400 pregnant adults, found that those who received medication to lower their blood pressure below 140/90 mm Hg were less likely to have a preterm birth or experience one of several severe pregnancy complications, such as preeclampsia, a condition marked by sudden high blood pressure and early signs of organ dysfunction. The hypertension treatment did not impair fetal growth.

"The impact of treating chronic hypertension during pregnancy represents a major step forward for supporting people at high risk for adverse pregnancy outcomes," said Alan T. N. Tita, M.D., Ph.D., a principal investigator of the study and the John C. Hauth Endowed Professor of Obstetrics and Gynecology at the University of Alabama at Birmingham Marnix E. Heersink School of Medicine.

The findings from the Chronic Hypertension and Pregnancy(link is external) (CHAP) trial (NCT 02299414), currently the largest trial to study chronic hypertension in pregnancy, published simultaneously in the New England Journal of Medicine(link is external) and were presented on April 2 at the American College of Cardiology's 71st Annual Scientific Session and Expo. The study is funded by the National Heart, Lung, and Blood Institute (NHLBI), part of NIH.

Diane Reid, M.D., a program officer in the Division of Cardiovascular Sciences at NHLBI, said early antihypertensive treatment could be significant for the thousands of U.S. adults who are at risk for preeclampsia or preterm births. Chronic hypertension in pregnancy occurs in more

than 2% of people and can more than triple the risk for severe complications.

The CHAP trial enrolled pregnant people with hypertension at 61 U.S. medical centers from 2015-2021. At the start of the trial, hypertension was defined in this study as having systolic blood pressure (top number) above 140 mm Hg and diastolic blood pressure (bottom number) above 90 mm Hg. (Current guidelines define normal blood pressure for non-pregnant adults as less than 120/80 mm Hg.) Participants enrolled in the trial before 23 weeks of pregnancy. As part of the study, they were followed through delivery and for six weeks after giving birth.

Participants were randomized into one of two groups. Those in the intervention arm, 1,208 participants, received antihypertensive medication to keep their blood pressure below 140/90 mm Hg. Those in the control arm, 1,200 participants, did not receive medication to lower their blood pressure unless it rose above 160/105 mm Hg, a threshold for severe hypertension.

Researchers found that of the participants who received antihypertensive treatment, 70% experienced no major negative pregnancy outcome, while 30% experienced one of the following outcomes: preeclampsia with severe features, which usually presents after 20 weeks of pregnancy; placental abruption; preterm birth at less than 35 weeks; or fetal or neonatal death. In comparison, 37% of participants in the control arm experienced a similar negative event. In other words, the researchers said, for every 14-15 people treated for hypertension early in pregnancy, one was spared from experiencing a severe complication measured in the study.

Additionally, the birth weight of the infants did not appear to be affected by antihypertensive treatments. The birth weights of infants remained similar between groups – most had normal weights. Approximately 11.2% of babies born to participants who received medication and 10.4% of babies born to those in the control group had impaired fetal growth, which was defined as birth weight being below the 10th percentile for babies of the same gestational age.

"The study helps reassure that treating hypertension in pregnancy is safe and effective," said Reid.

She explains the research will also help inform treatment decisions that have varied because of a shortage of evidence about the benefits of these antihypertensive medications, as well as their effects on fetal growth and development. Some medical organizations recommend the treatments; others discourage them, except in cases of severe hypertension. The authors note that this study should inform clinical practice guidelines.

The researchers also note the importance of future studies, such as those looking at long-term health outcomes of participants and their children, to further clarify the use of hypertension treatments during pregnancy.

To learn more about hypertension in pregnancy, visit https://www.nhlbi.nih.gov/health-topics/education-and-awareness/heart-truth/listen-to-your-heart/heart-health-and-pregnancy.

To learn more about ways to support cardiovascular health at every age, visit https://www.nhlbi.nih.gov/health-topics/education-and-awareness/heart-truth.

About the National Heart, Lung, and Blood Institute (NHLBI): NHLBI is the global leader in conducting and supporting research in heart, lung, and blood diseases and sleep disorders that advances scientific knowledge, improves public health, and saves lives. For more information, visit https://www.nhlbi.nih.gov.

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

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

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

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

- Connect with other AAP members who share your interests in improving effective drug therapies and devices in children.
- Receive the SOATT newsletter containing AAP and Section news.
- Access the Section's Website and Collaboration page – with current happenings and opportunities to get involved.

- Network with other pediatricians, pharmacists, and other health care providers to be stronger advocates for children.
- Invitation for special programming by the Section at the AAP's National Conference.
- Access to and ability to submit research abstracts related to advancing child health through innovations in pediatric drugs, devices, research, clinical trials and information technology; abstracts are published in Pediatrics.

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

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

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

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

NT

Wreaths Across America Announces Expanded TEACH Program

Access to curriculum and resources specific to character and service-based learning

COLUMBIA FALLS, Maine — April 12, 2022 — This year's theme for Wreaths Across America (WAA) is "Find a Way to Serve." In keeping with this, and the organization's commitment to teach the next generation the value of freedom through stories of courage and character, we are proud to announce the launch of our revamped TEACH program. The program, which both shares established curriculum from like-minded organizations, and introduces new educational materials, focuses on character development and service projects for young people of all ages.

The expanded TEACH program will help serve as a conduit to share the established curriculum materials from partner organizations like The Unites States of America Vietnam War Commemoration, the American Rosie MovementTM, Random Acts of Kindness Foundation, The Congressional Media of Honor Society, and IKEducation at the Eisenhower Foundation. Additionally, WAA has developed a Veterans' Oral History Project for youth from 4th -12th grades that encourages young people to interview a veteran, service member, or Gold Star Family member to learn about the sacrifices our military make on behalf of our country.

To learn more and download WAA's TEACH materials, please visit www.wreathsacrossamerica.org/teach

"As Executive Director, founding family member, and mother of six kids whose lives have been greatly impacted by the opportunity to meet so many in the military community, I know that the teaching aspect of our mission is the most important," said Karen Worcester, executive director, Wreaths Across America. "Last year, this long-standing desire to develop a more robust education program took a giant step forward when past President of American

Gold Star Mothers, Inc. and retired teacher, Cindy Tatum, stepped forward to help us achieve this dream."

Lesson plans for all grade levels and learning abilities have been designed by WAA's new Curriculum Developer, Cindy Tatum. "Being a part of helping Wreaths Across America teach younger generations about the value of freedom and the importance of honoring those who sacrificed so much to protect those freedoms, is something I know I am supposed to be doing and I know my son Daniel would want me to do," said Tatum. "I want America's youth to learn that as citizens of this world, there are things they can do to lift the human spirit, things that are easy, things that are free, things that they can do every day."

This year, National Wreaths Across America Day is Saturday, December 17, 2022. It is a free event and open to all people. For more information on how to volunteer locally or sponsor a wreath for an American hero, please visit www.wreathsacrossamerica.org. To follow stories throughout the year from across the country focused on this theme, please use the hashtag #FindAWay2022

# # #

About Wreaths Across America

Wreaths Across America is a 501(c)(3) nonprofit organization founded to continue and expand the annual wreath-laying ceremony at Arlington National Cemetery begun by Maine businessman Morrill Worcester in 1992. The organization's mission – Remember, Honor, Teach – is carried out in part each year by coordinating wreath-laying ceremonies in December at Arlington, as well as at thousands of veterans' cemeteries and other locations in all 50 states and beyond.

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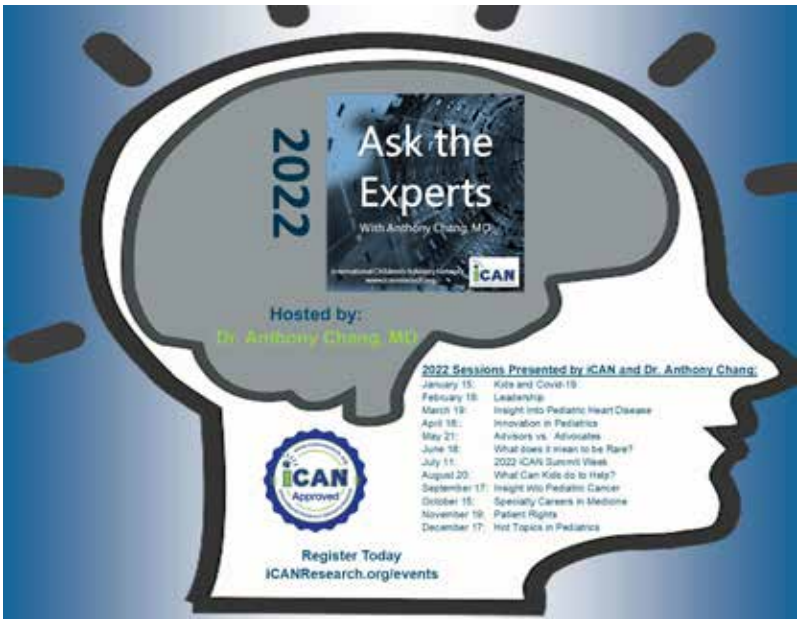

Keeping Your Baby Safe

during the COVID-19 pandemic

How to protect your little one from germs and viruses

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

Here's what you can do...

Wash Your Hands

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

Limit Contact with Others

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

Provide Protective Immunity

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

Take Care of Yourself

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

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

WARNING

Never Put a Mask on Your Baby

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

If you are positive for COVID-19

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

We can help protect each other.
Learn more
www.nationalperinatal.org/COVID-19

National Perinatal Association

PROTECT YOUR FAMILY FROM RESPIRATORY VIRUSES

flu · coronavirus · pertussis · RSV

WASH YOUR HANDS
often with soap and warm water.

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

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

USE AN ALCOHOL-BASED HAND SANITIZER.

