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# The Pattern of Changes in Body Mass Index Before and During Pregnancy. The Maternal and Neonatal Outcome

Gamal Sayed, Husam Salama, Lina Abdulla, Sawsan Al-Obaidly, Mai Al. Qubasi, Ashraf Mansour

#### Abstract:

**Background**: Obesity compromises the health of a woman's pregnancy and her newborn.

**Aim:** To describe weight-gaining changes throughout pregnancy and evaluate outcomes for the mother and the baby.

Methods: A retrospective review of women who delivered singletons using a Large perinatal registry was undertaken. Based on their body mass index (BMI), patients were categorized into four categories: underweight, normal, overweight, and obese. Mode of delivery, gestational diabetes, hypertensive disorders, obstetric cholestasis, and postpartum hemorrhage (PPH) were the main maternal outcome measures. The newborn outcome indicators were birth weight, neonatal intensive care unit (NICU) hospitalization, premature birth, and stillbirth.

**Results:** The study sample included 2,352 natives (25.0%) and 7,058 expatriates (75.0%). Most of the sample (4,726) were aged 20-29; 43.6% were aged 30-39; 2.1% were aged 19; and 3.9% were aged 40 years. The incidence of hypertension, obstetric cholestasis, diabetes, postpartum hemorrhage, and cesarean section varied among the sample. In the underweight group, the incidence of cesarean section (C.S.) was 15.7%; in the normal weight group, 24.9%; in the overweight group, 31.3%; and in the obese group, 41.0%.

Hypertensive disorders were three times more prevalent in obese women than in normal-weight women (2,0%), and 5.3% of obese women had PPH compared to 5.6% of women of normal weight. The underweight group gained the most weight during pregnancy, whereas the obese group gained the least.

**Conclusions:** A significant proportion of pregnant women in our sample will become obese by delivery. Obesity during pregnancy is associated with adverse maternal and fetal outcomes.

**Keywords:** BMI, maternal outcome, neonatal outcome, Obesity, Qatar, pregnancy.

## **List of Abbreviations:**

BMI Body Mass Index

EMR Electronic Medical Record

GDM Gestational Diabetes Mellitus

HMC Hamad Medical Corporation

NICU Neonatal Intensive Care Unit

PPH Postpartum Hemorrhage

## Introduction:

Obesity has reached an alarming proportion around the world. This has been described as a "global epidemic" and a "major public health issue" by the World Health Organization (1). The expansion may be related to the evolving cultural, social, and economic

forces affecting numerous nations. Obesity has been more common in the general population since the 1990s, affecting both the general public and women of reproductive age, particularly pregnant women (2,3). Obesity during pregnancy increases the risks to both the mother and the newborn (4). Furthermore, it places pregnant women and their infants at risk for unfavorable pregnancy outcomes, including postpartum weight retention, which increases the potential for long-term obesity (5).

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Obesity is also an issue for healthcare workers. It has become one of the most severe healthcare complications for pregnant women in the last decade, putting an additional strain on healthcare systems, and there is a strong relationship between Body Mass Index (BMI) and healthcare spending (6).

"The obesity pandemic has also been prevalent in Qatar, a country with a population of 2.6 million, of which only 12.0% are natives. This country is rapidly modernizing, quickly becoming one of the world's largest liquid gas exporters, ranking in the top ten countries in per capita GDP (7-9)."

The obesity pandemic has also been prevalent in Qatar, a country with a population of 2.6 million, of which only 12.0% are natives. This country is rapidly modernizing, quickly becoming one of the world's largest liquid gas exporters, ranking in the top ten countries in per capita GDP (7-9). Women constitute around 25% of the country's population (10, 11). Rapid modernization, a diverse

population, increased availability of various varieties of food and fast food, a high intake of processed foods, and a lack of physical activity, among other things, have all been linked to an increase in the number of obese persons (7). According to the Qatar National Health Strategy, 70.1% of adults (including ex-pats and indigenous) residing in Qatar are either overweight (28.7%) or obese (41.4%) (9). This research aims to discover how BMI is distributed and changing among pregnant women in Qatar and how it affects pregnancy outcomes and other health consequences.

## **Study Methods:**

This study used data from the Qatar Pearl-Peristat Registry funded by The Qatar National Research Fund. The registry is a retrospective study focusing on maternal and newborn medical records from four government-run hospitals in the country, with information on the perinatal and postpartum periods. The private sector has been omitted from the registry because it accounts for less than 15.0% of all births in Qatar and does not use the same electronic health record system. Most of the registry data came from Cerner™ shared electronic medical records connecting all four government hospitals.

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In addition, a post-delivery social data questionnaire was used to collect socioeconomic and demographic health information about the parturient women's social status. Under the guidance of a full-time, qualified research associate, the registry research team comprises 12 research assistants who collect patient data directly from the family (social data) or through the electronic clinical data, Cerner™. The collected data was assessed and saved in software developed specifically for the Dendrite® database system, and it was analyzed with both Dendrite® and Statistical Package for the Social Sciences (SPSS®) version 21. The Medical Research Center of Hamad Medical Corporation granted ethical approval from the Pearl-Peristat Registry. For participants, no written consent was required. Before getting social data, participants provided verbal agreement and were handed patient information pamphlets.

The current study looked at the BMI of singleton babies at the four main state-run hospitals where women were delivered. The BMI was measured before pregnancy (or early in the first trimester), during the antenatal clinic visits, and at the time of birth.

## **Body Mass Index Calculation and Classification:**

In this study, pregnant women were categorized based on their Body Mass Index (BMI) into four groups as in non-pregnant women: underweight (BMI < 18.5), normal weight (BMI 18.5–24.9),

overweight (BMI 25–29.9), and obese (BMI ≥ 30) (12). The prepregnancy, booking, and delivery BMIs were calculated using hospital weight and height data. The BMI of everyone was computed by dividing their weight (in kilograms) by their height (in centimeters). For the analysis, the pre-pregnancy BMI variable was determined. The pre-pregnancy BMI is the BMI before pregnancy or the BMI during the first trimester of pregnancy. Moribund obesity has been combined with the "obesity" category to allow for more meaningful comparisons, referred to as obesity in this study. The following BMI categories were statistically compared: (1) "underweight," (2) "normal weight," (3) "overweight," and (4) "obesity."

#### **Outcome metrics:**

Maternal variables include maternal age, gravidity, parity, mode of delivery, gestational diabetes mellitus (GDM), hypertension, cholestasis, and postpartum hemorrhage (PPH). Neonatal variables included low birth weight (less than 2500 grams), gestational age less than 37 weeks, live births or stillbirths, and postnatal ward or neonatal intensive care (NICU) admission.

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## Statistics for analysis:

Descriptive statistics were generated using IBM SPSS 21 statistical software to understand the distribution of the variables. A two-sided P value of 0.05 was used to assess statistical significance. Both univariate and multivariate analyses were used in the modeling technique. We used univariate and multivariate logistic regression to evaluate the association between BMI and research findings. The univariate method was used to investigate the basic (unadjusted) association. A multivariable analysis was performed to investigate the relationship between BMI and pregnancy outcomes, considering the influence of other relevant confounding variables.

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## Results:

The study comprised 2960 single pregnant women who had their pre-pregnancy or early pregnancy BMI calculated. Underweight women accounted for 83, normal-weight women for 1053, overweight women accounted for 937, and obese women accounted for 887 (Table 1).

was 15.7% in the underweight group, 24.9% in the normal weight group, 31.3% in the overweight group, and 41% in the obese group. GDM was diagnosed in 37.5 percent of obese women, 31.8 percent of overweight women, 23 percent of normal-weight women, and 16.7 percent of underweight women. Hypertensive conditions were three times as common in obese women than in normal-weight women. Women who were overweight or obese did not have an increased risk of postpartum hemorrhage; 5.3% of obese women versus 5.6% of normal-weight women experienced PPH (Table 2). The proportion of overweight and Obesity among Qatari women was 32% and 37%, compared to 31% and 28% in non-Qatari women, respectively. Throughout pregnancy, the rate of obesity and overweight was noted to increase significantly; where only 29% of the sample size was labeled as obese in the pre-pregnancy period, the rate increased to 56% at delivery. In other words, the underweight group gained the most weight during pregnancy, whereas the obese group gained the least. The mean weight gain in underweight was 13 (±9 kg), 11(±6) in normal weight, kg 9 (kg ±6) in overweight, and 6.8 (±7 kg.) in obese women with a total weight gain of 9 (±7 kg) in all age groups (Figure 2).

Table 1: Distribution according to measured pre-pregnancy BMI category (2960 Women)

Variables	Underweight	Normal	Overweight	Obese	P*
	N= 83 (2.8%)	N=1053 (35.0%)	N=937 (31.6%)	N=887 (30.0%)	
Maternal age					<.0001
**≤19 years	0 (0)	29 (2.8)	15 (1.6)	10 (1.1)	
20-29 years	65 (78.3)	609 (57.8)	447 (47.7)	308 (34.7)	
30-39 years	15 (18.1)	397 (37.7)	440 (47)	503 (56.7)	
≥40 years	3 (3.6)	18 (1.7)	35 (3.7)	66 (7.4)	
Gravidity					<0.0001
1	37 (44.6)	362 (34.4)	199 (21.2)	115 (13)	
2-4	41 (49.4)	573 (54.4)	551 (58.8)	484 (54.6)	
≥5	5 (6)	118 (11.2)	187 (20)	288 (32.5)	
Parity					<0.0001
Nulliparous	42 (50.6)	433 (41.1)	246 (26.3)	144 (16.2)	
Multiparous ≥1	41 (49.4)	620 (58.9)	691 (73.7)	743 (83.8)	
Nationality					<0.0001
Qatari	18 (21.7)	182 (17.3)	212 (22.6)	242 (27.3)	
Non-Qatari	65 (78.3)	870 (82.7)	725 (77.4)	645 (72.7)	

<sup>\*</sup>Chi-square tests for association pre-gestation BMI and maternal age, gravidity, parity, and nationality. \*\* 19-year group had no underweight.

Obesity risk increased linearly as maternal age increased. Obesity was found in 19% of women younger than 20 years old, 22% of 20- to 29-year-old women, 37% of 30- to 39-year-old women, and 54% of women over 40 years old (Figure 1). The pre-pregnancy BMI was calculated to be 2,960. 2.8% (83) of women were underweight, 35.6% (1105) were normal weight, 31.6% (937) were overweight, and 30% (887) were obese, according to their pre-pregnancy BMI (Table, Figure 1).

Increased BMI increases the risk of cesarean section, gestational diabetes (GDM), and hypertension. The incidence of C.S.

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Table 2: Comparison of Maternal outcomes between underweight, Normal, Overweight, and Obese

	Under	Normal	Over	Obese	Over vs Normal		Obese vs Normal	
	(83)	(1053)	(937)	(887)				
	N	N	N	N	aOR*	p-value	aOR*	p-value
	(%)	(%)	(%)	(%)	(95% CI)		(95% CI)	
Cesarean	1 3	262 (25.0)	2 9 3	364 (41.0)	1.29	0.014	1.82	0.000
	(15.7)		(31.0)		(1.05–1.57)		(1.48–2.22)	
PPH	6	59	48	47	1.05	0.814	1.21	0.366
	(7.2)	(5.6)	(5.1)	(5.3)	(.70–1.56)		(.79–1.84)	
GDM	14	242 (23.0)	2 9 8	333 (37.5)	1.51	0.000	1.87	0.000
	(16.7)		(31.8)		(1.23–1.85)		(1.52–2.29)	
Hypertension	2	21	38	54	2.37	0.002	3.68	0.000
	(2.4)	(2.0)	(4.1)	(6.1)	(1.36–4.13)		(2.13–6.36)	
All types of D.M.	15	266	337	394 (44.6)	1.66	0.001	2.36	0.0001
	(18)	(25.4)	(36.1)		(1.37–2.01)		(1.95–2.86)	

<sup>\*</sup>Adjusted for maternal age, parity, and nationality. Underweight excluded from the analysis.

Table 3: BMI and Neonatal outcomes

	Underweight (83)	Normal (1053)	Overweight (937)	Obese (887)	Overweight vs Normal		Obese vs Normal	
	N (%)	N (%)	N (%)	N (%)	aOR* (95% C.I)	p-value	aOR* (95% C.I.)	p-value
NICU**	12	1 1 8	116	128 (14)	1.21	0.18	1.50	0.005
	(14.5)	(11.3)	(12.5)		(0.92 - 1.59)		(1.13 – 2.0)	
Stillborn	0	7	5	10	0.74	0.61	1.55	0.394
	(0.0)	(0.7)	(0.5)	(1.1)	(0.23 - 2.35)		(0.56 - 4.27)	
Preterm**	9	61	75	88	1.59	0.014	1.84	0.001
	(10.8)	(5.8)	(8.0)	(9.9)	(1.09 - 2.29)		(1.26 - 2.68)	
≤ 2499g**	11	75	54	66	0.90	0.595	1.13	0.543
	(13.3)	(7.1)	(5.8)	(7.4)	(0.61 - 1.32)		(0.77- 1.66)	
≥ 4000g**	1	32	63	62	2.12	0.001	2.09	0.001
	(1.2)	(3.0)	(6.7)	(7.0)	(1.37 - 3.29)		(1.33 - 3.28)	
Died in	0	2	1	2	0.56	0.41	1.19	0.17
DR/OT§	(0.0)	(.2)	(0.1)	(0.2)	(0.01 -6.20)		(0.17- 8.5)	

<sup>\*</sup>aOR: odds ratio adjusted for maternal age, parity, and nationality. Underweight excluded from the analysis.

The percentage of babies admitted to the neonatal intensive care unit (NICU) in the pre-pregnancy BMI-tested sample was higher for obese mothers than for women with a normal BMI. 14.6% of babies born to obese mothers were admitted to the NICU, compared to 11.3% of newborns born to normal-weight mothers. The probability of stillbirth in the obese group was not significantly high in the obese group. Preterm births were more common in the underweight (11.8%) and obese (9.9%) groups than in the normal

BMI (4.9%) group. It was typical for babies born to overweight or obese mothers to weigh more than 4000 grams. Just 7% of obese women had newborns weighing more than 4000 grams, compared to 3% of women with a normal BMI (Table 3).

### **Results of Logistic Regression:**

There was no link between overweight or obese and stillbirth or low birth weight. An above-normal BMI, on the other hand, was

<sup>\*\*</sup>Live-born only. § DR/OT= delivery room or Operating theater

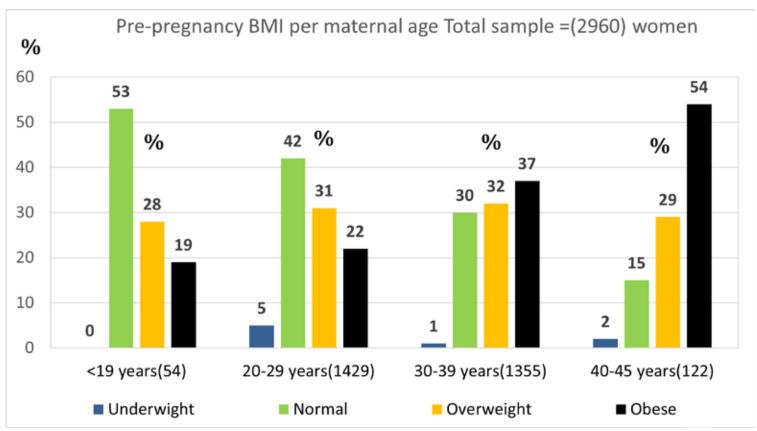
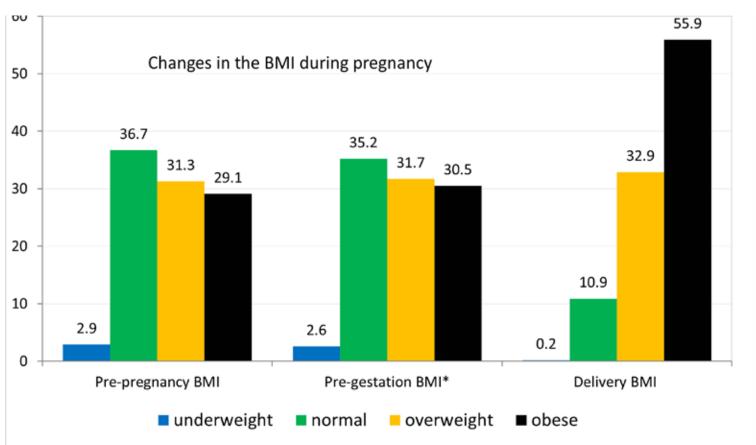


Figure 1: Pre-pregnancy BMI and maternal age. Older women are more likely to become obese.



**Figure 2:** During the first four weeks of pregnancy, there is no significant difference from the period before conception. However, at delivery, there was a noticeable change. A large percentage of pregnant women considered healthy, or underweight before their pregnancies will be classified as obese after giving birth.

linked to a 1.5-fold greater risk of preterm birth, macrosomia, and NICU hospitalization (see Table 3). Overweight women were 1.3 times more likely than normal-weight women to have a cesarean section, 1.5 times more likely to develop GDM, and two times more likely to have hypertensive issues. Obese women's traits were enhanced. They were twice as likely to have a cesarean birth, gestational diabetes, and hypertensive issues throughout pregnancy (Table 2).

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## Discussion:

The Maternal and Neonatal Registry data were used in this hospital-based study to learn more about the association between BMI and various perinatal outcomes in our population. Pregnant women with a high BMI were more likely to have a cesarean section, develop gestational diabetes, and develop hypertension in our study. For overweight and obese mothers, however, there was no increase in postpartum hemorrhage (PPH). PPH was found in 5.3% of obese women and 5.6% of average-weight women (Table 2). Various research studies have disputed the precise effect of Obesity on PPH. Our findings do support that weight is not a significant risk factor for postpartum hemorrhage, consistent with the previous research findings (13). However, another study encountered a positive relationship between obesity and postpartum hemorrhage, implying that as obesity levels rise, so will the incidence of atonic postpartum hemorrhage (14). Inconsistencies in definitions, variations in practices and health care systems, racial compositions, and study participant variability are all possible causes of the rise in PPH in various studies (13,14). One of the study's strengths is that it was carried out at a single institution with slight changes in some confounding variables found in other research.

"The risk of gestational diabetes (GDM) grows linearly with obesity. GDM was diagnosed in 37.5% of obese women, 31.8% of overweight women, 23% of normal-weight women, and 16.7% of underweight women."

The risk of gestational diabetes (GDM) grows linearly with obesity. GDM was diagnosed in 37.5% of obese women, 31.8% of overweight women, 23% of normal-weight women, and 16.7% of underweight women. This finding is consistent with previous research that shows that the higher the BMI, the higher the incidence of GDM (15). Obesity prevalence increased linearly with maternal age. Obese women increased from 19% in the 19–40 age group to 54% in the >40 age group. Obesity was more prevalent among natives than foreigners (Figure 1), and it is an essential factor to consider when counseling women of various ages. Basic health care and weight-loss programs should be emphasized more strongly in older age groups considering childbearing. Obesity is linked to aging, which raises the risk of insulin resistance and metabolic syndrome (16).

"Some of our study's participants may have gained more weight than necessary, putting them at risk of retaining extra weight after the pregnancy and reaping no legitimate advantage. In one study, 47% of pregnant women gained more weight than the Institute of Medicine (IOM) recommendations, implying an increased risk of adverse maternal and infant outcomes (19)."

In our study, mothers with a low BMI at the start of their pregnancy gained more weight than mothers with a higher BMI (Figure 2). This observation is worth debating. The allowable weight gain parameters during pregnancy are a source of significant debate. Weight gain ranges are not provided in the U.K. recommendations (16). The North American Institute of Medicine (IOM) recommends that underweight women gain up to 18 kg and obese women gain up to 9 kg. (18) Our findings can help with prenatal counseling and tailoring the optimal weight gain during pregnancy conversation. Some of our study's participants may have gained more weight than necessary, putting them at risk of retaining extra weight after the pregnancy and reaping no legitimate advantage. In one study, 47% of pregnant women gained more weight than the Institute of Medicine (IOM) recommendations, implying an increased risk of adverse maternal and infant outcomes (19). Given our findings and that Qatar is a cultural melting pot, fully adhering to IOM norms may not be prudent.

Six parameters were used in this study to examine the influence of greater BMI on neonatal outcomes (Table 3). The neonatal intensive care unit (NICU) admission was chosen as the criterion for measuring the physical status at birth and as an indicator of the effect of the mother's BMI on the baby's health. Underweight and obese mothers had a higher percentage of babies admitted to the NICU when compared to women with a normal BMI. Babies delivered to obese mothers were admitted to the NICU at a rate of 14.6%, compared to 11.3% of children born to normal-weight mothers (p=0.005). This finding is consistent with previous research that indicated an increased likelihood of newborn critical

care admission for infants born to obese mothers (20-22). In a study of 3,388 women, there were no differences in NICU admissions between obese and normal mothers (23). The disparity in findings may be due to differences in identifying and prioritizing infants who can benefit from NICU treatment among institutions.

Using birth weight as a proxy for intrauterine growth, researchers observed that the probability of delivering a baby weighing more than 4,000 grams rose as maternal BMI before conception increased. 7% of obese women had newborns weighing more than 4000 grams, compared to 3% of women with a normal BMI (p=0.001). This discovery adds to previous studies that found a 1.5–2.3% increase in the likelihood of obese mothers giving birth to large-for-gestational-age infants. Obesity in the mother is a well-known risk factor for rapid intrauterine growth, with fetal macrosomia consistently associated with a higher maternal body mass index (24). Obesity is significantly linked to the delivery of newborns in the 90th percentile (24).

Few researchers raised concerns regarding an association between obesity and an increased risk of stillbirth (26). In our report, the incidence of stillbirth was 1.1% in the obese group versus 0.7% in the normal BMI group with low significance (Table 3). In contrast, there were no stillbirths in the underweight group, confirming previous studies that found a reduction in stillbirths among mothers with a low BMI (27). There are several unresolved questions about the specific role of obesity on stillbirth.

"In our report, the incidence of stillbirth was 1.1% in the obese group versus 0.7% in the normal BMI group with low significance (Table 3). In contrast, there were no stillbirths in the underweight group, confirming previous studies that found a reduction in stillbirths among mothers with a low BMI (27). There are several unresolved questions about the specific role of obesity on stillbirth."

#### Conclusion:

Obesity and stillbirth are both challenging issues with multiple complicating factors. These risk factors for increased obesity may also place the baby at risk for stillbirth. As such, increasing BMI is a significant proxy to validate an increased risk for stillbirth. (27) Furthermore, because our study is based on a single institution with a diverse population, numerous confounding factors observed in earlier studies may not apply to this study. Based on our findings and previous reported data, we believe that encouraging weight loss programs before pregnancy can help reduce stillbirth rates in subsequent pregnancies in our demographic as well, in addition to the many benefits of weight loss. As well as following a more nutritional program during pregnancy to avoid unnecessary excessive weight gain by the end of pregnancy.

Weakness, Strengths, and Limitations:

The prospective cohort nature of this study is a major strength of our investigation. Because of the large cohort size, a phenotype may be chosen to investigate the effects of high BMI on maternal and infant outcomes. Several confounding variables associated with diverse healthcare systems or practices are avoided by conducting the study in a single institution (Hamad Medical Corporation) that follows the same clinical protocols and shares the same rotating medical and nursing staff with a reasonably large sample size. Furthermore, our findings can be applied to a broader range of populations because the study population and sample are distinct.

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# NOVEMBER 9TH FCC TASKFORCE WEBINAR



11-12:30PM PT



Helping Parents Cope in the NICU **Annie Janvier**, MD, PhD

- Professor of Pediatrics and Clinical Ethics at Université de Montréal
- Neonatologist and Clinical Ethicist at CHU Sainte-Justine



Next Level FCC: How FICare Can Benefit US NICUs

Linda S. Franck, RN, PhD, FRCPCH, FAAN (she/her)

- Professor & Jack and Elaine Koehn Endowed Chair in Pediatric Nursing
- University of California San Francisco
   Department of Family Health Care Nursing



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## Respiratory Syncytial Virus is a

# Really Serious /irus

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





www.nationalperinatal.org/rsv

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

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

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

\*Source: Respirator Syncytial Virus and African Americans

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



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



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## August 26-27, 2023 **WASHINGTON, DC**

Walter E. Washington Convention Center

## The 5th International PDA Symposium in Partnership with the 8th World Congress of Pediatric Cardiology and Cardiac

## Program highlights

Joint statement on management recommendations for PDA in the extremely premature infants from the International PDA symposium, World Congress of Pediatric Cardiology and Cardiology Surgery and the NeoHeart Society.

- In depth discussion of PDA treatment options in the extremely premature infants, indications, patient selection, follow-up, and outcomes.
- Examination of current evidence and clinical trials.
- Updates on ongoing clinical trials.
- Hands-on workshop on performing echocardiography to image the PDA in the newborn.
- Hands-on workshop on transcatheter device closure of the PDA in the newborn.
- Debates on whether PDA needs to be closed or not, timing of PDA closure, techniques of PDA closure and interventions to keep the PDA patent in the newborn period.
- Case discussions including taped cases of transcatheter PDA closures.
- Meet the experts session.
- Abstract presentations.
- Updates in interventional techniques to treat PDA is in the extremely low birth weight infants.
- Discussion of long-term outcomes of extremely low birth weight infants with PDAs.
- Global trends in PDA management in the extremely premature

## **Featured Speakers**

































8th World Congress of Pediatric Cardiology and Cardiac Surgery AUGUST 27 - SEPTEMBER 1, 2023 WASHINGTON D.C.





## First Candle: Understanding and Addressing Infant Loss Bereavement is the Focus of the October 2023 Conferences

Barb Himes, CD

As the research, medical, and healthcare professions continue their dedicated work to reduce infant mortality, the reality is that infants do die, and their deaths do leave an emotional mark on the universe of family, friends, and caregivers that surround them.

Understanding and acting on the effects of grief and bereavement are critical and necessary for the health of those affected by infant loss, and in October 2023, two conferences will focus on aspects of this need.

Examining causes of infant death, the latest research, and addressing bereavement will feature in the biennial **International Conference on Stillbirth, SIDS, and SUDI (ISPID)**, to be held in Florence, Italy, 5 – 8 October 2023. This conference is *Baby Survival: Global Achievements and Future Challenges* and is open to professionals, families, students/medical residents, and individuals worldwide. The programs and workshops will cover advances in epidemiology, pathology, physiology, prevention, and bereavement. Topics include sessions on, among others:

- SIDS pathophysiology and SUID and Stillbirth epidemiology
- SUID Bereavement
- SUIDS and SIDS pathology
- Genetics and Metabolomics
- Individual sessions include topics on, among others:
- Deaths in the neonatal units A parental perspective on guidelines for professionals.
- Improving support available for healthcare professionals experiencing professional grief and loss in response to neonatal death within a neonatal intensive care unit in a tertiary maternity hospital.
- A Genomic Investigation of Sudden Unexpected Postnatal Collapse in Hospitalized Neonates.

Some conference topics are a reminder that those affected by infant loss include healthcare professionals themselves. They become part of the family's fabric during perinatal care and should a perinatal or infant death occur. It does happen that the families will continue to reach out to the neonatology professionals they have come to know as they weather their grief.

In addition, a new training initiative that will be held immediately after the conference is the ISPID Peer Support Program, an international certification program designed to provide individuals with the skills and knowledge needed to support bereaved families. Its first session will occur on 8-9 October in Florence, and conference attendance is not required. ISPID committee members have developed the program in partnership with Harvard Medical School.

Those enrolling in the program will learn about current research in bereavement and peer support and the hands-on and practical skills needed to facilitate groups. Information about the ISPID Conference presentations and workshops and the certification program can be found at <a href="https://ispid2023florence.com/">https://ispid2023florence.com/</a>.

In the United States, First Candle will be hosting an **Infant Loss and Stillbirth Bereavement Conference** on October 21 in Connecticut. The one-day live/remote hybrid conference is directed at parents.

"It's difficult for friends and colleagues to truly understand someone's grief after losing their precious baby," said Alison Jacobson, chief executive of First Candle. "The conference will allow them to meet other families experiencing the same thing they are and learn how to navigate the grief journey and find healing practices."

### Sessions will include:

- A three-hour workshop with Kelly Farley, author, speaker, and founder of <u>Grieving Dads</u>. He and his wife have suffered loss through miscarriage and stillbirth, which has led to his ongoing work with bereaved fathers.
- Respecting Your Partner's Grief Style.
- Managing a Sibling's Grief.
- Healing through Art, led by <u>Asami Green</u>.
- A Rainbow Baby, Maybe? Understanding the mixed feelings around having another baby and the possible fear and anxiety.
- The conference will also include a celebration of life to remember all our babies gone too soon.
- Information and registration can be found at <u>www.firstcan-dle.org</u>.

About First Candle: First Candle, based in New Canaan, CT, is a 501c (3) non-profit corporation committed to eliminating Sudden Unexpected Infant Death while providing bereavement support for families who have suffered a loss. Sudden Unexpected Infant Death (SUID), which includes SIDS and Accidental Suffocation and Strangulation in Bed (ASSB), remains the leading cause of death for babies one month to one year of age, resulting in 3,500 infant deaths nationwide per year.

**Disclosures**: The author is a Certified Doula and the Director of Education and Bereavement Services at First Candle, Inc.

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January 22-25, 2024 Baltimore, MD In-Person

## **NeoCram**

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> March 22-24, 2024 Scottsdale, AZ In-Person

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## Ethics and Wellness Column: What Happens After a Wrongful Accusation?

Mitchell Goldstein, MD, MBA, CML, Mita Shah, MD, Munaf Kadri, MD, T. Allen Merritt, MD, MHA, Elba Fayard, MD

The title of this piece makes it sound too much like a legal question that involves patient care, but in this case, it is not. Instead, this situation can arise when a physician is accused of something, be it an action, inaction, failure, or mistake that subsequently turns out to be misstated or flat-out wrong (1). These instances are increasingly common even as we work to figure out ways to cast aside individualized blame and work towards systems improvement.

"The title of this piece makes it sound too much like a legal question that involves patient care, but in this case, it is not. Instead, this situation can arise when a physician is accused of something, be it an action, inaction, failure, or mistake that subsequently turns out to be misstated or flat-out wrong (1)."

A medical director or division chair is typically involved in the "initial" encounter. In many situations, the "investigation" has concluded, and the accused is guilty until proven innocent. This supervisor may be incredulous that the accused has no recollection or a different recollection of the incident. The issue is often so compelling that the accused faces punishment or some action of compunction designed to remediate the deficiency. The wrongfully accused's hurt and perceived loss of face is almost too much to bear.

In many cases, there is a loss of trust, compassion, and a feeling of exile from the team dynamic. Indeed, the initial punitive response may involve separation from the institution or relegating the individual to a less prestigious position. If not, this individual is at high risk of leaving that institution in search of another position where they feel they can be treated fairly.

"In many cases, there is a loss of trust, compassion, and a feeling of exile from the team dynamic. Indeed, the initial punitive response may involve separation from the institution or relegating the individual to a less prestigious position."

If there is a recognition by the leadership team of its error before this individual has left the institution or been relegated to a position from which they cannot recover (e.g., transferred or referred to another department or division), how does reconciliation take place? Indeed, the first step is an apology, but is this enough? A simple apology is never enough; it is merely a first step. Often, there has been such a significant trajectory change experienced by the accused that subsequent opportunities are kept from them based on a misunderstanding of the facts. Let us look at an example.

Suppose a programming or configuration error in the electronic health record was to prevent other physicians from seeing notes authored by a physician (2). In that case, it may be "reasonably" concluded that the physician in question is not preparing patient notes or making only minimal changes to the notes authored on a day-by-day basis. This information is passed on to nursing, the other physicians in the group, the practice's medical director, and finally to the accused individual. The physician in question, the accused, is identified as a problem and is then "finally" made aware of the deficiency - days to months after the process has begun. What happens when it is determined that the notes were completed and updated but not visible to the accuser? The accuser indicates to the accused that the notes have been found but does not necessarily apologize. There is vindication, but the damage is done. Aside from the initial accuser, everyone believes the accused still has a problem with note writing. It may show up in evaluations, perceptions of this individual as a less than-careful physician, loss of leadership opportunities, and predilections to additional accusations in the future. When another issue occurs in the unit, the accused's name will always rise to the top of the usual suspects.

"Why is it that the apology cannot undo the accusation? It is because the apology was incomplete. No one knows that it occurred. Where accusations have a broad base and involve many individuals so that a pattern can be "identified," apologies are generally very private affairs that involve a single accuser and the accused."

Why is it that the apology cannot undo the accusation? It is because the apology was incomplete. No one knows that it occurred. Where accusations have a broad base and involve many individuals so that a pattern can be "identified," apologies are generally very private affairs that involve a single accuser and the accused. The accuser may use particular language to avoid indemnifying their apology, such as, "This time you were not to blame," "We

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will watch to make sure this issue does not occur again," or "You should feel relieved that we have resolved this issue." The accused still feels on edge, barely legitimized, but no one else knows that the issue has been resolved in favor of the accused. Everyone else involved in the initial accusation is still of the impression that the accused is guilty. Indeed, they may be of the impression that the accused "got off easy," "was given another chance," or "used influence" to avoid having to answer the initial concern. An apology is just the start of the process.

The team philosophy in QA/QI process improvement needs to find its position in the apology to the team member wrongly singled out for correction (3). As we should avoid blaming the individual in the first place and look for systemic problems that contribute to errors or omissions, we should look for team and system modalities of recognizing and alleviating the harm done to the individual. Everyone aware of the accusation must be made aware of the apology. Those who were complicit or complacent in the process must also apologize. There must be no equivocation or attempt to save face. The accusers were wrong. Further, depending on how the accusers handled the issue, they may be subject to discipline instead and, at the very least, required to read a manuscript like this one so that they understand the consequences of their actions (4).

"As we should avoid blaming the individual in the first place and look for systemic problems that contribute to errors or omissions, we should look for team and system modalities of recognizing and alleviating the harm done to the individual."

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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 alcoholbased sanitizers

## Limit Contact with Others

- Stay home when you can.
- Stay 6 feet apart 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-skir
- 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.



# VARNING

## 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.

www.nationalperinatal.org/COVID-19



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March 6-9, 2024

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## **Letters to the Editor**

Letter to Editor: "Gravens by Design: Family Integrated Care: An Evidence-Based and Inclusive Model for Delivering on Your NICU's Commitment to Family-Centered Care"

Dear Editor,

It is with great interest that I read "Gravens by Design: Family Integrated Care: An Evidence-Based and Inclusive Model for Delivering on Your NICU's Commitment to Family-Centered Care" Franck, L; O'Brien, K (Gravens by Design: Family Integrated Care: An Evidence-Based and Inclusive Model for Delivering on Your NICU's Commitment to Family-Centered Care, Neonatology Today. June 2023; 82-83).

"Some of the improvements that I thought were particularly compelling for family involvement in neonatal healthcare include robust self-regulation of the neonate, fewer challenges with sleeping, and improved mental health for mothers and fathers. Their paper encouraged the implementation of FICare as a starting point and then tailoring aspects of this integrated model to each NICU's and patient's needs."

In this article, Drs Franck and O'Brien advocate for neonatal care involving family members in the healthcare team. The authors provide details on a care model, Family Integrated Care (FICare), and the promising research results on patient outcomes in NICUs where this model was implemented. Some of the improvements that I thought were particularly compelling for family involvement in neonatal healthcare include robust self-regulation of the neonate, fewer challenges with sleeping, and improved mental health for mothers and fathers. Their paper encouraged the implementation of FICare as a starting point and then tailoring aspects of this integrated model to each NICU's and patient's needs. Due to the importance of community and relationships on a child's survival and wellbeing, I thought it necessary to elaborate further on this topic.

The thought of having a loved one, let alone your newborn baby, with incomprehensible healthcare needs in the intensive care unit is stressful. Fear, anger, guilt, and powerlessness are a few feel-

ings that can describe a parent's feelings when their child is in the NICU (1). The period immediately after birth is a time of crucial family bonding, and this is often right when the baby is whisked away to the NICU, leaving the parents in further confusion and mental disarray. Up to 20% of mothers of hospitalized infants experience depression. About 35% of mothers and 24% of fathers experience acute stress disorder in the days after their newborn is hospitalized, with 15% of mothers and 8% of fathers experiencing ongoing PTSD symptoms (2). In addition to parents, other family members can also be involved; however, for clarity, this letter will focus on parental involvement.

"Parents can feel left out and insufficiently involved in their newborn's healthcare plan, just as an adult patient may feel helpless and lost if they do not control their own healthcare. NICU patients do not have autonomous decision-making capacity. Thus, having the parents be more involved in their infant's healthcare can be beneficial because more informed choices can be made with more knowledge about the healthcare plan and NICU environment."

Not only is the healthcare team tasked with communicating the healthcare plan to the parents and obtaining consent, but also, the doctors and nurses must educate the parents about the highly technologized environment that is the NICU while empathizing with them. Despite this, parents of babies in the NICU report that they were met with professionalism, good information-giving, and empathy. However, their negative comments focused on organizational problems, including impaired communication between departments, continuity, and being met with different staff members each time (3). Parents can feel left out and insufficiently involved in their newborn's healthcare plan, just as an adult patient may feel helpless and lost if they do not control their own healthcare. NICU patients do not have autonomous decision-making capacity. Thus, having the parents be more involved in their infant's healthcare can be beneficial because more informed choices can be made with more knowledge about the healthcare plan and NICU environment. Being part of the healthcare team and knowing what is going on with their child can replace helplessness and fear with empowerment and hope.