STAY AWAY FROM SICK PEOPLE
Avoid crowds. Protect vulnerable babies and children.

www.nationalperinatal.org

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Peer Reviewed

Genetics Corner: Syndromic Etiology of Apparently Isolated Clubfeet: a Child with Loeys-Dietz Syndrome

Subhadra Ramanathan MSc, MS, CGC, Robin Dawn Clark, MD

Clinical Summary:

A 2-year-old male with prenatally diagnosed clubfeet presented for a genetics evaluation in the Craniofacial team clinic for suspected craniosynostosis. The pregnancy history was noteworthy for the prenatal diagnosis of bilateral and isolated clubfeet in the second trimester but was otherwise noncontributory. He was born in a regional hospital at term by NSVD to a 35-year-old G2P1→2 mother. The birth weight was appropriate at ~7 lbs. There were no other postnatal complications, and he was discharged home from the regular newborn nursery with his mother. His clubfeet were treated with serial casting. He had a strabismus that had been surgically repaired. His mother noticed a bony prominence on his anterior skull in the first year of life that prompted a referral to the Craniofacial team clinic. His motor milestones were appropriate, but he had a speech delay. The family history was noncontributory.

"His mother noticed a bony prominence on his anterior skull in the first year of life that prompted a referral to the Craniofacial team clinic. His motor milestones were appropriate, but he had a speech delay. The family history was noncontributory."

He was tall, at the 91st percentile for height, and slender. His physical exam was notable for scaphocephaly with a bony prominence over the anterior sagittal suture and depression over the (closed) anterior fontanel. He had dysmorphic facial features (Figure 1): hypertelorism, prominent eyes, shallow orbits, mild beaking of the nose, micrognathia, and a previously undocumented bifid uvula. Arachnodactyly was present with significant hypermobility of the joints of the hands and wrists and prominent heels. His subcutaneous tissue had a soft and doughy consistency. His skin was thin, and his veins were visible. There was moderate bruising on both shins. Loeys-Dietz syndrome was suspected based on his clinical features.

Laboratory and Imaging Studies

Molecular genetic testing detected a *de novo* likely pathogenic variant in *TGFBR2,* c.1178G>A (p.Cys393Tyr*),* confirming the diagnosis of Loeys-Dietz syndrome 2 (LDS2, OMIM 610168)(1).

An echocardiogram detected a dilated aortic root, and a pediatric cardiology consultant initiated therapy with an angiotensin II receptor antagonist, losartan (0.1 milligrams/kg/d; 0.7 mg PO bid). CT scan of the head detected pan-craniosynostoses with premature fusion of the sagittal, lambdoid, and bicoronal sutures. Flexion/extension radiographs of the cervical spine revealed atlantodental instability. Whole-body MRA and brain MRI studies will be completed prior to the planned surgical repair of his craniosynostoses.

Discussion

"Flexion/extension radiographs of the cervical spine revealed atlantodental instability. Whole-body MRA and brain MRI studies will be completed prior to the planned surgical repair of his craniosynostoses."

Congenital talipes equinovarus, or clubfoot, is a common disorder in 1-3/1000 live births. The sex ratio favors males: 2M:1F. In about 50-70% of cases, the clubfoot is an isolated anomaly (2), and the rest are considered to be complex with associated structural or genetic anomalies. Notably, the prenatal diagnosis of an isolated clubfoot is not reliable and should be confirmed with a careful examination after birth. A prenatally diagnosed isolated clubfoot is confirmed postnatally in only 70-75% of cases because 10-20% are false positives, and 5-13% are mislabeled as isolated and are, in fact, complex cases with other associated anomalies (3, 4) In our patient, the postnatal diagnosis of Loeys-Dietz syndrome type 2 provided a monogenic etiology for what was complex. However, it had previously been treated as isolated clubfeet.

"Some of his other anomalies were evident in photographs that we reviewed from the newborn period (Figure 1). Interestingly, his craniosynostosis was not evident until later in infancy."

The syndromic nature of his clubfeet might have been diagnosed earlier had his associated anomalies been appreciated. Some of his other anomalies were evident in photographs that we reviewed from the newborn period (Figure 1). Interestingly, his craniosynostosis was not evident until later in infancy. However, his stra-

TABLE: Syndromes associated with clubfoot

CONDITION/SYNDROME NAME	KNOWN GENES
Arthrogryposis, distal type 3	*PIEZO2*
Barth syndrome	*TAZ*
Bruck syndrome	*PLOD2, FKBP10*
Carey-Finerman-Ziter syndrome	*MYMK*
Catel-Manzke syndrome	*TGDS*
Charcot-Marie-Tooth Disease Type 4D	*NDRG1*
Charcot-Marie-Tooth Disease, axonal type	*LMNA, GDAP1*
Diastrophic dysplasia	*SLC26A2*
Ehlers-Danlos syndrome, musculocontractural types	*CHST14, DSE*
Ehlers-Danlos syndrome, vascular type	*COL3A1*
Epileptic encephalopathy	*AARS*
Joubert syndrome	*ATXN10, TCTN2*
Larsen syndrome	*FLNB, CHST3*
Loeys-Dietz syndrome	*TGFBR1, TGFBR2, SMAD2, SMAD3, TGFB2, TGFB3*
Marfan syndrome	*FBN1*
Moebius syndrome	*PLXND1, REV3L*
Multiple epiphyseal dysplasias	*COL9A1, COL9A2, COL9A3, COMP, MATN3, SLC26A2*
Multiple synostosis syndrome	*GDF5*
Peroxisomal biogenesis disorder 7A	*PEX26*
Richeri-Costa – Pereira syndrome	*EIF4A3*
Santos syndrome	*WNT7A*
Saul-Wilson syndrome	*COG4*
Shprintzen-Goldberg craniosynostosis syndrome	*SKI*
Simpson-Golabi-Behmel syndrome	*GPC3*
TARP syndrome	*RBM20*
Van Maldergern syndrome, 2	*DCHS1, FAT4*
VISS syndrome	*IPO8*

Some of the more common causes of syndromic clubfoot are listed with their associated genes (adapted from Sadler et al., 2019)(6). Several of these syndromes are connective tissue disorders, including Ehlers-Danlos, Loeys-Dietz, Marfan, and Schprintzen-Goldberg syndromes.

bismus, joint hypermobility, arachnodactyly, and bifid uvula could have been detected with a careful physical exam in the newborn period. His strabismus was recognized early. A search of the Online Mendelian Inheritance in Man (OMIM) database (www.omim.org) using the search terms "clubfoot and bifid uvula" returns 31 entries, which include three different types of Loeys-Dietz syndrome in the first ten responses.

Loeys-Dietz syndrome (LDS) describes a group of connective tissue disorders that cause dysmorphic craniofacial features, joint instability, and significant vascular anomalies characterized by arterial tortuosity and aortic dilation, which can lead to an aortic aneurysm in childhood. The phenotype of LDS overlaps Marfan syndrome and other connective tissue disorders. Many genetic disorders that can present with clubfeet are listed (Table).

Craniofacial features of Loeys-Dietz syndrome(5) include hypertelorism (widely spaced eyes), craniosynostosis of any suture, and cleft palate/bifid uvula. Skeletal manifestations include talipes equinovarus and arachnodactyly. Approximately 15% of individuals with Loeys-Dietz syndrome have cervical spine instability, and all patients should be examined for this with flexion-extension X-rays. Joint instability manifests in clubfoot, flat feet, scoliosis, pectus anomalies, and joint hypermobility. Approximately 25 to 30% of affected individuals can also have gastrointestinal complications and severe food allergies.

There is wide clinical variability and severity in LDS. The most

Figure 1a:

Figure 1b:

Caption for Figure 1a-d: Craniofacial features of Loeys-Dietz syndrome, a) as an infant and b) at two years of age, are evident: hypertelorism, shallow orbits, mildly beaked nose, short columella, micrognathia; Note the unusual posture of the fingers as a newborn. Strabismus and mild ptosis of the left eye were present from birth, although subtle in the newborn period. His hypertelorism and unusual head shape are less evident as a newborn. c. Bilateral talipes in the newborn period d. Arachnodactyly, camptodactyly of the little fingers, and hypermobility of interphalangeal joints at age 3

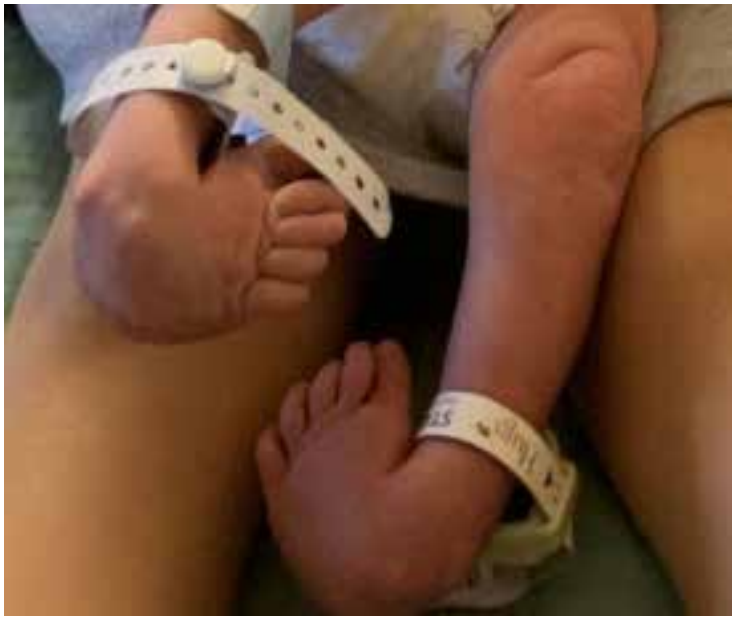

Figure 1c:

Figure 1d:

"Lowering the blood pressure, reducing the pulse pressure, and slowing the heart rate reduce morbidity and mortality."

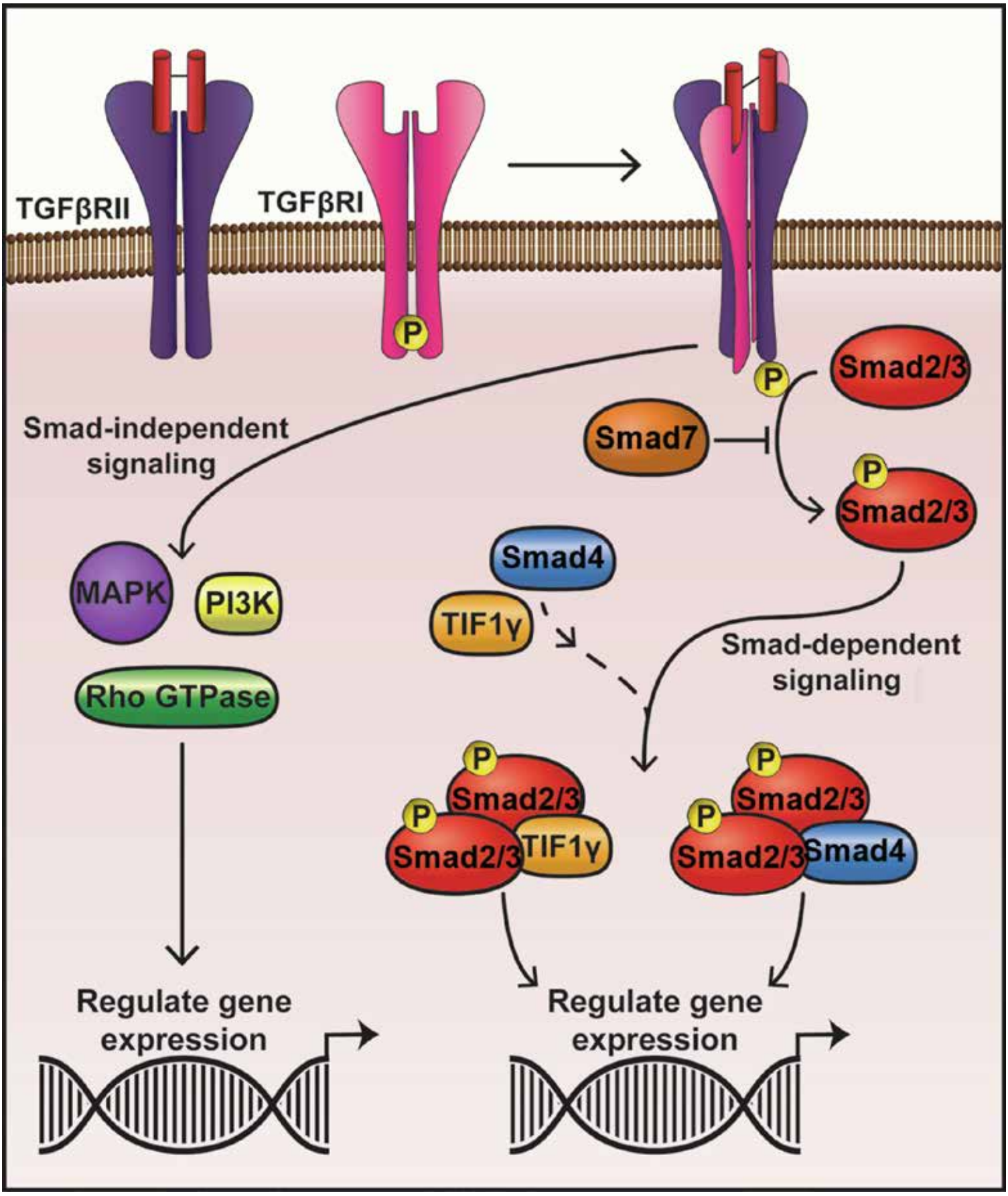

Figure 2 Diagram of TGF beta signaling pathway TGFβ signaling pathways work in a Smad-dependent or Smad-independent manner. Upon binding of active TGFβ to a TGFβRII dimer, a tetrameric receptor complex is formed with a TGFβRI dimer. This activates the kinase activity of TGFβRI and can trigger signaling either through a Smad-dependent or -independent manner. Adapted from Kelly et al. (2017)(7)

serious sequelae are arterial tortuosity, cerebral, thoracic, and abdominal arterial aneurysms, and/or dissections. Management of individuals with LDS includes surveillance with echocardiograms at least annually and annual head to pelvis CTA/MRA to assess for arterial tortuosity and aneurysms. The major morbidity and early mortality in LDS are from aortic dilatation at the sinuses of Valsalva, which predispose to aortic dissection and rupture that can occur in childhood. Mitral valve prolapse and enlargement of the proximal pulmonary artery are also seen. Individuals with LDS have a more aggressive vascular course than those with other connective tissue disorders such as Marfan syndrome. Aortic root replacement is recommended earlier in LDS than in Marfan syndrome, at 4 cm. Early diagnosis of Loeys-Dietz syndrome can change the course of the disease. Lowering the blood pressure, reducing the pulse pressure, and slowing the heart rate reduce morbidity and mortality. Beta-adrenergic blockers or angiotensin receptor blockers are the mainstay of medical treatment.

"LDS is inherited in an autosomal dominant manner but new, de novo mutations are responsible for most cases of LDS. Only 25% have an affected parent, which means negative family history is not reassuring. Heterozygous pathogenic variants in 6 known genes cause LDS."

LDS is inherited in an autosomal dominant manner but new, *de novo* mutations are responsible for most cases of LDS. Only 25% have an affected parent, which means negative family history is not reassuring. Heterozygous pathogenic variants in 6 known genes cause LDS. These genes are part of the transforming growth factor-β (TGF β) signaling pathway (Figure 2): *SMAD2* (mothers against decapentaplegic homolog 2), *SMAD3* (mothers against decapentaplegic homolog 3), *TGFB2* (TGF-β2), *TGFB3* (TGF-β3), *TGFBR1* (TGF-β receptor type I), or *TGFBR2* (TGF-β receptor type II). Variants in *TGFBR2* make up over 50% of the variants found in affected individuals (5).

Practical applications:

1. Think outside the foot. Examine every infant with clubfoot for associated anomalies to identify those with a syndromic etiology.
   a. Recall that 30% of infants with clubfoot have additional congenital anomalies.
   b. Examine affected infants for craniofacial, palatal, ocular, skeletal, joint, cardiac, or skin manifestations.
   c. Refer patients with clubfoot, whether unilateral or bilateral, for a genetic evaluation when associated anomalies are present,
2. Do not rely on a negative prenatal ultrasound to rule out associated anomalies in infants with clubfoot. A prenatal ultrasound cannot reliably detect complex or syndromic clubfoot.
3. Do not be reassured by negative family history. Many genetic disorders are caused by a *de novo* pathogenic variant in the infant.
4. Be familiar with connective tissue disorders associated with clubfeet, such as Loeys-Dietz and Marfan syndromes. These conditions are more likely to have serious cardiac vascular sequelae that can be modified by early treatment.
5. Be aware of the potential benefits of early diagnosis of syndromic clubfoot and the harms associated with later diagnosis beyond the newborn period. Losartan treatment was only begun after aortic root dilation was detected in this patient.

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Disclosures: The authors have no disclosures

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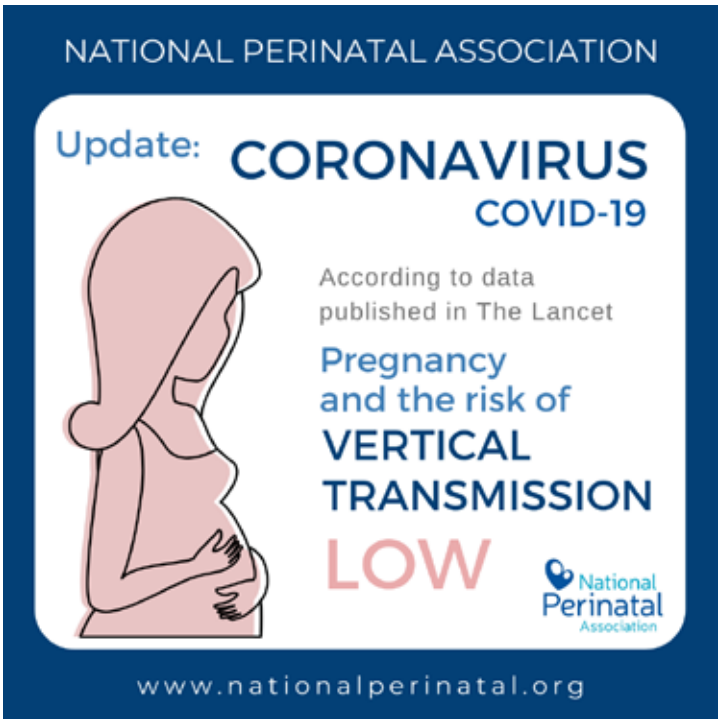