With the immense and honorable task of caring for a premature infant who has just entered this world, the healthcare team has many responsibilities. Involving parents can relieve some of the burden on the healthcare team. Family-centered care is associated with several positive outcomes, such as efficient use of services, better health status, improved communication, and greater family functioning (4). In particular, the increased family functioning has the potential for more significant benefits even after the infant is discharged from the NICU. Additionally, with greater family

involvement, solace can be found in the company of others going through the same stressful event. Even having parents around during physician rounds has enhanced decision-making, a better understanding of care plans, and increased feelings of inclusion and teamwork (4). It does raise concerns about confidentiality by having family members in the NICU during the ongoing care of multiple patients who are often in the same room and within earshot, as well as increased confusion about medical terms and NICU technology (4). Nevertheless, with family-centered care, there is a higher potential for collaboration with the valuable resources of the NICU, including social work services, peer and family support, and culturally competent services.

"In addition to the healthcare benefits of the patient, the outcomes extend beyond the patients and into their lives. With parents in the NICU, the possibility of bonding with their child can outshine the numerous health scares of their child. It was found that greater social integration and family bonding lower the risk of physiological dysregulation in early and later life (6)."

In addition to the healthcare benefits of the patient, the outcomes extend beyond the patients and into their lives. With parents in the NICU, the possibility of bonding with their child can outshine the numerous health scares of their child. It was found that greater social integration and family bonding lower the risk of physiological dysregulation in early and later life (6). It is nothing new that a fundamental characteristic of human society needs to participate in healthy relationships for wellbeing. With a greater sense of control and familiarity with what is going on with their child, parents may breathe a sigh of relief in knowing more about the "hows" and the "why's" of the NICU and feel a sense of satisfaction that they know more about what is happening with and within their baby. Not all parents may be able to come to the NICU, perhaps due to work hours, childcare, and other responsibilities. Nevertheless, involvement in their child's care would still help more than not being involved.

So, what could family-centered care look like? The following could be implemented based on the facilities' resources. Firstly, parents could get oriented to the NICU with familiarization of the technologies and terminologies used. From a presentation workshop to brochures to in-person orientation, there are many ways that this can be accomplished. Parents can also be involved in support groups to help deal with the stresses and traumas of seeing their child with so many tubes and lines and knowing the procedures their child is going through.

Moreover, if something has happened to their baby or needs to be changed immediately, a parent's first thought might be, "I want to see my baby." This could be accomplished by having overnight rooms at the NICU so parents can stay overnight and stay with their babies throughout their admission. If changes are made to

the baby's plan, they can be accessible to hear what the health-care team is thinking and be with their child to comfort them. Family-centered care would allow the resources to be in place so that the family unit can still function as much as possible despite the baby being in the NICU. Of course, this would take some getting used to on the part of the healthcare team that would have to communicate more with the parents. However, I believe this could bring more benefit than harm not only for the baby but also parents and the functioning of the family as a unit. This would help

"Likewise, gender-affirming surgery can impact pregnancy and be delayed if pregnancy is desired. The preconception phase is also an appropriate time to screen for adverse health conditions and promote risk-reducing behaviors."

the baby beyond their NICU admission.

With the long-standing and growing trend of integrative care homes, the NICU is no exception to this trend. In a time when the healthcare system has been put to the test (such as throughout COVID19 era), it is now more important to be creative and fortify our healthcare system to withstand future challenges involving family-centered care. The barriers to integrating families in NICU care must be elucidated and mitigated. Possible barriers could be not knowing where to start, in which case, the FICare model is an excellent foundation for building a family-integrated care model. However, other barriers may include insufficient staff members, inability to train others, or finances. With sincerity and gratitude, I thank the NICU doctors, nurses, and all parts of the healthcare team for continuing to provide care to these patients every day with a positive attitude.

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Sincerely,

Bhumika Patel, OMS III

Western University Health Sciences.

Dear Doctor to be Bhumika Patel:

The commentary on "Gravens by Design: Family Integrated Care: An Evidence-Based and Inclusive Model for Delivering on Your NICU's Commitment to Family-Centered Care," recently published in Neonatology Today (June 2023; 82-83), has provoked a strong interest and prompted a profound reflection on the importance of family involvement in critical healthcare settings.

The comprehensive exploration of the Family Integrated Care (FI-Care) model and the compelling research findings from NICUs that have embraced this approach illuminate its potential for transformation. Notably, the significant impacts on neonatal self-regulation, sleep patterns, and the mental well-being of both parents are worth noting. The suggestion to establish FICare as a foundational framework and then tailor it to address the distinctive requirements of each NICU and patient presents a practical and actionable path toward optimal outcomes.

The discussion on the emotional challenges parents of NICU patients face resonates deeply. The disruption of the essential bonding phase shortly after birth due to NICU admissions underscores the urgency of addressing this issue. Statistics revealing parental depression, stress disorders, and ongoing PTSD symptoms emphasize the critical need for reform.

Recognizing the complexity of effectively conveying medical plans, nurturing empathy, and educating parents within the NICU context is vital. Acknowledging positive communication aspects and the need for organizational improvements provides a well-rounded perspective. Drawing parallels between parental involvement in neonatal care and an adult patient's engagement in healthcare decisions underscores the power of knowledge and active participation.

The argument favoring family-centered care yielding efficient resource utilization, improved health statuses, better communication, and enhanced family functioning aligns with logic and empathy. The potential for sustained benefits beyond NICU discharge is particularly compelling. The testimony of parents' involvement during physician rounds elevating decision-making and teamwork further underscores the value of collaboration.

"The argument favoring family-centered care yielding efficient resource utilization, improved health statuses, better communication, and enhanced family functioning aligns with logic and empathy. The potential for sustained benefits beyond NICU discharge is particularly compelling."

Anticipating potential challenges, such as privacy concerns and comprehension of medical terminology, exhibits a holistic approach. Balancing the benefits of family involvement with these considerations is pivotal for a successful transition toward a family-centered approach.

The discussion on the emotional and societal implications of

family-centered care resonates deeply. Emphasizing the positive impact of social integration and family bonding on physiological well-being underscores the intricate relationship between relationships and health. The emphasis on understanding the intricacies of NICU care to alleviate parental anxiety and foster a sense of control is a crucial takeaway. Acknowledging diverse circumstances that might hinder physical presence in the NICU reflects an inclusive mindset.

The proposed strategies for implementing family-centered care, encompassing orientation workshops, support groups, and accessible overnight rooms, are both pragmatic and heartening. Providing parents the opportunity to be present during critical moments and decisions promises to nurture family units amid challenging circumstances.

"The call to action to embrace family-centered care as a cornerstone of evolving healthcare is timely and inspiring.

Addressing potential obstacles while advocating for family integration reflects a commendable approach. Expressing gratitude to NICU healthcare providers for their unwavering dedication is a testament to the collaborative effort required to effect transformative changes."

The call to action to embrace family-centered care as a cornerstone of evolving healthcare is timely and inspiring. Addressing potential obstacles while advocating for family integration reflects a commendable approach. Expressing gratitude to NICU healthcare providers for their unwavering dedication is a testament to the collaborative effort required to effect transformative changes.

This thought-provoking letter is greatly appreciated, as it undoubtedly contributes to shaping a compassionate, informed, and inclusive future for neonatal care. The anticipated positive impact of this work on this crucial aspect of healthcare is eagerly anticipated.

Sincerely,

Sincerely,

mountill.

Mitchell Goldstein, MD, MBA, CML

Editor in Chief



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c/o Mitchell Goldstein, MD

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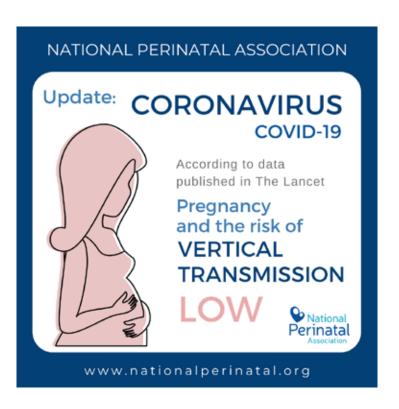
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Neonatology Today is not aware of the erratum affecting the July, 2023 edition.

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## **A Review of Infantile Hemangiomas**

Kundan Malik' MS, Tram Dinh' MS, Saba Saleem, DO, MPH, Luna Samman

#### Introduction:

Infantile hemangiomas (IHs), the most prevalent vascular tumors among infants, have garnered considerable attention due to their unique characteristics and clinical challenges. These tumors, initially defined distinctively by Mulliken and Glowacki (1982), emerge postnatally, undergo phases of proliferation and involution, and typically regress over time (1,2). While many IHs resolve without complications, some may lead to impairment of vital functions, scarring, or disfigurement. The complex pathogenesis of IHs remains enigmatic, with various risk factors implicated in their development. Correct diagnosis and appropriate treatment are crucial aspects of managing IHs. This article will review the current literature on the risk factors, pathogenesis, clinical presentation, treatment, and prognosis of IHs.



Figure 1. Resolving infantile hemangioma on arm after treatment (17).

"Infantile hemangiomas (IHs) are multifactorial vascular tumors whose etiology involves a combination of genetic predisposition and environmental factors. Female sex has been identified as a consistent risk factor, with IHs occurring more frequently in girls."

#### **Risk Factors:**

Infantile hemangiomas (IHs) are multifactorial vascular tumors whose etiology involves a combination of genetic predisposition and environmental factors. Female sex has been identified as a consistent risk factor, with IHs occurring more frequently in girls. Prematurity, low birth weight, and Caucasian ethnicity have also been associated with an increased likelihood of IH development (5). Additionally, there is a higher prevalence of IHs among infants with a family history of these tumors, suggesting a genetic component. Maternal factors such as advanced maternal age and certain pregnancy-related conditions, like preeclampsia, have been explored as potential risk factors, though further research is needed to elucidate their precise contributions (6,7). While these factors offer insights into the complex pathogenesis of IHs, ongoing research is necessary to understand the interplay between genetic susceptibility and environmental influences better.

## Pathogenesis:

Infantile hemangiomas (IHs) are infancy's most common benign vascular tumors, characterized by rapid growth during the first few months of life, followed by gradual regression over several years. The pathogenesis of IHs involves complex interactions between genetic, hormonal, and environmental factors (8). Recent studies have highlighted the role of somatic mutations in genes such as GLUT1 (SLC2A1) and KRAS, which contribute to the aberrant endothelial cell proliferation observed in IHs (7,8). These mutations lead to dysregulated angiogenesis, vasculogenesis, and vascular

"Infantile hemangiomas (IHs) are infancy's most common benign vascular tumors, characterized by rapid growth during the first few months of life, followed by gradual regression over several years."

Risk severity	Manifestation			
Low	IH >2cm on trunk WITHOUT sharp transition to unaffected skin OR <2cm on extremities			
Intermediate	IH >2cm on trunk with sharp transition to unaffected skin or rapidly evolving OR focal perineal WITHOUT ulceration			
High	Any IH w/ ulceration or if located on:  • Large (>5cm) truncal or extremity IH  • Breast  • Oral mucosa  • Neck or scalp >2cm (during a growth phase)  • Face  • Nasal tip or lip of any size  • OR if >1cm at <3mo  • OR >2cm at ≥3mo			
Highest	Large or segmental scalp, face, lumbosacral, perineal IH, OR >5 IH with abdominal U/S findings of IH OR any periorbital IH impacting vision, eyelids, or causing ptosis or proptosis			

Figure 2. Table adapted from Frieden et al. 2020 outlining the levels of severity with the clinical presentations to determine management (15).

maturation, ultimately forming the hemangioma (9).

Moreover, emerging research has demonstrated the involvement of various signaling pathways, including the Rho/ROCK, VEGF, and Notch pathways, in the pathogenesis of IHs. These pathways contribute to endothelial cell proliferation, migration, and survival, as well as interactions between endothelial cells and pericytes. Recent studies have also highlighted the potential influence of immune dysregulation in IH development, focusing on the role of macrophages, T cells, and cytokines in promoting angiogenesis and inflammation within the tumor microenvironment (9). While advances have been made in understanding the pathogenesis of IHs, further research is needed to uncover the intricate molecular mechanisms underlying their initiation, growth, and involution, which could potentially lead to more targeted and effective therapeutic interventions (7,9).

"While advances have been made in understanding the pathogenesis of IHs, further research is needed to uncover the intricate molecular mechanisms underlying their initiation, growth, and involution, which could potentially lead to more targeted and effective therapeutic interventions (7,9)."

#### **Diagnostic Challenges:**

The diagnosis of infantile hemangiomas (IHs) poses a multifaceted challenge owing to their heterogeneous clinical presentations and potential overlap with other cutaneous and subcutaneous conditions, common sequelae prior to initiation of therapeutic measures include ulceration (16). Consequently, accurate diagnosis and appropriate management are pivotal in preventing complications and optimizing outcomes. IHs often exhibit characteristic features, yet atypical manifestations may mimic various congenital or acquired anomalies, necessitating a comprehensive diagnostic approach. Differential diagnosis involves discriminating between IHs and vascular malformations, vascular tumors, or other dermatological conditions, particularly when IHs deviate from the prototypical raised, red appearance (13). Moreover, the natural evolution of IHs, marked by initial proliferation followed by involution, further complicates diagnostic certainty. In certain instances, IHs may also be associated with underlying syndromes or systemic anomalies, warranting a thorough evaluation to ascertain their clinical implications. Whether diagnosis occurs following an in-person or telemedicine examination, the most crucial point in diagnosis is risk stratification to initiate treatment when indicated (15, Figure 2). Integration of clinical assessment, imaging modalities such as ultrasound or MRI, and histopathological examination remains essential for accurate diagnosis and appropriate management of IHs.

"Various treatment options exist, with nonselective beta-blockers, particularly propranolol, emerging as the preferred agents. These medications have demonstrated efficacy in halting proliferation and accelerating involution."

#### Management:

Various treatment options exist, with nonselective beta-blockers, particularly propranolol, emerging as the preferred agents. These medications have demonstrated efficacy in halting proliferation and accelerating involution. Furthermore, treatment with propranolol requires minimal monitoring, such as vital sign checks, to ensure safety during the treatment course (14). Early intervention, specialist collaboration, and tailored follow-up plans are essential for IH management, ensuring optimal outcomes and minimizing potential morbidities. Complications in management include rebound IH following a course of propranolol that may occur in roughly 25% of children, necessitating further treatment (16).

Managing infantile hemangiomas (IHs) involves a range of therapeutic approaches tailored to each lesion's specific characteristics and clinical course. Pharmacological interventions have been a cornerstone of treatment, with oral propranolol emerging as a first-line therapy for rapidly proliferating IHs (10). Propranolol, a non-selective beta-blocker, has shown remarkable efficacy in reducing hemangioma size and improving appearance. Topical beta-blockers, such as timolol, have also demonstrated success, particularly for smaller, superficial IHs (11).

Other systemic options include oral or intralesional corticosteroids, which can be effective for certain IHs, especially those less responsive to beta-blockers. Laser therapies, such as pulsed dye laser (PDL) and Nd: YAG laser, have been used to target vascular components of IHs and can benefit specific cases, particularly those with residual telangiectasia (11,12).

A multidisciplinary approach involving dermatologists, pediatricians, and other specialists may be necessary to ensure comprehensive management and minimize potential complications in complex or refractory cases.

"Infantile hemangiomas (IHs) present a complex and intriguing clinical entity, necessitating a multifaceted approach to understanding their risk factors, pathogenesis, diagnosis, and management. The evolving research landscape has shed light on genetic predisposition, environmental influences, and intricate molecular pathways contributing to IH development."

#### Conclusion:

Infantile hemangiomas (IHs) present a complex and intriguing clinical entity, necessitating a multifaceted approach to understanding their risk factors, pathogenesis, diagnosis, and management. The evolving research landscape has shed light on genetic predisposition, environmental influences, and intricate molecular

pathways contributing to IH development. While diagnostic challenges arise from the diverse clinical presentations and potential overlap with other conditions, an integrated diagnostic strategy involving clinical assessment, imaging modalities, and histopathological examination remains pivotal. Management of IHs has seen significant advancements, with nonselective beta-blockers like propranolol emerging as a cornerstone treatment, complemented by other systemic options and laser therapies. The collaboration of multidisciplinary healthcare teams underscores the importance of a comprehensive approach to IH care, ensuring optimal outcomes and minimizing potential morbidities.

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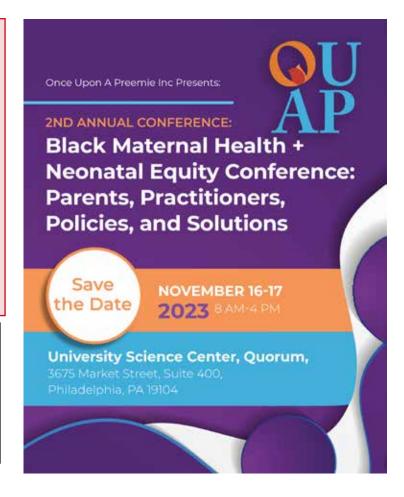
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# Improvisation in High-Reliability Organizing (HRO): 2. A Function that Closes Gaps

Daved van Stralen, MD, FAAP, Sean D. McKay, Element Rescue, LLC, Thomas A. Mercer, RAdm, USN (Retired)

#### Abstract

We encounter the unexpected without previous preparation. Likely, this occurs from energy entering our environment as a forcing function or causing abrupt change. Some rules continue to apply while others do not — and we cannot know which is which. Our theories and concepts become separated from our practice and what we are experiencing. Improvisation closes that gap, but not through trial and error. We act and begin learning by doing. As we learn, we adjust our actions to changing situations — this is motor cognition. Our actions generate information and create structure. Responding at the local level leads us to self-organizing improvisation. Improvisation is optimism. Improvisation is where resilience begins.

"Critically, improvisation operates in the transitional, or liminal, state between stability and the flux of events from uncontrolled energy (3). The brain rapidly adapts cognition and behaviors to abrupt change. Lastly, improvisation is optimism – if there is not a path now, we will soon develop one."

## Introduction

The problem of improvisation is its reputation of "trial and error," the "cowboy," and "freelancing," or the question posed by a new PICU nurse, "Do you know what you're doing?" (Personal experience, DvS.) Nevertheless, improvisation solves the gap between theory and practice (1) or between classical logic and logic practice (2). Critically, improvisation operates in the transitional, or liminal, state between stability and the flux of events from uncontrolled energy (3). The brain rapidly adapts cognition and behaviors to abrupt change. Lastly, *improvisation is optimism* – if there is not a path now, we will soon develop one.

Improvisation describes our actions when encountering an unexpected event (4, 5). This is not an element of HRO, a tool in an already heavy toolkit, nor a skill learned in training. Improvisation is how the High-Reliability Organization organizes into High-Reliability Organization o

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ability *Organizing*. Improvisation is the function of High-Reliability *Operations*.

We may encounter the unexpected without previous preparation. Our initial responses are "spur of the moment" before we become aware of the magnitude of the situation. Often, we have only immediately available resources. Initial leadership is the first person to identify a discrepancy or encounter a disruption. Hope will not help you. If you do not have it, then it does not exist. We do have improvisation.

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The improvisation functions have adaptive significance for survival value. The act of improvising initiates *motor cognition* to support *learning by doing*. Significant information is generated, and structure forms as improvisation continues.

### Trial, Error, Cowboys, and Freelancers

The first belief we encounter during discussions about improvisation is that individuals will "go rogue," randomly use "trial and error," operate as if they were renegade "cowboys," or irresponsibly "freelance." As indicated, the organization can address any maladaptive behavior through education or discipline. However, the organization that depreciates improvisation as an adaptive operation should also become prepared to fail.

## Trial and Error

Duncan Dieterly (6) described the three elements of a problem: the situation, intervention, and objective. Knowing all three makes the problem *trivial* and quickly dealt with using rules and protocols. Knowing the situation defines the problem; we only need to identify an effective intervention or acceptable objective. Knowing the initial situation leads us to select the decision tree, algorithm, or clinical pathway. The trivial and defined problem focuses on the proper diagnosis and appropriate efforts to diagnose.

In this manner, the problem is prepared for the problem-solver solution space. That is, the individual operates in a precisely specifiable domain where the solution is known to lie. These limitations on uncertainty form what Herbert Simon (7) defined as the "well-structured problem." Herbert Simon defined these problems as having a precisely specified process of trial and error that will lead to a desired solution in a practical amount of time (7).

Error has come to be considered as an action deviating from what is prescribed rather than a means of identifying novel or changing circumstances. We, too, readily think of trial and error as a non-selective search for information and a rapid, cursory evaluation of data. The person only considers limited alternatives and does not review their decisions. Thought processes are simplistic and easily disrupted. If an action is not fruitful, the person develops a new action plan, continuing this cycle in response to local successes and failures.

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However, Irving Janis and Leon Mann (8) identified this pattern as *hypervigilance*. This is one of five patterns of *conflicted decision-making* they identified as responses to abrupt stress. The other four patterns are unconflicted adherence, unconflicted change, defensive avoidance, and vigilance. Janis and Mann studied stress from unexpected threats, specifically when faced with time pressure, having no good choices, restrictions on activity, sensory deprivation, and lack of contact with supportive people.

However, problem-solving as trial and error is directed toward a solution rather than a random selection of actions. The individual has some knowledge and insight toward a solution to the direction in which a solution might lie. Trial and error approaches are better described as trial, fail, learn, revise, and then trial again (8). This is not a random selection of an action to see what works or the gratuitously pejorative phrase, "Throw it on the wall to see what sticks."

"Instead, on hazardous cattle drives in areas of unreliably enforced law, cowboys would keep the cattle calm, fed, and watered. Breaking the rules and loud, boisterous behavior disrupted camp life, could stampede the cattle, and likely lead to someone's death."

#### The Cowboy

Cowboys are considered rule breakers and renegades. This image derives from 19<sup>th</sup> Century novels and 20<sup>th</sup> Century movies and television. Instead, on hazardous cattle drives in areas of unreliably enforced law, cowboys would keep the cattle calm, fed, and watered. Breaking the rules and loud, boisterous behavior disrupted camp life, could stampede the cattle, and likely lead to someone's death.

Most cowboys did not have a gun. Partly for their safety, as having a gun made one a target. As described by one cowboy, 'If someone were going to shoot me, he would most likely shoot me first.' Some outfits forbade the possession of guns. Also forbidden was gambling and often alcohol. Trail drivers maintained discipline and

expected cowboys to keep their differences under control. Cowboys would calm the herd at night by singing to prevent stampeding cattle. Over time, they learned that cattle liked slow, mournful songs (9, 10).

"At noon, you would see the men throw them [the cattle] off the trail, and half the crew would go to dinner while the other half would graze them onto water. No orders were given; every man knew his place and what to do," CE "Teddy Blue" Abbott, 1955 (9).

"I borrowed fifty cents from her [Calamity Jane in a random meeting] to buy a meal. I thanked her for the fifty cents and said: "Some day I'll pay you."... "I never saw her again until twenty-four years later. It was in 1907, and she was standing on a street in Gilt Edge... I walked up to her and said, "Do you know me?" and gave her the fifty cents." CE "Teddy Blue" Abbott, 1955 (9).

Maybe we should all be cowboys.

## Freelancing

While one of the authors (DvS) was writing a book that presented HRO for healthcare, the editor requested a definition of "freelancing" as used in healthcare. The author found one article in the medical literature that used the term. Non-medical literature considers the freelancer to have an honorable position in their industry.

"The freelancer is derided as a "loose cannon" who lacks the control necessary to join others, conform to medical practice, or follow medical direction. This latter situation is an educational problem rather than a result of using HRO."

How the authors of these *Neonatology Today* articles use deference to expertise, initiative, creativity, and decision migration was codified from naval air operations, military operations, and wildland firefighting. For healthcare professionals, a context-independent translation allows unconstrained "freelance" behavior. The freelancer is derided as a "loose cannon" who lacks the control necessary to join others, conform to medical practice, or follow medical direction. This latter situation is an educational problem rather than a result of using HRO.

#### The Color of Noise

## White Noise

No energy frequency dominates in the white noise environments. Data *decreases* variance, making the environment information sensitive. We focus on clarification of the study question and precision of the data measurements. The decreasing variance from the increase in data then forms the Gaussian curve. We can now calculate descriptive statistics and probability predictions. We can assume white noise when we linearize the curve. That is, we work with short-time segments that have little temporal variation. Long frequencies, a characteristic of red noise, may appear as white noise if the segment is longer than our experience in the environment. Pink noise causes abrupt change that appears out of a white noise environment, such as earthquakes.

We develop our theories, concepts, and models in a white noise environment, for example, evidence-based medicine from prospective studies using randomized controlled trials. This is not to say such research does not function in reddened noise environments. We must consider that. Classifications and standards developed in white noise environments may not fit during red noise forcing functions or encountering abrupt pink noise events. We must guard against allowing principles and practices developed in white noise environments to become expectations.

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### Red and Pink Noise

Environments may experience energy fluxes over long periods. The more extended periods are like the longer frequencies of red light and are called "red noise" (11). Longer wavelengths carry more power than shorter wavelengths, which are also forms of red noise. The longer wavelengths force a response by elements within the environment; these surges of energy are called *forcing functions*. A unique pattern occurs at the 1/f frequency when an abrupt but rare event occurs. This is called "pink noise" because it has a frequency midway between white and red noise (12) (Table 1).

On the other hand, energy fluxes may occur in environments from long time wavelengths such that events are few and far between. These wavelengths carry the power to force a response, and they are called forcing functions. During red noise forcing functions, rules conflict or compete, or gaps form between rules. The abrupt change from a pink noise event not only alters the relevance of rules, but the abruptness distorts cognition, and we observe stress-induced symptoms, fear circuitry behaviors, and amygdala-driven behaviors (13, 14). More mild situational cognitive distortions can affect people who otherwise are capable leaders or performers (14, 15). Unfortunately, these are not regularly distinguishable and commonly have become normative in most organizations.

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Common cognitive distortions include (16, 17):

- Anger
- Frustration
- Avoidance
  - Complete or avoid tasks
  - Focus on inconsequential tasks
  - o Addressing easily accomplished tasks first
- Distractive comments
  - Responding to distractions
- Freeze ("attentive freeze")
- Actual cognitive or physical freezing
- Nausea and avoidance
  - Urge to urinate or defecate
- Confusion
- Mental freeze
  - Inability to solve simple problems
  - Failure to recall knowledge
  - Impaired working memory

## **The Actual World**

Forcing functions and abrupt change can be described by the energy flux (VUCA-2T) or the affective experience. The VUCA-2T environment disrupts order and bedevils classification systems. We can borrow from art historians to evaluate the visible amount

Table 1. Patterns and Characteristics of Noise (11)

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

of structure and degree of randomness present (18). The structure is a measure of complexity that identifies discrete objects through borders and edges, demarcating change and flat surfaces denoting continuity. Randomness is a measure of entropy that measures disorder and uncertainty, a fuzziness that disconnects various parts of what we can observe, making invisible the causes and effects (19).

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### The VUCA-2T Environment

The military concept of "VUCA" describes the new global environment at the end of the Cold War (20, 21) – volatile, uncertain, complex, and ambiguous. As a military concept, VUCA carries the implicit assumption of a dangerous and lethal environment (Table 2). Consequently, the concept of threat is not translated into civilian applications (15). Discussions between a special group in SO-COM (Special Operations Command) and the author (DvS) led to the separation of time compression from volatility. Time compression has meaning and carries special environmental information, distinguishing these events from urgency or time dependence (15, 22). The group now uses VUCA-2T or VUCA-T² (Sean McKay, personal communication) (23).

Table 2. VUCA-2T (3)

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

### The Liminal Environment

VUCA-2T fits the anthropological experience of liminality as a transition (24) and the operational environment of the HRO. The liminal zone is the space between the world we know and the world we do not. Old rules do not apply, we have not learned new rules, and we do not know what rules will work. In this area of experience, we must engage the situation to leave, yet we do not know what works (25).

Liminality magnifies the gap between theory and practice (1), discrete concepts and continuous perceptions (26), abstractions

and concreteness (Karl Weick, personal communication), and the static normative stance and the pragmatic stance from within the trajectory of events (27).

"Liminal zones are not continuous with routine operations or with each other. Abrupt changes disrupt operations. Our treatments may abruptly disrupt the disease process and the neonate's physiology."

Liminal zones are not continuous with routine operations or with each other. Abrupt changes disrupt operations. Our treatments may abruptly disrupt the disease process and the neonate's physiology. Such a sequence of experiences creates the more common "punctuated experience" of resuscitation that necessitates constant evaluation and re-evaluation. Rather than sensemaking guiding us from the immediate past to the immediate future. "HRO is a trajectory of engagement that fuses now with the experience of then into simultaneous inquiry and redescription," Karl Weick (personal communication). Karl Weick describes the repeated presentation of abrupt changes as "punctuated sensemaking" (personal communication). Every action is a failure, and every action creates an unrelated or disconnected experience (Table 3).

Table 3. Liminality (3)

Conventional Operations	Liminal Operations	
Familiar	Threshold of Transition	
Structured	Passage for travel, but not traveling	
Knowledge by description	Gaps in knowledge (28)	
Hierarchical support	Alone	
Standards	Learn by doing	
Known rules	Old rules do not apply	
Familiar relations	New rules unknown	
Prevent Failure	Consequence driven	

The Self-Organizing Environment

Self-organization promotes stability and stable patterns. A volatile event may not seem to be achieving stability, but all elements reach a lower energy state through self-organization. Volatility develops as energy enters the open system or is released in a closed system.

Order comes out of chaos through self-organization (29). These systems stabilize and develop order by self-organizing through local, nonlinear feedback. Positive feedback contributes to growth and structure, while negative feedback restricts growth. These oscillatory, self-organizing processes bring stability and order to the environment, but the nonlinear interactions degrade any ability for predictions. Environmental self-organizing processes create stochastic noise that can increase to a level that forces a system or population to respond. The system or population responses to these forcing functions are also self-organizing oscillatory processes with poor predictability of outcomes. The noise process is independent of timescale or magnitude. We need not characterize normal environmental variation differently from catastrophes (30).

The events that we engage in are made up of many small interactions (complexity science) and a few nonlinear rate-dependent interactions (deterministic chaos (31)). Novel properties then emerge from these interacting interactions. We must respond to these emerging exigencies with the capabilities we have.

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### **Engaging the Gap**

Gaps are insidious. Operating in a single environment or context normalizes experience and keeps gaps from being visible. The observer will likely interpret the gap as due to the other side being wrong. Nevertheless, gaps form at various levels of analysis – prevention and response, planning, training, organizing, logistics, prevention, recovery, et cetera. The essential basis for gaps in a high-reliability system is between order and disorder. We can thus use entropy to explain the origins of gaps.

Without being trite, we will call disorder the absence of order. A cardiac arrest on the ward is a disorder in the hospital, yet the ICU has an ordered response to a cardiac arrest. A fire in the ICU is disorder, but the responding fire department has an ordered response, and so forth. HROs address the gap that develops from unexpected disorders.

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The most basic gap is that between *abstractions and context*. Concepts are abstractions that support theory. Concepts as ordered images of reality must not be mistaken *for* reality. Context is the actual world as experienced; it is the domain of practice. Discrete, abstract concepts, in a reality of continuous perceptions, thus create gaps that are subject to misspecification, misidentification, and misunderstanding (26). Contextual systems are those systems where the environment interacts with and changes the problem (32). These are the fundamental gaps between theory and practice (1) or between classical logic and logic practice (2).

Engagement generates information and creates structure during the flux of events. The environment is self-organizing through local nonlinear interactions in response to local entropy changes over time. Humans bring local internal processes for the self-organization of these systems. The emergence of order is a complex phenomenon that resolves the crisis (33).

Engagement as an extemporaneous activity using immediately available resources. Engagement *is* improvisation.

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### What We Engage

Exigencies from forcing functions and abrupt change create a VUCA-2T environment. Stated in this manner, the urgency for good planning, protocols, and rules seems obvious. The event itself, however, is experienced by those within the situation – they may not have full awareness of events or available resources. The event transforms from what is stable and familiar to a world with threat and flux. However, both are actual worlds. People have entered a liminal space that distorts their cognitions.

We need not have special training or experience. On December 2, 2015, an active shooter incident occurred near a state center for the medical care of disabled children.

"A shooting victim with an injured arm had escaped and reached an office where a pediatrician was evaluating children. The victim was pale and feeling faint but did say there had been a shooting in the conference room, and they needed a doctor. The pediatrician used the victim's sweater to improvise a sling for her arm, then went to the building where his associates were working on the second floor" (22).

[Because the pediatrician thought the assailants were in the conference room, he ran upstairs to check on his friends. He realized his friends likely thought he was a shooter and that law enforcement might also think he was a shooter because he was of Middle Eastern descent. He returned to his office to aid those suffering severe emotional trauma during the incident. Two minutes elapsed between the shooter's escape and the arrival of law enforcement.

Another example of improvisation on a larger scale is the *Pasadena Chemical Complex Explosion* in Pasadena, TX, on October 23, 1989.

Responders to an industrial emergency usually depend on the available plant personnel to bring them up to speed. The people who knew anything were dead, hurt, or gone at the Pasadena explosion.

With the human element on-site so completely incapacitated, Doug Miller, fire chief at a nearby chemical plant, fell back on what emergency responders call "pre-planning." Pre-plans include structural diagrams, details about available fire protection systems, and, most importantly, an inventory of hazardous materials. The emergency pre-plan became critical at Pasadena with no

management personnel immediately available.

However, pre-plans have limitations. In an emergency, the plant trained workers to report to pre-arranged assembly points where headcounts would be conducted. Panic drove the evacuation at Pasadena. Understandably, those still able to move put as much distance between themselves and the plant as humanly possible.

The pre-plan broke down in other critical ways. Triage means assigning the injured to one location where they can be assessed as to who gets treated first. Seriously injured are treated before the walking wounded, and so on. Responders at Pasadena — police, fire, and ambulance — too often grabbed the first injured person they found and rushed them to the hospital. Others with more life-threatening injuries had to wait.

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Doug had more to worry about than just the polyethylene facility. He was now in charge of a badly damaged industrial complex the size of a small city.

"It was nearly a mile long and a quarter mile wide," he said. "There was hydrocarbon everywhere. It was packed with possibilities with risks. I bounced a lot of ideas off others about what could be the next high risk we were going to have to deal with."

Most important, Doug needed a large-diameter hose. The blast sheared off most of the fire hydrants at ground level. Shut-off valves to prevent water loss were out of reach in the burning wreckage.

Firefighting water would have to be brought in using a hose laid to remote sources — settling ponds, a cooling tower, a water main at a neighboring plant, and even the ship channel. Every drop of water became precious. Backhoes dug ditches on Highway 146 to the west to capture the runoff from the plant's damaged water system. Pumpers drafted from those ditches to bring the escaping water back to the plant.

"Most industrial chiefs didn't see the need for five-inch hose because their plants had a fire hydrant on every block and monitors attached to the fire hydrants," Joe said. "We had all these appliances that could deliver water on the fire. We didn't think in terms of delivering it from anything but an internal source."

One of the Lessons Learned: "Pre-plans cannot cover every eventuality. The key to a good pre-plan is providing a structure while remaining flexible enough to adapt to the changing situation." (34) [Emphasis the authors, article courtesy of Bruce K. Vaughen]

In each situation, the individual acted extemporaneously without a plan.

"Improvisation as a knowledge-based tactic or strategy (37) for an event transcends rules and experience (38, 39). Physical actions taken to initiate improvisation initiate thinking and learning by doing."

### **Adaptive Significance**

You cannot improvise unless you have taken some action, initiating motor cognition for *thinking while acting*. Improvisation plays off knowledge, experience, and the immediate past responses to actions (35), incorporating common sense and tacit knowledge (36). Improvisation as a knowledge-based tactic or strategy (37) for an event transcends rules and experience (38, 39). Physical actions taken to initiate improvisation initiate thinking and learning by doing.

### Motor Cognition

Motor cognition describes how we adjust our actions to changing situations and learn through physical actions (40). Effective action responding to a changing environment integrates, from opposite ends of the brain, perception, hastily created plans and motor activity. The dorsolateral prefrontal cortex (DPFC) and the posterior parietal cortex (PPC) functionally cooperate during time-based contingencies between continuous perception and emerging motor action (41).

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The cognitive function for this to occur must include timing and coordination, the mode of information analysis of environmental events, and the temporal sequencing of the analytic processes as concurrent, reciprocal processing (42). The executive functions, acting hierarchically, coordinate temporary behavioral structures and "integrate actions with perceptions in the presence of novelty and complexity" (42).

Motor cognition comes from the coupling of perception and action, which is also the mechanism of common sense. During mo-

tor cognition, the parietal cortex distinguishes oneself from others, an essential aspect of agency (43). As social knowledge, common sense is the background knowledge for expectations, meaning, and the "rules of the game." It gives the ability to share activities with others (44-46) spontaneously. Contextual understanding and motor cognition increase the capacity for attunement the ability to appreciate and be involved with the mental states of others (44).