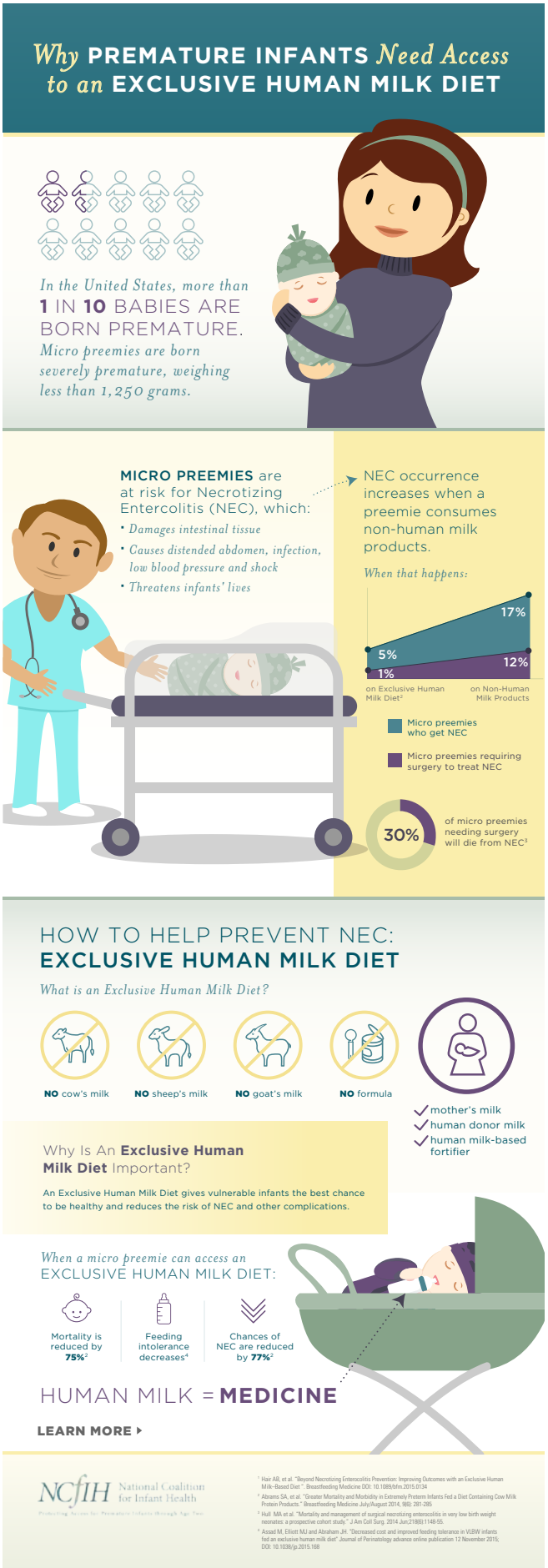

Peer Reviewed

From The National Perinatal Information Center: National Minority Health Month: Amplifying Perinatal Nursing Leadership Disparities through Data

Elizabeth Rochin, PhD, RN, NE-BC

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

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

NPIC
National Perinatal Information Center

"April is National Minority Health Month, a time to recognize health disparities that continue to impact people from racial and ethnic minority groups and provide a forum for discussion, education, and information. (1) "

April is National Minority Health Month, a time to recognize health disparities that continue to impact people from racial and ethnic minority groups and provide a forum for discussion, education, and information. (1) Five years ago, the Black Mamas Matter Alliance launched Black Maternal Health Week, a week each April that would highlight and amplify the sustained increase in Black maternal deaths. (2) Within the global COVID-19 pandemic, the outcome disparities within Black and Brown maternal health communities continued to grow and were impacted at greater rate. (3,4) On April 13, 2022, Vice President Kamala Harris convened Cabinet secretaries to address the ongoing maternal morbidity and mortality crisis in the United States. The President's FY23 budget includes $470 million to address additional maternal disparities projects, including supporting the perinatal health workforce.

The perinatal health workforce has become an important discussion point as healthcare providers and professionals continue to leave the workforce during and after the COVID-19 pandemic. Open nursing positions within Women's and Children's service lines, once rarely available or open, now sit vacant for weeks and, in some cases, months. These include frontline nursing leadership positions, which are pivotal to assuring quality outcomes, staff satisfaction, and organizational effectiveness of inpatient care units. An area of healthcare leadership that is not often studied is that of frontline perinatal nursing leaders.

"During the past two years, there has never been a greater emphasis on the role of the frontline nurse leader in healthcare. Academicians, scholars, and administrators were quick to offer recommendations and suggestions on how nurse leaders could support their nursing teams during the pandemic."

During the past two years, there has never been a greater emphasis on the role of the frontline nurse leader in healthcare. Academicians, scholars, and administrators were quick to offer recommendations and suggestions on how nurse leaders could support their nursing teams during the pandemic. Advocating for supplies, resources, and how nursing teams could practice self-care during patient care surges of the pandemic were, but a few of the areas of emphasis nurse leaders were called upon and encouraged to support their staff. However, there was a dearth of recommendations on how to support nurse leaders during the pandemic, what contributed to their stressors, and what resources may be of assistance to them.

So how does this connect to National Minority Health Month?

In late 2021, Synova Associates commissioned the National Perinatal Information Center to study the effects of chronic stress on perinatal nursing leaders (*Supporting Perinatal and Neonatal Nurse Leaders: Identification and Moderation of Chronic Stress*, IRB #1321780). These nursing leaders represented inpatient settings throughout the United States, such as neonatal intensive care (NICU), labor and delivery, postpartum, well-baby nurseries, lactation services, antepartum, and those nursing leaders responsible for multiple units. The findings of this study revealed significant racial disparities in many areas, including turnover intent ($p < .001$), job control ($p < .001$) and organizational constraints ($p < .001$). These findings will soon be shared more broadly and further developed with nursing leaders most impacted.

While study specifics and findings are not discussed here, it is crucial that as we discuss National Minority Health Month, we not only focus on the patients we care for but also on diverse nursing leaders caring for these patients and care teams.

As a result of this study, the following recommendations are suggested for hospital leadership to address:

1) We must be acutely aware of the extrinsic stressors for Black/African American, Asian/Asian American, Native Hawaiian/Pacific Islander, and Native American/Alaska Native perinatal nursing leaders. This study population described stressors as physical symptoms (chest pain, shortness of breath) that cannot be ignored and require additional research and development for strategies by and for those most impacted by these findings.

2) Turnover intention, particularly as described in this study ("*I won't be working here one year from now*") for Black and Brown perinatal nursing leaders, must be more thoroughly explored and the urgency of this finding addressed. It will be important to replicate this study within other service lines to establish if these findings are unique to perinatal services or are more global to diverse nursing leaders regardless of setting.

3) Job Control, or the perceived ability to make decisions or the freedom to decide how to work, was also significantly decreased for Black and Brown nursing leaders ($p < .001$). In addition, organizational constraints (hospital rules/procedures; adequate help from others) were also significant ($p < .001$), which continues to generate a further need for examining systems and structures in place that create these real and/or perceived barriers to effective leadership. Exploring these differences is critical and may aid in better understanding turnover intent as well as the symptoms of chronic stress described by perinatal nurse leaders.

"During National Minority Health Month this year, let us celebrate the richness and diversity of our healthcare leadership team members, commit ourselves to amplifying their voices and experiences and follow their lead for sustainable solutions."

Assuring the health of our diverse patients and communities must continue to be a priority in our healthcare systems. It is just as important to ensure that we are providing that same level of effort and intensity to ensure the health and well-being of our diverse healthcare teams ***and their leaders*** within our systems. During National Minority Health Month this year, let us celebrate the richness and diversity of our healthcare leadership team members, commit ourselves to amplifying their voices and experiences and follow their lead for sustainable solutions.

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Peer Reviewed

Coding and Documentation for Gastrointestinal Failure in the NICU

Kate Peterson Stanley, MD, FAAP

> ***"The decision to code for critical care is based on the severity of the patient's illness and the intensity of services rendered by the medical provider. "***

The decision to code for critical care is based on the severity of the patient's illness and the intensity of services rendered by the medical provider. The CPT coding definition states the patient's illness or injury must "acutely impact one or more vital organ systems. There is a high probability of imminent or life-threatening deterioration in the patient's condition. The care provided involves high-complexity decision-making to assess, manipulate, and support vital system function to treat vital organ system failure and/or prevent further life-threatening deterioration of the patient's condition. It often requires interpretation of multiple physiological parameters and/or application of advanced technology" (1,2).

Organ failure is a common criterion used by clinicians when coding for critical care in the Neonatal Intensive Care Unit (NICU). Failure occurs when the organ or organ system cannot functionally meet the body's demands. Most neonatologists agree respiratory failure is relatively well-defined and occurs when a patient cannot oxygenate or ventilate to meet metabolic demands. Common clinical signs in neonates include respiratory distress or apnea with a sustained SaO_2 < 90%, paO_2 < 60 or a $paCO_2$ > 50 (acute). To maintain respiratory homeostasis, patients require invasive or non-invasive ventilation, CPAP, or high flow nasal cannula > 2lpm (1). In these cases, patient acuity and service intensity are easily justified in the documentation. Consider this scenario:

> ***"Organ failure is a common criterion used by clinicians when coding for critical care in the Neonatal Intensive Care Unit (NICU). Failure occurs when the organ or organ system cannot functionally meet the body's demands."***

A 2-day-old 880-gm SGA 29-week female infant has RDS requiring CPAP. The neonatologist is called to evaluate the infant because she has worsening respiratory distress and requires more oxygen. The neonatologist intubates the infant, gives surfactant, and initiates mechanical ventilation.

The correct CPT code for this encounter is 99469: subsequent critical care, neonate 28 days or less. This scenario meets the definition of critical care based on the presence of worsening respiratory failure due to RDS that required intervention with ventilation to prevent life-threatening deterioration. The care provided involved high complexity decision-making and the use of advanced technology.

The definition of "failure" is not as clear when applied to other organ systems such as the gastrointestinal (GI) system. Definitions are inconsistent and commonly based on diagnoses rather than function (3,4). Because of this, GI failure is not included in many clinical acuity scores despite its independent effects on mortality (5). GI failure is associated with worse ICU and 90-day outcomes in adults (6) and a mortality rate of 25% in children (3). Neonates with GI-specific diagnoses that result in failure, such as necrotizing enterocolitis, have increased mortality rates and poor neurodevelopmental outcomes (6). GI failure leads to a "high probability of imminent or life-threatening deterioration in the patient's condition," meeting the definition of critical care. Although medical providers recognize this, they often fail to document this association when describing a patient with GI failure in the medical record.

Adult GI failure is defined in multiple ways and may include specific GI disorders, ileus, hemorrhage, or food intolerance (4,5). In contrast, there is greater consensus for a common functionally based definition for pediatric intestinal failure. This is driven by the need to evaluate treatments for short bowel syndrome (3,7,8). According to O'Keefe, GI failure "results from obstruction, dysmotility, surgical resection, a congenital defect, or disease-associated loss of absorption and is characterized by the inability to maintain protein-energy, fluid, electrolyte, or micronutrient balance" (7). Goulet published a similar definition stating GI failure is "a reduction of functional gut mass below the minimal amount necessary for digestion and absorption adequate to supply nutrient and fluid requirements for maintenance in adults and growth in children" (9). Examples include short bowel syndrome, gastrointestinal motility disorders, and congenital enterocyte disorders (7,8,9). Based on these two definitions, GI failure occurs when the current state of the GI system is functionally unable to meet the body's nutritional, fluid, and/or energy demands, which is consistent with "organ failure." Clinical indicators that demonstrate inadequate function and lack of homeostasis support the definition of "failure" and should be documented in the medical record when managing a case.

T*he infant described above is now 16 days old and weighs 930-gms. She has apnea of prematurity that is managed with caffeine and 1 lpm of room airflow by nasal canula. She is tolerating goal-gavage breastmilk feedings. The neonatologist is called to the bedside secondary to abdominal distention, oliguria, poor perfusion, and hematochezia. An abdominal radiograph shows right lower quadrant pneumatosis and distended bowel consistent with NEC. The neonatologist volume resuscitates the infant, decompresses the abdomen with continuous gastric suction, initiates antibiotics after obtaining cultures and laboratory studies, and follows serial radiographs. Although her respiratory status remains stable, the neonatologist monitors her condition closely.*

The correct CPT code for this encounter is 99469: subsequent critical care, neonate 28 days or less. Note that this patient does not have respiratory failure. Rather, the infant presents with hemodynamic compromise due to NEC. Evidence of GI functional

failure includes abdominal distention, feeding intolerance, pneumatosis, and shock, putting the patient at high risk for bowel perforation and death. Clinical management requires high complexity decision-making and interpretation of multiple parameters to prevent life-threatening deterioration. Documenting the level of decision-making and risk of mortality supports using a critical care code.

This scenario is different from other encounters involving organ failure because "advanced technology" was not required to prevent life-threatening decompensation. Advanced technology is not a common term to describe therapeutic interventions for GI failure. Management of GI failure often involves judicious serial assessments of vital signs, physical exams, radiographs, fluid status, electrolyte balance, and growth. Common treatments are continuous gastric decompression, antibiotics, bowel rest, parenteral nutrition, and fluid replacement. The keyword in the CPT critical care definition is "often." Critical care requires high-level decision-making. But the application of advanced technology and interpretation of multiple physiologic parameters are not "always" required. Thus, management of GI failure can be considered high intensity despite the lack of "advanced technologic" treatment options. This specific scenario is "critical" because it requires high complexity decision-making and evaluation of multiple parameters to prevent life-threatening deterioration. High complexity decision making is defined by three elements: 1) the number and acuity of managed problems, 2) the amount and type of interpreted data, and 3) the patient's risk of mortality[2]. Documentation of two of these three elements supports the complex decision-making required for critical care coding.

Not all organ failure, however, requires critical care. As clinical status improves and the organ system recovers, the mortality risk, decision-making complexity, and intensity of interventions decrease, which means critical care services may not be necessary to support the patient's needs.

The infant described above is now 32 days old and weighs 1200 gms. Her clinical status is improved. She is tolerating room air and requires caffeine for intermittent cardiorespiratory events. Nutrition consists of parenteral nutrition via a PICC line and 40ml/kg/day of human milk gavage feedings. She is well-perfused and resting comfortably in an incubator. Abdominal exam and electrolytes are normal. Weight gain over the past 4 days is 18gm/kg/day. The neonatologist increases the enteral feedings by 20ml/kg/day and adjusts the parenteral nutrition to maintain fluid, electrolyte, and nutritional balance.

The appropriate CPT code for this scenario is 99478: Subsequent intensive care, infant, < 1500 gram. In contrast to the patient's initial presentation of NEC, the medical decision-making in this scenario is less complex. Although the patient requires slow feeding advancements after recovering from NEC, functional GI "failure" is improved based on patient stability and lack of clinical indicators. This scenario does not meet the definition of critical care based on the severity of illness and intensity of services provided. Determining when a patient's condition no longer requires critical care is indistinct and individualized. When coding for critical care, documentation should reflect the patient acuity and risk, level of decision-making, and interventions required to prevent life-threatening decompensation.

Consider these documentation tips when caring for a patient with GI failure who requires critical care services:

1) Describe the clinical indicators and laboratory/test evidence demonstrating a failure of function and risk of life-threatening decompensation due to nutritional, energy, fluid and/or electrolyte imbalance.

2) Document the high complexity of decision-making required to manage the patient's current state and prevent life-threatening decompensation and or/death.

3) Be consistent: consider a group definition to clarify the definition and critical care management of GI failure. Varying CPT codes among providers without documented patient conditions or treatment changes put practices at risk for audits.

4) Use ICD-10 codes for the specific GI condition/disease. If unknown, use a symptom code before using the unspecified codes, such as P78.9: Perinatal digestive system disorder, unspecified or K59.9: Functional intestinal disorder, unspecified (use for patients > 28 days or when the condition originates outside the perinatal period) (10).

5) Although prematurity is an abnormal physiologic state, GI failure is not intrinsic to its definition. Dependence on parenteral nutrition secondary to prematurity does not qualify as GI failure.

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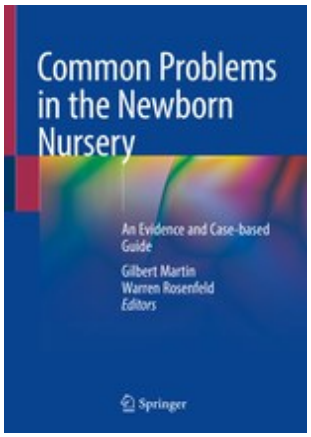

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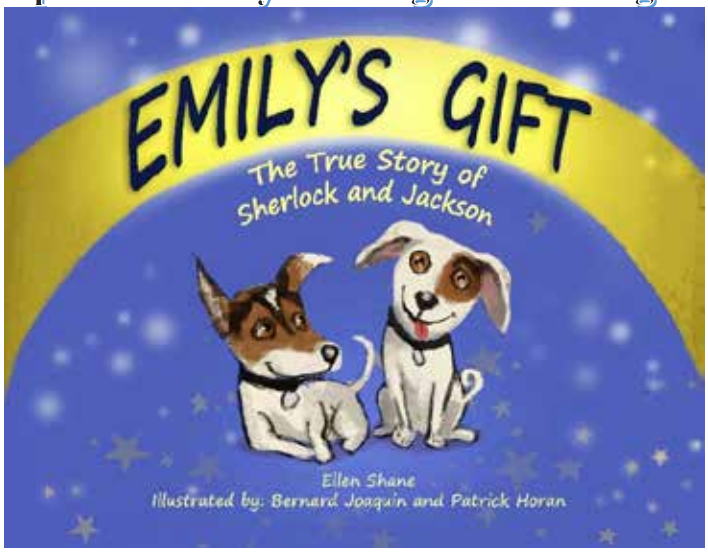

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A POSITION PAPER FROM

NCfIH National Coalition for Infant Health

Protecting Access for Premature Infants through Age Two

Monoclonal Antibodies

Inclusion in the Vaccines for Children Program

2022

Susan Hepworth, Mitchell Goldstein, MD, MBA

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Diseases like respiratory syncytial virus pose a serious risk to all infants and young children, but preventive monoclonal antibodies can make a life-saving difference. Once approved, these passive immunizations should be available and accessible through the Vaccines for Children Program. Families will then have greater access to preventive care, ensuring that their infants and children are protected against RSV.

OVERVIEW

By warding off diseases like influenza and pertussis, immunizations play a critical role in infant and early childhood health. Immunizations protect infants from life-threatening diseases, which can lead to both hospitalization and long-term complications.

One such disease common among infants is respiratory syncytial virus or RSV. RSV affects most children by the time they are two years old (1) and is the leading cause of hospitalization for all infants under age one. (2) Infants younger than one are 16 times more likely to be hospitalized for RSV than for the flu, (3) and RSV accounts for 500,000 emergency room visits in young children each year. (4) One in seven infants receive medical attention for a lower respiratory tract infection during the RSV season. (5)

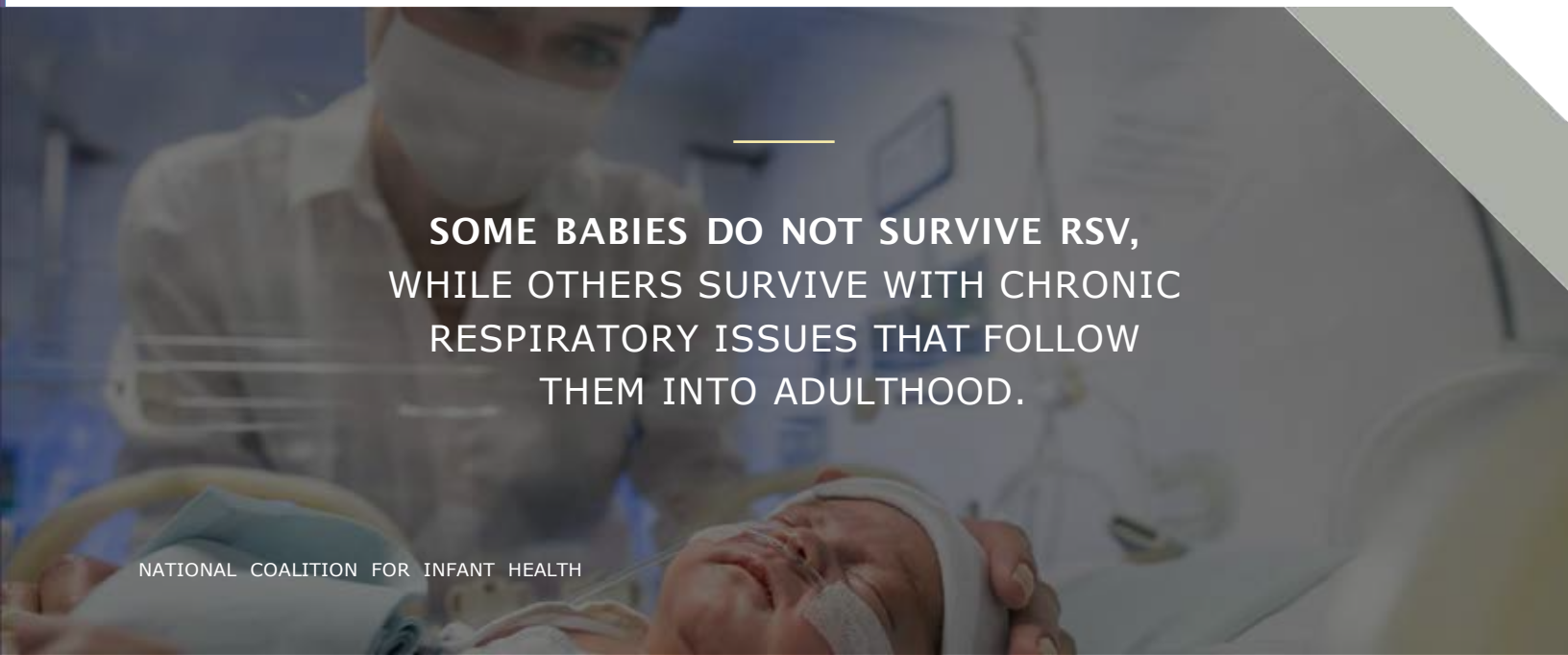
Some infants experience only mild cold-like symptoms, but for others, RSV can cause bronchiolitis, pneumonia, and respiratory distress, which can lead to hospitalization and mechanical ventilation. Some babies do not survive, while others survive with chronic respiratory issues that follow them into adulthood.