Motor cognition contributes to somatic common sense when actively engaging in an uncertain situation. Tacit knowledge is both somatic and cognitive. "Somatic knowledge," a form of biological knowledge like riding a bicycle, is difficult to describe but easy to demonstrate. Therefore, it provides little contribution to Artificial Intelligence (45). Motor cognition is missing as combined somatic and cognitive knowledge, enhancing thinking while acting (46).

"I cannot know what I think until I act. Intention cannot cause our actions because conscious intention occurs after preparatory brain activity in the frontal and parietal brain areas (47). It would make sense that purposive action derives from intention, which would mediate between cognitive desires and purposive motor behavior. Rather than mediating, the two distinct brain operations, cognitive intention and motor behavior, must coordinate."

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Karl Weick's 'sensemaking recipe' now applies to topological events: "How can I know what I think until I see what I say?" (49).

Consider the process implied by the phrase, "How can I know what I think until I see what I say." There are four verbs and four actions in the sensemaking recipe: to know, to think, to see, and to say. Organizing around those four verbs can be done in ways that enact higher reliability. Think about what happens when someone asks you about the story or your opinion. When you start describing your opinion, you often listen to what you are saying and discover that your opinion is a little different than you thought it was. You and I always do this when we try to make sense of things. When we make sense, we talk; we look back over what we said, and finally, we discover what we were thinking. People need to act in order to discover what they face, they need to talk in order to discover what they think, and they need to feel in order to discover what things mean when you say something that involves action and animation; when you see what you said, that involves directed observation; and when you conclude what your words mean, that finally tells you what you've been thinking.

Usually, we assume that we think and then we act. We do that less often than it appears we do. Instead, we often make sense using the opposite sequence. We act in order to think; we think while acting, our thoughts are defined by what we do. If you substitute planning for thinking, you can see the relevance for this gathering. How can I know what I've planned until I see what I've checked off? Plans reflect the words you use to describe something and what you see in those words. You act your way into plans rather than plan your way into acts. This is why sensemaking is not the same thing as decision-making. And this is why sensemaking affects your decisions.

-Karl Weick (personal communication)

"Actions create what we think, which continuously changes until we finish acting. During our behavioral interactions with the environment, our brain specifies desirable actions as the environment changes (50). Through the motor system, continuous, bottom-up feedback for sensorimotor control detects prediction errors, updating ongoing action. This feedback enhances or cancels some sensorimotor signals."

Actions create what we think, which continuously changes until we finish acting. During our *behavioral* interactions with the environment, our brain specifies desirable actions as the environment changes (50). Through the motor system, continuous, bottom-up feedback for sensorimotor control detects prediction errors, updating ongoing action. This feedback enhances or cancels some sensorimotor signals. Self-generated cancellation as a motor function also explains why we cannot tickle ourselves. It is due to the sensory feedback through the motor system (51). Alternative actions continue to be mentally processed (50). This may extend to language comprehension, social cognition (52), and interpreting sensory signals (53). This makes it visible.

"The clash between a mistaken old belief and an updated belief would seem to be a form of dissonance...The more you engage in dynamic reasoning [processes], the less chance there is for dissonance between the old belief and the updated, [improving] belief to develop, the fewer errors you make, but at risk of a new set of cues being neglected."

Karl Weick (personal communication)

Motor cognition is how we understand our movement and how movement helps us understand events.

Learning by Doing

Some problems involve unknown or uncertain pathways, inexact or unknown interventions, and other difficulties. These are ill-structured problems (7). Learning by doing almost always addresses ill-structured problems (8). Learning by doing in the HRO differs from the manufacturing sense (54) in that the HRO uses motor cognition. Improvisation is learning by doing.

Improvisation through learning by doing generates solutions and

reduces damage in unforeseen ways. Engagement is the act of learning by doing in context, not an outcome of rational deliberation, and cannot be objectified for theory-making (1). Engaged action comes from insight and immediate feedback, with negative feedback marking the safe boundary of performance and positive feedback generating growth. All feedback generates information. "Mistakes" indicate a change in circumstances (55) or interference from the environment (8). Nevertheless, mistakes are observable and, therefore, correctable (56). Effective responsiveness brings strength through change and allostasis.

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### Structure and Information

Reciprocal decision-making describes how we observe the response to our action and how that response guides our next action. We learn what works through action. Decisions linked to action are probes to learn structure, redirect trajectory, create structure, and engage a threat. This is not trial-by-error or random action but is focused on the objective and what is observed in the situation. It is also not simple feedback, a component of decision trees or algorithms.

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

It is dangerous during an emergency to think that people from different socio-economic statuses make their decisions differently. More likely, their decisions are influenced by stress and fear and are more alike than is recognized (17). Inexperienced or untrained people are equally likely to make decisions for the good of others.

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

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

Correcting negative feedback may be an error, but it is a mark of safety, resilience, and adaptability. As we operate in this unstable environment, we will also test the boundaries between our performance capabilities and the limits for safety and harm. These boundary checks can sometimes only be performed in real-world situations in real-time. Failures are helpful in these situations be-

cause they mark our performance *boundaries*. The outsider, not appreciating the exigencies of the situation, may have a different, negative interpretation of this level of operation.

"Hurricane damage forced several NICUs to improvise neonatal care for prolonged periods. In nearly all the published hurricane experiences we reviewed, problem-solving happened locally (57). One outside hospital directing evacuation efforts relied on a government agency's report that all hospitals were empty."

### **NICU Improvisations**

Hurricane damage forced several NICUs to improvise neonatal care for prolonged periods. In nearly all the published hurricane experiences we reviewed, problem-solving happened locally (57). One outside hospital directing evacuation efforts relied on a government agency's report that all hospitals were empty. Reached by a text message from a NICU following a circuitous route, they learned of an entrapped NICU and hospital. Neonatologists and NICU staff may look to government agencies and emergency services for help, but they must rely on their own capabilities and improvisations to save babies.

- One preterm neonate arrived in the NICU with umbilical catheters in place. While preparing for intubation and surfactant administration, the lights flickered and went out. "I grabbed my penlight and flashed it so that a nurse could see to position a baby's Ambu bag," reported a nurse (58).
- Without intubation, a nurse improvised CPAP for an infant with tubing and forced air. Her system supported the infant for the next ten hours and through evacuation to the other hospital. This is how she started her twenty-one-hour shift in a hurricane (58).
- The Israeli Defense Forces (State of Israel) Field Hospital (59) improvised neonatal care for a premature newborn of 31 weeks gestation, 1,520 grams. The preterm infant deteriorated to apnea with bradycardia. The team improvised a CPAP device for respiratory stability. They chose CPAP over intubation because the infant would be transported by ground ambulance for three hours.
- Premature neonates developed hypothermia during five hurricanes, including a tropical cyclone. Four were treated with skin-skin contact; other treatments included warming pads (peri-pads), plastic wrap, blankets, and multiples in a single incubator.
- An orthopedic surgery resident received a one-minute-inservice on hand ventilating a premature infant to enable transport by canoe (60)

The capability to improvise care attests to the quality of neonatal personnel (and orthopedic surgery residents).

### **Self-organizing Improvisation**

The authors developed an After-Action Report for the San Bernardino (CA) County Fire Department for the previously described active shooter incident on December 2, 2015 (22). The Law Enforcement (LE) officers and SWAT team organized and improvised solutions to secure the building while at the same time initiating casualty care. Probation officers, who are not usually part of an

active shooter response, arrived early and organized themselves to provide aid to the wounded, extract casualties, and then drive them to Triage A. SBFD organized for a large number of casualties and organized a team to enter the warm zone, improvising as they approached. Then, these self-organizing units merged at various times to create larger self-organized groupings.

"The "leader-leader" (61) form of leadership contributed to the initiative and improvisation demonstrated throughout the event. "Visual communication" played a prominent role in these operations. Various small unit actions are self-organized to merge and rapidly improvise solutions on the spot, a type of "self-organizing improvisation." This did not arise from a specific plan or training."

The "leader-leader" (61) form of leadership contributed to the initiative and improvisation demonstrated throughout the event. "Visual communication" played a prominent role in these operations. Various small unit actions are self-organized to merge and rapidly improvise solutions on the spot, a type of "self-organizing improvisation." This did not arise from a specific plan or training.

We characterize *self-organizing improvisation* as HRO made visible, emerging from each organization's shared culture and leadership. Their plans were not improvised. Improvisation *was* the plan. Training can support this approach.

This active shooter incident drove actions (self-organization), and the incident drove their solutions (improvisation). This contrasts with abiding by a well-thought-out plan, which would have forced the first responders to wait for the accepted thresholds to be identified as having been reached prior to acting. Participants learned that the system may not have a solution to the problem, a belief supporting improvisation (4).

"This active shooter incident drove actions (self-organization), and the incident drove their solutions (improvisation). This contrasts with abiding by a well-thought-out plan, which would have forced the first responders to wait for the accepted thresholds to be identified as having been reached prior to acting."

### Conclusion

Improvisation is operations in a liminal state. Everyone has ex-

perienced being thrust into an unfamiliar circumstance. We have crossed a threshold into an environment of exigency and flux where the rules we know do not apply. We have improvisation in this transition between a world we know and a world we are unsure of. When hope does not help us, we have to improvise. When everything we tried has failed, we have improvisation.

Improvisation is not simply conceptual knowledge and application of those concepts. Though we may master concepts, we never master experience (25). Creating experience and extending knowledge come out of improvisation.

Improvisation can only come from a *first* action. Karl Weick addresses this in his "recipe" for improvisation. You cannot improvise unless you have taken some action. Improvisation plays off knowledge, experience, and the immediate past responses to actions (35). "HRO is a trajectory of engagement that fuses now with the experience of then into simultaneous inquiry and redescription," Karl Weick (personal communication) said.

Jens Rasmussen also recognized this at the local level of a crisis. We rely on local or special knowledge when the particular is novel, such as deference to expertise (5). Rasmussen classifies these situations into a *knowledge-based* system.

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

Jens Rasmussen (62)

"When pre-plans cannot cover every eventuality or the designer's imagination fails, as they will in a crisis, we must recover quickly. Those at the point of contact will improvise. Their improvisation, driven by their optimism, is when resilience begins."

When pre-plans cannot cover every eventuality or the designer's imagination fails, as they will in a crisis, we must recover quickly. Those at the point of contact will improvise. Their improvisation, driven by their optimism, is when resilience begins.

Improvisation is our adaptive survival function, encountering forcing functions and abrupt change. If improvisation is the "figuring out mechanism" for HRO, how do we figure out *how* to improvise? That is article #3 in *Neonatology Today*'s Improvisation Series.

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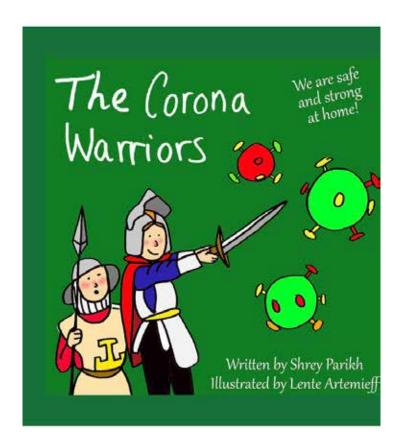
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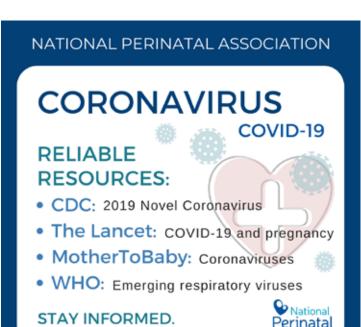
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- Are the parents of each baby fully integrated into the  $\underline{\text{team}}$  and treated as essential partners in decision-making and care of
- What are the strategies and measurements used to improve and sustain IFCDC in the unit?

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



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during the COVID-19 pandemic

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### Wash Your Hands

- This is the single, most important thing you can do to stop the spread of viruses
- Use soap
- more than 20 seconds
- · Use alcoholbased 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
  - 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



### **Never Put a Mask on Your Baby**

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

### If you are positive for COVID-19

- Wash with soap and water and put on fresh clothes before holding or feeding your baby.
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# Post-Traumatic Thriving

The Art, Science, & Stories of Resilience



Randall Bell, Ph.D.

### Briefly Legal: Delays in Intervention for a Spontaneous Arterial Thrombus Causes Limb Loss

Maureen E. Sims, MD; Barry Schifrin, MD

A 37-year-old G3 P0 presented to a small community hospital at 37 weeks gestation for an elective cesarean section due to cholestasis of pregnancy with bile acid levels close to 100 micromol/L. Except for the complaints of itching and the elevated bile acid values, the pregnancy, including antepartum testing, had all been normal. At delivery, the 3100-gram appropriately grown female infant received Apgar scores of 8 and 8 at 1 and 5 minutes, respectively. After cleaning, stabilization, and the intramuscular injection of vitamin K into the left anterior thigh, the baby was brought to the mother for breastfeeding. The baby showed severe irritability when placed on the breast, with an abnormal cry and a high pain score. She became dusky with obviously diminished tone in the left lower extremity. The baby was quickly placed on a warmer and given blow-by oxygen. The neonatologist was called; on examination, she encountered a dusky infant with a piercing cry and a mottled left leg with obvious bruising at the site of the earlier vitamin K injection. The left femoral pulse was normal, but the left popliteal pulse was diminished.

"A 37-year-old G3 P0 presented to a small community hospital at 37 weeks gestation for an elective cesarean section due to cholestasis of pregnancy with bile acid levels close to 100 micromol/L. Except for the complaints of itching and the elevated bile acid values, the pregnancy, including antepartum testing, had all been normal."

The baby was admitted to the Newborn Intensive Care Unit, where the physical exam had the following: HR: 163 bpm, RR 85 bpm. The BP was normal, but the pulse oxygen saturation was only 70% on 100% inspired oxygen. The remainder of the exam was unremarkable.

A complete blood count revealed a hematocrit of 50%, a white blood count of 15.6 10³/UL with an IT ratio of 0.327, and a platelet count of 208 10³/Ml. A capillary blood gas 1 hour of life revealed a pH of 7.13, a pC02 of 59 mmHg, a p02 of 30 mmHg, and a base excess of-11.2. A chest radiograph was normal. Prostaglandins were briefly administered while awaiting a cardiac ultrasound (which was normal). A radiograph of the left lower extremity was also found to be normal. A Doppler ultrasound of the leg showed no blood flow below the iliac artery. The baby was intubated after failing to maintain sufficient oxygenation on continuous positive airway pressure (CPAP) of +6cm H20. Four hours after birth, the neonatologist arranged for transport to a higher level of care, which, nevertheless, could not provide proper care for the obvious problem involving the blood supply to the affected leg. The transport team arrived 2 hours after the referral call (6 hours after birth).

At the referral hospital, only a faint femoral pulse was detectable

in the left lower extremity; the entire left leg was mottled and had a slow capillary refill of 5 seconds. During the baby's 6-hour sojourn at this facility, various pediatrics, vascular and orthopedic surgery, and radiology specialists were consulted. However, none felt equipped to provide care and recommended that the patient be referred to the regional Children's Hospital, where a pediatric vascular surgeon would be available. The call to the children's hospital was made five and a half hours after admission. During the observation period, the leg became cold to touch, a deeper purple capillary refill was further delayed to 10 seconds, and the femoral pulse disappeared. Six hours after arriving at this facility, a helicopter transported the affected child to a children's hospital.

On arrival at the children's hospital, the baby required highfrequency oscillatory ventilation and inhaled nitric oxide because of the development of profound hypoxemic respiratory failure. She also needed dopamine and hydrocortisone for blood pressure support. Nitroglycerin paste was applied to the leg while various consultants evaluated her condition. Studies showed no Doppler flow in the leg; a magnetic resonance angiogram (MRA) showed a thrombus in the left iliac and femoral arteries completely occluding the vessels. Recalculation procedures were found to not be possible due to the small size of the vessels. Intervention cardiology placed a catheter into the right common femoral artery traversing the patent foramen ovale and infused a thrombolytic agent, tissue plasminogen activator (t Pa, Steeplechase) and heparin in an attempt to lyse the clot. The efforts to save the leg proved futile, and a below-the-knee amputation was performed four days after admission. Extensive hematological and clotting evaluations of the baby and parents were unremarkable. The placenta was not examined. The deposition testimony of the nurse who administered the vitamin K did not reveal any circumstance or action that was considered remarkable.

The neonatologists at the birthing and first referral hospitals were sued. In each case, the allegation included the failure to properly appreciate the seriousness of the situation and delay in getting the patient to a proper referral center with the personnel and resources to assess and intervene.

"The neonatologists at the birthing and first referral hospitals were sued. In each case, the allegation included the failure to properly appreciate the seriousness of the situation and delay in getting the patient to a proper referral center with the personnel and resources to assess and intervene."

In addition, the neonatologist of the first referral hospital was sued for negligently accepting the transfer of a baby with a known ischemic leg without the resources to treat such a condition properly. Indeed, the parents consented to the transport to the first referral hospital only after they were told that a team would be waiting there to take care of their daughter upon arrival. The experts retained by the plaintiff maintained that the delays from the birth hospital cost the baby to lose her leg. The parties settled without going to trial.

As an incidental detail, the hospital the infant was initially referred to had a financial arrangement with a small community hospital.

### Discussion:

### Intrahepatic cholestasis of pregnancy:

Intrahepatic cholestasis of pregnancy (ICP) is characterized by pruritus and elevated serum bile acid concentrations, typically developing in the late second or third trimester and rapidly resolving after delivery. In the United States, the incidence ranges from 0.32-5.6%. The etiology of ICP is not completely understood but likely involves a combination of genetic susceptibility, hormonal factors, and environmental factors. Transplacental gradients facilitate the fetal clearance of bile acids in normal pregnancies but are reversed in cholestatic pregnancies, which causes the accumulation of bile acids in the fetus and amniotic fluid. The accumulation of bile acids in the fetus and amniotic fluid carries a risk of fetal demise, preterm birth, meconium-stained amniotic fluid, and respiratory distress syndrome (which appears to be associated with bile acids entering the lungs). Speculation of cause for fetal death may be related to the sudden development of fetal arrhythmia or vasospasm of the placenta chorionic surface vessels induced by high levels of bile acids. Although pruritis is bothersome, ICP is not associated with other serious maternal sequelae. There are several approaches to the timing of delivery in such patients. Some favor early delivery to reduce the risk of fetal demise, especially with high bile acid levels. American Colleges of Obstetrics and Gynecology published in 2021, #831 for patients with ICP: 1) if total bile acid levels <100 micromol/L, delivery is recommended at 36 0/7 to 39 0/7 weeks' gestation, or at diagnosis if diagnosed at >39 0/7 weeks). if total bile acid levels ≥100 micromol/L, delivery is recommended at 36 0/7 weeks or at diagnosis.

In the case discussed above, the care providers considered numerous etiological pathways connecting the ICP with the thrombus, but none were compelling. The relationship between the thrombus and the injection of Vitamin K was explored at length. No details other than the bruising at the site were documented.

"In the case discussed above, the care providers considered numerous etiological pathways connecting the ICP with the thrombus, but none were compelling."

The questions about the etiology of the thrombus notwithstanding, it was generally conceded that the unconscionable delays beginning in the birthing hospital and continuing in the first referral center were directly responsible for the ultimate loss of the child's leg. Indeed, 15 hours elapsed between detecting the ischemic leg and the baby's arrival at the children's hospital.

### **Thrombosis in Neonates:**

#### General:

Neonates, particularly those critically ill, have a significant risk of developing thrombosis.

The neonatal coagulation profile represents a prothrombotic state compared to children and adults. Neonates have decreased concentrations of procoagulant proteins, naturally occurring anticoagulants, and hemostatic control proteins. This prothrombotic state protects from excessive bleeding during birth but at the expense of an increased risk for thromboembolism. Although evolving, the hemostatic system in healthy fetuses and infants must be physiologic. In the face of various conditions, this balance is disrupted.

**Risk factors** implicated in the development of neonatal thrombosis

#### Maternal-Fetal risk factors:

Pre-eclampsia, autoimmune disorders, oligohydramnios, twin-to-twin transfusion, drug abuse (cocaine), and infertility and its treatment

### Intrapartum risk factors:

Difficult deliveries (especially assisted by instrumentation), emergency cesarean sections, fetal heart rate abnormalities, and asphyxia

### Neonatal risk factors:

Intravascular catheters, infection, congenital heart disease, polycythemia, extracorporeal membrane oxygenation, dehydration, and hypoglycemia

### Inherited or acquired prothrombotic conditions:

Rare, including factor V Leiden and prothrombin gene mutation; deficiencies of protein C, protein S, and antithrombin; elevated factor VIII, lipoprotein (a) and homocysteine; and antiphospholipid antibodies. In determining the etiology of a neonatal thrombus, the physiologic levels of many coagulation proteins in neonates are low, thereby inviting the diagnosis of some inherited and acquired hemostatic problems.

Over the last 30 years, the incidence of thromboembolic issues, especially for premature babies, have increased, with ranges reported up to 5.1 per 100,00 live births and 2.4 per 1000 NICU admissions, with 45% to 55% of these events affecting preterm infants. In a prospective Canadian registry study, 61% of thromboembolism cases were venous, 31% were arterial thrombotic events, and 4% had both venous and arterial thrombosis.

"Over the last 30 years, the incidence of thromboembolic issues, especially for premature babies, have increased, with ranges reported up to 5.1 per 100,00 live births and 2.4 per 1000 NICU admissions, with 45% to 55% of these events affecting preterm infants."

#### **Neonatal Arterial Thrombosis:**

### latrogenic thrombosis:

### **Umbilical arterial catheters:**

An indwelling arterial catheter causes most cases of arterial thrombosis in the newborn infant. Umbilical artery catheters (UAC) remain the basic means of arterial sampling and blood

pressure monitoring in critically ill neonates. The most common visible problem from a UAC is blanching or cyanosis of part or all of a distal extremity or the buttock area. This complication may be reduced by high placement, with the catheter tip at the level of T7 or T8, as opposed to lower placement at L3 or L4 just above the aortic bifurcation. Small amounts of heparin added to the continuous infusion appear to reduce the risk of arterial thrombi. Hypertension can result if a renal artery is involved.

A thrombus can form when the catheter tip causes mechanical injury to the vascular endothelium exposing subendothelial tissue and collagen to circulating blood, causing adherence and aggregation of platelets, thereby releasing adenosine diphosphate (ADP) and thromboxane A2 (a platelet stimulator and potent vasoconstrictor). Initially, vasospasm occurs around the catheter, then vessel occlusion, tissue ischemia, and clot formation.

"A thrombus can form when the catheter tip causes mechanical injury to the vascular endothelium exposing subendothelial tissue and collagen to circulating blood, causing adherence and aggregation of platelets, thereby releasing adenosine diphosphate (ADP) and thromboxane A2 (a platelet stimulator and potent vasoconstrictor)."

The UAC should be securely anchored to avoid any movement of the catheter to keep it in the intended place, avoiding or minimally creating mechanical injury to the intima of the aorta and the development of thrombi. The position of the catheter should be documented and regularly checked to ensure that it does not move. Multiple attempts to insert a UAC also create arterial intima harm, which is a perfect nidus for thrombus development and should be avoided. If the sterile field is broken after the UAC has been placed, the catheter should never be advanced to avoid inserting organisms into the vessel and avoiding endothelial injury. Once the catheter is removed, another should not be inserted. Studies have shown that UACs in place for even one day are associated with a 16% incidence of aortic thrombosis, with an incidence of 32% at seven days.

Most UAC-associated thromboses are asymptomatic, and 50% disappear by discharge. Long-term consequences of UAC-associated thromboembolisms have been linked to mesenteric ischemia, hypertension, renal dysfunction, sepsis, loss of an extremity, and death. In long-term follow-up studies, leg length discrepancy has been found. The potential short and long-term morbidities underscore the need to use UACs only when indicated, to monitor their placement carefully, and to remove them timely. Optimally, umbilical artery catheters should not be left in place for >5 days.

### Peripheral arterial line (PAL):

The radial artery is the primary site for the cannulation of a peripheral artery. The overall risk of ischemic injury to this site is approximately 5%. Because of the potential risk of ischemic injury to the entire hand or arm, the most distal location of the radial artery is generally the preferred site, and only if insertion is unsuccessful should alternative sites be tried. The posterior tibial

artery is a reasonable alternative to the radial artery and has been shown to be viable when inserted under ultrasound guidance. The ulnar, brachial, and axillary arteries are used infrequently because of the risk of harm. Proper care requires the demonstration of collateral circulation in the hand by the Allen Test before the radial artery is catheterized. Further, monitoring the tips of the fingers for signs of vascular compromise is crucial. Documentation by the nurses in the medical record needs to be done hourly, and the physician needs to be called immediately if blanching, duskiness, or any evidence of decreased perfusion occurs.

### Rescuing ischemic tissue - Catheter removal is the first step:

When the clinician faces a neonate with any evidence of ischemia in an extremity, digit or of any anatomical ischemic region, the catheter must be removed immediately. If skin color and pulse do not return, this is a medical emergency, and consultation and referral immediately to a facility with the complete resources to evaluate and treat the patient, potentially with anticoagulation, thrombolysis, or clot removal. There is much truth in the adage that "Time = tissue."

"When the clinician faces a neonate with any evidence of ischemia in an extremity, digit or of any anatomical ischemic region, the catheter must be removed immediately ... There is much truth in the adage that "Time = tissue." "

Other treatments may include 2% nitroglycerin as a topical ointment when vasospasm is suspected while waiting for the various consults to provide input or while transporting to a specialized center. Nitroglycerin may directly affect vascular smooth muscle producing arterial and venous dilatation. Acute vascular dilatation relieves vasospasm permitting blood flow around the microthrombi, thereby improving collateral circulation to the affected areas.

Indeed, occasional success has come from placing the ointment on a contralateral area resulting in increased blood flow to the ischemic area.

### Perinatal Arterial Ischemic Stroke (PAIS):

The risk of stroke is highest during the perinatal period. The incidence of PAIS ranges from 17.8/100,000 to 35/100,000. The incidence estimates have increased over time, but whether this is due to a true increase or improved detection is unclear. PAIS represents 71% of all perinatal strokes and has a male predominance. While multiple pathophysiological mechanisms have been suggested, Martinez-Biarge, Gomez, and their colleagues have underscored common intrapartum risk factors for HIE and PAIS. Thrombophilia is an uncommon finding in these patients. A popular medico-legal theory suggests that the thrombi from the placental circulation pass through the patent foramen ovale to the cerebral arterial vasculature. This theory still requires validation.

PAIS affects both preterm and term infants, mainly occurring in the left hemisphere with the middle cerebral artery distribution. Maternal factors linked to PAIS include pre-eclampsia, premature prolonged rupture of membranes, prolonged 2<sup>nd</sup> stage of labor, difficult deliveries, especially those involving instrumentation, fetal distress, and asphyxia. Factors linked to PAIS after birth include

the need for resuscitation with 5-minute Apgar <7, hypoglycemia, congenital heart disease, and infection. The babies often present with seizures, but other neurological symptoms of lethargy, hypotonia, apnea, and feeding difficulties have been identified. The management of the infant with NAIS should begin with careful attention to fluid, electrolyte, and glucose status and supportive measures related to cardiorespiratory function and prompt treatment of seizures. Thrombolytic therapy is not a practical consideration because the initiating lesion's timing is generally unknown and is generally many hours before diagnosis.

It is essential to understand that PAIS may not induce immediate signs and symptoms in neonates but manifest problems weeks to months after birth. This has been termed "Presumed perinatal stroke."

### **Spontaneous Arterial Thrombosis:**

Spontaneous arterial thromboses are rare. Timely assessment of the location and extent of the thrombus and evaluation for a prothrombotic disorder is necessary. A referral center with a full complement of resources is essential. Treatment depends on the findings similar to the approach with catheter-related ischemia.

### **Neonatal Venous Thrombosis:**

### Central venous catheter-related thrombosis:

Umbilical venous catheters (UVC) and peripherally inserted central catheters (PICC) are routinely used in the NICU. Occlusion and infection remain the most commonly encountered problems. Clinical manifestations may include catheter dysfunction, limb, face or chest, or groin swelling, discoloration of the skin and/or distension of the superficial veins, persistent chylous effusion, pleural effusion, and superior vena cava syndrome. Sometimes the baby is asymptomatic, and the thrombus is only incidentally identified. For thrombosis involving the upper central venous system (proximal subclavian vein, brachiocephalic vein, superior vena cava). Doppler ultrasound has low sensitivity; magnetic resonance, computed tomography or conventional venography or echocardiography may be required to make the diagnosis in this location. Intervention depends on the location and extent of the resulting pathology. Studies have found that 20% of babies with UVCs have thrombus formation in the inferior vena cava or portal vein. Twenty to 65% have evidence of thromboembolism on autopsy. The Centers for Disease Control and Prevention currently recommend that the use of UVCs be limited to 14 days. Long-term complications of venous thromboembolism include chronic venous obstruction, chylothorax, portal hypertension, and post-thrombotic syndrome.

"Umbilical venous catheters (UVC) and peripherally inserted central catheters (PICC) are routinely used in the NICU. Occlusion and infection remain the most commonly encountered problems."

Suspicion or confirmation of a venous thrombus warrants prompt catheter removal due to the risk of emboli. However, based on limited data, some have advocated delaying the removal after 3 to 5 days of anticoagulant therapy. No clinical evidence at this point supports this practice in neonates. Management of venous thromboembolism in the newborn period varies depending on the location and extent of the thrombus and the risk for acute embolic complications and later vascular compromise. Therapeutic

decisions are guided by practitioners' experience, published case reports and case series, several large registries, and extrapolation from the results of clinical trials in adults with thromboembolic disease. Whether management includes expectant (observation) or intervention with anticoagulants, thrombolytics, or surgical removal of a clot, the baby needs to be at a center with the full array of resources for diagnosis and potential interventions. Multicenter, prospective, controlled clinical trials in this important patient population are needed to provide evidence-based data to inform optimal management.

### **Neonatal Portal Vein Thrombosis:**

"Whether management includes expectant (observation) or intervention with anticoagulants, thrombolytics, or surgical removal of a clot, the baby needs to be at a center with the full array of resources for diagnosis and potential interventions."

Neonatal portal vein thrombosis (PVT) is an under-recognized thrombotic event that is most commonly encountered in association with UVC placement, especially mal-positioned catheters (low or intrahepatic), and prolonged catheterization. The reported incidence of UVC-related PVT is highly variable, ranging from 1.3% to 43%. A large, single-center retrospective study reported an estimated incidence of at least 3.6 per 1000 NICU admissions. Besides malposition of the UVC, other risk factors include transfusion through the UVC and patient-related factors, including low birth weight, low-flow state, hypoxia, infection, sepsis, congenital malformations, and gestational diabetes mellitus. Portal vein thrombosis is often associated with subtle, nonspecific, or absent clinical and laboratory signs. Unexplained thrombocytopenia may be an initial manifestation. Diagnosis is usually established by Doppler ultrasound. Management is similar to DVT with any central venous line, although it is unclear if anticoagulation improves outcome. Long-term complications of PVT include portal hypertension and hepatic lobar atrophy, which is usually asymptomatic. As such, PVT is the primary cause of childhood extrahepatic portal hypertension and gastrointestinal bleeding.

### **Neonatal Renal Vein Thrombosis:**

Neonatal renal vein thrombosis (RVT) is the most prevalent noncatheter-related thrombotic event during the neonatal period, accounting for up to 20% of all thrombotic events in newborns. Risk factors include a history of perinatal asphyxia, gestational diabetes mellitus, prematurity, dehydration, infection, and congenital heart disease. Involvement of renal veins may also be seen in the context of central venous line-related thrombosis of the inferior vena cava. Males are more commonly affected than females, representing 67.2% of cases. Approximately 70% of neonatal RVT cases are unilateral, with a left-sided predominance. Most neonates with RVT will manifest one or more of the three cardinal clinical features of macroscopic (or microscopic) hematuria, palpable flank mass, and thrombocytopenia. Doppler ultrasonography confirms the diagnosis. Acute complications of RVT include adrenal hemorrhage and distant embolization. Long-term complications include chronic renal insufficiency and hypertension.

### **Cerebral Sinovenous Thrombosis (CSVT):**

Cerebral sinovenous thrombosis accounts for 20% of neonatal strokes and is more common than previously expected in the era before MR imaging. Pre-eclampsia, which involves a hypercoagulable state, is a common maternal risk factor. Other maternal factors include gestational diabetes and chorioamnionitis. Peripartum complications include hypoxia, acidosis, meconiumstained fluid, and the need for newborn resuscitation. In a report of 52 well-studied neonates with CSVT from the Netherlands, 60% experienced a complicated delivery, including vacuum or forceps delivery. This finding underscores the possibility that pressure on the cranium during delivery creates venous sinus obstruction: congenital heart disease, dehydration, sepsis/ meningitis. Seizures are often the presenting sign, with the onset usually in the first 48 hours after birth. Lethargy, poor feeding, apnea, hypotonia, irritability, or respiratory distress may precede the seizures. The acute therapy of CSVT is similar to that noted for NAIS, namely careful attention to fluid, electrolyte, and glucose status and supportive measures related to cardiorespiratory function and prompt treatment of seizures. Thrombolytic therapy is not a practical consideration because the initiating lesion's timing is generally unknown and is generally many hours before diagnosis. In CSVT, such comorbidities as sepsis, meningitis, and dehydration require exceptionally prompt treatment.

### **Intracardiac Thrombosis:**

Intracardiac thrombosis is associated with central venous lines placed incorrectly into the right atrium instead of at the junction of the right atrium with the superior or inferior vena cava. Not only does a catheter in this position carry the risk of perforation of the right atrium, which is wet-paper thin, but intracardiac thrombi may form. This is a life-threatening condition due to the risk of dissemination of emboli into the lungs or obstruction of the right pulmonary artery. Neonates with congenital heart disease, especially those undergoing cardiac surgery, are at high risk for thrombosis. Blood flow disturbances due to hypoplastic ventricles with limited inflow/outflow, dilated atria, arterial or femoral venous catheters, and surgically placed shunts create an environment conducive to thrombus formation. Other risk factors include cardiac surgery with platelet dysfunction/activation, inflammation, and blood hypercoagulability.

### **Conclusion:**

Some avenues exist for clinicians to minimize the risk and prevent arterial or venous thromboses in several situations. Antenatal management of pre-eclampsia and twin pregnancies to optimize fetal well-being, avoidance of hypoxia, and mechanical trauma will likely minimize the risk or potentially avoid the problem.

Better outcomes beget less need for invasive procedures that appear to increase the risk of thrombosis. When catheterization is deemed necessary, they should be inserted using impeccable technique, carefully monitoring the insertion depth, observing for early signs of tissue compromise (ischemia, swelling, or organ involvement), and timely removal will likely reduce the risk of complications. Once a thrombus (ischemia) is suspected, it must be considered a medical emergency, and timely recruitment of experienced resources capable of dealing with the problem is required. Every neonatology service must have already identified such services.

"Better outcomes beget less need for invasive procedures that appear to increase the risk of thrombosis."

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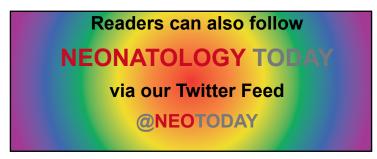


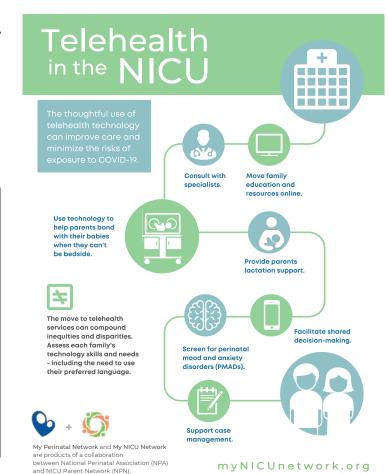
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### Where is The Evidence? The Problem with Ventilation Research

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.

"Writing a monthly column on ventilation and respiratory issues presents a challenge -finding evidence to support practice. Although there are numerous studies and papers on the topic, finding definitive support for modes of ventilation or clinical practice is difficult."

Writing a monthly column on ventilation and respiratory issues presents a challenge -finding evidence to support practice. Although there are numerous studies and papers on the topic, finding definitive support for modes of ventilation or clinical practice is difficult.

This is not surprising given the highly varied practices out in the clinical world. Even the most carefully designed study cannot control what happens at the bedside when investigators are "out of sight, out of mind." How are patients suctioned? Are manual breaths given, and with what pressures? How are babies manually ventilated, and with what devices and pressures? What monitoring is used, and how accurate is it? What ventilators are used? Even third-generation microprocessor-controlled ventilators have subtle (and sometimes not so subtle) differences in function and accuracy (1,2). Other clinical interventions, such as blood transfusions, may also impact outcomes.

Before enrolling in a study involving ventilation, what happens to a baby in the delivery and resuscitation rooms has far-reaching effects on outcomes, ranging from pulmonary to neurological. Similarly, how a patent ductus arteriosis is managed and treated (if at all), the presence of reflux (if indeed it can be detected), and antenatal factors all may sully the findings of an investigation.

A well-designed study can factor out confounding variables if known, but as the number of variables involved increases, so does the complexity of accounting for them. As a result, recruiting for large investigations is challenging and takes a lot of time. Additionally, studies involving ventilation cannot be quickly blinded, if at all.

"A well-designed study can factor out confounding variables if known, but as the number of variables involved increases, so does the complexity of accounting for them."

For example, studies on high-frequency oscillatory ventilation (HFO) are all over the map; some have shown benefits, some have not, and some have found a negative effect. Here, equipment differences come into play, as all HFO studies out of the U.S. have been done using the Sensormedics® oscillator. 3rd generation ventilators that offer HFO mode are currently unavailable to U.S. clinicians. This machine cannot be compared to newer ones; it is not apples to apples. It is apples to carports. Then, the infamous "HiFi" study from the 1980s almost stopped HFO in its tracks (3). Babies in the HFO group had significantly more severe intraventricular haemorrhages and periventricular leukomalacia than those in the conventional arm. The study did not use the "open lung" approach to ventilation, now universally recognised as being essential to the success of any form of ventilation, whether HFO, conventional, or even non-invasive. We at least learned that from this otherwise flawed work.

Stratifying results by gestational age has become more common of late, but many older studies have failed to do so. The resulting data may fail to identify study interventions that benefit or are to the detriment of one vs. another.

"Stratifying results by gestational age has become more common of late, but many older studies have failed to do so."

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The difficulty conducting and interpreting ventilation research notwithstanding, the question that crosses my mind when reading them is often, "What did they expect would happen?" Parameters used may differ from those typical in my practice, be they targeted volumes,  $\rm PaCO_2$  and  $\rm SpO_2$  targets, or pressures used and/or accepted. The marked differences in pulmonary development between gestational ages make a one-size-fits-all approach dubious when ventilating premature infants.

Following are a few examples of, in my opinion, poor study designs from personal experience.

A study examining higher CPAP pressures vs. NIPPV used these NIPPV parameters: rate of 30 with an inspiratory time of 0.5 seconds. Humans do not breathe with a 1:1 I: E ratio. Additionally, babies had to be supine (generally a position not preferred by most babies) and use non-invasive nasal prongs, again an interface many babies do not tolerate, as well as nasal masks.

A study of aerosolised surfactant limited CPAP pressures to a maximum of 7 cmH<sub>2</sub>O, a pressure that will fail to recruit the lungs of many babies. Trying to deliver aerosolised surfactant to lungs that are not recruited will not meet with great success.

There is another factor involved in any research, that being equipoise. Many years ago, the unit I work in was invited to participate in a large trial involving high-frequency jet ventilation (HFJV). We were generally excited to participate, but upon examining the entry criteria, we concluded that we would have already started HFJV before those criteria were met; we did not have equipoise and thus had to decline participation.

While there are many studies involving HFJV, further study is stymied by the fact that, for the most part, clinicians who routinely use HFJV (and thus likely do so well) are unlikely to be involved because, to them, there is nothing to prove -- there is no equipoise.

This begs the question: Are studies *always* required to establish the efficacy of practice? The question of evidence to back up common practice within my workplace often comes up, particularly from trainees. Many of these trainees hail from countries with few allied health professions, particularly respiratory therapists. Outcome statistics for our unit are available going back decades, and they are consistently world-class, particularly regarding our low incidence of chronic lung disease. The chances of consistently excellent outcomes year over year are unlikely the result of chance. One might say we **are** the evidence.

"This begs the question: Are studies always required to establish the efficacy of practice? The question of evidence to back up common practice within my workplace often comes up, particularly from trainees. Many of these trainees hail from countries with few allied health professions, particularly respiratory therapists."

Finally, respiratory therapists are largely excluded from research on ventilation. There are notable exceptions, but there are also roadblocks in the way of our participation. In Canada, for instance, respiratory therapy is not a degree program. Those who do not have at least an undergraduate degree are rarely sought out for advice on study design and are even more rarely listed as contributing authors. Outside North America, respiratory therapists are generally unknown, degree-holding or otherwise. Other obstacles include shift work, bedside duties, scarcity of funding, and a lack of protected time for clinical research participation. We are often called upon to do "the dirty work," but this is after the fact.

It is unfortunate for all concerned, not the least of our patients, for the nature of our specialisation makes us a logical go-to for advice on ventilation and the intricacies of various equipment. I urge those contemplating researching mechanical ventilation to seek us out. You may be surprised at what we can teach you.

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

NT

Corresponding Author



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

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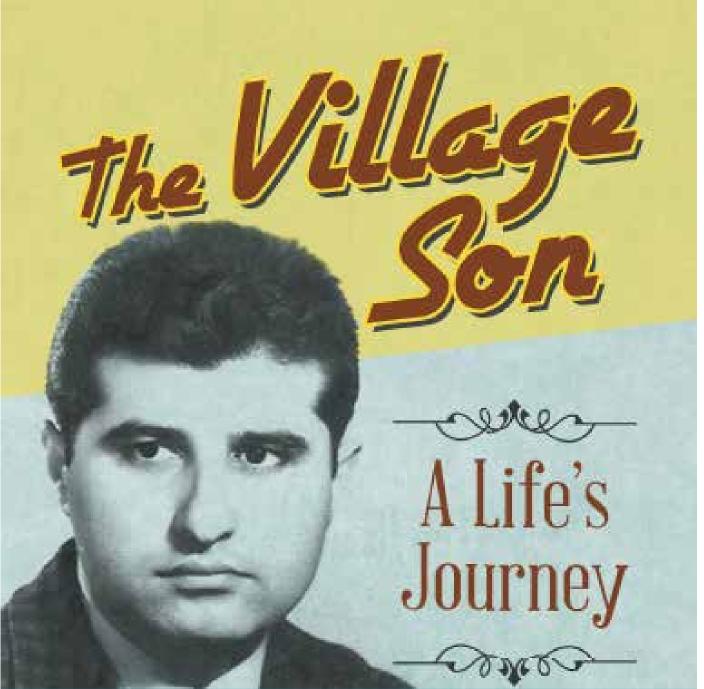
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1 week	\$30
1 month	\$120
1 semester	\$540
1 year	\$1,080
Middle School	\$3,240

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



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

# There's new information and rulings on safe sleep. Are you ready to speak with your patients?



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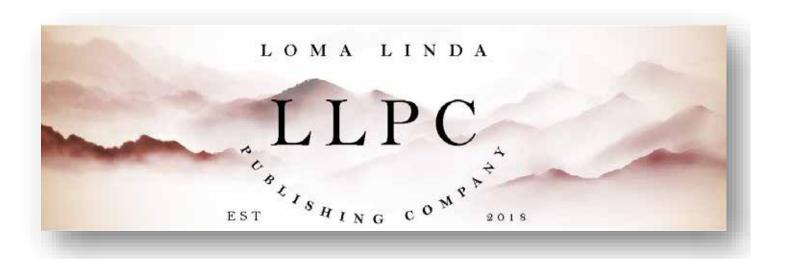
As we indicated last month, we look forward to a number of new features as well.

- An online submission portal: Submitting a manuscript online will be easier than before. Rather than submitting by email, we will have a devoted online submission portal that will have the ability to handle any size manuscript and any number of graphics and other support files. We will have an online tracking system that will make it easier to track manuscripts in terms of where they are in the review process.
- 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
- 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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National Perinatal Association NICU Parent Network My Perinatal Network and My NICU Network are products of a collaboration between NPA and NPN.

### **TOP 10**

### RECOMMENDATIONS FOR THE PSYCHOSOCIAL SUPPORT OF NICU PARENTS



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

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

### 1 PROMOTE PARTICIPATION

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

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.



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.



Provide comprehensive staff education and support on how to best meet families' psychosocial needs, as well as their own.

Acknowledge and address feelings that lead to "burnout."



### 10 HELP US HEAL

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

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### 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



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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What parents need to know this RSV and flu season



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





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

The fewer germs your baby is exposed to, the less likely they are to get sick. Limit visitors. Avoid crowds. Stay away from sick people.





Immunizations save lives. Stay upto-date with your family's flu and COVID-19 vaccinations. This helps stop the spread of deadly viruses.

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





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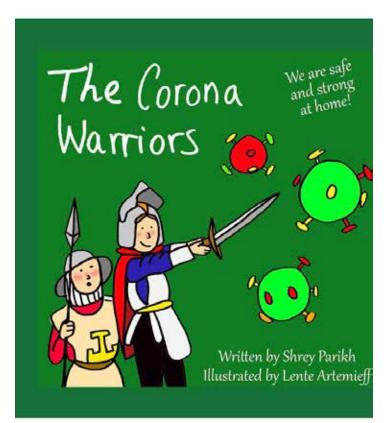
The RSV Research Group from professor Louis Bont, pediatric infectious disease specialist in the University Medical Centre Utrecht, the Netherlands, has recently launched an RSV Mortality Awareness Campaign during the 5<sup>th</sup> RSV Vaccines for the World Conference in Accra, Ghana.

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 <a href="https://www.rsvgold.com/awareness">www.rsvgold.com/awareness</a> 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.





A Global Mortality Database for Children with RSV Infection



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Middle School	\$3,240

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

### Gravens By Design: NIDCAP Nursery Program: Implementation of the NIDCAP model of care

Dorothy Vittner PhD, RN, FAAN, Deborah Buehler, PhD

The NIDCAP Nursery Program: Implementation of the NIDCAP model of care

#### **Abstract**

The Newborn Individualized Developmental Care and Assessment Program, NIDCAP, was established to provide education and consultation in neurodevelopmental evaluations with healthcare professionals caring for infants and families in hospital settings. Systematic behavioral observation and assessment methodologies include the NIDCAP Observation and the Assessment of Preterm Infant Behavior, APIB. These instruments were designed to document the complexity of preterm and at-risk newborn infants' neurobehavioral functioning by focusing on the interplay of the infant's autonomic, motoric, state organizational, and attentional functioning. NIDCAP and APIB assessments provide the basis for estimating the infant's current behavioral functioning and goals, which form the basis for individualized recommendations to support the infant's developmental trajectory. The NIDCAP Nursery Program, NNP is a model and guide toward consistently well-integrated NIDCAP careThe NIDCAP Nursery Program offers educational and consultative support to healthcare organizations towards effective infant care in an individualized neuro-developmentally supportive, family-centered framework (https://nidcap.org).

**Keywords**: NIDCAP; high-risk infants; individualized developmentally supportive care; infant & family

### Introduction

Over 15 million premature infants are born annually around the world. One million children die from related complications. (1) Perinatal and newborn intensive care advances support infants returning home with their families. However impressive the advanced medical technology, the incidence of disability and neurodevelopmental problems among survivors of newborn intensive care remains high and problematic. (3-5) Neurodevelopmental dysfunctions such as learning disabilities; low intellectual functioning; attention deficit; hyperactivity disorder; neuropsychological deficits, including visual motor integration and executive function; varying temperament difficulties; language delays; emotional problems; and overall regulatory disorders are present in up to 50-70% of extremely prematurely born infants. (6-9) More than 50% of infants born prematurely will go on to require special education and mental health services, and more than 20% will require self-contained disabilities management. (5,7) These challenges are significantly exacerbated in developing countries with sparse or lacking resources.

"Research indicates that the early social environment influences the neurobiology of the infant's brain; thus, opportunities for and assurance of parent engagement are essential factors in the health of a premature infant."

For survivors, the long-term implications of prematurity, including differences in brain development, cognition, educational achievement, and behavior (including social and emotional regulation), are significant. (3, 7) Research indicates that the early social environment influences the neurobiology of the infant's brain; thus, opportunities for and assurance of parent engagement are essential factors in the health of a premature infant. (8-10) Mothers of preterm infants are more likely to have difficulty with attachment than mothers of full-term infants. (7,12) This can be attributed to decreased synchrony or responsiveness with parent-infant interactions as well as the contribution of the subtle behavioral cues among premature infants that may be difficult to interpret. (6,12) Evidence suggests that early dysfunctional contacts due to the infant's disorganized behavioral patterns during infant and parent interactions lead to poorer attachment and behavioral problems in childhood. (7-8, 13) Conversely, early responsive and synchronous contacts may positively influence cognitive and developmental outcomes for the infant. (11,13)

"There is increasing evidence that the NICU environment involves sensory overload and stands in stark sensory mismatch to the developing nervous system's growth requirements."

### The NICU Environment and Infant Brain Development

The preterm infant's sensory experience may include exposure to bright lights, high sound levels, and frequent noxious interventions in hospital settings. These inputs and experiences appear to exert deleterious effects on the immature brain and alter its subsequent development. (8,14-16) The match between the environment and the brain's expectations is critical during these critical or sensitive periods of brain development to support developing relationships between infants and their families. (15-17) For term infants, axonal and dendritic proliferation and the massive increase in outer layer cortical cell growth and differentiation leading to the human brain's enormous gyri and sulci formation (8) occurs within mother-mediated protection from environmental perturbations. The intrauterine environment provides a steady supply of nutrients, temperature control, and the multiple regulating systems, including those of chronobiological rhythms. (8, 15) For preterm infants, these mechanisms are replaced by stimuli from a very differently organized Newborn Intensive Care Unit, NICU environment. There is increasing evidence that the NICU environment involves sensory overload and stands in stark sensory mismatch to the developing nervous system's growth requirements. (8, 15) How does one estimate the potential effects on an infant's nervous system when the infant moves from the relative equilibrium of the intrauterine aquatic environment to the extra uterine terrestrial environment of the NICU? (14-15) How does one identify an infant's current vulnerabilities, strengths, and strivings in the mismatch of the brain's expectations and the input from the physical and social/emotional environment?

### Newborn Individualized Developmental Care and Assessment Program

The Newborn Individualized Developmental Care and Assessment Program, NIDCAP, provides formal developmental observation and assessment education for healthcare professionals responsible for high-risk infants and families' long- and short-term care. (14) The NIDCAP model of care evolved from the seminal work of the Synactive Theory. (14-15) This theory holds that individuals constantly interact with their environments from the womb to the extra-uterine environments, from the NICU with transitions to home. Further, infants are understood as actively striving for their next developmental steps. Based on these principles, a priority of the NIDCAP program is the educational and consultative support to organizations towards effective infant and family care in a neuro-developmentally supportive, individualized, and familycentered framework. (15) The evidence suggests early experiences alter the premature and critically ill infant's brain structure and functioning. (8,16) NIDCAP care is a system-based, processoriented, attuned, responsive support of individualized, familycentered developmental care for each infant and family. (14-15) Results show that the medical and developmental outcomes for infants and parents' competence when infants and their families are cared for in such a developmental framework are much improved. (16-27) Evidence also suggests that the NIDCAP model of care improves outcomes for healthy preterm infants. (27)

"Results show that the medical and developmental outcomes for infants and parents' competence when infants and their families are cared for in such a developmental framework are much improved. Evidence also suggests that the NIDCAP model of care improves outcomes for healthy preterm infants."

The NIDCAP Federation International, NFI, is a nonprofit, incorporated international professional membership organization. The NFI is the certifying organization for all NIDCAP Training and Certification levels to safeguard the quality of all training and education within the NIDCAP model. The NFI promotes the advancement of the philosophy and science of the NIDCAP model of care and assures the quality of NIDCAP education, training, and certification for professionals and hospital systems. The NFI envisions a global society where all hospitalized newborns and their families receive care in the evidence-based NIDCAP model. The NIDCAP model supports development, enhances strengths, and minimizes stress for infants, families, and staff who care for them. It is individualized and uses a relationship-based, family-integrated approach that yields measurable outcomes. For more information, please go to <a href="https://nidcap.org">https://nidcap.org</a>.

The challenge confronting healthcare professionals who care for infants and families in hospital settings is to ensure the infants' survival and optimize neurodevelopmental trajectories. Through assessment and documentation of infants' competencies and behavioral thresholds of disorganization, healthcare professionals may gain a better understanding of the infant's developing nervous system. (14-15) This, in turn, supports providing individualized and developmentally appropriate experiences creating opportunities for developing relationships with infants and their

families in the hospital setting. Structuring a physical and social environment supportive and nurturant of the individual infant's immature or dysmature nervous system and the family's sense of competence becomes a critical component of care in the nursery and of follow-up care in the home and the community. (15, 21, 30)

"Structuring a physical and social environment supportive and nurturant of the individual infant's immature or dysmature nervous system and the family's sense of competence becomes a critical component of care in the nursery and of follow-up care in the home and the community."

### **NIDCAP NURSERY PROGRAM**

The NIDCAP Nursery Program is based on the goal of complete emotional and physical integration of infants and families within the nursery (16-27). Research has documented the synchronous factors that influence preterm infant health between parents and infants. (10) Early parent-infant contact is fundamental to the infant's developmental trajectory. It is a dynamic process focused on enhancing and supporting the parent-infant experience, explicitly targeting the acquisition of skills for parent problem-solving and providing appropriate infant care based on the infant's needs at a particular time. (10-12) Through a parent's involvement and selfmotivation to set goals and utilize informational resources about the unique care necessary for their infant, they can increase their engagement while simultaneously improving their infant's health progression. (11, 12) Translating research on individualized developmental care into clinical practice provides opportunities to improve infant outcomes through increasing mother-infant contact, monitoring infant physiologic regulation, and understanding the resiliency of the mother-infant dyad. (13) The evolution of the NIDCAP model of care implemented through systems change efforts utilizing the NIDCAP Nursery Program enhances early parent-infant interactions as an essential step in developing therapeutic modalities to improve health outcomes.

"The evolution of the NIDCAP model of care implemented through systems change efforts utilizing the NIDCAP Nursery Program enhances early parentinfant interactions as an essential step in developing therapeutic modalities to improve health outcomes."

The NIDCAP Nursery Program supports infant health and development and relates parents' engagement and participation as their infant's primary caregivers and lifelong advocates. (12, 21, 30) The NIDCAP Nursery Program provides a framework for healthcare teams to understand how infant and family care is delivered in their nursery. Further, it offers a guide with detailed

recommendations for incorporating NIDCAP, individualized developmentally supportive care, into all aspects of the nursery and experience of care for infants and families and the healthcare professional team. The NIDCAP Nursery Program provides a dynamic environment for the full integration of expert medical, nursing, and therapy (OT, PT, SLP, SW, Psychology) care securely embedded within the active pursuit of mutual respect, caring, nurturance of and collaboration with infants and families, and among all healthcare professionals on the team. The *Model of the NIDCAP Nursery: From Self-Assessment to NIDCAP Nursery Certification* elegantly demonstrates consistently well-integrated NIDCAP care and Nursery Certification (<a href="https://nidcap.org/nidcap-nursery-program-overview/">https://nidcap.org/nidcap-nursery-program-overview/</a>).

"The individual and the summary scales address the level of individualization, family-centeredness, and developmental support that a nursery provides for the infants and families in its care, along with the support provided to the healthcare professionals involved in delivering such care."

#### Measures

The NIDCAP Nursery Program's key resource is the Nursery Assessment Manual. This instrument is used in support of nursery self-evaluation and the process of NIDCAP Nursery Certification. (31) It consists of 121 scales grouped into four major categories of a nursery's characteristics and functioning, four Category Summary Scales, and one Overall Nursery Summary Scale. (31) The individual and the summary scales address the level of individualization, family-centeredness, and developmental support that a nursery provides for the infants and families in its care, along with the support provided to the healthcare professionals involved in delivering such care. (31) The individual scales are organized into the following four categories:

- (1) Physical Environment of the Hospital and Nursery;
- (2) Philosophy and Implementation of Care: Infant;
- (3) Philosophy and Implementation of Care: Family; and
- (4) Philosophy and Implementation of Care: Healthcare Professionals.

The five-point scale scores of the NNP Nursery Assessment Manual evaluate a nursery's philosophy and implementation of care about the NIDCAP model of care for infants and families requiring hospital care. Each of the five score points on the NIDCAP Nursery Program's ratings represents a level or degree of NIDCAP implementation as follows:

- (1) Traditional, conventional care;
- (2) The beginning of a minimal degree or level of NIDCAP im-

- plementation;
- An inconsistent, variable, or moderate degree or level of NI-DCAP implementation;
- (4) A consistent well-integrated level or degree of NIDCAP implementation; and
- A highly attuned, distinguished level or degree of NIDCAP implementation.
- (NA) Not applicable is scored when care aspects do not apply to a specific nursery system.

One end of the continuum of nursery implementation describes *Traditional Care*. These include hospital and nursery practices that strive to meet the standards of safe care, with little to no attention to family-centered, individualized, developmentally supportive care for infants and families. *Infants* are considered patients. *Parents* are considered visitors. *Family Members* are considered bystanders and occasional visitors. *Healthcare Professionals* are schedule-driven, task and protocol-oriented. *Nursery and Hospital Environment & Culture* are focused on efficiency, occupancy, productivity, cost-effectiveness, and consumer/customer satisfaction.

"Integrating NIDCAP care into hospital and nursery care is an ongoing process that begins with Nursery healthcare teams, which includes parent participation, assessing and identifying current strengths and challenges. This nursery self-assessment is used for goal setting and planning."

The other end of the continuum of nursery implementation describes consistently well-integrated NIDCAP care. This includes hospital and nursery practices that consistently promote the best short- and long-term health and developmental outcomes for all infants and families. Infants are considered individuals, persons, collaborators in care, supported, and nurtured by their parents. Parents are considered infants' key nurturers, advocates and caregivers, and collaborators in care decisions. Family Members are considered primary supporters of parents and infants. Professionals and staff are partners in care with infants, parents, and family members. Nursery and Hospital Environment & Culture are focused on supportive effectiveness, patient and family relationship orientation, and the promotion of individualized health, growth, strengths, and development. (31) Integrating NIDCAP care into hospital and nursery care is an ongoing process that begins with Nursery healthcare teams, which includes parent participation, assessing and identifying current strengths and challenges. This nursery self-assessment is used for goal setting and planning. Supports for nursery change may include introductory, foundational NIDCAP education.

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#### Conclusions

The NIDCAP model of care was built from the seminal work of the Synactive Theory. (14-15) A priority of the NIDCAP program is the educational and consultative support to organizations towards effective infant care in a neuro-developmentally supportive, individualized, and family-centered framework. The evidence suggests that early experiences alter the premature and critically ill infant's brain structure and functioning. (8, 16) The NIDCAP Federation International (NFI) is a nonprofit, incorporated international professional membership organization. The NFI is the certifying organization for all levels of NIDCAP Training that safeguards the quality of all training and education within the NIDCAP model. For more information on NIDCAP, APIB, and the NIDCAP Nursery Program, please contact info@nidcap.org or use the website <a href="https://nidcap.org">https://nidcap.org</a>.

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NIDCAP Federation International Board of Directors. Dr. Buehler currently serves as NFI President; Dr Vittner is NFI Vice-President.

NT



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#### **Gravens Diversity Travel Award**

As part of an initiative to increase diversity at the Gravens Conference, the Gravens Diversity, Equity, Inclusion, and Justice (DEIJ) Committee will provide travel awards to individuals from historically underrepresented groups (i.e., people from racially and ethnically diverse backgrounds, members of the LGBTQ+ population, individuals with cognitive disabilities, individuals with physical disabilities). Applications will open for the 2024 Gravens Diversity Travel Awards on August 21, 2023. Applications should be submitted no later than Monday, October 30, 2023, at 5:00pm EST.

Several competitive travel awards are expected to be given. The amount awarded will be based on the award availability for that year. Notice of awards are expected to be made no later than December 15, 2023. Please contact Kelly McGlothen-Bell (<a href="mailto:mcglothen@uthscsa.edu">mcglothen@uthscsa.edu</a>) or Christie Lawrence (<a href="mailto:Christie Lawrence@rush.edu">Christie Lawrence@rush.edu</a>) for questions regarding your application.

#### **Eligibility:**

- Identify as a member of a historically underrepresented group.
- Must serve the neonatal and/or pediatric intensive care population in a professional capacity.

#### **Application:**

- Completion of Gravens Diversity Travel Award Survey, which provides contact information for the applicant and specifies the applicant's eligibility for the award.
- CV or Resume
- Submission of written or video response to the following statements:
  - Describe your personal and professional background.
  - Describe how you believe you will benefit from attending the Gravens Conference.
  - Describe how you'd like to advance DEIJ initiatives for the care of infants and their families.
- Letter of Support detailing the following attributes:
  - Administrative support from applicant's leadership team to participate at the Gravens Conference.
  - Evidence of the applicant's skills, knowledge, experiences in research, practice, service/volunteering, and/or leadership.
  - Commitment to support commitment to DEIJ in practice.

#### Awardee Responsibilities:

- Plan to attend the full 2024 Gravens Conference.
- Engage with an assigned Gravens Conference buddy.
- Provide post-conference statement (written or video) about the conference experience and how they plan to adopt or incorporate what they've learned at the conference into practice.
- Awardees are highly encouraged to submit an abstract to the subsequent Gravens Conference.



#### Our message to the supporters, attendees, and participants in the Gravens conferences.

We want to acknowledge concerns regarding holding the 2024 meeting in Florida. For all those who have communicated your thoughts about attending the meeting, we want you to know that we appreciate your forthrightness and wish to offer a statement of our collective thinking on this crucial matter. As our society grows more diverse and connected, we must acknowledge how the social and political climates continue to affect how we live, move, and interact.

Our Gravens community seeks to affirm our commitment to addressing issues of racism and bias and audit our systems to ensure that we are proactive in implementing strategies that promote health equity and social justice. We strive to provide a supportive, inclusive, and welcoming space to all individuals involved in the physical and developmental environment of the neonatal intensive care unit (NICU), including family members, healthcare providers, designers, and industry supporters.

The Gravens community approach is to remain non-political. However, some of the current policies and practices in the state where the Gravens conference is historically held are not consistent with the ideals and values of the Gravens community. The Co-Chairs and Planning Committee are reviewing all opportunities to ensure that the individual identities and lived experiences of those most impacted by the current political landscape are valued and respected.

Should you choose to attend the conference in Clearwater in person, we hope you recognize that there are those whose livelihood depends on tourism and who do not hold the same views as Florida's current prevailing social and political environment. That way, you can support small businesses, specifically those owned by people of color.

As we plan for upcoming Gravens meetings, our priority is to ensure that all attendees can participate in a safe and welcoming environment. The Planning Committee for the 2024 Gravens Conference has discussed the pros and cons of going forward with holding our meeting in Florida, given the recent political decisions that threaten an open and inclusive society. We have explored the possibility of moving the conference to another state; however, we will not be able to do so for the 2024 conference due to fiscal and contractual obligations. We are actively exploring alternative sites for future meetings.

We understand that diversity, equity, inclusion, and justice are principles that must work together to result in fair treatment, access, opportunity, and advancement for all. Therefore, we respect each participant's decision to attend the conference in person or virtually, and we hope you will join us in whatever format suits you best. Through our perseverance and dedication to advancing the care of infants and families, we aim to continue to promote our message of inclusivity and health equity.

Regardless of your position on attending the Gravens conference, you might like to use these strategies right now to make a difference:

- Commit to learning and reflecting on how racism and bias impact us today and how our history led us here.
- Vote for political candidates that are in line with your values.
- Use your voice, lived experience, and privilege to bring awareness and action to address health outcomes and healthcare quality disparities.

We are continuing to work to ensure that the co-chairs, planning committee, and conference attendees reflect both the workforce and the people they serve so that we can best meet the needs of our field. You can support the Gravens Conference Diversity Fund to help ensure the participation and growth of our ever-changing society.

Together, we can create environments where every individual or group will be fully and authentically welcomed, respected, supported, and valued to shape the world for future generations equitably.

For questions or comments, please contact lomalindapublishingcompany@gmail.com.

# FCC TASKFORCE WEBINAR September 28





## Family Integrated care: where are we now?

Karel O'Brien, MD (she/her)

- Staff Neonatologist, Mount Sinai Hospital
- Professor of Pediatrics, University of Toronto

11-12:30pm PT

## NICU DAD PERSPECTIVE: DISPARITIES IN FAMILY-CENTERED CARE

Alex Zavala (he/him)

- Founder, The NICU Dad & The NICU Dad Podcast
- VON Family Advisor
- Dell Children's Ascension NICU Network PFAC Chair
- NICU Children: Emerson & Mia





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#### Infant and Family-Centered Care Standards, Competencies, and Best Practices: Feeding, Eating, and Nutrition Delivery

Erin Sundseth Ross, Ph.D., CCC-SLP, Joan C. Arvedson, Ph.D., CCC-SLP, BCS-S



All infants depend on others to meet their nutrition and hydration needs to grow and thrive. The dependence on others is regardless of being born term, preterm, with or without major underlying genetic/medical/surgical etiologies. The uniqueness of each infant must be respected and nurtured by primary caregivers and all concerned with their care, particularly in a Neonatal Intensive Care Unit (NICU). For high-risk babies to attain full oral feeding, whether by breast, bottle, or combination, there is no "cookbook" as a guide. In order to achieve optimal feeding and growth, it is vitally important to avoid stress, discomfort, and the possibility of feeding aversion that often occurs in infants in intensive care. Recommended Standards, Competencies, and Best Practices for Infant and Family-Centered Developmental Care (IFCDC) focus on providing systems thinking within intensive care settings that exemplify best practices and include feeding, eating, and nutrition delivery (FEND) recommendations. These best practices provide the practitioner with an ever-expanding evidence base for supporting successful feeding in high-risk babies.

"When one considers the multi-factorial influences on successful feeding in the NICU, oral feeding logically should be the final milestone to be achieved."

"Despite medical advances in the last two decades, the average age for infants to achieve full oral feedings has not changed."

#### Introduction

Typical requirements for safe discharge from a neonatal intensive care unit (NICU) to home include oral feeding skills at breast and/or bottle sufficient to meet weight gain and growth. [1] Oral feeding is often the last required skill achieved by an infant who spends their early days, weeks, or months in the NICU. [2] Many professionals continue to think that slow advances in oral feeding are primary factors in holding infants back and extending the length of stay (LOS). [3] Interestingly, and in a sense contradictory, the course for infants to achieve full oral feedings is directly influenced by gestational age at birth and the medical course during the first weeks of life, in addition to underlying genetic or surgical diagnoses. [2, 4] For instance, gestational age at first and full enteral feedings correlate with the attainment of full oral feeding and length of hospital stay. [12] When one considers the multi-factorial influences on successful feeding in the NICU, oral feeding logically should be the final milestone to be achieved. [5-7].

Infants need to make global neurological developmental gains to eat safely and efficiently. These include stability in breathing, heart rate, oxygenation, digestion, and motor and neurobehavioral skills. [5-7, 10, 11] Oral feeding relies on the ability of the infant to breathe via the nose without signs of stress to coordinate the sucking, swallowing, and breathing sequencing. [8, 9] the infant must also maintain pulmonary stability while feeding orally at the breast or via bottle/nipple, along with appropriate digestion. [9] These basic neurological mechanisms for safe eating should develop before an infant is expected to meet the requirements for oral feeding.

"The Infant and Family Centered Developmental Care (IFCDC)
Recommended Standards, Competencies, and Best Practices for Infant and Family-Centered Developmental Care focus attention on the provision of care within intensive care settings that exemplify best practices, and includes recommendations for feeding, eating and nutrition delivery."

Although there has been a great deal of emphasis on "getting infants to eat earlier so they can go home sooner", length of stay is influenced by factors other than oral feeding skill development. [2, 12] Despite medical advances in the last two decades, the average age for infants to achieve full oral feedings has not changed. [13] Healthy preterm infants typically achieve full oral feedings at 36 ½ weeks, plus or minus two weeks. [2, 13] This finding appears persistent despite multiple clinical approaches and research studies to get infants to eat earlier. Infants with medical comorbidities or are extremely premature at birth often achieve oral skills well after 36 weeks and may not achieve full oral feedings

#### FEEDING, EATING, AND NUTRITION DELIVERY (FEND) STANDARDS

Standard 1, Feeding: Feeding experiences in the intensive care unit (ICU) shall be behavior-based and baby-led. Baby-led principles are similar whether applied to enteral, breast, or bottle feeding experience.

Standard 2, Feeding: Every mother shall be encouraged and supported to breastfeed and/or provide human milk for her baby.

Standard 3, Feeding: Nutrition shall be optimized during the ICU period.

Standard 4, Feeding: Mothers shall be supported to be the primary feeders of their baby.

Standard 5, Feeding: Caregiving activities shall consider the baby's response to input, especially around the face/mouth, and aversive non-critical care oral experiences shall be minimized.

Standard 6, Feeding: Professional staff shall consider smell and taste experiences that are biologically expected. Standard 7, Feeding: Support of baby's self-regulation shall be encouraged, especially as it relates to sucking for comfort.

Standard 8, Feeding: Environments shall support an attuned feeding for both the feeder and the baby.

Standard 9, Feeding: Feeding management shall focus on establishing safe oral feedings that are comfortable and enjoyable.

Standard 10, Feeding: ICUs shall include interprofessional perspectives to provide the best feeding management.

Standard 11, Feeding: Feeding management shall consider short and long-term growth and feeding outcomes.

before discharge. [2, 12, 13] Despite attempts to get infants to eat earlier, a small percentage of healthy preterm infants require supplemental tube feedings at discharge. [12]

Perhaps it is past time to recognize that, like other developmental skills, there is a lower age limit that we can expect for an infant to achieve full oral feeding. Given the preponderance of the evidence, that limit appears to be 36 ½ weeks, plus or minus two weeks. Disregarding the developmental aspect of the achievement of infant eating skills contributes to feeding difficulties that even late preterm infants experience. [14] Within and among infants, variability is often the most prominent characteristic. It is worth remembering that "each infant writes her/his book," which

continues throughout infancy, early childhood, and beyond.

Feeding eating and nutrition delivery standards to guide practice

"Rather than asking questions such as "What gestational age shall we use to start oral feedings with an infant?", the focus should shift to identifying behaviors of the infant that indicate a readiness to begin oral experiences."

The Infant and Family Centered Developmental Care (IFCDC) Recommended Standards, Competencies, and Best Practices for Infant and Family-Centered Developmental Care focus attention on the provision of care within intensive care settings that exemplify best practices, and includes recommendations for feeding, eating and nutrition delivery (FEND https://nicudesign.nd.edu/nicu-care-standards/ifcdc--recommendations-for-best-practices-for-feeding-eating-and-nutrition-delivery/). Currently there are eleven standards in this area (Table 1).

Table 1: Feeding, Eating, and Nutrition Delivery (FEND) Standards

Below are highlighted several of the Standards that emphasize the need for understanding how to support the development of feeding skills in high-risk newborns.

"Several FEND standards focus attention on the need to provide oral experiences that are biologically expected and that consider the infant's response to input."

Standard 1 for FEND highlights that all feeding experiences shall be provided with the infant's behaviors guiding the experience.

Standardization of practice within the framework of individualized care for infants and families begins with recognizing that the lived experiences of both the infant and the family influence feeding experiences and eating skill development. Rather than asking questions such as "What gestational age shall we use to start oral feedings with an infant?", the focus should shift to identifying behaviors of the infant that indicate a readiness to begin oral experiences. "Cue-based" or infant-led feedings have been associated with a faster transition to oral feedings and with more physiologic stability of the infant during feedings. [15-18]

Standards two and four focus on encouraging and supporting mothers to breastfeed, provide human milk, and support families to be their babies' primary feeders.

Several FEND standards focus attention on the need to provide oral experiences that are biologically expected and that consider the infant's response to input. Human milk is the best nutrition for infants, especially preterm infants. [23-27] Sensory environments contribute to successful feeding, and parents' bodies provide the best sensory environment for infants. Skin-to-skin hold-

ing has been associated with improved outcomes, including a 40% decrease in mortality in reports from developing countries. [19-22]

In recent years, evidence has increased our understanding of what mothers need to breastfeed successfully. There is mounting evidence that breastfeeding does not increase the length of stay when the mother is in an intensive care setting that provides appropriate environmental and family-integrated support. [28-30] [29] In areas where breastfeeding is expected and supported, infants, on average, achieve exclusive direct breastfeeding at similar ages

"Many of the caregiving activities within NICUs are painful but necessary. The best we can do for those potentially aversive activities is to provide positive oral and facial experiences to counteract the negative ones."

without increased length of stay. For instance, a publication from Denmark in 2014 found that 99% of 1221 mothers of infants born between 24 and 36 weeks gestation initiated breastfeeding, and 68% of the infants were discharged with exclusive breastfeeding. [31] In contrast, a study from 2019 of 76,855 infants admitted to a NICU in the United States reported that breastfeeding was not even initiated in 39.4% of them. [32] Another study of breastfeeding in Greece reported that only 58.1% of infants were exclusively fed human milk during their first month. [33]

Every neonatal intensive care unit has opportunities to help infants and their families get off to the best start possible with attention to the standards, competencies, and best practices for breastfeeding provided within the framework for FEND. There is no question that human milk is the best nutrition for infants and direct breastfeeding is the best option for most infants.

Standards five, six, and seven highlight the importance of

"Maintaining homeostasis while engaged in the feeding process is fundamental to both the safety and enjoyment of eating."

minimizing and protecting against aversive experiences while promoting positive associations with oral-facial touch.