While there is no vaccine for RSV, vaccine-like interventions are under development, and one is approved for a narrow population of infants born preterm or with certain underlying health conditions. These interventions are called monoclonal antibodies, which protect infants and young children from RSV.

Preventive monoclonal antibodies are considered vaccine-like because they offer protection against disease but in a different way. Instead of delivering a harmless strain of the virus to the immune system as vaccines do, these treatments provide the body's immune system with readily available, protective antibodies.

But while vaccines for diseases like influenza and pertussis may be widely accessible, preventive monoclonal antibodies can be more difficult to access. Even though vaccine-like interventions can offer life-saving preventive treatment, insurance companies may not cover them.

Questions of coverage are especially important when it comes to the Vaccines for Children program. (6) The program provides free child vaccinations for families who may not be able to afford them. Because infants covered under Medicaid are disproportionately impacted and experience higher hospitalization rates, (7) the question of whether an intervention is on the program's list of pediatric vaccines makes a world of difference.



POSITION

RSV is a threat to all infants. From severe symptoms to hospitalization, this disease can take a serious toll on infants and their families. Ensuring all infants have equitable and timely access to interventions for this disease is key.

The National Coalition for Infant Health supports the Advisory Committee on Immunization Practices (ACIP) schedule, including these preventive monoclonal antibodies on the Vaccines for Children program's list of pediatric vaccines based on the following principles:

PROTECTION FROM RSV SHOULD BE STANDARD FOR ALL INFANTS.

RSV is a common and highly contagious disease that almost all infants experience. Without a vaccine or vaccine-like intervention, it can be difficult to prevent RSV or decrease the disease burden in infants. These preventive monoclonal antibodies provide an effective solution for preventing RSV altogether, saving infants from potentially life-threatening illnesses and other life-long complications that may develop.

VACCINES AND VACCINE-LIKE INTERVENTIONS BENEFIT ALL INFANTS AND CHILDREN.

Monoclonal antibodies are like vaccines because they protect the body's immune system from diseases. The list of pediatric vaccines is not restricted to only vaccines, and because of their similarities, vaccine-like interventions meet the Vaccines for Children program's requirements.

INFANTS DESERVE ACCESS TO PREVENTIVE INTERVENTIONS, REGARDLESS OF THEIR FAMILY'S FINANCES OR INSURANCE COVERAGE.

The Vaccines for Children program, which covers half of America's children, provides vaccines recommended by the ACIP to families at no cost. Vaccines included in the Vaccines for Children program are also covered by private insurance companies, as required by the Affordable Care Act.

ROBUST COVERAGE ENCOURAGES CONTINUED MEDICAL INNOVATION TO PROTECT INFANTS.

By including these vaccine-like interventions on the Vaccines for Children pediatric vaccine list, the ACIP will demonstrate its commitment to "prevention and control of communicable diseases" and support for innovative, life-saving interventions and equitable access for all infants.

RECOMMENDATION

To make a marked reduction in the burden of RSV, **all infants and children need timely and equitable access to preventive monoclonal antibodies.** This can be achieved by including these interventions on the recommended list of pediatric vaccines in the Vaccines for Children program.

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NCfIH National Coalition for Infant Health

Protecting Access for Premature Infants through Age Two

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National Coalition for Infant Health Values (SANE)

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

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

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

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

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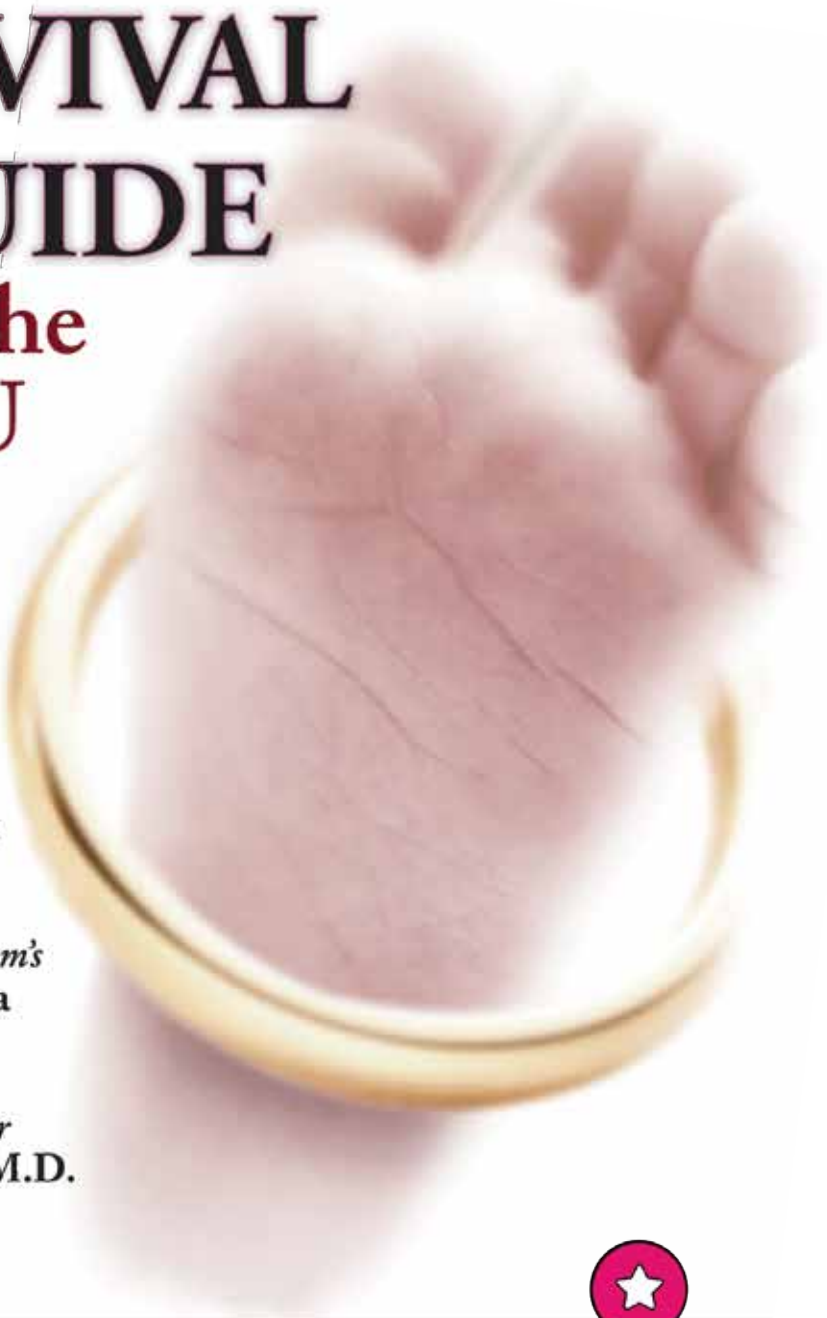

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- Runny Nose
- Struggling to Breathe *(breastbone sinks inward when breathing)*
- Difficulty Eating
- Lethargy
- Wheezing

RESPIRATORY SYNCYTIAL VIRUS
is a highly contagious seasonal virus that can lead to hospitalization for some babies and young children.

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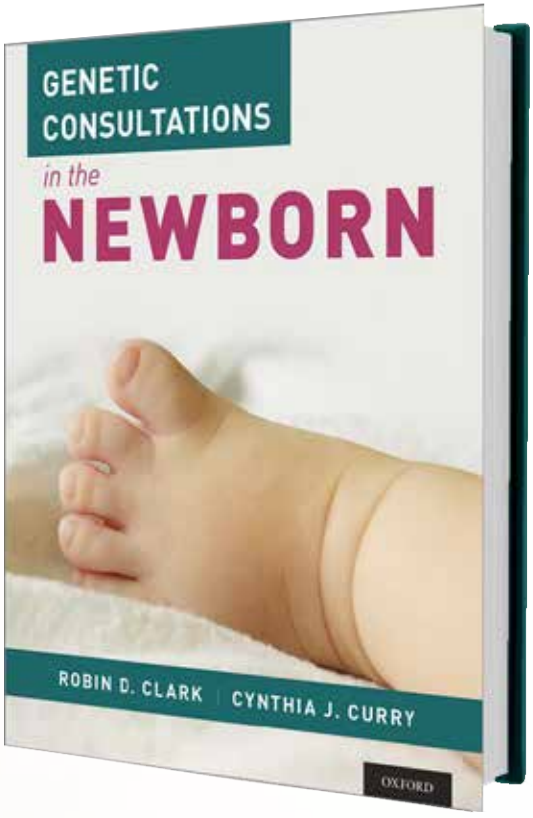

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Clinical Pearl: Vitamin K Refusal by Parents: How did we get here, and what can we do?