Many of the caregiving activities within NICUs are painful but necessary. The best we can do for those potentially aversive activities is to provide positive oral and facial experiences to counteract the negative ones. Within this conceptual framework, the most biologically expected and nonaversive experience of feeding is at the breast and in the context of a primary caregiver, typically the mother.

Eating requires safely breathing, sucking, and swallowing in coordinated, efficient ways. Research shows that the ability to do so is not achieved simultaneously for every infant. For example, in a report on the development of pharyngeal structures and function, "pressures were more consistent at 35-36 weeks PMA" than those found at earlier ages. [34, 35] Bottle-fed infants are more likely to struggle to coordinate sucking, swallowing, and breathing than breastfeeding infants. Infants have fewer desaturation episodes and more stable heart- and respiratory rates at the breast. [36-38] Each potential physiologically dysregulating experience could contribute to the infant perceiving feeding as an aversive experience. This finding highlights the importance of the more biologically expected feeding mode – breastfeeding. [36]

The focus of standard nine is that feeding management shall focus on establishing safe oral feedings that are comfortable and enjoyable.

"When NICU staff and families work together to follow the infant's lead, focusing on direct breastfeeding as the best way to achieve feeding experiences, these infants are more likely to be comfortable and safe.

No matter how badly all persons involved with infant care want every infant to be a successful total oral feeder before discharge home, they must pay close attention to the infant's cues. Behaviors indicate a readiness or lack of readiness to engage in the challenge of eating. Maintaining homeostasis while engaged in the feeding process is fundamental to both the safety and enjoyment of eating. Behaviors that indicate a loss of homeostasis are considered disengagement behaviors. "Quality" feedings will lead to improved quantity unless underlying factors impede the infant's development.

Infants must be adequately nourished without stress to infants or caregivers. Otherwise, the infant is likely to become aversive to oral feeding, whether breast or bottle (and often a combination in the early months of life). As time passes, those aversions may lead to undernutrition and "picky eating" with resistance to the ad-

"A recent review article revealed that 40% of infants struggle with feeding and growth after discharge from the NICU."

vance of diet in the second half of the first year of life. [50] It is essential to point out that infants begin eating with primitive motor responses while they learn to eat with every feeding experience. [9, 48] What are they learning if the feeding experiences are negative? When pairing negative experiences with food, perhaps they are learning that eating is not pleasurable and sets the stage for food aversion. [48]

When NICU staff and families work together to follow the infant's lead, focusing on direct breastfeeding as the best way to achieve feeding experiences, these infants are more likely to be comfortable and safe.

Standard 11 addresses feeding management considering short- and long-term growth and feeding outcomes.

Following signs of infant behavioral readiness and organization for successful feeding will enhance short-term outcomes and facilitate discharge from NICU to home. Aversion to eating does not often present while the infant is in the NICU. Instead, it presents at the time of transition to volitional eating, which occurs between two and four months of corrected age, or with the transition to complementary foods, which, according to the American Academy of Pediatrics, is when appropriate skill levels are reached at approximately six months of age. [27, 49-52] A recent review article revealed that 40% of infants struggle with feeding and growth after discharge from the NICU. [53] A similar prevalence rate (40%) applies even to infants who did not show evidence of struggles with eating while in the NICU.

"Some care practices lack evidence or have low-quality and potentially highbiased evidence. Many studies that have been initiated have resulted in varied approaches and outcomes."

These feeding problems frequently do not just disappear. In a study of preterm children at the age of two years, 23% (18/80) had definite feeding difficulties as measured by a standardized assessment. Another 26% (21/80) were at high risk of developing feeding problems. [54] A more recent systematic review and meta-analysis showed that 43% of infants and 25% of children born preterm demonstrated oromotor eating problems. [55] Families report challenging feeding behaviors with both infants and children into school ages. [50, 55] [56] It follows that feeding approaches within the NICU may contribute to aversive learning about eating and later feeding difficulties.

"The meta-analysis concluded that the benefit of oral stimulation programs is uncertain for reducing time to transition to total oral feeding, duration of hospitalization or intensive care stay, or exposure to parenteral nutrition."

#### Considerations and caution regarding feeding practices in intensive care

The complexities of feeding physiology, behavior, and development are clear, prompting various clinical and research approaches and supports to enhance short and long-term outcomes. Some care practices lack evidence or have low-quality and potentially high-biased evidence. Many studies that have been initiated have resulted in varied approaches and outcomes.

#### Documentation of safe feeding practices

A recent review of feeding an infant requiring continuous nasal positive airway pressure (nCPAP) and/or high flow nasal cannula (HFNC) examined the variability in practices within NICUs and Pediatric ICUs in New Zealand and Australia. [39, 40] Only one of these studies used instrumental swallowing assessments, and these authors highlighted the lack of safety data. Research has previously shown that 80-90% of infants who are aspirating do so silently rather than demonstrating signs of unsafe swallowing

(e.g., no cough or gag.) [41-43]

Initiation of earlier feeding to reduce the length of hospital stay

A recent quality improvement study advocated beginning oral feedings with all infants at gestational ages younger than 33 weeks. [44] When changing to a cue-based oral feeding program AND beginning infants at <33 weeks PMA, the mean age for acquiring full oral feedings decreased from 37.4 to 36.5 weeks PMA, the commonly reported accepted mean age for reaching this milestone, and is clinically insignificant. [44] The study did not report any direct evaluation of the safety of swallowing with the earlier introduction of oral feeds.

"Until large studies of feeding incorporate neurophysiologically and methodologically sound, clinically relevant, and family-inclusive strategies, research studies should be critically reviewed for their relevance and scientific rigor before acceptance into practice."

#### Oral stimulation to encourage earlier feeding success

Many NICU professionals use oral stimulation programs to "speed up the learning." A recent Cochrane meta-analysis highlighted the methodological flaws and high potential for bias in most oral stimulation reports [45]. One flaw is that oral stimulation is not uniformly administered. Some would consider sucking on a pacifier/soother/dummy or an emptied breast as oral stimulation. Others would say oral stimulation is a systematic approach to touching and moving oral structures to teach motor movements. The meta-analysis concluded that the benefit of oral stimulation programs is uncertain for reducing time to transition to total oral feeding, duration of hospitalization or intensive care stay, or exposure to parenteral nutrition. [45] In another series of studies, an oral stimulation program did not improve suction while in the hospital, nor did it improve breastfeeding rates after discharge. [46, 47]

Until large studies of feeding incorporate neurophysiologically and methodologically sound, clinically relevant, and family-inclusive strategies, research studies should be critically reviewed for their relevance and scientific rigor before acceptance into practice.

"As DW Winnicott stated, "Feeding is a putting into practice a love relationship between two human beings." [59]

#### Changing the culture of feeding practices.

Feeding practices are varied and may constitute a "feeding culture" in any particular intensive care unit. Changing the culture around feeding practices in intensive care is challenging and complex. To support feeding, NICU teams and families must work together. A study was designed to change the feeding culture in the NICU and work towards improving feedings in-hospital and post-discharge. Implementation of the program resulted in fewer infants needing feeding therapy services in the 3-5 month corrected age follow-up period. [18] The study provides hope for address-

ing feeding approaches that will ameliorate feeding aversion and later feeding challenges. Successful approaches such as this one provide evidence that it is time to change intensive care feeding culture, optimize feeding experiences, and shift focus to avoiding short- and long-term adverse outcomes.

"IFCDC standards and competencies for FEND focus on pleasurable non-stressful enteral, breast, and bottle-feeding experiences that support the regulation of the infant and the development of the parent-infant relationship."

#### Recommendations to optimize short and long-term feeding outcomes

- When considering feeding the preterm or ill newborn within the NICU setting, the primary focus must be on feeding as the baby's experience, not accomplishing the act of feeding.
- Feedings should be based on the availability and stability of the infant, thus "infant-led." Studies of the change to infantled feedings have shown a decrease in the gestational age at which infants reach full oral feedings (although the length of stay has not changed). [18, 57]
- Feeding plans should be individualized for each infant to offer and alter feeding opportunities based on the behavioral and physiological responses of the infant. Since each infant's medical course is different, the path to eating is different. [58] These differences mean that feeding supports need to be individualized to the family's goals and the infant's needs.
- Feeding experiences should be designed to provide a foundation for building parent-infant relationships in the most meaningful ways critical for carrying over into childhood.
- Approaches to change the feeding culture towards a more evidence-based, infant-led, and with parents as primary feeder model should be initiated.
- Rather than "do to," feedings should be a time to "enjoy with."
   As DW Winnicott stated, "Feeding is a putting into practice a love relationship between two human beings." [59]

#### **Summary and Conclusions:**

In summary, infant feeding is incredibly complex. The challenges change as each infant changes in multiple ways over time. Feeding cannot be considered in isolation but as one piece of a complex puzzle involving all aspects of medical comorbidities and neurodevelopment that are beyond the scope of this article. Caregivers spend a great deal of time feeding their infant, so the enrichment of all interactions between infant and caregiver is fundamental to the physical and mental health of the dyad. While nutrition and hydration needs must never be jeopardized, infantled feeding experiences provide opportunities to develop a lifelong love of eating and a family mealtime interaction around trust. Team members from multiple disciplines with primary caregivers must work together to use integral collaborative processes with

the infant "leading the charge."

Every neonatal intensive care unit has opportunities to help infants and their families get off to the best start possible with attention to the standards, competencies, and best practices within the FEND framework. IFCDC standards and competencies for FEND focus on pleasurable non-stressful enteral, breast, and bottle-feeding experiences that support the regulation of the infant and the development of the parent-infant relationship. The focus is not solely on the quantity and volume of breast milk and/or formula consumed per feeding or every 24-hour period. Instead, safe, comfortable, enjoyable, and predictable feedings support trust in the world, which leads to improved infant and family mental health.

"The model used to develop the IFCDC standards makes it clear that infants are seen as competent communicators. Thus, feedings are infant-led. Also within the IFCDC model are the concepts of environmental protection to provide neuroprotection of the developing brain, with infants and families at the center. Infants expect to be with their families."

The model used to develop the IFCDC standards makes it clear that infants are seen as competent communicators. Thus, feedings are infant-led. Also within the IFCDC model are the concepts of environmental protection to provide neuroprotection of the developing brain, with infants and families at the center. Infants expect to be with their families. Families expect to be the primary caregivers of their infants. The standards are being updated and revised to include the most recent published evidence. Although limitations are expected with a wide range of levels of evidence in the subject selection, research procedures, data collection, and interpretation of the findings, evidence-based practice is emphasized as the necessary standard.

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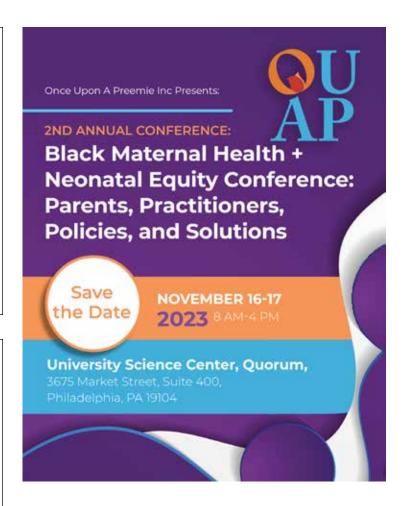


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#### Breastfeeding Awareness Month: Breast/ Chestfeeding Considerations for Children, Families, and Diverse Communities

Benjamin Hopkins, OMS IV, Christy Gliniak, PhD, OTR/L, CNT, CPXP, NT-MTC

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.

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"August is Breastfeeding
Awareness Month, and
every year, the National
Perinatal Association (NPA)
uses this opportunity to
educate others regarding
the benefits of breast/
chestfeeding, techniques,
and challenges encountered
with feeding and lactation
using a culturally sensitive
approach."

August is Breastfeeding Awareness Month, and every year, the National Perinatal Association (NPA) uses this opportunity to educate others regarding the benefits of breast/chestfeeding, techniques, and challenges encountered with feeding and lactation using a culturally sensitive approach.

"These educational campaigns promote cross-cultural understanding, dismantle barriers, and expand initiatives for healthy breast/chestfeeding practices across all communities."

Breastfeeding Awareness Month is dedicated to protecting, promoting, and raising awareness of breast/chestfeeding and decreasing the cultural and racial barriers that can harm the feeder and the child. As a result, Breastfeeding Awareness Month is separated into culturally specific weeks such as World Breastfeeding Week, August 1st-7th, Indigenous Milk Medicine Week, August 8th-14th, Asian & Pacific Islander Breastfeeding Week, August 15th-21st, Black Breastfeeding Week, August 25th-31st, and Latina/x Breastfeeding Week, September 5th-11th. These educational campaigns promote cross-cultural understanding, dismantle barriers, and expand initiatives for healthy breast/chest-feeding practices across all communities.

Breast/chestfeeding is highly beneficial to both the feeder and the child. In the United States, over 80% of birthing parents start breast/chestfeeding but discontinue before the recommended time of 12 to 24 months (1). Although any amount of breast/chestfeeding is better than none, research has indicated that the benefits of breast/chestfeeding increase with prolonged duration (1).

Human milk is a critical source of infant nutrition that contains special components (image 1.) that extensively affect cognition, behavior, mental health, and a sense of security and attachment between the feeder and child (3). Benefits for breast/chest-fed children include decreased atopic dermatitis, gastroenteritis, asthma, allergies, sudden infant death syndrome, type 2 diabetes, childhood obesity, certain cancers, ear infections, respiratory illnesses, antisocial behaviors, and atypical social development (2, 3). Breast/chestfeeding can also help increase age-appropriate weight gain, intelligence, cognitive development, memory retention, language skills, whole brain volume, cortical thickness, white matter volume, myelination, and temperament (2-4). Furthermore, there are several advantages for the feeder, such as decreased risks of breast cancer, ovarian cancer, type 1 diabetes, type 2 diabetes, hypertension, cardiovascular disease, postpartum depression, anxiety, obesity, hyperlipidemia, muscle contractions, and postpartum bleeding (1-4). Breast/chestfeeding can also increase cardiac vagal tone, generate higher quality sleep, postpregnancy weight loss, oxytocin release, social bonding, trust, love, relaxation, and uterine involution (2, 3).

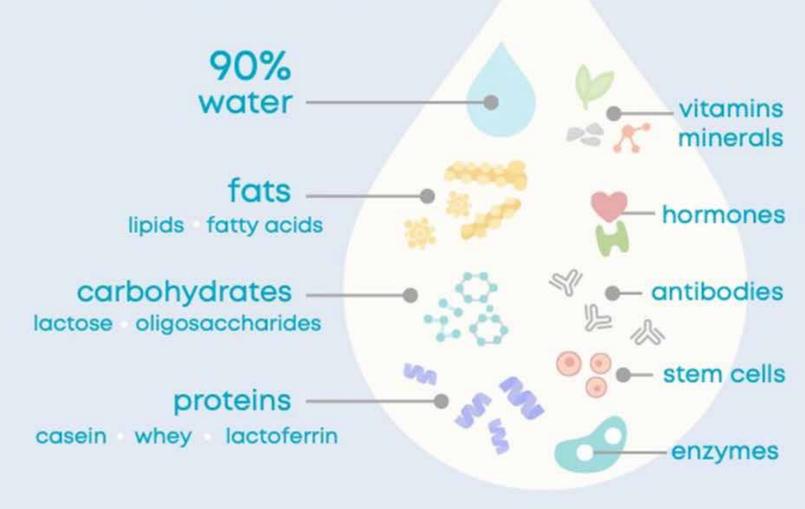
"Due to the numerous benefits, every major health organization recommends exclusive breast/chestfeeding for the first six months of life (1, 2) and introducing complementary foods after six months. Despite these recommendations, many feeders discontinue breastfeeding early or do not initiate breast/ chestfeeding at all. In the United States,"

Due to the numerous benefits, every major health organization recommends exclusive breast/chestfeeding for the first six months of life (1, 2) and introducing complementa-

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ry foods after six months. Despite these recommendations, many feeders discontinue breastfeeding early or do not initiate breast/ chestfeeding at all. In the United States, 81% of women initiate breastfeeding, with 52% continuing for six months and 31% continuing for 12 months (1). The reasons for ceasing breast/chestfeeding are not always known and are always highly personal and complex. Not all factors can be expressed due to the complexity of the physical and emotional nature of breast/chestfeeding. The most common factors that lead to the cessation of breast/chestfeeding are an insufficient milk supply, inadequate latching, and painful nipples or breasts (1).

"Not all factors can be expressed due to the complexity of the physical and emotional nature of breast/chestfeeding. The most common factors that lead to the cessation of breast/chestfeeding are an insufficient milk supply, inadequate latching, and painful nipples or breasts (1)."

There are several ways to address the difficulties that feeders experience with breast/chest feeding, yet these strategies are not always well implemented. One of the most effective methods to increase rates and duration of breast/chestfeeding is to provide post-discharge primary care support (1). This primary care support should promote skin-to-skin contact, early initiation of breast/ chestfeeding, lactation support, the Baby Friendly Hospital Initiative (which adheres to The Ten Steps to Successful Breastfeeding), and breast/chestfeeding education (1). It is essential to position the infant correctly to address insufficient milk supply and poor latch; this promotes oxytocin and prolactin release, facilitating milk production (1). To achieve an optimal position, "the infant's head and body should face the mother's body, and the infant's neck should not be hyperextended or flexed to reach the nipple. The nipple should be guided toward the roof of the infant's mouth, filling the mouth with as much of the areola as possible" (1). Common causes of nipple and breast pain were a result of poor positioning, flat or inverted nipples, ankyloglossia/palatal abnormality, infections, and vasospasm (1). When these concerns were addressed, over half (58%) of the feeders reported decreased pain; however, after common issues were addressed, many breast/chestfeeders continued to report pain, indicating that nipple and breast pain are multifactorial (1).

"When these concerns were addressed, over half (58%) of the feeders reported decreased pain; however, after common issues were addressed, many breast/ chestfeeders continued to report pain, indicating that nipple and breast pain are multifactorial (1)."

In addition to providing accurate education about the benefits of breast/chestfeeding, one of the most important ways a healthcare provider can support parents is to communicate without projecting pressure or passing judgment on feeding choices. All healthcare providers must be approachable and use cultural humility when communicating with patients about breast/chestfeeding and the challenges they are experiencing. Feeders are often met with unrealistic and unachievable expectations for breast/chestfeeding, which results in added pressure and intimidation when communicating with healthcare providers (2). There is a common notion that "breast is best," which implies that formula feeding is wrong. Some formula-feeding parents may fear harming their infant and avoid conversations about formula feeding with medical staff (2). Some parents may also feel intimidated when healthcare providers promote breast/chestfeeding, which can lead to feelings of discrimination in situations where promotion is not necessarily appropriate (2). Breast/chestfeeding difficulties can contribute to depression and anxiety, and feeders with negative breast/chestfeeding experiences are more likely to have depression and anxiety following birth (2). In addition to the proper medical aid, it is crucial to provide emotional support to feeders and reinforce their identity as a parent when breast/chestfeeding difficulties arise (2). This can be accomplished through support systems such as lactation consultants and support groups to aid in the emotional trauma of breast/chestfeeding difficulties (2).

"Minority populations exclusively breast/ chest feed for a decreased amount of time compared to non-Hispanic Whites (7). For new immigrants to the United States, bottle-feeding is more likely to be chosen, even if their country of origin has high breast/chestfeeding rates (6). A parent's ethnic background and culture can impact who influences the breast/ chestfeeder's view on feeding practices."

Cultural identities and community affiliations significantly affect the feeder's perception of breastfeeding/chestfeeding. These cultural influences have an enormous impact on minority populations and initiatives. Breast/chestfeeding rates have increased among all minority groups in the United States, although they remain relatively low (6, 7). Minority populations exclusively breast/chest feed for a decreased amount of time compared to non-Hispanic Whites (7). For new immigrants to the United States, bottle-feeding is more likely to be chosen, even if their country of origin has high breast/chestfeeding rates (6). A parent's ethnic background and culture can impact who influences the breast/chestfeeder's view on feeding practices. For example, among the White population, the male partner, mother's mother, grandmother, and best friend greatly influence breast/chestfeeding choices (6).

Similarly, within the Hispanic population, the mothers, grandmothers, and sisters were a much greater influence than the physicians or nurses (6). Among Southeast Asian communities, the mother-in-law and significant others had the largest influence on breast/chestfeeding, while the healthcare providers had the most significant influence on the Black population with minimal impact from family members (6). In addition to attitudes about breast/chest-

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- chestfeeding
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feeding, cultural practices influence feeding and lactation. For example, specific foods are believed to promote milk production in some cultures. As long as it is not harmful, healthcare providers should encourage the consumption of these foods to support an individual's cultural beliefs (6). Weaning practices from breast/chestfeeding also vary according to culture; however, weaning processes should always be collaborative between the feeder and the healthcare providers. To support the specific needs of minority groups, healthcare providers require culturally specific resources and additional education in cross-cultural sensitivity.

Minorities with lower education levels and socioeconomic status are at a heightened risk for breast/chestfeeding problems; Programs and training that increase the well-being of these minority families are imperative (6). Returning to work due to low socioeconomic status leads to suboptimal breast/chestfeeding outcomes (7). Black feeders, in particular, were found to be the most likely to work while trying to breast/chestfeed (62%), followed by Hispanic (59%), Asian (59%), then White (58%) (7). Black and Hispanic populations are more likely to be uninsured, leading to a greater chance of not being educated about the benefits of breast/chestfeeding or receiving medical care if difficulties arise (6). Being in a Baby Friendly Hospital helped improve breast/chestfeeding outcomes in diverse groups and decreased the gap among Black feeders (7).

"Breastfeeding Awareness Month is essential in optimizing breast/ chestfeeding practices and reducing disparities in lactation support for minority groups. No matter the cultural group, breast/chestfeeding promotion programs are found to be successful in improving overall breast/chestfeeding rates (6). More interagency collaboration is required to educate parents on the mutual benefits of breast/chestfeeding with innovative strategies that support extended production and use of human milk to optimize development."

Breastfeeding Awareness Month is essential in optimizing breast/ chestfeeding practices and reducing disparities in lactation support for minority groups. No matter the cultural group, breast/ chestfeeding promotion programs are found to be successful in improving overall breast/chestfeeding rates (6). More interagency collaboration is required to educate parents on the mutual benefits of breast/chestfeeding with innovative strategies that support extended production and use of human milk to optimize development. These educational programs are most effective when they are designed to be culturally sensitive and developed by individuals from within the target culture (5). When minority populations identify limiting factors, healthcare providers can address the barriers and become more culturally responsive. More advocacy initiatives are needed to ensure that healthcare providers are well

informed and treat all breast/chestfeeding dyads in such a way that is respectful and accepting of all cultural or socioeconomic backgrounds.

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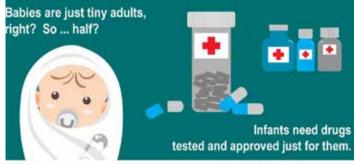


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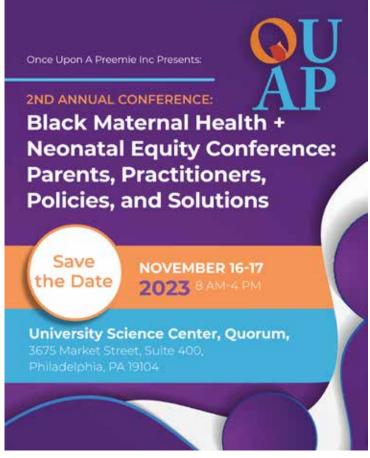


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Certain diagnoses can make children and babies more vulnerable for serious complications from respiratory viruses

- including prematurity, chronic lung disease, and heart conditions.



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



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



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

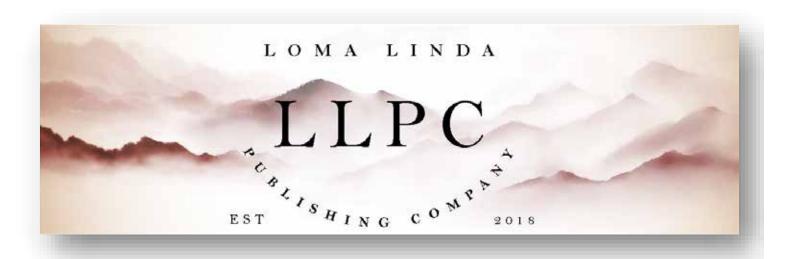


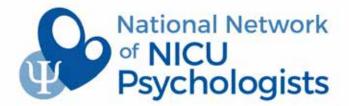
Babies older than 6 months can get a flu shot and COVID-19 vaccinations. There is no vaccine for RSV, but monthly antibody shots during RSV season can help protect them.



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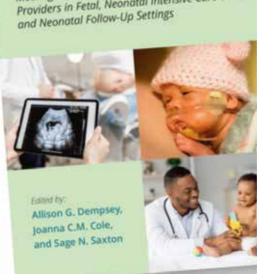






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## Navigating the Future of Pediatric Leadership: The American Academy of Pediatrics Election Process

Mitchell Goldstein, MD, MBA, CML

"This manuscript explores the significance of these elections, highlighting the current board composition, the role of diversity, equity, and inclusion, and the evolving landscape of pediatric leadership."

Abstract: The American Academy of Pediatrics (AAP) stands at a crossroads of leadership as it prepares for its upcoming elections for second-term subspecialty at-large seats, president-elect, and other crucial positions. This manuscript explores the significance of these elections, highlighting the current board composition, the role of diversity, equity, and inclusion, and the evolving landscape of pediatric leadership.

#### Introduction:

The American Academy of Pediatrics (AAP) serves as a beacon of excellence in pediatric healthcare, advocating for children's well-being and supporting the professional development of pediatricians across subspecialties. The AAP's commitment to staying abreast of evolving healthcare dynamics is evident in its election process, which seeks to align leadership with modern pediatrics' diverse and dynamic landscape.

#### **Election Dynamics and Board Composition**

The AAP's forthcoming elections hold significant importance, particularly regarding the second-term subspecialty at-large seats. These seats represent a pivotal juncture for shaping the academy's leadership, ensuring that voices from medical and surgical subspecialties are heard and integrated into decision-making. The current term has seen the dedicated leadership of Charles Macias, a pediatric emergency medicine specialist, and Connie Houck, a pediatric anesthesiologist. However, the upcoming elections offer an

opportunity to enhance the diversity of expertise at the helm.

"The AAP's forthcoming elections hold significant importance, particularly regarding the secondterm subspecialty atlarge seats. These seats represent a pivotal juncture for shaping the academy's leadership, ensuring that voices from medical and surgical subspecialties are heard and integrated into decision-making."

Furthermore, the AAP's board includes an at-large seat to amplify diversity, equity, and inclusion (DEI) perspectives. Joelle Simpson's presence in this capacity reflects the academy's commitment to addressing these critical dimensions within pediatric healthcare. Simultaneously, Joe Wright's appointment as the inaugural AAP Diversity Officer underscores the academy's recognition of the imperative to foster a more inclusive environment.

"Simultaneously, Joe Wright's appointment as the inaugural AAP Diversity Officer underscores the academy's recognition of the imperative to foster a more inclusive environment."

#### President-Elect: Pinnacle of Leadership:

In addition to the at-large seats, the election of the AAP's president-elect holds unparalleled significance. This individual will be pivotal in guiding the AAP's overarching vision and priorities. The president-elect serves as a torchbearer for the academy, setting the tone for collaboration, innovation, and advocacy. As the academy faces evolving challenges in pediatric healthcare delivery, the president-elect's perspective will be instrumental in steering the course toward improved child health outcomes.

"In addition to the atlarge seats, the election of the AAP's presidentelect holds unparalleled significance. This individual will be pivotal in guiding the AAP's overarching vision and priorities. The president-elect serves as a torchbearer for the academy, setting the tone for collaboration, innovation, and advocacy."

#### Electronic Polling and Member Engagement:

The AAP's commitment to accessibility and inclusivity is further demonstrated by its adoption of electronic polling. By opening the polls electronically from September 13th to 27th, the AAP enables widespread member engagement, transcending geographical barriers and facilitating participation from diverse pediatric professionals nationwide. This digital approach reflects the academy's responsiveness to the evolving preferences of its members, ensuring that the election process is efficient and inclusive.

"For more information about the candidates and the election process, all are encouraged to visit the AAP's official elections webpage at https://www.aap.org/elections."

Conclusion:

The AAP's election process is a testament to its unwavering commitment to pediatric excellence, innovation, and inclusivity. As the academy readies itself for the elections for second-term subspecialty at-large seats, president-elect, and other pivotal positions, the landscape of pediatric leadership is poised for evolution. In the spirit of progress, AAP members must engage with the candidates actively, considering their diverse expertise, leadership experiences, and visions for the future. By doing so, AAP members collectively steer the trajectory of pediatric healthcare, champion-



ing children's best interests and fostering a united voice for the profession.

For more information about the candidates and the election process, all are encouraged to visit the AAP's official elections webpage at <a href="https://www.aap.org/elections">https://www.aap.org/elections</a>.

Disclosures: There are no reported disclosures

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## **Empowering Pediatric Excellence: Why Lily Lou, MD Deserves Your Vote**

Mitchell Goldstein, MD, MBA, CML

"One standout candidate who embodies these qualities is Lily Lou, MD, a seasoned neonatologist with an impressive clinical practice, research, leadership, and advocacy track record."

As the American Academy of Pediatrics (AAP) prepares for its upcoming elections, it is crucial to consider candidates with diverse perspectives and the experience and dedication to drive the organization forward. One standout candidate who embodies these qualities is Lily Lou, MD, a seasoned neonatologist with an impressive clinical practice, research, leadership, and advocacy track record.

"Dr. Lou's candidacy is especially noteworthy due to the lack of neonatologists on the board, despite the substantial impact of the Section of Neonatal-Perinatal Medicine (SONPM), which constitutes 7% of the AAP membership."

The AAP's subspecialty at-large seats are essential positions that contribute to shaping the future of pediatrics. Lily Lou's candidacy holds significant promise for advancing the academy's mission. Dr. Lou's candidacy is especially noteworthy due to the lack of neonatologists on the board, despite the substantial impact of the Section

of Neonatal-Perinatal Medicine (SONPM), which constitutes 7% of the AAP membership. Her representation would bring a much-needed voice to the table, ensuring that the concerns and expertise of neonatologists are fully integrated into the AAP's discussions and decisions.

Dr. Lou's extensive background reflects a breadth of experience that uniquely equips her for this role. With a comprehensive range of practice settings, from academic institutions to private practices and public health sectors, she has garnered invaluable insights into the various facets of pediatric care. Her involvement in basic science and clinical research demonstrates a commitment to evidence-based practices. At the same time, her current focus on civic engagement and pediatric outcomes signifies her forward-thinking approach to healthcare.

"Dr. Lou's extensive background reflects a breadth of experience that uniquely equips her for this role. With a comprehensive range of practice settings, from academic institutions to private practices and public health sectors, she has garnered invaluable insights into the various facets of pediatric care."

Leadership is another cornerstone of Dr. Lou's candidacy. Her leadership portfolio is extensive and diverse, spanning roles as NICU Medical Director, Pediatric Department Chair, Executive Medical Director of a children's hospital, and contributions to the hospital system and state public health leadership. This rich experience exposes her to many healthcare scenarios, from urban and inner-city environments to rural areas. Her interactions with Native American, Alaska Native, and military popula-

tions underscore her ability to understand and address diverse communities' unique challenges.

Dr. Lou's relationship with the AAP further solidifies her suitability for the board. Her decade-long involvement in the Section of Neonatal-Perinatal Medicine, including roles as District 8 Representative, Chair-Elect, Chair, and Past Chair, demonstrates her commitment to advancing the field and fostering collaboration within the academy. With 18 years of chapter leadership, she possesses a comprehensive understanding of pediatrics beyond her subspecialty.

"Dr. Lou's relationship with the AAP further solidifies her suitability for the board. Her decadelong involvement in the Society of Neonatal-Perinatal Medicine, including roles as District 8 Representative, Chair-Elect, Chair, and Past Chair, demonstrates her commitment to advancing the field and fostering collaboration within the academy."

Her dedication to advocacy and member engagement truly sets Dr. Lou apart. Her fervent belief in a united front for all pediatricians, regardless of subspecialty, resonates deeply with the AAP's ethos. Dr. Lou envisions a cohesive professional home that promotes collaboration and growth across all pathways. Her passion for nurturing member engagement and providing opportunities for professional development reflects her commitment to the continued excellence of the pediatric community.

As we prepare to cast our votes between September 13th and 27th, let us consider the future we envision for the American Academy of Pediatrics. Dr. Lily Lou's candidacy encapsulates the values of diversity, experience, leadership, and advocacy essential for the AAP's growth and impact. By electing Dr. Lou to the board, we take a step closer to a future where all pediatricians unite under one professional home led by a visionary dedicated to advancing the field to improve children's health nationwide.

"By electing Dr. Lou to the board, we take a step closer to a future where all pediatricians unite under one professional home led by a visionary dedicated to advancing the field to improve children's health nationwide."

**Disclosures:** This is an unpaid endorsement. Neither Dr. Goldstein nor Neonatology Today received any consideration for their support of Dr. Lou's campaign.

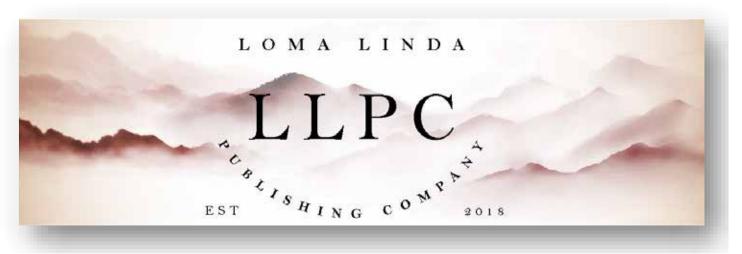
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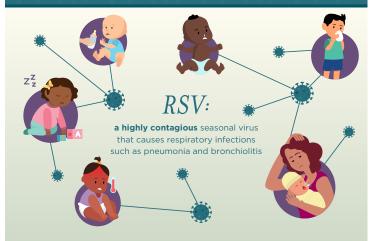
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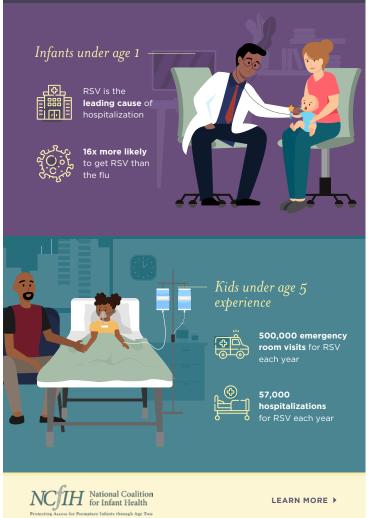


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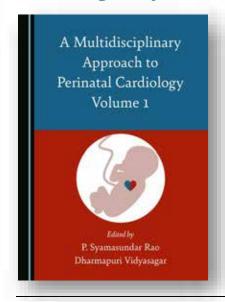
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## A Multidisciplinary Approach to Perinatal Cardiology *Volume 1*

Edited by P. Syamasundar Rao and Dharmapuri Vidyasagar



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#### **Book Description**

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

#### **About the Editors**

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

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

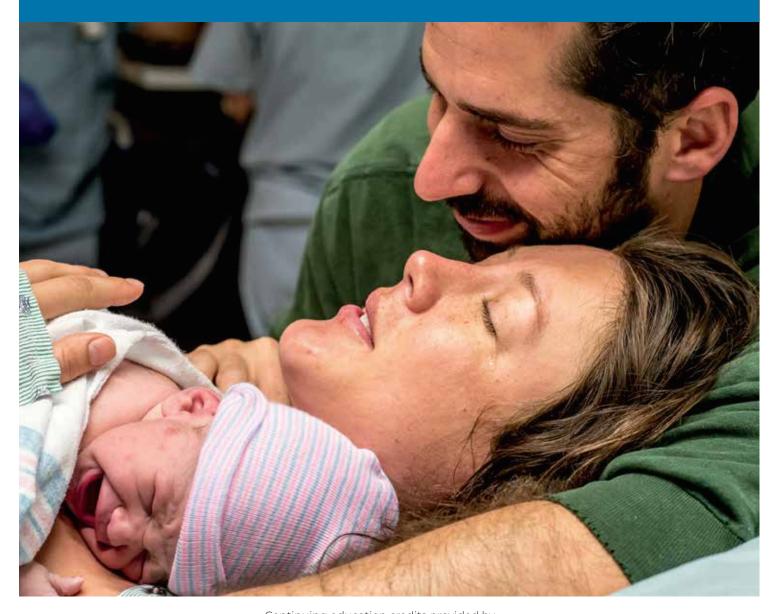


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#### About the Program

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

#### Program Objectives

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

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

#### PROGRAM CONTENT



#### **COMMUNICATION SKILLS** CEUs offered: 1

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

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



#### PERINATAL MOOD AND ANXIETY DISORDERS CEUs offered: 1

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

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



#### PROVIDING ANTEPARTUM SUPPORT CEUs offered: 1

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

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



#### PROVIDING INTRAPARTUM SUPPORT CEUs offered: 1

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

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



#### **PROVIDING POSTPARTUM SUPPORT** CEUs offered: 1

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

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



#### SUPPORTING STAFF AS THEY SUPPORT FAMILIES CEUs offered: 1

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

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

#### Cost

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

Contact help@myperinatalnetwork.org to learn more.

# Faculty

## Linda Baker, PsyD

Psychologist at Unstuck Therapy, LLC, Denver, CO.

# 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.

Follow us online at @MyNICUNetwork





# SHARED DECISION-MAKING 'PROTECTS MOTHERS + INFANTS

**DURING COVID-19** 



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
F 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.





# Coping COVID-19





A viral pandemic

A racial pandemic within a viral pandemic









Will mental illness be the next inevitable pandemic?

WWW.MYNICUNETWORK.ORG



# **Human Milk Supports Health and Growth for Babies**

Josie Cooper

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





A new study confirms what mothers and doctors have long believed: human milk is the best source of nutrition for infants.

"A new study confirms what mothers and doctors have long believed: human milk is the best source of nutrition for infants."

The wholesome sufficiency of "mother's milk" is not just a turn of phrase; it is a biomedical reality. Access to human milk, whether through mothers or donors, can majorly support neonatal health.

According to a new study in the <u>American Journal of Preventive Medicine</u>, breastfed babies are 33% less likely to die during the post-perinatal period than infants who were not breastfed. The study included 10 million US infants born between 2016 and 2018. The new data joins a growing body of research supporting breastmilk's health benefits. Infants born preterm or with health challenges in particular, benefit from breastmilk.

# Human milk supports health and growth for preterm babies.

In particular, babies born preterm or with health challenges benefit from consuming human milk, whether from their mother or a

screened donor.

Recent research on infants with congenital heart conditions affirms that a diet rich in human milk can have a life-changing impact on health and development. These babies typically struggle to gain the healthy weight associated with normal growth. Human milk-derived fortifiers supply nutrients, prebiotics, and immunological components to support infants' growth. It is also better tolerated than milk products from other mammals.

Babies with congenital heart disease or defects also often undergo surgery before they are released from the hospital. When they receive a diet of exclusively human milk, those infants show improved growth and decreased risk of complications immediately after surgery.

"Babies with congenital heart disease or defects also often undergo surgery before they are released from the hospital. When they receive a diet of exclusively human milk, those infants show improved growth and decreased risk of complications immediately after surgery."

#### Human milk also offers other benefits.

In addition to providing nutrition and immunological protection, human milk may confer other benefits. Human milk has been shown to protect against diabetes, obesity, asthma, cardiovascular diseases, and autoimmune disorders.

Some cultures even value other "milk therapies," including topical applications to treat everything from pink eye to diaper rash. Scientists have made treatments directly from compounds in human milk, and many alternative and folk remedies show signs of having health benefits.

"A compound as powerful as human milk — available widely, inexpensively, and with minimal side effects — shows great promise. With additional research, scientists and healthcare providers can continue learning about human milk's complex impact and benefits."

A compound as powerful as human milk — available widely, inexpensively, and with minimal side effects – shows great promise. With additional research, scientists and healthcare providers can continue learning about human milk's complex impact and bene-

fits. Increased understanding can, in turn, encourage full use and equal access to the wonder drug produced by the human body.

#### Reference:

- https://www.news-medical.net/news/20230724/Breastfeeding-linked-to-reduced-post-perinatal-infant-mortality.aspx
- 2. <a href="https://authors.elsevier.com/a/1ggke\_WXIDGWc">https://authors.elsevier.com/a/1ggke\_WXIDGWc</a>

Josie Cooper is the executive director of the Alliance for Patient Access.

Disclosure: The authors have no disclosures.

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www.99nicu.org

Immunizing Yourself Against COVID-19

# COVID-19 vaccines have been shown to:

- Lessen the severity of symptoms<sup>1</sup>
- Reduce disease transmission<sup>3</sup>
- Reduce risk of mortality<sup>2</sup>
- Make communities healthier and safer<sup>4</sup>



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



## **mRNA VACCINES**

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



# PROTEIN SUBUNIT VACCINES

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



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



## **VECTOR VACCINES**

Used for decades against chickenpox, malaria and tuberculosis.



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

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

the immune system to the virus.

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

# Safe and Sound

**COVID** vaccines have been:



# Thoroughly tested

through multi-phase trials with tens of thousands of participants<sup>6</sup>



Proven safe and effective

for adults as well as children<sup>7</sup>



**Vetted and approved** by the US FDA and EMA and endorsed by the WHO<sup>8-10</sup>

# **Get Your Jab**

Vaccines are available at your:



Doctor's office



Neighborhood pharmacy



Community health center

- https://www.mayoclinic.org/diseases-conditions/coronavirus/symptomscauses/syc-20479963
- 2. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8782520/
- https://www.nejm.org/doi/full/10.1056/nejmc2107717
   https://royalsocietypublishing.org/doi/full/10.1098/rsif.2020.0683
- https://www.cdc.gov/vaccines/covid-19/clinical-considerations/interim considerations-us.html
- considerations-us.ntml

  6. https://doh.wa.gov/emergencies/covid-19/vaccine-information/safety-andeffectiveness
- https://doh.wa.gov/emergencies/covid-19/vaccine-information/safety-andaffectiveness
- https://www.fda.gov/emergency-preparedness-and-response/coronavirus-disease-2019-covid-19/covid-19-vaccines
- https://www.ema.europa.eu/en/human-regulatory/overview/public-health-threats/coronavirus-disease-covid-19/treatments-vaccines/vaccines-covid-19 covid-19-vaccines-authorised
- http://www.bccdc.ca/Health-Info-Site/Documents/COVID-19\_vaccine/WH0-EUA-qualified-covid-vaccines.pdf



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





Join Us! For the 37th International **GRAVENS** meeting on the **Environment of Care for** High Risk Newborns and their Families

March 6-9, 2024

Sheraton Sand Key Resort Clearwater Beach, Florida

For more information go to https://paclac.org/https-paclac-org-gravens-conference/ or PACLAC.org Abstracts due October 1, 2023







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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 alcoholbased 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.
- - 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.



# VARNING

# Never Put a Mask on Your Baby

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

# If you are positive for COVID-19

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

# We can help protect each other.

Learn more

www.nationalperinatal.org/COVID-19



# The Gap Baby: An RSV Story



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



# The National Coalition for Infant Health advocates for:

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

www.infanthealth.org

# Empowering Transformations: From Diversity Advocacy, Nursing Journey, to Ask the Experts – Chronicles from the Heart of iCAN

Sabina Schmidt Goldstein-Becerra



Get involved today and Join the iCAN Parent Council!

"iCAN, or the International Children's Advisory Network, is committed to providing numerous opportunities for the pediatric community to come together and hear from the most crucial stakeholders in healthcare: the patients. Our organization empowers all pediatric patients worldwide by facilitating their active participation in innovation, research, and medicine."

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<u>Cultivating Inclusivity and Empowerment: Introducing Michelle Burgess as the Diversity, Inclusion, and Equity Chair at iCAN.</u>



iCAN is thrilled to introduce our newly appointed Diversity, Inclusion, and Equity Chair, Michelle Burgess. Hailing from the vibrant city of Chicago, Michelle's journey has been diverse and inspiring. At the tender age of three, she embarked on a transformative move to a quaint Kentucky town, where she embraced a rustic farm lifestyle, nurturing a deep appreciation for the natural world. Later, at the age of nine, Michelle returned to the urban landscape of Chicago, discovering a passion for performing arts, particularly singing and acting.

"iCAN is thrilled to introduce our newly appointed Diversity, Inclusion, and Equity Chair, Michelle Burgess. Hailing from the vibrant city of Chicago, Michelle's journey has been diverse and inspiring."

Her academic journey led her to DePaul University in Chicago, where she pursued her undergraduate studies. During her time at DePaul, Michelle felt a calling to explore journalism, with a strong inclination toward broadcasting. This led to her earning an undergraduate degree in Communication. Beyond academics, Michelle's time at DePaul also marked a significant personal milestone—she married her life partner, Terrell Burgess, in June 2000.

Michelle's path took yet another enriching turn, balancing the joys of motherhood and a growing family. She returned to education, undertaking a master's degree in theology from a seminary. During this phase, Michelle's quest for learning expanded to include Diversity, Equity, and Inclusion (DEI) studies. Eager to contribute positively to her community, Michelle initiated workshops to challenge conventional perspectives and foster open-mindedness.

Diversity, Equity, Inclusion, and emotional intelligence became the cornerstones of Michelle's commitment to caring for others. Her passion for these areas provided a strong foundation for her to stand upon as she dedicated herself to improving people's lives. Throughout her journey, community service has remained a driving force for Michelle. Her unwavering dedication to promoting equity and justice has led her to seek innovative ways to uplift and empower her surroundings.

With Michelle at the helm of our Diversity, Inclusion, and Equity initiatives, iCAN is poised to embark on a new chapter of growth and enlightenment. Her unique background, multifaceted experiences, and unyielding dedication make her a beacon of change and progress. We are excited to witness the positive impact Michelle will undoubtedly bring to our organization and the communities we serve.



<u>Celebrating Remarkable Progress: Empowering iCAN Uganda</u> Chapter Member's Pathway to Nursing and Medical Advance-

ment

We are thrilled to share a heartening success story that exemplifies the transformative influence of iCAN's initiatives. One of our esteemed members from the iCAN Uganda chapter is charting a promising trajectory towards a career in nursing, poised to make substantial contributions within the medical domain thanks to the instrumental role iCAN has played in her journey. This inspiring narrative is a testament to the profound impact of iCAN's endeavors and the tangible outcomes they foster.

"One of our esteemed members from the iCAN Uganda chapter is charting a promising trajectory towards a career in nursing, poised to make substantial contributions within the medical domain thanks to the instrumental role iCAN has played in her journey."

This remarkable individual's fervent dedication and relentless efforts are a testament to the nurturing environment and empowerment that iCAN provides. Her pursuit of a nursing career in Poland underscores the profound ripple effect that grassroots initiatives like iCAN can have on shaping lives and driving positive change.

As we witness the unfolding of her journey, we are reminded of iCAN's core mission: to provide a platform that educates, informs, and empowers individuals to transcend boundaries and realize their potential. This accomplishment fills us with immense pride and reaffirms our commitment to fostering avenues of growth, education, and empowerment within our diverse and global iCAN community.

"We eagerly anticipate the continued progress and success of our dedicated iCAN Uganda member as she embarks on this transformative path within the medical realm. Her journey exemplifies the impact that passionate individuals, supported by organizations like iCAN, can have on shaping the healthcare landscape and beyond."

We eagerly anticipate the continued progress and success of our dedicated iCAN Uganda member as she embarks on this transformative path within the medical realm. Her journey exemplifies the impact that passionate individuals, supported by organizations like iCAN, can have on shaping the healthcare landscape and beyond.

Navigating Medical Challenges: Insights from Experts and Their Transformative Journeys on "Ask the Experts"



On Saturday, August 19th, an engaging and thought-provoking Ask the Expert Session centered around the compelling theme of "Transforming Adversity into Strength." This event featured a distinguished panel of experts: Meghan, Rhiannon, Regina, and Valeria, all of whom possess an unparalleled level of expertise as authorities on their medical conditions. The crux of their discussions revolved around introspective inquiries, delving into their unique diagnostic journeys and the profound implications these journeys have had on their lives.

"This event featured a distinguished panel of experts: Meghan, Rhiannon, Regina, and Valeria, all of whom possess an unparalleled level of expertise as authorities on their medical conditions. The crux of their discussions revolved around introspective inquiries, delving into their unique diagnostic journeys and the profound implications these journeys have had on their lives."

A prevailing topic that emerged was the transformative influence of confronting medical challenges. The panelists delved into how their encounters with adversity had fundamentally shifted their perspectives on life and its multifaceted hurdles. The exploration of positive aspects and silver linings that have emerged amidst the complex landscape of medical adversity was particularly captivating. These individuals generously shared instances where they had gleaned valuable life lessons from their medical experienc-

es—lessons that proved instrumental in surmounting challenges extending far beyond healthcare.

This event was a symphony of inspiring personal narratives, conveying how these medical journeys have shaped the panelists' lives and ignited an unwavering desire to provide support and inspiration to others navigating similar hardships. Each panelist elaborated on their unique approaches to motivating, assisting, and providing solace to individuals facing similar struggles.

"The impact of this session was palpable, serving as a resounding testament to its profound influence on attendees. The engaged and inquisitive audience seized the opportunity to pose thought-provoking questions, fostering a dynamic discourse that further enriched the collective experience."

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and inquisitive audience seized the opportunity to pose thoughtprovoking questions, fostering a dynamic discourse that further enriched the collective experience.

# Uma to Everyone 7:35 AM

What would you want to tell healthcare providers about your experience and what to consider when working with other future patients like you?





how did you get started with advocacy / find resources and support?



Our iCAN community is excited to extend an invitation to you for the ongoing journey of enlightenment and empowerment through our highly anticipated Ask the Experts (ATE) series. This monthly series showcases luminaries from diverse fields, including health-care, technology, and innovation. We wholeheartedly encourage you to secure your participation in the forthcoming ATE session in September by registering on our website. By engaging in these sessions, you open the door to engaging discussions and the accumulation of invaluable insights.

We warmly welcome all interested parties to join us in these enlightening sessions. To stay informed about upcoming ATE topics and session dates, please follow our Instagram account, @

"This monthly series showcases luminaries from diverse fields, including healthcare, technology, and innovation. We wholeheartedly encourage you to secure your participation in the forthcoming ATE session in September by registering on our website."

icanresearch.

At the core of iCAN's mission lies an unwavering dedication to providing a platform for experts to share their sagacity and perspec-

tives. If you possess expertise in pediatric healthcare—whether in innovation, medicine, or technology—we enthusiastically invite you to contribute as a speaker for our ATE sessions. For additional information, kindly contact us at abbyclark@icanresearch.org.

This presents a rare opportunity to deeply immerse yourself in the knowledge and insights of top-tier healthcare experts. We urge you to promptly reserve your spot for the upcoming ATE session, as we eagerly anticipate your active engagement and participation. Your journey toward enlightenment and empowerment commences here.

Excitement Builds for the iCAN 2024 Summit in Bari, Italy- Sponsorships Needed!



We are thrilled to announce that our much-anticipated 2024 summit will be hosted in Bari, Italy! The excitement among our kids is palpable as they eagerly look forward to this incredible event. However, we need your help to make it an unforgettable experience for all!

"We are thrilled to announce that our much-anticipated 2024 summit will be hosted in Bari, Italy! The excitement among our kids is palpable as they eagerly look forward to this incredible event. However, we need your help to make it an unforgettable experience for all!"

Our annual summit provides invaluable opportunities for our young members, similar to the ones previously offered by Empath Labs and Pfizer. It is a transformative platform for fostering innovation, compassion, and collaboration in pediatric healthcare.

If you believe in the power of education and inspiration, we invite you to participate in this life-changing event. There are two ways you can contribute:

# 1. Sponsor the 2024 Summit:

By becoming a sponsor, you will play a crucial role in supporting the logistics and organization of the summit. Your generous contribution will enable us to create an impactful and seamless experience for all participants. To sponsor the event, please reach

out to sabinaschmidtgoldstein@icanresearch.org.

#### 2. Sponsor a Child to Attend the Summit:

Your sponsorship can directly impact a child's life, providing them with a once-in-a-lifetime opportunity to attend the summit in Bari. Your support will cover their travel, accommodation, and participation fees, allowing them to immerse themselves in a world of learning, inspiration, and empowerment. To sponsor a child, please visit our donation page at https://www.icanresearch.org/ donate.

Together, we can shape a brighter future for pediatric healthcare by nurturing the potential of our young members. Your contribution, no matter how big or small, will significantly pave the way for innovative advancements in the field.

"Thank you for considering this opportunity to support the next generation of healthcare leaders. We are deeply grateful for your generosity and dedication to our cause. Let us come together in Bari, Italy, and create an unforgettable summit experience to inspire and empower young minds for vears to come!"

Thank you for considering this opportunity to support the next generation of healthcare leaders. We are deeply grateful for your generosity and dedication to our cause. Let us come together in Bari, Italy, and create an unforgettable summit experience to inspire and empower young minds for years to come!

Disclosures: There are no reported disclosures

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Sabina Schmidt Goldstein-Becerra

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Email: sabina.goldstein@icanresearch.org

# Your Pregnancy and Substance Use

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



# Get Prenatal Care

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



# Reduce Your Use

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

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



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



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

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



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



# Take Good Care of Yourself

You deserve a healthy pregnancy & childbirth.

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

# Your Health Matters





www.perinatalharmreduction.org | www.nationalperinatal.org



**GLO Preemies** 

# Healthcare Executive Roundtable

Talk Openly, Share Opinions & Ask Burning Questions

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

KEEPING

**MOTHERS** + INFANTS TOGETHER

Means balancing...





# **EVIDENCE**

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

# PARTNERSHIP

SHARED DECISION-MAKING

What is the best for this unique dyad?

S EEK PARTICIPATION

H ELP EXPLORE OPTIONS

A SSESS PREFERENCES

R EACH A DECISION





# 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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# **Keeping Your Baby Safe**



# from respiratory infections

How to protect your little ones from germs and viruses

This year is an especially dangerous cold and flu season - especially for vulnerable infants and children. Fortunately, there are proven protective measures that we can take to stay healthy.

# Here's what you can do...

# Wash Your Hands

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



# **Limit Contact with Others**

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

# **Provide Protective Immunity**

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



# Take Care of Yourself

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



## **Get Immunized**

WARNING

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



COVID-19

# Never Put a Mask on Your Baby

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

# If you feel sick or are positive for COVID-19

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



We can help protect each other. www.nationalperinatal.org/rsv



# PROTECT YOUR FAMILY FROM RESPIRATORY VIRUSES

flu

coronavirus

pertussis





# 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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# Coping During COVID-19

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

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HELPING CHILDREN AND FAMILIES COPE

CAREGIVERS NEED CARE TOO





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

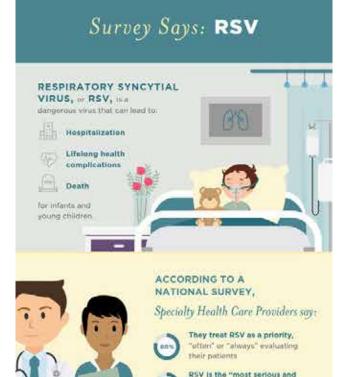
Tell insurers what families need

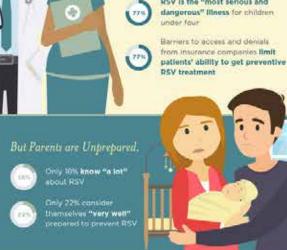


and provide the supporting evidence



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





RSV EDUCATION & AWARENESS CAN HELP

After parents learned more about RSV, they were:

65%

"More concerned" about their child contracting the disease

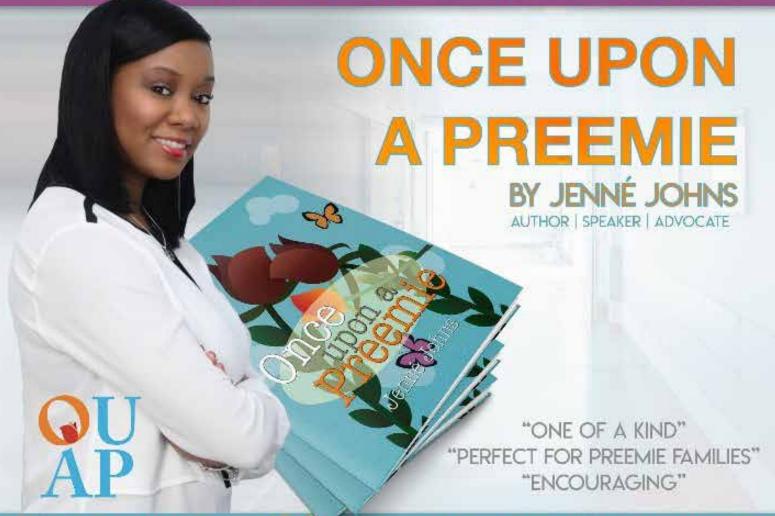
Likely to ask their doctor about RSV



NCIIH National Condition
for Infant Health

Caum More about RSV at www.infantHealth.org/RSV

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# MEDIA APPEARANCES



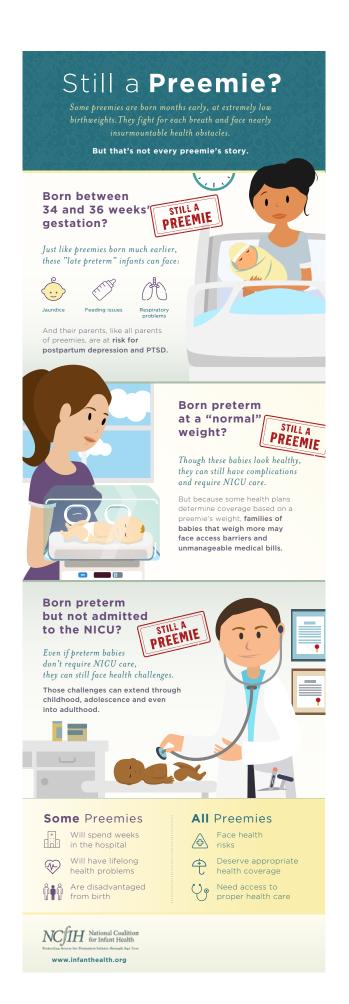












# **OPIOIDS** and NAS

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.



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!

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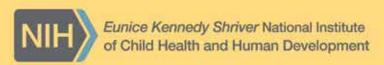
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The CE activity explains safe infant sleep recommendations from the American Academy of Pediatrics and is approved by the Maryland Nurses Association, an accredited approver of the American Nurses Credentialing Center's Commission on Accreditation.







# **Medical News, Products & Information**

Compiled and Reviewed by Sandeep Lankireddy, BA, OMS IV

# Severe maternal morbidity rates in a US-based electronic health record database, 2018–2022

**NEWS PROVIDED BY** 

Journal of Perinatology

by Son, M., Culhane, J.F., Louis, J.M. et al..

August 28, 2023

#### Introduction

Severe maternal morbidity (SMM) result in short and long-term health consequences and increased costs, representing a major public health problem. More insight into the risk factors and health disparities that contribute to SMM would inform potential strategies to reduce SMM. Our objective was to determine contemporary rates of delivery-related SMM and provide evidence to enhance understanding of risk factors associated with delivery-related SMM in a large diverse US population using electronic health record (EHR) data.

#### **Methods**

This retrospective cross sectional study utilizes Epic Systems Corporation's (Epic) Cosmos research platform, a newly available US-based EHR database which provides anonymized patient-level data [1]. Epic provides services to one-third of US hospitals. To date, approximately 200 health systems (>1000 hospitals) contribute data to Cosmos, containing data from >190 million patients. Individuals with an inpatient delivery hospitalization encounter or billing and diagnostic codes for childbirth from 01/01/2018 to 12/31/2022 were included. There were no exclusion criteria. For individuals with >1 delivery during the study period, we randomly selected 1 delivery for inclusion. SMM cases were identified using the US Centers for Disease Control and Prevention (CDC)'s algorithm based on 21 SMM indicators and corresponding ICD-10 codes [2]. We calculated rates of overall SMM with and without blood transfusion during the delivery hospitalization. Additionally, rates of SMM were calculated based on patient sociodemographic factors such as age, race and ethnicity, insurance type, and social vulnerability index (SVI) [3], medical comorbidities, and delivery mode. Deaths during the childbirth encounter were identified by an "expired" discharge disposition. This study of deidentified data was deemed exempt from review by the Nemours Children's Hospital Institutional Review Board.

#### Results

Of 1,625,133 individuals, 31,232 had at least one SMM including blood transfusion, 13,922 had at least one SMM without blood transfusion, and 60 died. Rates (95% CIs) of SMM with and without blood transfusion were 192 (190–194) and 87 (85–88) per 10,000 delivery hospitalizations, respectively. The most frequent SMM rate per 10,000 [95% CI] was blood transfusion (105 [104–

107]) followed by disseminated intravascular coagulation (23.5 [22.8–24.3]) and ventilation (15.8 [15.3–16.5]) (Supplement). SMM rates (95% CI) were highest in patients with diabetes (457 [437–478]) and hypertension (414 [405–424]), and those delivered by cesarean (460 [452–467]) (Table 1). Additionally, individuals aged <20 and ≥35 years, those of Non-Hispanic Black race, those with public insurance, obesity, heart disease, asthma, current smokers, and those residing in high SVI ZIP codes all had higher overall SMM rates (Table 1).

#### **Conclusions**

The rates of SMM in this large EHR database are consistent with recent published trends [4]. SMM rates were highest for patients with medical comorbidities and those considered socially vulnerable. While these data encompass the coronavirus-19 pandemic, a prior analysis of this EHR-based population showed that SARS-CoV-2 positivity did not alter the rate of adverse pregnancy outcomes [5]. Limitations include restriction to the delivery hospitalization as data are mapped to the calendar year of delivery to maintain patient anonymity; therefore, prenatal and postpartum SMM rates could not be determined. Additionally, SMM events occurring in non-Cosmos hospitals are not captured. Strengths include a large, diverse, and recent study population (Cosmos data can be current within 2 weeks), and availability of sociodemographic and clinical data from individual medical records. As the Cosmos platform evolves, direct availability of EHR data will offer increased granularity, identification of preventable factors, and opportunities for quality improvement to reduce maternal morbidity, all of which are improvements over administrative data.

## Citation

Son, M., Culhane, J.F., Louis, J.M. et al. Severe maternal morbidity rates in a US-based electronic health record database, 2018–2022. J Perinatol (2023). https://doi.org/10.1038/s41372-023-01765-7

NT

# CHOC neonatologist Dr. Terrie Inder's study on preterm brains published in New England Journal of Medicine

**NEWS PROVIDED BY** 

Children's Hospital of Orange County

August 2, 2023

# **Background**

DCHOC neonatologist Dr. Terrie Inder, an expert on the newborn brain, is the lead author of an authoritative review paper published in the New England Journal of Medicine (NEJM). Dr. Inder's "Defining the Neurological Consequences of Preterm Birth," appears in the Aug. 3, 2023, issue of the NEJM, a leading global medical journal.

Director of the Center for Neonatal Research at CHOC, Dr. Inder wrote the comprehensive review with a mentor and longtime collaborator, Dr. Joseph J. Volpe, a founder of neonatal neurology with his seminal book, Neurology of the Newborn, and Peter J. Anderson, Ph.D., another research partner of Dr. Inder who is affiliated with Boston Children's Hospital.

Review articles that appear in the NEJM are considered specialty-defining works that will be cited by thousands of researchers moving forward.

Experts on the newborn brain will build on the conclusions of Dr. Inder's paper, which focuses on brain injuries and long-term adverse neurologic effects of preterm babies (those born after less than 37 weeks' gestation) and very preterm children (those born between 32 weeks and 26 weeks).

"This is the new authoritative text on the neurological consequences of pre-term birth," said Dr. John Crawford, medical director of neurology at CHOC and co-medical director of the CHOC Neuroscience Institute. "We have one of the world's leading experts on neonatal brain injury right

here in Orange County."

Dr. Inder, who joined CHOC in summer 2022 after being recruited from Brigham and Women's Hospital, a major teaching hospital at Harvard Medical School, provides in the paper a comprehensive overview of what is known about the neurological consequences of pre-term birth and highlights gaps in current knowledge.

"CHOC is thrilled to be leading in this area of science and I am humbled to be recognized by having leading authorship on the review of this topic," said Dr. Inder, a dual-boarded neonatologist and child neurologist who is a professor of pediatrics in UC Irvine's Department of Pediatrics, which is chaired by CHOC Senior Vice President and Pediatrician-in-Chief Dr. Coleen Cunningham.

"Dr. Inder is a world leader in this field and we are delighted to have her here at CHOC and UCI," Dr. Cunningham said.

The last time a review article on a similar subject was published in the NEJM was about a decade ago, Dr. Inder said.

# Injuries and development

Globally, an estimated 15 million infants are born preterm (between 37- and 32-weeks' gestation).

Despite advances in healthcare that are keeping more of these, as well as very preterm infants, alive, the risk of long-term neurological and developmental disabilities remains high, the NEJM paper concludes.

Dr. Inder and her colleagues detail how the immature brain is vulnerable to three types of brain injuries: those affecting the white matter, germinal matric-intraventricular hemorrhage, and cerebellar hemorrhage.

"We know these brain injuries occur commonly, although they are often unrecognized without magnetic resonance imaging (MRI) scans of the infant's brain," said Dr. Inder. "We're still working on preventative strategies and remediating these injuries from having adverse neurological outcomes in later life through rehabilitation."

In addition to these three injuries, a preterm infant's time spent in the neonatal





www.nationalperinatal.org/mental\_health

intensive care unit (NICU) can influence brain development with neurological consequences – for example, being cared for in an environment with lights, noises, and smells.

Other important factors include nutrition and nurturing, such as parent voice and touch/holding. There are also influences after discharge such as rehabilitation therapies and family care.

"An understanding of these factors will assist neonatal clinicians in using future neuroprotective strategies to improve long-term neurological outcomes in the preterm infant," Dr. Inder and her colleagues write.

# Second appearance in NEJM

The review article is Dr. Inder's second appearance in the NEJM. In 2006, she and Dr. Anderson had a study published in the journal. Together, they now have co-authored 78 papers in various publications.

Dr. Inder has published often with Dr Volpe and has joined him as a co-editor of Neurology of the Newborn, the leading text in the field.

Competitive and high-impact medical journals such as the NEJM, which has published continuously for more than 200 years, accepts only the top 1% of research submissions received each year.

#### Lifetime work

"Dr. Inder has spent a large part of her career looking at MRIs to track the development of injuries and how the brain develops in preterm infants, and her new NEJM paper is a distillation of this lifetime work," Dr. Crawford said.

"While this is also a review article of others' work, Dr. Inder, Dr. Volpe and Dr. Anderson have significantly contributed to the literature and background studies that are the basis of this review article," he added.

"This paper provides a very comprehensive study of what we know about the neurological consequences of preterm birth and also highlights our gaps and

our knowledge in this area and paves the way for future studies," Dr. Crawford said. "There's still much work to be done, as this paper so eloquently describes."

"These are children that have the potential of living 70, 80, 90 years, and we should be investing in making sure they have the best possible outcomes."

Such an effort, Dr. Crawford noted, will take teamwork.

"It really requires a collaboration between neonatologists, child neurologists, and neuropsychologists," he said. "It really spans a whole spectrum of disciplines to care for these children."

Added Dr. Inder: "We shouldn't be focusing on the just the survival of these babies, but on optimizing their long-term neurological health. This is also our mission at CHOC with 'Long Live Childhood."

#### NT

# UI study shows hemodynamic screening halves risk of death, brain bleed in premature babies

# **NEWS PROVIDED BY**

<u>University of Iowa Stead Family Children's</u> <u>Hospital</u>

August 17, 2023

When neonatologists Patrick McNamara and Regan Giesinger started the hemodynamic screening program at the University of Iowa Stead Family Children's Hospital in 2018, they were confident it would increase survival rates and reduce complications for their premature patients.

A new study provides scientific validation of how right they were.

The study, published recently in the American Journal of Respiratory and Critical

Care Medicine, shows that when hemodynamic screening was added in the 24 hours after birth to the care of babies born at fewer than 27 weeks, the combined rate of death or severe brain bleeding fell by half

The addition of hemodynamic screening was linked to lower incidence of several other complications including severe lung disease and necrotizing enterocolitis, a serious intestinal disease.

"This work is precedent-setting for neonatology," Dr. McNamara, a UI professor of pediatrics and director of the Division of Neonatology, said in a release. "We have demonstrated for the first time that this new field of neonatal hemodynamics can have a major impact not just on survival but also on long-term quality of life for extremely preterm babies. The reduction in some of the serious health conditions is just spectacular — not only reducing severe brain bleeding but almost eliminating necrotizing enterocolitis, a killer in many premature infants."

# Using hemodynamic screening to guide treatment plans improves outcomes

Hemodynamics involves using ultrasound to obtain detailed images of the baby's heart, valves and vessels that allow doctors to assess heart function and blood flow to all parts of the body, including the brain and the lungs.

These assessments are performed by hemodynamic specialists — neonatologists who have completed one additional year of structured echocardiography training.

The physiologic information acquired on hemodynamics screening can then be used to identify the underlying cardiovascular problem and target treatment precisely.

Dr. McNamara and Dr. Giesinger had already seen the benefits of a hemodynamics program firsthand. The doctors were both expert neonatologists that had helped make hemodynamics a standard protocol in neonatal intensive care units (NICUs) across Canada. When they arrived at UI Stead Family Children's, where the NICU was already world-renowned, they saw an opportunity to assess just how impactful hemodynamics can be at improving survival rates and reducing complications.

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Dr. Giesinger, Dr. McNamara and their colleagues at the UI Stead Family Children's Hospital followed 423 babies, born before 27 weeks, between January 2010 and December 2017. This control group did not get hemodynamic screening and is representative of the situation at most high-level NICUs currently in the U.S. The team also followed 191 babies, also born before 27 weeks, between October 2018 and April 2022. All these babies received hemodynamic screening within 12 to 18 hours of birth.

The hemodynamic screening group had lower levels of all the adverse events measured: severe brain bleeding, death, death within the first week of life, necrotizing enterocolitis, and severe bronchopulmonary dysplasia.

Overall, introducing the hemodynamic screening program halved the risk of death or severe brain bleed from 29% to 16%. The risk of necrotizing enterocolitis also fell from 6% to 1%. These improvements are even more noteworthy because the proportion of extremely premature babies who are born between 22 and 23 weeks, who are most at risk for bad outcomes, was actually higher in the cohort that received hemodynamic screening.

# Heart, circulation problems are common and deadly in premature babies

Very premature babies are more likely to survive now than they were 20 years ago, but these infants are still at high risk for severe cardiovascular complications because their hearts are not developed enough.

These underdeveloped cardiovascular systems lead to unstable blood flow that may be a root cause of many serious complications — such as lung problems, necrotizing enterocolitis, and severe brain hemorrhage — that affect these medically fragile patients.

Between 50 and 75% of infants who survive severe brain bleeding develop long-term neurological problems. These include intellectual disability, hydrocephalus, and cerebral palsy and have few effective treatments. Therefore, mitigating the risk of brain injury is a priority for neonatologists.

Dr. Giesinger died in May, but Dr. McNamara believes her efforts and contributions to the field of hemodynamics will leave a lasting legacy.

"Regan Giesinger was absolutely integral in establishing this program five years ago. She was the best sonographer of small babies I have ever seen; she could do a comprehensive study within less than 10 minutes," Dr. McNamara said. "This work was so important to her, and her last study has provided landmark findings that will have a huge impact on the care of these tiny babies in the future."

In addition to Dr. McNamara and Dr. Giesinger, the UI study team included Danielle Rios, Trassanee Chatmethakul, Adrianne Bischoff, Jeremy Sandgren, Alison Cunningham, Madeline Beauchene, Amy Stanford, Jonathan Klein and Patrick Ten Eyck.

### NT

# Pilot study of an interprofessional pediatric mechanical ventilation educational initiative in two intensive care units

**NEWS PROVIDED BY** 

### **BMC Medical Education**

by Mehrzai, P., Höfeler, T., Ebenebe, C.U. et al.

August 28, 2023

### **Abstract**

# Introduction

Inappropriate ventilator settings, non-adherence to a lung-protective ventilation strategy, and inadequate patient monitoring during mechanical ventilation can potentially expose critically ill children to additional risks. We set out to improve team theoretical knowledge and practical skills regarding pediatric mechanical ventilation and to increase compliance with treatment goals.

#### **Methods**

An educational initiative was conducted from August 2019 to July 2021 in a neonatal and pediatric intensive care unit of the University Children's Hospital, Hamburg-Eppendorf, Germany. We tested baseline theoretical knowledge using a multiple choice theory test (TT) and practical skills using a practical skill test (PST), consisting of four sequential Objective Structured Clinical Examinations of physicians and nurses. We then implemented an educational bundle that included video self-training, checklists, pocket cards, and reevaluated team performance. Ventilators and monitor settings were randomly checked in

all ventilated patients. We used a process control chart and a mixed-effects model to analyze the primary outcome.

#### Results

A total of 47 nurses and 20 physicians underwent assessment both before and after the implementation of the initiative using TT. Additionally, 34 nurses and 20 physicians were evaluated using the PST component of the initiative. The findings revealed a significant improvement in staff performance for both TT and PST (TT: 80% [confidence interval (CI): 77.2-82.9] vs. 86% [CI: 83.1-88.0]; PST: 73% [CI: 69.7-75.5] vs. 95% [CI: 93.8-97.1]). Additionally, there was a notable increase in self-confidence among participants, and compliance with mechanical ventilation treatment goals also saw a substantial rise, increasing from 87.8% to 94.5%.

#### **Discussion**

Implementing a pediatric mechanical ventilation education bundle improved theoretical knowledge and practical skills among interprofessional pediatric intensive care staff and increased treatment goal compliance in ventilated children.