Homa Shaabarf, MD, Melanie Wielicka, MD, PhD

"No shots. I just want my baby to be natural." Despite Vitamin K being a component of many foods and playing a vital role in coagulation and bone health, increasing vaccination hesitancy has discouraged many parents from considering this important component of early neonatal care. As the rising rates of refusal of prophylactic intramuscular vitamin K put newborns at risk for life-threatening bleeding, in 2019, the American Academy of Pediatrics made public education about intramuscular vitamin K administration at birth one of its top ten public health priorities. (1) The increasing prevalence of this issue highlights the growing mistrust between patients and the medical community and the need for increased patient education in a culture where misinformation is prevalent.

" The increasing prevalence of this issue highlights the growing mistrust between patients and the medical community and the need for increased patient education in a culture where misinformation is prevalent."

Vitamin K is essential in producing clotting factors, placing infants with inadequate levels at risk of bleeding. The clinical presentation of VKDB can vary but should be considered in any infant who presents with gastrointestinal bleeding, bruising, lethargy, or fussiness. Vitamin K deficiency bleeding (VKDB) is classified by the time of onset. (2) Early-onset VKDB begins within the first 24 hours of age. There may be a low transplacental transfer of Vitamin K. Alternatively, vitamin K activity may also be affected by certain maternal medications, including warfarin or anticonvulsants. Classic VKDB occurs between two days and one week of life and is often idiopathic. Late-onset VKDB occurs between one week and six months of age, is most frequently seen in exclusively breastfed infants, and can be attributed to a low supply of vitamin K in breast milk or immature gut flora resulting in poor vitamin K absorption. Infants may also have underlying pathology that results in liver dysfunction or malabsorption, contributing to vitamin K deficiency or ineffective utilization of vitamin K. Late VKDB can present with intracranial bleeding. Diagnosis can be made by an international normalized ratio (INR) and prothrombin time (PT) that rapidly normalize after the administration of vitamin K. Since 1961, the AAP has recommended a prophylactic intramuscular injection of vitamin K administration shortly after birth, which has virtually eliminated all classic and late-onset VKDB. (1) Without prophylaxis, the estimated incidence per 100,000 birth ranges from 250 to 1,700 for early VKDB and 10.5 to 80 for late VKBD. (1)

"Given the high risk of potential complications, healthcare workers need to receive education and training on recognizing the presenting signs and symptoms of VDKB and its management. This problem is relevant to pediatricians and other types of providers, particularly those working in emergency departments. In a recent study, authors report that 75 to 85% of the participating emergency department physicians and nurses rated their preparedness for caring for a sick infant as poor or very poor. (5)"

Given the high risk of potential complications, healthcare workers need to receive education and training on recognizing the presenting signs and symptoms of VDKB and its management. This problem is relevant to pediatricians and other types of providers, particularly those working in emergency departments. In a recent study, authors report that 75 to 85% of the participating emergency department physicians and nurses rated their preparedness for caring for a sick infant as poor or very poor. (5) This gap in medical education has been recognized by Sanseau et al., who designed and implemented a medical simulation curriculum on VKDB for fellows and attending physicians. With the current rates of vitamin K refusal, 94% of participants rated the case as relevant. (6) This situation suggests there is a potential need for including this topic

when developing curricula for physicians and other learners in the medical field.

Vaccine-hesitant parents and those who decline prophylactic vitamin K often have similar ideologies and concerns regarding overmedicalization and the desire for natural health remedies. These groups often distrust the medical system and prefer to use the internet or alternative health care providers as trusted sources of information. (3) A retrospective cohort study published out of Alberta, Canada, found that families who refused intramuscular vitamin K had a 14.6 higher relative risk of having no recommended vaccines at 15 months. (3) Families who have planned home births, delivered in a birth center, or elect for midwife-assisted deliveries are more likely to decline intramuscular vitamin K than those selecting physician-led hospital delivery. Surveys have found other major reasons reported for vitamin K refusal were the belief that the injection was unnecessary, harm to the infant from preservatives in the injection, or to avoid pain. (4)

"The growing body of research that identifies reasons for vitamin K refusal highlights the opportunities to connect with and educate parents. For instance, some authors report that parents have refused vitamin K in the past as they were not aware of the role of vitamin K in coagulation and the high risk of bleeding."

The growing body of research that identifies reasons for vitamin K refusal highlights the opportunities to connect with and educate parents. For instance, some authors report that parents have refused vitamin K in the past as they were not aware of the role of vitamin K in coagulation and the high risk of bleeding. Others believe the injection can be avoided by increasing maternal dietary vitamin K intake during pregnancy. (1) Additionally, knowing that vitamin K refusal is a strong predictor of delay or refusal of immunizations can be used by healthcare providers to identify the families in need of early education regarding immunizations, preventing children from falling behind on their vaccination schedules. (3)

Our main tools in managing the increasing rates of vitamin K refusal are education and building strong family-provider relationships to help address mistrust towards the medical system. Discussions could potentially begin during prenatal visits to allow adequate time for answering questions and addressing reasons for hesitancy. Moreover, given the potential medical education gap in this area, curricula may be developed as a form of secondary prevention. This training would allow all types of providers to quickly and effectively diagnose and manage vitamin K deficiency-related bleeds.

Summary of Pearls:

1.) The rising rate of intramuscular vitamin K refusal at birth highlights the growing mistrust between patients and healthcare providers and puts infants at risk for VKDB, which was previously virtually eliminated by prophylaxis.

2.) Vitamin k refusal at birth can predict which children are likely to fall behind on their vaccine schedules or to be unvaccinated.

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Clinical Pearls are published monthly.

Submission guidelines for "Clinical Pearls":

1250 word limit not including references or title page.

May begin with a brief case summary or example.

Summarize the pearl for emphasis.

No more than 7 references.

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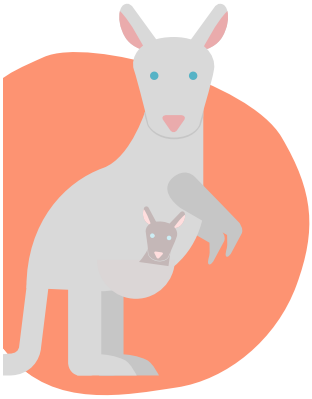

GET INFORMED ABOUT THE RISKS + BENEFITS

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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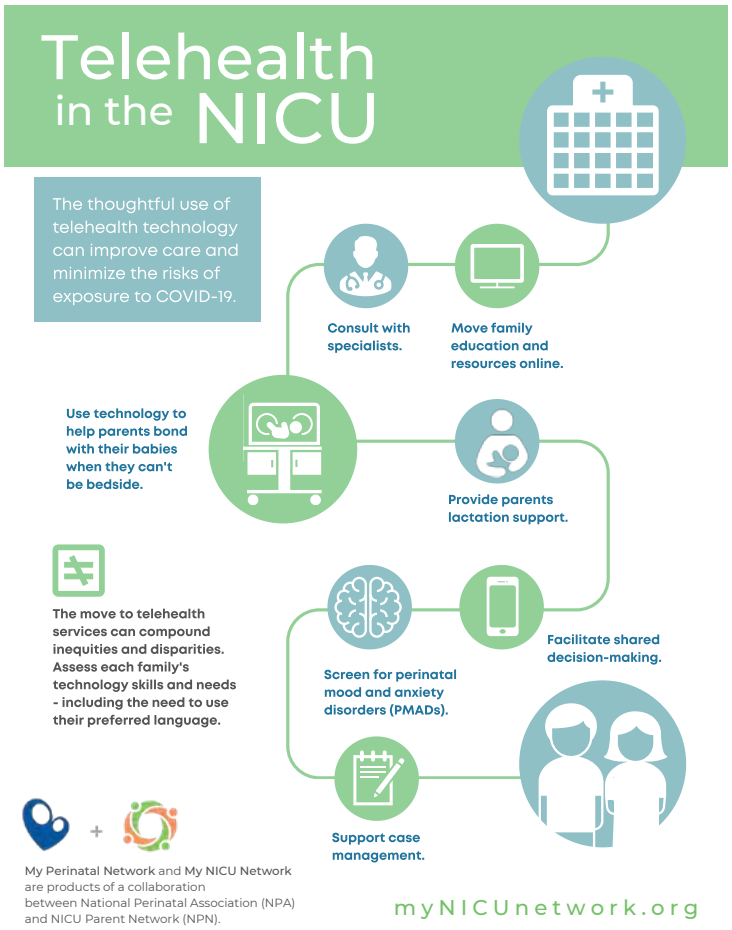

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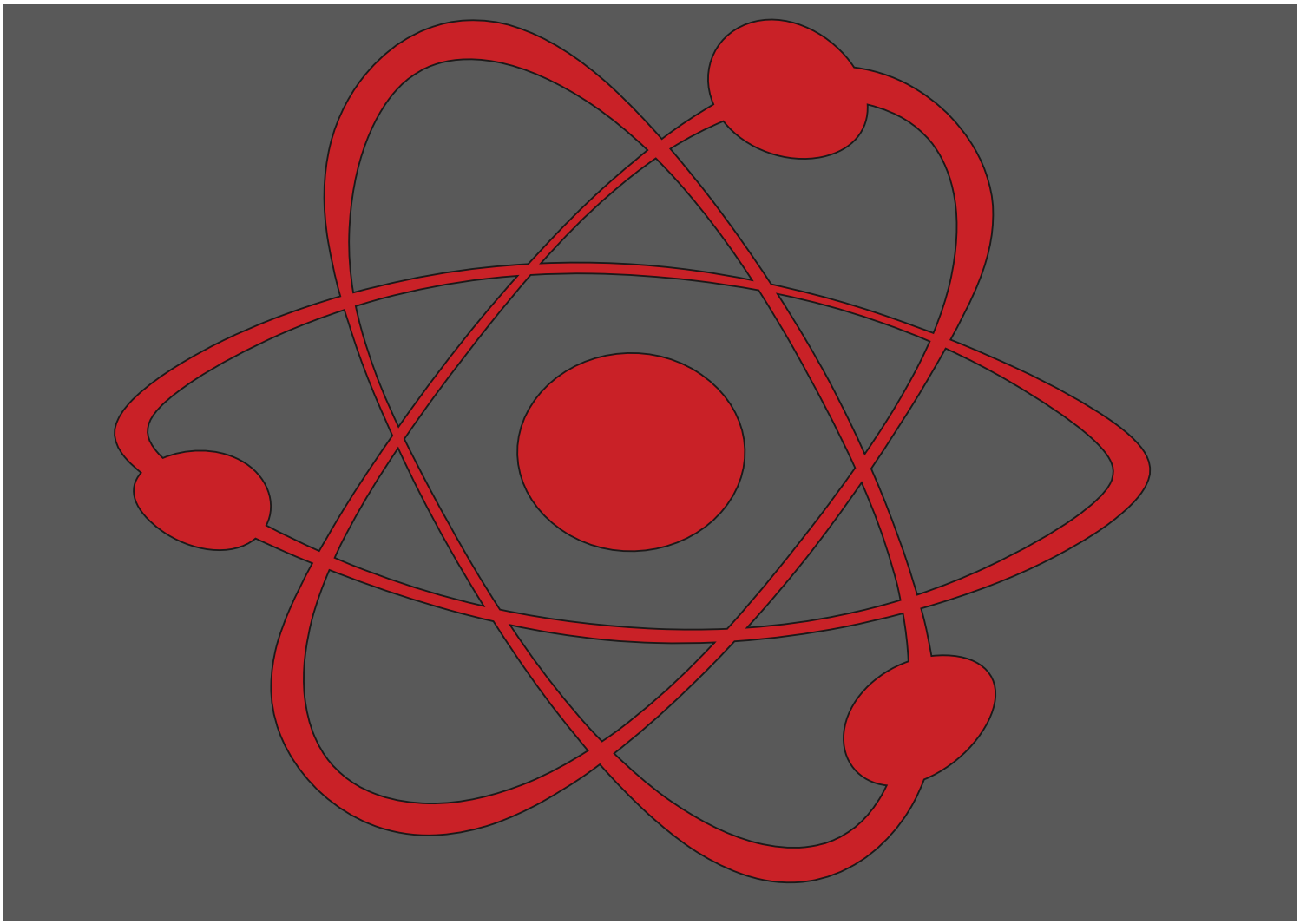

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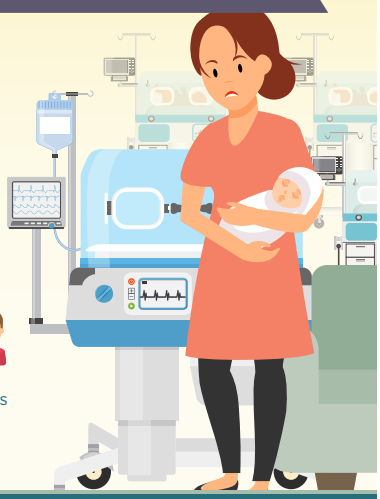
Will your **PRETERM INFANT** *need* **EARLY INTERVENTION** *services?*

Preterm infants are:

2x more likely to have developmental delays

5x more likely to have learning challenges

1 in **3** preterm infants will require support services at school

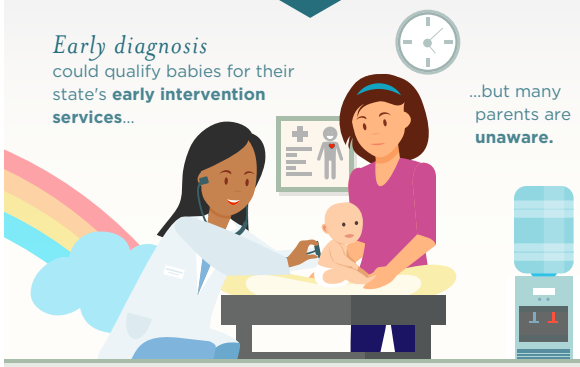


Early intervention can help preterm infants:

- Enhance language and communication skills
- Build more effective learning techniques
- Process social and emotional situations
- Address physical challenges
- Prevent mild difficulties from developing into major problems

Early diagnosis could qualify babies for their state's **early intervention services**...

...but many parents are **unaware.**



NICU staff, nurses, pediatricians and social workers **should talk** with NICU families about the challenges their baby may face.

Awareness, referral & timely enrollment in early intervention programs can help **infants thrive** and grow.

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

Visit **CDC.gov** to find contact information for your state's early intervention program.

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

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

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

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

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

La salud de la madre

El sueño, la alimentación y el comportamiento del bebé a medida que crece[2]

La capacidad para cuidar de un bebé y sus hermanos

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

LOS ENCARGADOS DE FORMULAR POLÍTICAS PUEDEN:

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

LOS HOSPITALES PUEDEN:

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

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

[1] American Psychological Association. Accesible en: http://www.apa.org/pi/women/resources/reports/postpartum-depression.aspx
[2] National Institute of Mental Health. Accesible en: https://www.nimh.nih.gov/health/publications/postpartum-depression-facts/index.shtml
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https://aapexperience.org/conference-event-locations/

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Neonatology and the Arts

This section focuses on artistic work which is by those with an interest in Neonatology and Perinatology. The topics may be varied, but preference will be given to those works that focus on topics that are related to the fields of Neonatology, Pediatrics, and Perinatology. Contributions may include drawings, paintings, sketches, and other digital renderings. Photographs and video shorts may also be submitted. In order for the work to be considered, you must have the consent of any person whose photograph appears in the submission.

Works that have been published in another format are eligible for consideration as long as the contributor either owns the copyright or has secured copyright release prior to submission.

Logos and trademarks will usually not qualify for publication.

This month we continue to feature artistic works created by our readers on one page as well as photographs of birds on another. This month's original artwork features Sophina Goldstein's "Rendition of an Owl." Your bird this month is "Two Birds in Flight" from Larry Tinsley, MD

Herbert Vasquez, MD,

Associate Neonatologist, Queen of the Valley Campus
Emanate Health, West Covina, 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, or pdf) for each figure. Preferred formats are ai, psd, or pdf. tif and jpg images should have sufficient resolution so as not to have visible pixilation for the intended dimension. In general, if acceptable for publication, submissions will be published within 3 months.

3. There is no charge for submission, publication (regardless of number of graphics and charts), use of color, or length. Published content will be freely available after publication. There is no charge for your manuscript to be published. NT does maintain a copyright of your published manuscript.

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

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

6. An abstract may be submitted.

7. The main text of the article should be written in formal style using correct English. The length may be up to 10,000 words. Abbreviations which are commonplace in neonatology or in the lay literature may be used.

8. References should be included in standard "NLM" format (APA 7th may also be used). Bibliography Software should be used to facilitate formatting and to ensure that the correct formatting and abbreviations are used for references.

9. Figures should be submitted separately as individual separate electronic files. Numbered figure captions should be included in the main file after the references. Captions should be brief.

10. Only manuscripts that have not been published previously will be considered for publication except under special circumstances. Prior publication must be disclosed on submission. Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.

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NICU Baby's Bill of Rights

1- The Right to Advocacy
My parents know me well. They are my voice and my best advocates. They need to be knowledgeable about my progress, medical records, and prognosis, so they celebrate my achievements and support me when things get challenging.

2- The Right to My Parents' Care
In order to meet my unique needs, my parents need to learn about my developmental needs. Be patient with them and teach them well. Make sure hospital policies and protocols, including visiting hours and rounding, are as inclusive as possible.

3- The Right to Bond with My Family
Bonding is crucial for my sleep and neuroprotection. Encourage my parents to practice skin-to-skin contact as soon as and as often as possible and to read, sing, and talk to me each time they visit.

4- The Right to Neuroprotective Care
Protect me from things that startle, stress, or overwhelm me and my brain. Support things that calm me. Ensure I get as much sleep as possible. My brain is developing for the first time and faster than it ever will again. The way I am cared for today will help my brain when I grow up. Connect me with my parents for the best opportunities to help my brain develop.

5- The Right to be Nourished
Encourage my parents to feed me at the breast or by bottle, whichever way works for us both. Also, let my parents know that donor milk may be an option for me.

6- The Right to Personhood
Address me by my name when possible, communicate with me before touching me, and if I or one of my siblings pass away while in the NICU, continue referring to us as multiples (twin/triplets/quads, and more). It is important to acknowledge our lives.

7- The Right to Confident and Competent Care Giving
The NICU may be a traumatic place for my parents. Ensure that they receive tender loving care, information, education, and as many resources as possible to help educate them about my unique needs, development, diagnoses, and more.

8- The Right to Family-Centered Care
Help me feel that I am a part of my own family. Teach my parents, grandparents, and siblings how to read my cues, how to care for me, and how to meet my needs. Encourage them to participate in or perform my daily care activities, such as bathing and diaper changes.

9- The Right to Healthy and Supported Parents
My parents may be experiencing a range of new and challenging emotions. Be patient, listen to them, and lend your support. Share information with my parents about resources such as peer-to-peer support programs, support groups, and counseling, which can help reduce PMAD, PPD, PTSD, anxiety and depression, and more.

10- The Right to Inclusion and Belonging
Celebrate my family's diversity and mine; including our religion, race, and culture. Ensure that my parents, grandparents, and siblings feel accepted and welcomed in the NICU, and respected and valued in all forms of engagement and communication.

Presented by:

NPN
NICU PARENT NETWORK

NICU Parent Network

Visit nicuparentnetwork.org to identify national, state, and local NICU family support programs.

*** The information provided on the NICU Baby's Bill of Rights does not, and is not intended to, constitute legal or medical advice. Always consult with your NICU care team for all matters concerning the care of your baby.**


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