NT

# Fatigue and fallibility: the perils of prolonged shifts for neonatologists

**NEWS PROVIDED BY** 

Journal of Perinatology

by Ryan M. McAdams

July 8, 2023

#### **Abstract**

Sleep deprivation is a major challenge for neonatologists, who face increasing demands in the complex healthcare system. Current neonatal intensive care unit (NICU) schedule models often include extended shifts and overnight call, which can lead to sleep deprivation. This lack of sufficient sleep poses adverse health risks to neonatologists and can impair cognitive function, which increases the risk of medical errors and compromises patient safety. This paper proposes reducing shift durations and implementing



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policies and interventions to reduce fatigue among neonatologists and improve patient safety. The paper also offers policymakers, healthcare leaders, and NICU physicians valuable insights on potential ways to promote the health of the neonatologist workforce and safety in the NICU.

NT

# Quality Indicators to Evaluate Essential Newborn Care in Low- and Middle-Income Countries

## **NEWS PROVIDED BY**

# **American Academy of Pediatrics**

by by Ellen K. Diego, MD, Danielle E.Y. Ehret, MD, MPH, Ashish K.C., MBBS, MHCM, PhD, and Carl L Bose, MD

August 23, 2023

# **Background**

Strategies to improve neonatal outcomes rely on accurate collection and analyses of quality indicators. Most low- and middle-income countries (LMICs) fail to monitor facility-level indicators, partly because recommended and consistently defined indicators for essential newborn care (ENC) do not exist. This gap prompted our development of an annotated directory of quality indicators.

# Methods

We used a mixed method study design. In phase 1, we selected potential indicators by reviewing existing literature. An overall rating was assigned based on subscores for scientific evidence, importance, and usability. We used a modified Delphi technique for consensus-based approval from American Academy of Pediatrics Helping Babies Survive Planning Group members (phase 2) and secondarily surveyed international partners with expertise in ENC, LMIC clinical environments, and indicator development (phase 3). We generated the final directory with guidelines for site-specific indicator selection (phase 4).

#### Results

We identified 51 indicators during phase 1. Following Delphi sessions and secondary review, we added 5 indicators and rejected 7. We categorized the 49 indicators meeting inclusion criteria into 3 domains: 17 outcome, 21 process, and 11 educational. Among those, we recommend 30 for use, meaning indicators should be selected preferentially when appropriate; we recommend 9 for selective use primarily because of data collection challenges and 10 for use with reservation because of scientific evidence or usability limitations.

#### Conclusions

We developed this open-access indicator directory with input from ENC experts to enable appraisal of care provision, track progress toward improvement goals, and provide a standard for benchmarking care delivery among LMICs.

NT

# Addressing bias and knowledge gaps regarding race and ethnicity in neonatology manuscript review

# **NEWS PROVIDED BY**

## Journal of Perinatology

by Karvonen, K.L., Bonachea, E.M., Burris, H.H. et al.

### **Abstract**

A recent shift in public attention to racism, racial disparities, and health equity have resulted in an abundance of calls for relevant papers and publications in academic journals. Peer-review for such articles may be susceptible to bias, as subject matter expertise in the evaluation of social constructs, like race, is variable. From the perspective of researchers focused on neonatal health equity, we share our positive and negative experiences in peer-review, provide relevant publicly available data regarding addressing bias in peer-review from 12 neonatology-focused journals, and give recommendations to address bias and knowledge gaps in the peer review process of health equity research.

#### Introduction

In response to the murders of Breonna Taylor and George Floyd there has been a shift in public and academic attention to address racism, racial disparities, and health equity. Health equity is achieved when every person has the ability to attain their health potential. One of many major barriers to health equity include racism, or discrimination on the basis of one's racial group. Racism can be individualized, internalized, and systemic and all forms contribute to racial disparities in health outcomes. Systemic racism is a form of racism that is embedded in laws, policies, and institutions, including academic medicine, that has resulted in a disparate distribution of goods, services, and opportunities for racial groups [1]. Despite an abundance of calls for papers addressing health equity in major journals, the extent that reviewers and editors are adequately trained to critically evaluate the use of social constructs, like race, in research studies is highly variable. A major contributor to this knowledge deficit is the historical false belief in race as a biological construct by the scientific community and a paucity of published articles naming racism as a major driver of racial disparities [2, 3]. Omission of rigorous research standards for evaluating race and racism has contributed to harmful rhetoric such as the biologic fallacy of race [4].

In addition to knowledge gaps by reviewers regarding the evaluation of social variables like race, explicit or implicit bias can occur in the manuscript review process [5, 6], which may be more epitomized during peer review of articles focused on health equity that use social variables in their approach. For example, microaggressions are a form of discrimination defined as "slights" that communicate a negative attitude toward marginalized groups. Microaggressions disproportionately impact marginalized groups and are commonplace in the workforce's daily lives; peer-review is no exception [7]. In order to combat bias in reviews, scholars have suggested diversification of editorial boards, as well as intentional recruitment, education, and compensation of diverse pools of peer reviewers [4, 8, 9]. Others have called for explicit standards for evaluation of race and ethnicity [4, 10, 11]. In light of these concerns, more recently, some journals have established new author guidelines for addressing race and racism [5, 12,13,14,15,16]. However, standardized criteria have not been agreed upon or adopted for many academic journals.

As health equity researchers in academic neonatology, we offer [1]. Our own personal positive and negative experiences within the last two years that highlight knowledge gaps and bias in the peer-review process [2]; A brief summary of publicly available data from major, neonatal-focused journals regarding existing processes to evaluate health equity research and address bias in the review process; and [3] Our recommendations for neonatology-focused journals regarding these aforementioned issues.

# Our experiences in peer-review of neonatology-focused journals

# Knowledge gaps during peer-review

"After submitting a study for peer review that tracked hospital practices by race/ ethnicity and language, a reviewer argued there was no rationale as to why such disparities in hospital practices could exist and questioned why we chose to examine this. Denial of disparities in care quality by this reviewer suggested a significant knowledge gap of long-standing literature. I alerted my concern to the editor who omitted this review and sent it out to a different reviewer."

"When exploring the experience of traditionally marginalized communities in a qualitative study, a reviewer suggested that to increase the validity of the study, we should compare the experience to the majority's experience. Centering whiteness and white normativity was problematic in a study designed to center at the margins [17]. Following this comment, our team opted to include prose in the discussion about findings of previous studies focused on white populations. It was eventually published."

"As a peer reviewer I suggested capitalizing the 'b' in Black when identifying race and to not use 'Blacks' when referring to Black persons. The authors responded that they preferred not to edit for readability, despite the possibility of offensive interpretation and accepted terminology.12

Upon re-review, the editor agreed and sent me a positive reply acknowledging the 'teaching moment' for the authors."

#### Bias in the peer-review process

"I revealed my identity in a commentary and received an inappropriate comment during the review process. I did not know where to anonymously report my experience of discrimination to avoid worrying about my future relationship with the journal."

#### **Evaluation**

To better understand the extent that journals serving the academic neonatology audience have guidance regarding evaluation of social variables, like race and ethnicity, in articles and processes to address bias in peer-review, we examined the websites of 12 major academic journals that publish in neonatology. Journals were chosen by combining our searches of academic journals with high frequency of neonatal-perinatal material based on a PubMed query (currently utilized by neopapers, an automated literature Twitter account that has been created to publish recent articles with content related to neonatology and an active account in the #neoTwitter community [18, 19]), and authors' familiarity. Journal characteristics were created by the authors to evaluate previous commitment to health equity topics, transparency of diversity, equity, and inclusion issues, intention to diversify editorial staff, and existence of an anonymous system of reporting discrimination in peer review. No formal recommendations or regimented criteria exist to evaluate journal processes for inclusion of health equity content or bias in review, thus our evaluation metrics were developed through iterative discussion by authors and guidance from previous literature [2,3,4, 8,9,10].

We summarize findings in Table 1. We found that more than 75% of journals have published at least one original research, commentary, and perspective piece on health equity since journal conception, suggesting recognition of addressing social variables in neonatology journals. Regarding processes which may improve

bias in peer-review more broadly, no journal had readily available data on racial, ethnic, or gender diversity of reviewers, editors, editorial board, but four (33%) had a statement of current efforts to diversify reviewers, editors, and/or editorial boards and only one (8%) journal provided information for how to apply to be an editorial board member on their website. Only one (8%) journal had a statement separate from Committee of Publication Ethics (COPE) guidelines for how to address bias in peerreview. COPE is an organization dedicated to providing resources and leadership on publication ethics which has recently published guidance on addressing bias in peer review. Although contact information was nearly always available for both editor-inchief and members of the editorial board as a potential pathway to report discrimination (83% and 100% respectively), we could find no evidence of journals with a transparent system of anonymous peer review feedback to report racism, bias, or discrimination on their website.







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#### **Discussion**

Our anecdotal experience and review of publicly available data from journal websites suggest that there is room for improvement to address knowledge gaps in peer-review of neonatology articles focused on health equity, which often utilize social variables like race and ethnicity in their methodology and therefore may increase potential for bias in the peer-review process. With heightened national attention on the role of race, racism, and other social factors on health outcomes, we anticipate that research in this area will continue to grow. Therefore, journal guidelines for authors and reviewers are needed to educate the neonatal research community and set standards on use of race and racism in research. While our experiences focus primarily on the social construct of race and ethnicity, we believe that our experiences and our recommendations may impact those doing research in other domains that also utilize social variables such as income, primary language, and immigration status.

Researchers also must be protected from discrimination and bias in the peer-review process. Few journals have made transparent efforts to diversify staff or develop mechanisms for providing anonymous feedback in the setting of perceived racism and discrimination in the review process. In our review, many journals have statements demonstrating commitment to adhere to COPE guidelines, which recently organized a Diversity Equity and Inclusion (DEI) committee that has provided resources and a commitment to addressing ethics and DEI for journals [20]. A few journals we evaluated have also signed the joint commitment for action on inclusion and diversity in publishing, launched in June 2020 by the Royal Society of Chemistry with ongoing efforts to set minimum standards for inclusion and diversity for scholarly publishing. Planned efforts include, but are not limited to, setting minimum targets to achieve diverse representation of authors, reviewers, and editorial boards, developing language standards, reviewing and revising editor and editorial board member selection processes, and publicly reporting their progress [21]. We are encouraged by the intention and progress made by several journals and publishing bodies, and hope to see fully transparent standards for DEI in the peer-review process across all neonatology publishing journals.

We consider the diversification of reviewer, editorial boards, and editors to be of particular importance for the health equity publication process in neonatology journals. Not only does the inclusion of perspectives of lived experience and participation in scholarly health equity activities advance the quality of work in our field, it also begins to address historical exclusion of minoritized individuals from scientific discourse [8, 10]. In our field, there continues to be underrepresentation of minoritized trainees and physicians scientists [22]. Harm during the peer review process can negatively impact the pursuit of antiracism and health equity work and disproportionately impacts minoritized researchers [10, 23]. Building infrastructure for transparency and accountability is necessary for ongoing publication of high quality health equity research [10]. We hope that our recommendations on how to improve the peer-review process in neonatology journals can help improve the trust of neonatal researchers and mitigate systemic inequities in publication in research focused on health equity.

Our review was limited to information readily available on journal websites. This may not fully encompass efforts made by academic journals to support health equity research and address bias in the peer-review process. The journal processes evaluated were designed by authors and thus are not previously validated and may not sufficiently evaluate the performance of journals. Our perspective piece does

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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.

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# NAS is a temporary and treatable condition.

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#### My mother may have a SUD.

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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

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not compare the performance of neonatology journals, which tend to be clinically focused, to social science or public health focused journals. Performance in neonatology journals may be different from journals dedicated specifically to health equity. Regardless we see importance in addressing bias and knowledge gaps within our field while understanding challenges may be different or similar to other fields.

#### Recommendations

We offer the following recommendations to improve the peer-review process:

A standard of proficiency of reviewers in evaluation of social variables and constructs, including race and racism. While there are a few resources available that address this topic [4, 12,13,14,15, 24], it is unclear what standard exists or should be followed among neonatology journals. At minimum, we recommend statements that confer that race is a social construct without biological basis and explicitly stating racism as a primary etiology of racial disparities.

Transparency of current demographics of authors, reviewers, editorial boards, and editors. Although lack of diversity in academia is a widely known problem and we suspect it is no different in neonatology, the demographics of the participants in the peer-review process was not explicitly stated in the journals reviewed. Transparency offers a route towards accountability.

Diversification of reviewers, editorial boards, and editors with transparent, publicly announced target dates and goals.

Transparency, evaluation, and equal opportunity of editorial board selection process to facilitate diversification.

Recruitment and appropriate compensation for subject matter experts for time. We are not aware of any current resources or guidelines that define subject matter expertise prior to review. In the case of health equity research, lived experience should be recognized as a form of subject matter expertise. Similarly, we are not aware of resources to guide overall reviewer recruitment nor compensation for reviewers by journals. If compensation for peer review is not provided by journals, institutions should consider ways in which to support faculty and trainees who participate in the peer-review process through financial incentives, promotion, or other forms of meaningful recognition.

Standardized and robust training on an antiracism and the measurement and evaluation of social constructs in academic medicine and biomedical research that begins early and continues throughout professional careers.

Anonymous reporting mechanism for authors to report racism and/or other types of bias in the peer-review process

#### NT

# AAP sets national standards for levels of neonatal care

## **NEWS PROVIDED BY**

# American Academy of Pediatrics

by Alyson Sulaski Wyckoff, Associate Editor

May 22, 2023

A new AAP document defines the care hospitals provide for newborns by establishing standards for levels of neonatal care, specifying the personnel, equipment and other services needed. The standards codify the minimum components of each level of neonatal care — from special care nursery (Level II) to complex subspecialty care including surgery (Level IV).

The document, Standards for Levels of Neonatal Care: II, III, & IV, is based on AAP policy, evidence-based literature and standards of professional practice. It will be available via a link in the June issue of Pediatrics (https://doi.org/10.1542/peds.2023-061957). It is a companion to the AAP policy statement Levels of Neonatal Care and the manual Guidelines for Perinatal Care, 8th edition.

The standards also uphold the AAP Equity Agenda by encouraging facilities to assess the health disparities of their patients, families and community, with an emphasis on family-centered care.

# **Verification Program**

The publication of the neonatal intensive care unit (NICU) standards also marks the beginning of the AAP NICU Verification Program's endeavor to expand nationally.

Until this time, the program has served

as a surveying body for levels of neonatal care in specific states, while direct oversight has been provided by a state-specific designating authority (i.e., public health department). With publication of the new standards, and when processes are in place, the AAP program will be able to verify a neonatal facility's compliance and designate that it provides a specific level of neonatal care (II, III or IV).

Hospitals will submit data and undergo a survey of their facility. Those that meet requirements will be able to state that they are AAP-verified at a particular level of neonatal care. The designation then will be transparent to physicians and families deciding where to deliver and/or seek care for their baby.

While all states regulate health care facilities, specifications for levels of neonatal care and adherence to requirements vary widely. Few states require verification by

a third-party surveying agency. Facilities that self-assess often rate themselves at a higher level than they actually are.

Therefore, a national neonatal verification program "is vital to high-quality and equitable care," the document states. Experts note that it is important to have an honest appraisal by an experienced survey team that can evaluate a facility carefully.

# **Multidisciplinary Effort**

The standards were developed by a team of neonatal leaders and experienced clinicians with a longstanding interest in risk-appropriate care and education and who comprise the NICU Verification Program Leadership Team. Others who provided input include the AAP Committee on Fetus and Newborn (COFN), Section on Neonatal-Perinatal Medicine and its Clinical Leaders Group, and experts from professional medical and nursing associations.

Boston neonatologist Ann R. Stark, M.D., FAAP, medical director of the AAP NICU Verification Program, heads the team.

She is a former chair of the COFN, was lead author of the initial *Levels of Neonatal Care* policy statement and is editor of the seventh edition of *Guidelines for Perinatal Care*.

Her work in this area dates to 2013, when the AAP was identified as one of two Texas-approved survey agencies to pilot the neonatal verification process, and the NICU Verification Program was officially launched. Dr. Stark put together a group of colleagues to do pilot surveys and develop a verification program for facilities in Texas and later in Georgia and Missouri.

"We were concerned that first, babies should be treated in a place with appropriate care and second, that the facility has the people and the equipment that are appropriate for their degree of illness or degree of immaturity," Dr. Stark said.

# **Growing need**

The NICU Verification Program has performed third-party surveys by experts, including neonatologists, neonatal nurses and pediatric surgeons, assessing whether facilities comply with state standards for neonatal care.

As the need has grown and more facilities have requested surveys, it became clear that the AAP needed to develop national neonatal care standards.

Parents also should understand the level of neonatal care available where they are delivering, Dr. Stark said.

In addition, she said, infants born in rural hospitals should receive the same kind of care as those in big-city academic medical centers, with advanced-level facilities educating lower-level facilities.

Quality and safety are large components of the program, with all facilities tracking their outcomes and making sure all patients are getting optimal care.

"Our whole thesis is to make sure babies get cared for in a place that's commensu-



rate with their problems, their degree of maturity and so on, so there is equity for babies across the country," Dr. Stark said.

"We have created these standards with a goal to improve outcomes, increase access to care, improve standardization across all levels of neonatal care and really achieve health equity."

NT

# Newly identified lipid in breast milk might reduce cerebral palsy in infants

#### **NEWS PROVIDED BY**

#### **Duke University Medical Center**

by Alyson Sulaski Wyckoff, Associate Editor

August 3, 2023

While it's known that the white matter loss will lead to neurological deficits, there is currently no treatment to help these infants avoid the outcome.

In experiments using neonatal mice, researchers at Duke Health have identified a fatty molecule in breast milk that triggers a process in which stem cells in the brain produce cells that create new white matter, reversing the injury.

The study appears Aug. 3 in the journal *Cell Stem Cell*. Eric Benner, M.D., Ph.D., is the study's corresponding author and is a distinguished assistant professor in the Department of Pediatrics at Duke University School of Medicine. Benner said further study in a clinical trial is needed, but the finding is promising.

"Developing therapies for children -- especially such medically fragile children -- is very difficult to do because there are justifiably strict safety concerns," Benner said. "The fact that this molecule is already found in something that is safe for premature babies -- breast milk -- is extremely encouraging.

"It's been known that fats in breast milk benefit a child's brain development, but there are many types of fats in breast milk," Benner said. "This work has identified a lipid molecule in breast milk that promotes white matter development. Now, we can begin to develop a therapy that isolates and delivers this lipid in a way that is safe for the unique challenges of these infants."

Benner is a neonatologist at Duke University and one of the co-founders of Tellus Therapeutics, a Duke spinout company developed with the help of the Duke University Office for Translation & Commercialization to bring this therapy from the bench into the neonatal intensive care unit.

The fatty molecule identified in the study will be administered intravenously to patients in an upcoming clinical trial. This is significant because many of the infants who are part of this vulnerable population also have gastrointestinal issues and cannot safely be given milk or medication by mouth.

The lipid molecule enters the brain and binds with stem cells there, encouraging the stem cells to become or produce a type of cell called oligodendrocytes.

The oligodendrocytes are like a hub that allow for the production of white matter in the central nervous system. This newly produced white matter in pre-term infants prevents the neurological damage that would otherwise impact the child's ability to move -- the hallmarks of cerebral palsy.

"The timing of brain injury is extremely difficult to predict, thus a treatment that could be safely given to all preterm babies at risk would be revolutionary," said Agnes Chao, M.D., a former fellow in the Division of Neonatology and first author of the paper.

"As a neonatologist, I'm so excited that I may be able to offer a treatment to families with babies that are affected by preterm brain injury who would otherwise have no other options," Chao said.

In addition to Benner and Chao, study authors include Pavle Matak, Kelly Pegram, James Powers, Collin Hutson, Rebecca Jo, Laura Dubois, J. Will Thompson, P. Brian Smith, Jason R. Gibson, Noelle E. Younge, Blaire Rikard, Simon G. Gregory, Ronald N. Goldberg, Mari L Shinohara, Estefany Y. Reyes, Chunlei Liu.

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# FDA Issues Guidance to Assist Drug Manufacturers in Assessing Nitrosamine-Related Impurities Risk

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Today, FDA issued a new guidance for immediate implementation, "Recommended Acceptable Intake Limits for Nitrosamine Drug Substance-Related Impurities (NDSRIs)," which provides drug manufacturers and applicants with a recommended framework for a risk-based safety assessment of NDSRIs that could be present in approved and marketed drug products, as well as products under review by FDA.

In connection with the guidance, the agency is also launching web content including, on an associated webpage, current recommended acceptable intake limits of certain NDSRIs that may be at risk of forming in human drugs, which illustrates the recommended framework described in the guidance for industry reference. Manufacturers and applicants are responsible for detecting and preventing unacceptable levels of impurities in their drug products, or avoiding their presence when feasible. Manufacturers and applicants are also responsible for developing and using suitable methods to detect and limit such impurities, including any new impurities that may arise when they make changes to their manufacturing processes.

FDA is committed to ensuring that the medicines Americans take are safe, effective, and of high-quality. We continually gain new knowledge about drugs, which allows us to identify and quickly address previously unknown risks to patients. When we identify drug quality issues that pose potential risks for patients, we make every effort to understand the issues and provide our best recommendations to the public as quickly and accurately as possible. We intend to continue to investigate and work to help ensure these types of impurities do not exceed acceptable intake limits so that patients can continue taking their medicines without concern.

For more information on nitrosamine impurities in medications, please visit FDA's nitrosamines webpage.

NT

Prenatal Metals Exposure Effects on Adverse Infant Behavior Enhanced by Co-exposure to Stress Hormones, Particularly in Girls

Corresponding Author: Francheska M. Merced-Nieves, PhD, Assistant Professor, Departments of Pediatrics and of Environmental Medicine & Public Health, Icahn School of Medicine at Mount Sinai

Bottom Line: Laboratory studies using animals have shown that offspring exposed jointly to both toxic metals, like lead, and higher levels of stress hormones, like cortisol, during prenatal development are more likely to exhibit adverse behaviors after they are born. These laboratory studies further indicated that these joint effects impact males and females differently. The research summarized in this paper is the first study in humans to examine the complex interactions between exposure to metals (such as lead, arsenic, and cadmium) during the prenatal period, increased levels of maternal cortisol, and child sex in relation to child behaviors assessed in 6 month olds that have been linked in other research to longer term psychological problems as they get older. Examining interactions between multiple factors such as done here will help researchers and clinicians better identify children at risk as early in development as possible. Explicating potentially modifiable environ-mental risk factors that contribute to early life behavioral domains that may indicate heightened risk for emerging psychological problems, so that interventions can be applied early to promote optimal development, could have significant implications for the prevention of chronic psychological disorders such as depression and anxiety.

Results: Girls born to mothers with higher exposure to seven non-essential metals and high cortisol during pregnancy had

greater fear and sadness temperament features, as assessed by the Infant Behavior Questionnaire-Revised at 6 months of age. These findings corroborate those of animal studies showing that both exposure to metals and prenatal stress can enhance central nervous system toxicity. Further, that these effects were sex dependent.

Why the Research Is Interesting: These findings suggest that studies of the sex-specific neurotoxic effects of metals and psychological stress that consider one exposure in isolation will not reveal the full scope of their adverse effects on early neurobehavioral outcomes. Also, if we do not consider co-exposure to elevated stress hormones and fetal sex, associations can be missed.

Who: The mother-infant pairs included in these analyses are participants in an ongoing prospective pregnancy cohort study – PRograming of Intergenerational Stress Mechanisms (PRISM) - designed to examine the effects of prenatal and early life psychosocial, physical, and chemical environmental exposures on child developmental outcomes. Women were eligible if they were English or Spanish speaking, 18 years or older, and pregnant with a singleton. Exclusion criteria included maternal intake of ≥7 alcoholic drinks per week prior to pregnancy, any alcohol intake after pregnancy recognition, and HIV+ status. Analyses included 226 (29% White, Non-Hispanic) mother-infant pairs with data on exposures and negative affectivity assessed using the IBQ-R in 6-month-olds.

When: The study has recruited women receiving prenatal care from the Beth Israel Deaconess Medical Center and East Boston Neighborhood Health Center in Boston, MA (from March 2011–December 2013) and Mount Sinai Hospital in New York City, NY (from April 2013–March 2021) who delivered a live newborn with no significant congenital anomalies noted at birth that could impact participation in follow-up procedures.

What: This study evaluated the joint association of prenatal exposures to a metal mixture and cortisol with infant negative affectivity, considering sex-differences.

How: Women collected a spot urine sample in their home on the morning of a scheduled clinic visit in mid-to-late pregnancy. Samples were kept frozen in the participant's freezer until transport to the PRISM laboratory, and were analyzed in the lab for elements.

Study Conclusions: Joint exposure to a mixture comprised of seven metals and elevated maternal cortisol in pregnancy were associated with infant Negative Affectivity attributes in a sexually dimorphic manner. Specifically, associations were stronger in relation to the Fear and Sadness temperament features in 6-month-old infants. The interaction in these models showed an increase in scores with higher exposure to the metal mixture in infants born to mothers with higher cortisol, particularly among girls.



Paper Title: "Associations between a metal mixture and infant negative affectivity: Effect modification by prenatal cortisol and infant sex"

for the latest updates.

Said Mount Sinai's Dr. Francheska M. Merced-Nieves of the research: "These results show that researchers, physicians, and public policy makers should continue to take into account multiple factors (in this case metals and stress), as these are necessary to more specifically identify those at early risk for psychopathy. These results exemplify more real life scenarios, as we are all exposed to multiple things at once. Further, there is a critical need to broaden screening programs for exposure to health-relevant metals to pregnant women."

### ###

To request a copy of the paper or to schedule an interview with Dr. Merced-Nieves, please contact Mount Sinai's Associate Director of Media and Public Affairs, Laura Ruocco-Duran, at Laura. Ruocco-Duran@mountsinai.org or at 646-877-6727.

NT

Human Milk-Based Synbiotic Safely Modulates Damaged Adult Gut Microbiomes; New Research Published in the Journal Cell Host & Microbe

DEDICATED TO THE HEALTH OF ALL CHILDREN

Bacteria Found in the Gut of Nursing Infants, Combined With Certain Sugars From Human Milk, May Enable 'Precision Microbiome Engineering' as Live Biotherapeutics

BOSTON, Mass., August 31, 2023 – Demonstrating a commitment to Advancing the Science of Human Milk®, Prolacta Bioscience® announced today that the peer-reviewed journal Cell Host & Microbe has published its study demonstrating that a synbiotic comprising human milk sugars, called human milk oligosaccharides (HMOs), and a strain of bacteria found in the gut of nursing infants, Bifidobacterium infantis (B. infantis), can safely and predictably control the gut microbiome in adults.

This is the first time that scientists have been able to modulate

the adult gut microbiome with significant precision. The prospect of "precision microbiome engineering" may open the door to the development of live biotherapeutic products that effectively reconstitute a damaged or out-of-balance microbiome, as is the case in numerous infectious, autoimmune, and metabolic disorders.

For the last decade, researchers have been working on methods to engineer the gut microbiome in patients, drawing inspiration from the success of fecal microbiome transplants for treating Clostridioides difficile (C. diff) infections. "While some of these attempts have been clinically successful, they have been quite crude and undefined, lacking in precision and reproducibility," said Greg McKenzie, vice president of product innovation at Prolacta.

In the current study "Precision Modulation of Dysbiotic Adult Microbiomes With a Human Milk-Derived Synbiotic Reshapes Gut Microbial Composition and Metabolites," researchers from Prolacta, MD Anderson Cancer Center, and the University of Texas Southwestern Medical Center observed:

- HMOs support engraftment of B. infantis in healthy adults with a median observed abundance of 45.9% and up to 81% relative abundance in antibiotic-treated adults; no serious adverse events were observed.
- Microbiome structure and gut metabolite levels were altered in engrafted subjects. When *B. infantis* was present, other members of the microbiome that are not directly influenced by HMOs changed in a reproducible manner. One notable example was a microbe called *Veillonella* that feeds on molecules produced by *B. infantis* and subsequently generates metabolites that are beneficial to human health.

"These findings are incredibly exciting, as we are starting to do ecology in the human microbiome," said Julie Button, Ph.D., director, non-clinical development at Prolacta. "The reproducibility of cross-feeding *Veillonella* is really striking, as this magnitude of downstream effects are normally seen only when treating patients with antibiotics."

"We expect that this human milk-based synbiotic will have the power to repair the microbiome of sick patients using the same biology that establishes a healthy microbiome in infants," said Scott Elster, CEO of Prolacta. "We plan to demonstrate what is essentially 'Nature's Microbiome Starter Kit' in extremely fragile stem cell transplant patients in a Phase 2a clinical trial starting in Q3 2023."

# About Human Milk Oligosaccharides (HMOs) and B. infantis

Human breast milk contains high concentrations of a collection of approximately 200 structurally diverse sugars called HMOs.¹ Unlike the nutritional components of breast milk, HMOs are not metabolized as an energy source by the infant. Instead, HMOs serve to guide the growth of appropriate bacteria in the gut, which helps to train the infant's immune system.² In this way, HMOs support protective responses such as suppression of inflammation and improved intestinal barrier function to minimize infections.³

One species of "good" bacteria in the infant gut that is known to influence these protective responses is *B. infantis*, which is unique in its ability to utilize the HMOs in human breast milk. After infants are weaned from human milk, *B. infantis* levels decline into adult-hood.<sup>4</sup>

# **Study Details**

This unblinded clinical study enrolled 56 healthy adult subjects. A control group completed a five-day course of antibiotics (known to disrupt gut bacteria) with no other intervention. A second group received the same course of antibiotics along with *B. infantis* for 14 days, and a third group additionally received HMOs for 28 days. Stool and blood were collected at set intervals for a total of 35 days. This trial built upon prior research from the same investigators <u>published in 2022</u> in which it was observed that dosing with a synbiotic of HMOs and *B. infantis* led to controllable, HMO-dependent engraftment of *B. infantis* in healthy adult subjects.<sup>5</sup>

# Phase 2a Investigational New Drug (IND) Trial

This fall, Prolacta will initiate a Phase 2a Investigational New Drug (IND) trial to evaluate the human milk-based synbiotic in patients undergoing stem cell transplant for blood cancers. Patients undergoing stem cell transplant often have disruptions in their gut microbiome, including an increase in numbers of potentially disease-causing species of bacteria and an overall loss of diversity. This leaves patients prone to opportunistic infections and graft-versushost disease (GVHD), which can result in multi-organ attack and mortality. The study will measure how well the synbiotic drives redevelopment of a healthy microbiome, like it does naturally in the newborn gut.

# **About Prolacta Bioscience**

Prolacta Bioscience® Inc. is a privately held, global life sciences company dedicated to Advancing the Science of Human Milk® to improve the health of critically ill patients. As the world's leading provider of human milk-based products for hospital use, Prolacta is exploring the therapeutic potential of human milk across a wide spectrum of diseases. The company's products have been evaluated in more than 20 peer-reviewed clinical studies. Prolacta maintains the industry's strictest quality and safety standards, and has developed, validated, and implemented more than 20 tests for the screening and testing of human milk. Prolacta's human milk-based products are vat pasteurized using a patented, FDAreviewed manufacturing process to ensure pathogen inactivation while protecting the nutritional composition and bioactivity of human milk. Established in 1999 and headquartered in Duarte, Calif., Prolacta operates the world's first and only pharmaceuticalgrade manufacturing facilities for the testing and processing of human milk. Learn more at prolacta.com, on X, Threads, Instagram, Facebook, and LinkedIn.

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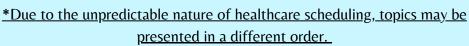




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# Genetic Corner: Two Different Unbalanced Translocations of 15q and 21q in Dizygotic Twins Presenting with Differing Phenotypes

Andrew Mueller, Skylar Muchmore, June-Anne Gold MD FACMG

"A genetic consult was requested for two 16-week-old dizygotic twins, one female and one male, born to G3P4 mother with advanced maternal age. At the time of the visit, the mother reported that she was concerned that both twins could have Prader-Willi Syndrome. Her doctor had told her this."

### Case history:

A genetic consult was requested for two 16-week-old dizygotic twins, one female and one male, born to G3P4 mother with advanced maternal age. At the time of the visit, the mother reported that she was concerned that both twins could have Prader-Willi Syndrome. Her doctor had told her this.

Baby Girl (BG) was born with respiratory distress at 31 3/7 weeks gestation. BW: 1435g BHC: 29cm BL: 35cm APGARS 1, 5: 4, 9. She was noted to have low tone and difficulty feeding following birth and was found to be plagiocephalic and brachiocephalic. Chromosome analysis studies found a translocation of chromosomes 15q and 21q. The chromosome microarray studies found 6.6 MB proximal deletion of 15q11.2q13.1 and 6.9 MB Proximal Duplication of 21q11.2q21.1, consistent with an unbalanced translocation of 15q and 21q. The 21q micro duplication observed in BG does not overlap the Down syndrome critical region and is not currently associated with a clinical disorder. The 15q deletion includes the region associated with the Type I deletion of either Prader-Willi syndrome (PWS) or Angelman syndrome (AS), and the PWS / Angelman Methylation testing confirmed the absence of the paternal SNRPN gene expression confirming Prader-Willi Syndrome (PWS).

On physical exam, BG had features typical for PWS bi-temporal narrowing, almond-shaped eyes with upslanting palpebral fissures, downturned corners to the mouth, and severe hypotonia with decreased reflexes (Picture 1). She had hypoplastic labia and was reportedly very still in pregnancy with decreased fetal move-

ments. Growth percentiles were as follows: Length <1% (z=-3.59), weight <1% (-2.83), and head circumference <1% (z=-3.5). She had a nasogastric tube(NG) to help with nutrition, given feeding difficulties due to failure to thrive, severe hypotonia, and difficulty sucking.

Her twin brother, Baby Boy (BB), was born at 31 3/7 weeks gestation with PTL and respiratory distress. BW: 1770g BHC: 30cm BL: 38cm APGARS 1, 5: 8, 9. His chromosomal microarray study found a 6.6MB terminal duplication of 15q11.2q13.1 and a 6.95MB terminal deletion of 21q11.2q21.1, consistent with an unbalanced translocation.

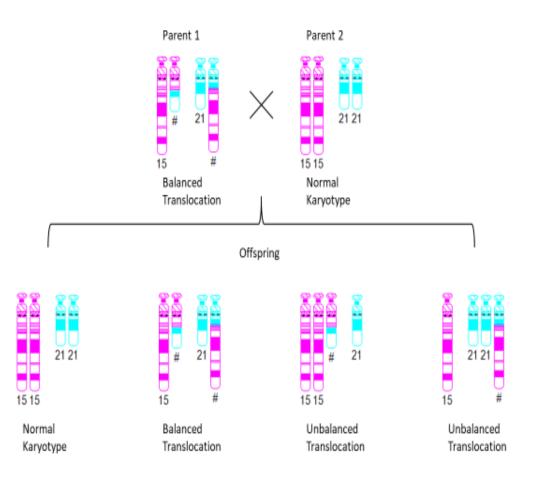
Compared to his twin, he was active during pregnancy, very fussy on examination, and had normal pigmentation. Growth percentiles at the time of the exam were: Length <1% (z=-3.13), weight 16% (z=-1.01), and head circumference 3% (z=-1.94) larger than his sister. He had different dysmorphic facial features with a broad nasal bridge, large low, set ears, deep nasolabial folds, wide open fontanelles, broad first toes, minimal 2-3 toe syndactyly, slightly increased tone, and deep palmar creases with short fingers and thumbs (Picture 2-3). During the examination, he was not fixing or following. His appearance and physical features are quite different from his sister's.

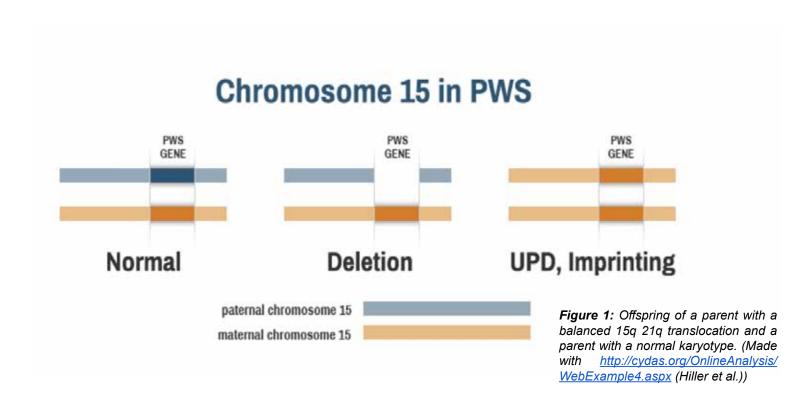
"The maternal family history was largely non-contributory. Mother had two healthy children from a previous relationship, and father has no other children. Parental consanguinity was denied. Maternal ancestry is from Guatemala, and paternal ancestry is from Honduras. One significant finding on the paternal side is that the paternal grandmother had three children who passed early in life. It is unclear why."

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Picture 1: Baby Girl (BG)



Picture 2: Baby Boy (BB)

Honduras. One significant finding on the paternal side is that the paternal grandmother had three children who passed early in life. It is unclear why.

#### **Assessment:**

The 15q 21q unbalanced chromosome translocations observed in the twins are most likely the result of a balanced translocation in one of the parents. Presumably, the father is Prader Willi due to 15q deletion being associated with paternal inheritance of a 15q deletion (Driscoll et al.).

"The 15q 21q unbalanced chromosome translocations observed in the twins are most likely the result of a balanced translocation in one of the parents."

The 15q 21q balanced translocation in the parent would result in 4 different chromosome arrangements in the children (Fig. 1),



**Picture 2:** Baby Boy (BB) Right Hand including the 15q duplication 21q deletion observed in BB and the 21q duplication 15q deletion observed in BG.

21q11.2q21.1 Duplication: Duplications of 21q have been associated with multiple phenotypic characteristics of Down syndrome when the Down Syndrome Critical Regions (DSCR) are duplicated (Olson et al.). In its most precise description, this region extends around 5.4 MB from between the *D21S17* and *D21S55* markers to *MX1* and *BCEI* markers (Olson et al.). The 21q11.2q21.1 duplication found in BG notably does not include the DSCR. Duplications in these regions that do not include DSCR have been reported in individuals without a Down Syndrome phenotype or other mental and physical anomalies (Su et al.).

<u>15q11.2q13.1 Deletion - Prader Willi Syndrome:</u> Prader-Willi Syndrome (PWS) is a complex neurodevelopmental disorder attributed to a lack of paternal gene expression within the chromosome 15q11-13 region. Three primary mechanisms lead to the lack of

paternal gene expression in the 15q11-13 region, including deletions, maternal uniparental disomy, and imprinting center defects. In this case, BG had a 15q deletion due to an unbalanced chromosome translocation, most likely resulting from a paternal balanced translocation of 15q and 21q. Since the Prader-Willi Syndrome is likely due to a paternal balanced translocation, the recurrence risk is expected to be 1 in 4 (Fig. 1).

PWS can be confirmed with methylation studies, which test for the absence of paternal SNRPN gene expression. While PWS is generally the result of the *de novo* gene alterations mentioned above, here we see an instance consistent with a balanced translocation in the father.

PWS is uniquely characterized by a hypoactive fetus, leading to a hypotonic baby failing to thrive. Feeding habits drastically change between the ages of 2 and 4, and the child becomes hyperphagic. Severe morbid obesity is common without lifestyle intervention.

It is recommended that parents lock food away and take other precautions.

Like most syndromes, there is no definitive cure for PWS; however, a multidisciplinary approach involving lifestyle management, nutrition, genetics, physical, speech, and occupational therapy is recommended for favorable outcomes. Of note, growth hormone therapy managed with endocrinology has been found to increase lean muscle mass, decrease fat mass, and lead to a more favorable BMI (Driscoll et al.).

"Like most syndromes, there is no definitive cure for PWS; however, a multidisciplinary approach involving lifestyle management, nutrition, genetics, physical, speech, and occupational therapy is recommended for favorable outcomes. Of note, growth hormone therapy managed with endocrinology has been found to increase lean muscle mass, decrease fat mass, and lead to a more favorable BMI (Driscoll et al.)."

15q11.2q13.1 Duplication: The 15q11.2q13.1 duplication detected in BB is within an imprinting region of the genome. Due to this, the phenotype is dependent on the inheritance. Maternally inherited 15q duplications are associated with hypotonia, motor delay, intellectual disability, autism, and epilepsy (Lusk et al.). Paternally inherited 15q duplications usually have milder phenotypes and have been reported in individuals with developmental delay, speech delay, and autism (Ageeli et al.). The inheritance of the 15q duplication in BB is expected to be paternal, so his phenotype is expected to be milder.

21q11.2q21.1 Deletion: The 21q11.2q21.1 deletion observed in BB is associated with variable phenotypes, which include developmental delay, short stature, microcephaly, clinodactyly, low set ears, scoliosis, and cardiac anomalies, (Jespersgaard et al.). The 21q deletion could account for some of BB's dysmorphic facial features. He is following up with cardiology for a hole in his heart that had reportedly closed.

Testing for the chromosome translocation was offered to the parents and declined at this time.

#### Take Away:

- 1.) Carefully review genetic testing reports: The mother was under the impression that both of the children had Prader Willi, which was reiterated during part of the appointment triage for the patients. A careful review of the genetic testing would have indicated two different diagnoses for the twins.
- **2.) Balanced Translocations:** Balanced translocations in a parent may result in 4 chromosome arrangements in their

children. The two unbalanced translocations in the offspring may be associated with two differing phenotypes, as observed in the twins.

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# Walking the PATH: Guidelines for Attending Physicians, APPs, and Trainees

Scott D. Duncan, M.D., M.H.A.

"In the sweltering heat of the summer, medical students, residents, and fellows begin the next stage of their career journey. Recently graduated fellows become attending physicians with expanded responsibilities, including supervision of trainees. However, in the current healthcare environment, provider shortages, and reduced intensive care training requirements demand unique solutions for the provision of patient care."

In the sweltering heat of the summer, medical students, residents, and fellows begin the next stage of their career journey. Recently graduated fellows become attending physicians with expanded responsibilities, including supervision of trainees. However, in the current healthcare environment, provider shortages, and reduced intensive care training requirements demand unique solutions for the provision of patient care.

One option to expand the workforce is to include APPs as employed qualified healthcare providers. Depending on the employment model, scope of practice, and state regulations, APPs may bill independently for services. In many academic institutions, both physicians and APPs are employed by provider organizations, separate from the hospital or university.

With the expansion of types of healthcare providers found in the NICU, a trainee may interact with an attending neonatologist and/ or APP. In some academic institutions, an APP may supervise a trainee. These different training and employment models require an understanding supervision and correct billing practices.

"In some academic institutions, an APP may supervise a trainee. These different training and employment models require an understanding supervision and correct billing practices."

Q 1: On the first day of service, a neonatologist in a teaching hospital attends a delivery with a pediatric resident. The infant is apneic at birth and requires PPV via face mask. The neonatologist instructed the resident to intubate the infant, which the resident accomplished under direct bedside supervision. The infant required additional PPV via an endotracheal tube, with subsequent recovery. The infant was subsequently transferred to the NICU.

" The neonatologist instructed the resident to intubate the infant, which the resident accomplished under direct bedside supervision. The infant required additional PPV via an endotracheal tube, with subsequent recovery."

Given the following codes, the correct coding for the neonatologist includes:



99465 - Delivery Room Resuscitation

31500 - Intubation

- A. 99465, 31500
- в. 99465
- c. 31500
- D. There was no billable service

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Q 2: On the first day of service, a neonatologist in a teaching hospital attends a delivery with an APP, is employed by the care provider group, and is permitted to bill under state regulations. The infant is apneic at birth and requires PPV via face mask. The neonatologist instructs the APP to intubate the infant, which was accomplished by the APP. The infant required PPV via an endotracheal tube, with subsequent recovery. The infant was subsequently transferred to the NICU. Correct coding includes:

"On the first day of service, a neonatologist in a teaching hospital attends a delivery with an APP, is employed by the care provider group, and is permitted to bill under state regulations. The infant is apneic at birth and requires PPV via face mask. The neonatologist instructs the APP to intubate the infant, which was accomplished by the APP."



- A. 99465 by the neonatologist, 31500 by the APP
- B. 99465 by the APP
- C. 99465,31500 by the neonatologist
- D. There was no billable service

Q 3: On the first day of service, an APP in a teaching hospital attends a delivery with a pediatric resident. The infant is apneic at birth and requires PPV via face mask. The APP instructed the resident to intubate the infant, which the resident accomplished under direct bedside supervision. The infant required PPV via an endotracheal tube with subsequent recovery. The infant was subsequently transferred to the NICU. Correct coding for the APP includes:

"On the first day of service, an APP in a teaching hospital attends a delivery with a pediatric resident. The infant is apneic at birth and requires PPV via face mask. The APP instructed the resident to intubate the infant, which the resident accomplished under direct bedside supervision. The infant required PPV via an endotracheal tube with subsequent recovery."



- A. 99465
- B. 99465, 31500
- c. 31500
- D. There was no billable service

In each of the preceding scenarios, the correct answer is A. The focus of the questions is based on the supervision of trainees and the collaboration of care providers. In the first scenario, the neonatologist is supervising a trainee. Supervision and proper coding are dictated by Teaching Physicians, Interns & Resident Guidelines, published by the Centers for Medicare & Medicaid Services, often referred to as Physician at Teaching Hospitals or PATH guidelines. These guidelines can be found here: <a href="www.cms.gov/outreach-and-education/medicare-learning-network-mln/ml-nproducts/downloads/teaching-physicians-fact-sheet-icn006437.pdf">www.cms.gov/outreach-and-education/medicare-learning-network-mln/ml-nproducts/downloads/teaching-physicians-fact-sheet-icn006437.pdf</a>.

When a teaching physician supervises a resident trainee, the physician must ensure proper documentation, demonstrating their involvement in the patient's care. In this case, a delivery room note detailing the request for attendance at delivery, services provided,

and disposition of the infant would be necessary. The medical record must be signed and dated with a legible signature or identity. Documentation may be:

- Dictated and transcribed
- Typed
- Handwritten and/or
- Computer-generated

The physician may place a 'macro' on the medical record; however, they must be placed anew daily. It is insufficient if a physician solely uses a macro for documentation purposes, without noting the physician's presence during the provision of services and a description of the patient-specific services provided on that date, justifying the billing level for that encounter.

In the second scenario, an APP is <u>not</u> considered a trainee under PATH guidelines. Hence the attending neonatologist may code for the attendance at delivery and resuscitation but cannot bill for the intubation performed by the APP. In contrast, the APP could bill for the intubation but would defer the bill for the attendance of delivery to the neonatologist. Appropriate documentation would include a delivery room note by the attending physician denoting the request for attendance at delivery, a summary of the delivery and resuscitative efforts, an appropriate physical examination, and the disposition of the infant. The APP should document the procedure accordingly.

"Similarly, according to PATH guidelines, an APP is not considered a supervising physician. As such, in the third scenario, the APP may bill for the resuscitation, as this would be considered their work. However, the APP cannot bill for the intubation performed by the resident. Appropriate documents should be included in the medical record by the APP for the attendance at delivery and the infant's resuscitation, as well as a procedure note by the resident for the intubation of the infant."

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As new models of providing patient care are developed and supervision of trainees shifts to include APPs, it is paramount to walk the correct PATHway!

Disclosures: There are no reported disclosures

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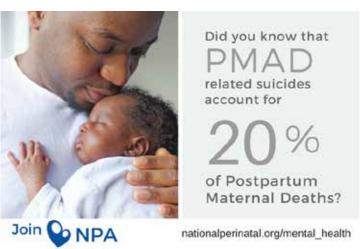


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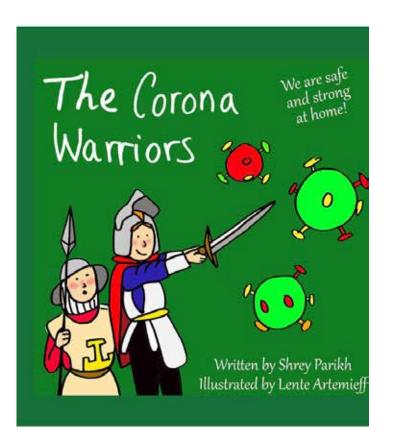
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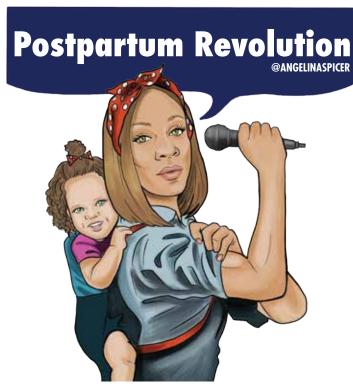
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#### **VACCINES**

### PREVENTIVE MONOCLONAL ANTIBODIES Introduce antibodies that are ready to

Teach the body to create antibodies that fight off a specific disease.

By introducing an inactive piece of a disease or proteins that look like the disease, they trigger an immune response, training the body to create antibodies that defeat the disease.



Instead of teaching the body to create antibodies and defenses, they provide antibodies that are readily

available.

Both support the immune system's defenses.

Many vaccines are readily and easily available.

The technology behind vaccines has been around for decades.



Preventive monoclonal antibodies can provide protection for diseases where there isn't an existing vaccine or there isn't an existing vaccine for certain patient groups.

Both protect against disease and provide a public health benefit by decreasing the burden of disease.

Polio Measles COVID-19 And more



RSV COVID-19

Both can provide tailored protection from a variety of diseases.

Yes



Both vaccines and preventive monoclonal antibodies undergo extensive testing for safety and efficacy.

### **Monoclonal Antibodies** WHAT'S THE DIFFERENCE?

**Preventive** 

Vaccines and

### The Importance of **Immunization**

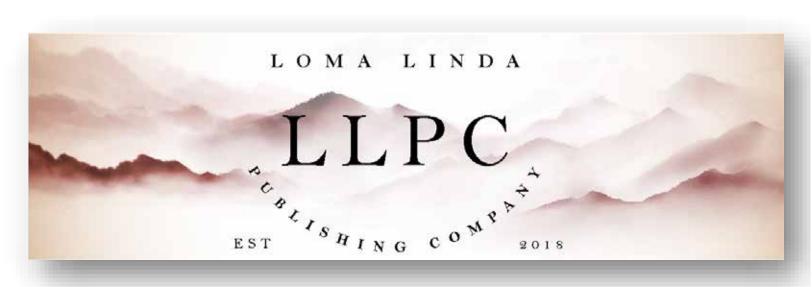
Vaccines and preventive monoclonal antibodies are two different types of immunization. While they function differently, they both serve the same purpose: protecting people from serious illnesses and diseases.

Different Technology, Same Protective Value



NPA's statement: BLACK LIVES MATTER





# The Indirect Impact of **RSV**



Susan Hepworth, Suzanne Staebler, DNP, APRN, NNP-BC, FAANP, FAAN, Mitchell Goldstein, MD, MBA, CML

#### **OVERVIEW**

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

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

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

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

#### **RSV PARENT SURVEY**

340 parents who had at least 1 child sick with RSV



**67**% of parents said their child was hospitalized for RSV

#### RSV HEALTH CARE PROVIDER SURVEY

175 health care providers across various pediatric and neonatal subspecialties



67% worked in an outpatient facility

**RESULTS** 

of providers agreed

that parents need

more information

#### **RESULTS**



#### FINANCIAL BURDEN

### More than 3/3 of parents said the costs of RSV posed a

costs of RSV posed a financial burden or financial crisis.

#### **7**%

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

#### **32**%

of parents reported losing potential income while their child had PSV

### (%)

#### EMOTIONAL BURDEN

#### **68**%

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

#### **69**%

of parents felt guilty that they could not do more to prevent their child's RSV. When parents found out there was no treatment for RSV, only supportive care:

- 48% felt angry
- 46% felt helpless

#### TREATMENT CHALLENGES

PARENT EDUCATION & AWARENESS

#### Nearly 1/3

routine care.

86%

of providers said

they include RSV

education as part of

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

#### 48%

99%

about RSV

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

#### 92%

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



#### SOCIAL BURDEN

### **43**%

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

#### **54**%

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

#### **42**%

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



#### MISCONCEPTIONS

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

#### CONCLUSION

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

The virus may lead to:

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

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

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

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

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

### The Umbrella of Immunizations

Susan Hepworth, Mitchell Goldstein, MD, MBA, CML



Protecting Access for Premature Infants through Age Two

The National Coalition for Infant Health is a collaborative of more than 200 professional, clinical, community health, and family support organizations focused on improving the lives of premature infants through age two and their families. NCflH's mission is to promote lifelong clinical, health, education, and supportive services needed by premature infants and their families. NCflH prioritizes safety of this vulnerable population and access to approved therapies.

This past July, the coalition released *The Umbrella of Immunizations*. The video was released in collaboration with the Alliance for Patient Access, to emphasize the message that "to boost public health and maximize disease prevention, all immunizations should be treated the same."

The text from the video follows. Please feel free to share it with your networks.

All infants, children, and adults need protection from infectious diseases. That's why immunizations are so important. There are

two types of immunizations.

The first is active immunization, which works by training the body to create antibodies that fight off diseases. These immunizations are commonly called vaccines. They are used to protect against diseases like polio, whooping cough, and the flu.

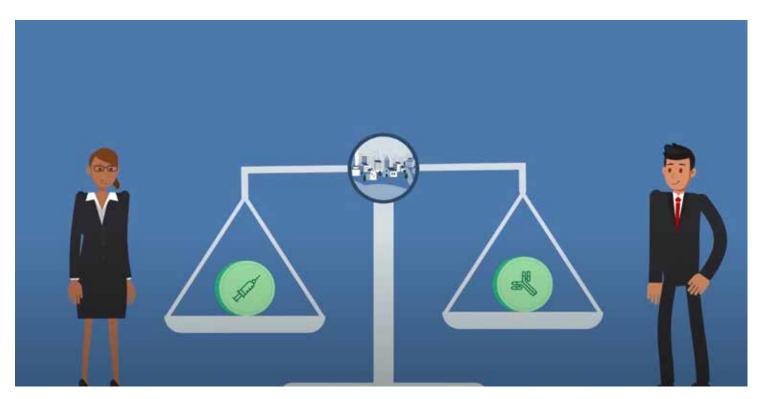
The second type of immunization is passive immunization, which works by providing the body with antibodies to fight off diseases. This type of immunization can help protect against diseases that traditional vaccines cannot address.

Whether it is a vaccine or a long-acting preventive monoclonal antibody, immunizations are critical for public health. That's why they must be accessible in a timely and equitable manner.

"Whether it is a vaccine or a longacting preventive monoclonal antibody, immunizations are critical for public health. That's why they must be accessible in a timely and equitable manner."

To boost public health and maximize disease prevention, all immunizations should be treated the same, ensuring coverage and access for both vaccines and long-acting preventive monoclonal antibodies. With good policy in place, families can have more opportunities to stay safe, healthy, and protected against infectious diseases.





\Disclosures: The authors have no disclosures

#### NT

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#### National Coalition for Infant Health Values (SANE)

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

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

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

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

### **The Honeymoon Period**

Kelly Lewis, BA, RRT-NPS

#### Objectives:

- · Take notice of the clues that a baby is decompensating
- · Decide if a baby needs CPAP or HFNC
- · Explain how the PDA affects a baby's work of breathing
- Describe why babies < 36 weeks are at risk
- · Watch for and determine the signs of sepsis

In most hospitals, babies under a certain gestational age will automatically go to an observation area or NICU. If a baby is over 36 weeks gestation, the baby may room with the mom after an initial assessment. Periodic assessments by the nurse or the doctor will then determine if the baby can stay with the mom or needs to go into an observation area or the NICU. This is the honeymoon period: the first 24 hours (up to 48 hours) when the baby initially looks good. Nevertheless, as circulation transitions to extrauterine life, and the baby must breathe independently and generate and maintain his body heat, you may notice some concerning things. At this point, the care must be elevated to a certain level. Otherwise, you are likely to be in trouble. The assessment intervals for these newborns need to be more frequent. Take notice of the clues they give that they are decompensating: Is the baby cold? Desaturating? Hypovolemic? Each of these needs to be addressed as soon as possible.

"This is the honeymoon period: the first 24 hours (up to 48 hours) when the baby initially looks good. Nevertheless, as circulation transitions to extrauterine life, and the baby must breathe independently and generate and maintain his body heat, you may notice some concerning things."

There is not so much of an age cut-off that you stop being concerned so much as how close to term the baby is. Is the baby feeding, staying in the mom's room, and maintaining temperature and vital signs? The closer to term, the better, but that first hour is critical to successfully transitioning to extrauterine life.

The question often arises, do all preterm infants require CPAP? Many hospitals have a protocol to automatically start CPAP on any baby less than a certain number of weeks. Any baby that is having any respiratory distress or increased work of breathing, that baby probably deserves a trial of CPAP. However, it is also essential to rule out other causes of respiratory distress.

If your hospital tends not to do any preemptive treatment and watch the baby, remember that preterm babies have neither mature muscles nor surfactant. Ensure the baby is warm and appears comfortable. Cold babies or otherwise uncomfortable babies do not do well. Ensure the baby's in a neutral thermal environment, or you can swaddle or have the baby skin – to skin with mom.

Monitor the temperature and the rest of the vital signs carefully, and continuously monitor saturations.

"The question often arises, do all preterm infants require CPAP? Many hospitals have a protocol to automatically start CPAP on any baby less than a certain number of weeks. Any baby that is having any respiratory distress or increased work of breathing, that baby probably deserves a trial of CPAP. However, it is also essential to rule out other causes of respiratory distress."

What liter flow or CPAP level should we start with these babies if needed? There are many different CPAP delivery systems. Some systems run on flow, and others run off a ventilator and only allow you to set pressure. With HFNC, the interface should only occlude 50% of the nares, allowing for a large leak. For NCPAP, approximately 80% of the nares should be occluded to generate pressure. However, there is still a leak to be accounted for. If you calculate the approximate minute ventilation requirements based on the baby's weight and factor in the leak, you will arrive at a starting point. For example, a 3-kilo baby's minute ventilation is approximately 900ml per minute. Given a leak of about 50%, you need 1.8 liters per minute to meet or exceed that baby's minute volume demand. For smaller babies, calculate accordingly, using 250-300ml/minute.

What settings do we put these babies on to avoid overshooting or undershooting the proper flow or pressure? Most NICUs start with a CPAP of +5 for the tiniest babies and +6 for larger babies. The work of breathing or level of respiratory distress should decrease. If not, the baby may require more pressure or flow until breathing appears comfortable.

How do we best determine if a baby is comfortable? Furthermore, what does the term 'comfortably tachypneic' mean? If you see the angst in the baby's face, a brow that looks frowning, or the baby pulling the sternum to the spine, those are subtle signs. If a baby

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appears comfortable yet is tachypneic, depending on the baby's

gestational age, that baby should still be watched closely.

Moreover, babies on CPAP should still get chest x-rays to determine if the baby is overdistended. If the baby appears overdistended, ensure your set flow or pressure is not too high. Even with a bubble CPAP device, with the column set to +6, much excess flow can lead to overdistention. Another way to determine overdistension is to transilluminate the baby's chest.

The ductus arteriosus is an integral part of the Honeymoon period. It is typically not a problem in the early hour because you have elevated pulmonary vascular resistance for a time. However, there can be very pronounced shunting as you move forward, and pulmonary relaxation occurs. That baby would have low blood pressure and could become the sickest kid in the intermediate area.

"The ductus arteriosus is an integral part of the Honeymoon period. It is typically not a problem in the early hour because you have elevated pulmonary vascular resistance for a time. However, there can be very pronounced shunting as you move forward, and pulmonary relaxation occurs."

Fluids affect the PDA in that too much fluids potentiate the PDA being open. Moreover, too few fluids cause the kidneys to clamp down. Some NICUs have used indomethacin for larger preterm babies, which does not seem to be all that helpful. Most PDAs close on their own. Certain smaller preterm babies do benefit from indomethacin. Then there is the phenomenon known as the "winking PDA." What is making the PDA close, then relax, then close again?

More than one data point needs to be followed with a winking PDA. If the PDA is opening in concert with falling blood pressure and difficulty in managing ventilation, we need to advocate for ligation or placing a plug by cath. A PDA can also be bidirectional, which has to do with cardiac issues potentially involving pulmonary artery hypertension, which we will discuss in a different talk. If there was a sudden increase in oxygen requirement AND more episodes of A's and B's, that situation requires much more attention.

If there was a sudden increase in oxygen requirement on these preemies, look for possible pneumothorax. Failing that, look for atelectasis. Transilluminate first, then call for an X-ray and look for atelectasis.

If a baby has more and more episodes of A's and B's, the first thought should be sepsis. Considering gestational age, is this the baby who would benefit from just caffeine? To be sure, get a CBC and a blood culture. Start antibiotics if indicated. There is a Kaiser scale for sepsis that is embedded in a lot of the EHRs.

As always, we need to consider the parents. They may be anxious about an early delivery, relieved that the baby initially looks OK, and a team of people are present to reassure them. Then, things start going south. The baby must be moved to the NICU - IVs, CPAP, and many machines. Their baby does not look like a baby

anymore. As we focus on the baby, remember that the parents need support as well.

In summary, besides the mantra of 'never trust a preemie,' make sure to give him a chance. It is true. Never underestimate what a preemie can do when you are not looking. Furthermore, be aware of the unavoidable and be prepared. If you must intubate or start antibiotics, keep those possibilities in your mind. Even though you hope for the best, always be prepared for the worst.

"In summary, besides the mantra of 'never trust a preemie,' make sure to give him a chance. It is true. Never underestimate what a preemie can do when you are not looking. Furthermore, be aware of the unavoidable and be prepared."

#### **POST-TEST**

 Once the baby is one hour old, he or she is past the danger zone

True

False

- 2. Signs that a baby is decompensating include:
- a. Increase in As and Bs
- b. Unstable blood pressure
- c. Unstable sats
- d. Increased work of breathing
- e. All of the above
- 3. A 36-week newborn is crying in the DR. This baby does not need any special assessment.

True. If they can cry, their lungs are fine.

False. Thirty-six weeks is not quite term, and this baby should have a respiratory assessment and be monitored closely.

- The determination to place a baby on CPAP vs. HFNC is often made by:
- a. Neonatologist preference
- b. Desaturating babies go on CPAP, while stable but tachypneic babies go in HFNC
- c. Availability of equipment and convenience
- 5. Signs of sepsis include:
- a. More episodes of Apneas and Bradycardias
- b. Dusky color
- c. Hypothermia
- 6. A swaddled 35 and 5/7 week baby has a core temp of 35 C.

This baby needs:

- a. More blankets
- b. To be moved to a warmer
- c. To be kept skin-to-skin with mom
- d. A NICU bed and close monitoring to ensure the baby will not become cold-stressed.
- 7. A preterm baby's minute volume demand is about:
- a. 100-150 ml/Kg/min
- b. 150 200 ml/Kg/min
- c. 250 300 ml/Kg/min
- d. 5 to 6 L/min
- 8. The correct flow or pressure to offset a baby's work of breathing is ensured by:
- a. The baby appears comfortable
- b. The baby does not appear to have any extra work of breathing
- c. The saturations are stable
- d. All of the above, together
- 9. In a one-week-old baby with a PDA and no cardiac defects, the blood usually shunts:
- a. Left -to-right
- b. Right -to-left
- A baby has a sudden increase in oxygen requirement. You should consider:
- a. Sepsis
- b. Pneumonia
- c. RDS
- d. Auscultating to assess for Pneumothorax

Disclosure: The author has no disclosures.

NT





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### Keeping Your Baby Safe



## 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 alcoholbased sanitize

### 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.



### Never Put a Mask on Your Baby

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

### If you are positive for COVID-19

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

### We can help protect each other.

Learn more

www.nationalperinatal.org/COVID-19



# The Signs & Symptoms of RSV RESPIRATORY SYNCYTIAL VIRUS

### Know the Signs & Symptoms of RSV



Cough



Runny Nose



Struggling to Breathe (breastbone sinks inward when breathing)



Difficulty Eating



Lethargy



Wheezing

## RESPIRATORY SYNCYTIAL VIRUS

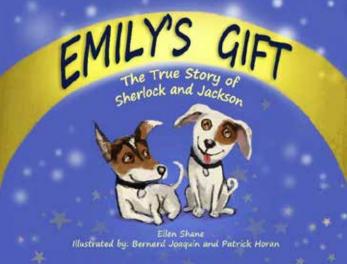
is a highly contagious seasonal virus that can lead to hospitalization for some babies and young children.

Know the Signs.



"Emily's Gift" can be purchased by clicking on the image of the cover below.







Purchases of this engaging **true story** provide disadvantaged middle school students, risking academic failure, the opportunity to attain their best personal and academic potential.

Purchasing options include a limited quantity of signed and numbered books specifically to support the SEA Program, an ebook, soft and hardcover versions, and the option to donate one or more books to support organizations supporting young children.

You can provide both reading entertainment for younger children, and make a difference in the lives of the disadvantaged middle schoolers we support.

Sales support our nonprofit charity's SEA Program. You can make a difference for these children!

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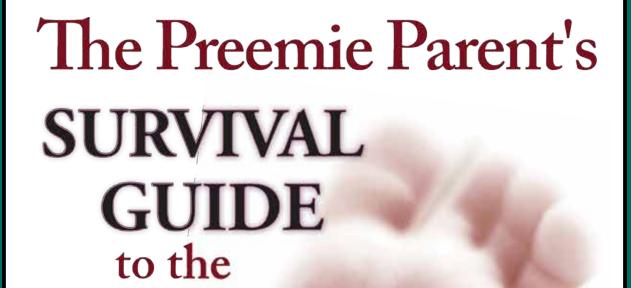
### **Direct SEA Support-Click Here**





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

For more information, please visit emilyshane.org.



By

**NICU** 

little man's Nicole Conn

&

PreemieWorld.com's

Deb Discenza

with

Medical Editor Alan R. Spitzer, M.D.



HOW TO second edition
MAINTAIN YOUR SANITY
& CREATE A NEW NORMAL

Vol. 04 08/2023

# 

Malathi Balasundaram. MD

### **FCC Core Team**

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### **Graphic Design**

Kavya Wazhi



### Want to strengthen FCC in your NICU?

Click this <u>link</u> or scan the QR code to join the FCC Taskforce for access to free webinars & resources.

### **Mission Statement**

The Family-Centered Care (FCC) Taskforce aims to educate, create guidelines, and facilitate unit-based interventions related to FCC in the NICU.

### **Check Out Our Website!**

Be sure to visit our website, fcctaskforce.org to view all past and upcoming webinars as well as shared resources.

Follow Us on Twitter: @FCCTaskforce

Contact us:

familycenteredcaretaskforce@gmail.com

### In This Issue

- Anniversary Report
- Webinar Review
- Family Partner Column
- Quarterly Recommendations
- Article Review

Generously supported by





### **ANNIVERSARY REPORT**

The FCC Taskforce started with 50 individuals in May 2022 and has now expanded to 520+ individuals representing more than **230 NICUs** from **36 states** and **16 countries**, all committed to learning more about FCC in the NICU. The FCC Taskforce stands as a pioneering force, being the FIRST international, multicenter, collaborative initiative solely dedicated to quality improvement in family-centered care. Its core principle of **equal partnership between healthcare professionals and family partners** embodies a critical component of family-centered care, creating an environment where collaboration and shared decision-making thrive.

One of the key strengths of the FCC Taskforce lies in its ability to **break down the silos** that often hinder progress in healthcare. Through its global network of institutions, the Taskforce connects healthcare professionals, researchers, and family partners, fostering collaboration, knowledge sharing, and the dissemination of best practices. The Taskforce employs a **small group model and large group webinars** (nine so far and many more already scheduled), enabling effective communication and facilitating change across various healthcare settings.

One of the primary challenges with FCC is changing the mindset of healthcare professionals to view families as integral to the care team, so we've created five small groups of 25 centers, each led by two neonatologists and one to two family partners with a goal of increasing the percentage of units with a functioning FCC Committee (already a 12% increase in the first six months).

### TESTIMONIALS FROM SMALL GROUP FCC AMBASSADORS

"Our unit in Israel joined the FCC Taskforce a year and a half ago. We have attended general and small group sessions in which we have received mentoring from leading figures in the field of FCC. We have learned a lot! We now have a better understanding of the core elements of FCC and are learning about different and practical ways we can implement FCC in our unit. We could not have made this possible without the support of our mentors, and we are very grateful for them and for this amazing model of support." -Rafi, Israel

"Thank you for all your hard work in engaging NICU teams all around the country on this Taskforce! Our unit has been able to share our FCC team's efforts as well as availability of rich information-sharing that has helped us refine our family-centered care processes in our NICU." -Sangeeta,

California

"I am so proud to be on this Taskforce and to see the widespread change that is happening in units. I feel very fortunate to have the opportunity to connect with colleagues who share my passion for FCC. I learn something new in every webinar!"

-Maria, Texas

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### WEBINAR REVIEW

### "The i-Rainbow: A flexible, evidence-based care path for providing developmental care in the NICU" by Melissa Scala, MD & Eilish Byrne, PhD

The i-Rainbow program is unique in that it prescribes developmentally appropriate ways for caregivers to interact with their infant based on the infant's physiological status. For example, a patient who is very unstable (Stage 1) would be stimulated only by a caregiver's smell, while a very stable patient (Stage 4), who tolerates holding for 15 minutes without physiological instability, would be deemed a suitable candidate for Kangaroo Care. The program has been used successfully at El Camino Health and Lucile Packard Children's Hospital NICUs.

### "Social Media: A tool for connecting with families" by Daphna Barbeau, MD

This webinar highlighted the importance of physician presence on social media for the purposes of dispelling misinformation and for better understanding the needs of current and former NICU families. Dr. Barbeau described how social media also gives physicians a channel to engage with families for research and advocacy purposes.

@DoctorDaphnaMD

### "How Mammha is Closing Gaps in Maternal Mental Health Care in NICUs" by Maureen Fura

Mammha connects NICU parents with mental health resources and provides a confidential, HIPAA-compliant remote depression screening tool for NICU parents. Those who screen positively are immediately connected with resources including no to low-cost mental health resources, education, CBT, and coping skills via text message as well as access to a care coordinator. Those who screen negatively are still offered resources in the form of links to educational materials and other opportunities to reach out for more mental health support.

### **SPOTLIGHT!**

### RAFI MENDELSOHN, MD AND THE NICU TEAM AT ICHILOV-TEL AVIV MEDICAL CENTER

NICUs participating in the Taskforce small groups are all working hard to improve their FCC practices. One ambitious and dedicated member, Dr. Mendelsohn from the Ichilov-Tel Medical Center, has been committed to attending all webinars and sharing the recordings with his team. He has been a devoted member of his Small Group 5 meetings, even attending them late at night due to the time difference, and often including his adorable children to make it family-inclusive. Dr. Mendelsohn painstakingly changed his unit's design plan to incorporate FCC with the help of an FCC Taskforce small group leader and has diligently worked towards changing the culture among staff to embrace family-centered care. We are incredibly proud of what he has accomplished in such a short amount of time and commend him for his leadership and perseverance to bring such an important aspect of care to patients and their families.

### **FAMILY PARTNER COLUMN**

NICU Family Partners play an important role in facilitating and supporting the principles and practices of family-centered care: to ensure every family is an essential and integral member of their baby's care team, and that no family has to navigate the NICU alone.

Their areas of focus and expertise come in many forms, from in-hospital program leaders to QI and research partners, as well as book authors, advocates, and organization leaders. As a way to get to know them better, our newsletters will profile one of our Family Partners in hopes to foster more collaboration with families in your unit!



### YAMILE JACKSON, PHD, PE, PMP

CEO, Nurtured by Design Founder, Int'l Kangaroo Care Awareness Day Parent of Zachary

### How were you personally activated to advocate for and support NICU families?

When Zach was 3 weeks old, weighing 2.5 lbs., Tropical Storm Allison hit Houston, TX, leaving the hospital and life-support equipment powerless. The NICU staff and we kept Zach alive "by touch" for 9 hours until he was evacuated. I held him skin-to-skin to keep him warm and calm, and Larry received a crash-course on "bagging," taking turns with the staff. In those dark hours, I promised Zachary that his pain and struggle to survive were not in vain and I would dedicate my life to supporting babies like him and families like ours. Zach is now healthy and in college.

#### How does your organization/company/hospital support NICU families?

We apply ergonomics engineering, risk management, and our personal and professional experiences in creating The Zaky® (products, consulting, and app) that are evidence-based, support families, zero-separation, aid kangaroo care, nonpharmacologic pain management, and individualized developmental and neuroprotection care.

### What insight or advice do you have for healthcare partners who want to implement/strengthen FCC practices in their hospital?

Neonatologists with a multidisciplinary team can create a trauma-informed culture of family inclusion in the NICU. Parents have superpowers for natural healing and mental health support. The healthcare team provides medical care and enables families to bond. Work as a team and rely on each other's strengths.

### What are the greatest needs of families in maternal-infant health you observe through your work?

The lack of parental leave in the USA, especially for families of NICU infants. Too much happens in the NICU; parents should be able to be there without barriers.

### What does being part of the FCC Taskforce mean to you personally?

I like working with a taskforce that understands that families suffer when a baby is in the NICU, and the best way to support them is to include them in the care of their babies while in the hospital and beyond.

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### **FAMILY PARTNER COLUMN**

### CONTINUED

What is your greatest wish in terms of the positive impact the FCC Taskforce members can make together in maternal-infant health?

I am an advocate for trauma-informed kangaroo care. I know that everything important is "counted and analyzed," from the grams of weight of the babies to the drops of milk the baby eats. I hope we give more importance to analyzing kangaroo care and include it in "count what counts."

Fill in the blank: NICU and bereaved parents are <u>traumatized but capable</u>.

**Fill in the blank: Healthcare partners are** in a position to make or break the seamless inclusion of the baby into their own family.



### **QUARTERLY RECOMMENDATIONS**

- We can **help families recognize milestones** by identifying small wins each week or periodically on rounds. The "Hope for HIE" team calls these "inchstones."
- Many units focus on families of preterm infants. Often, families of late-preterm or full-term babies can feel left out. Review your unit's policies and signage to make them more inclusive for all infants.
- Has your team had a hard week? Sometimes to care for families, we need to care for our teams too. Check in to see if **your team needs a pick-me-up** this week-free coffee, a group activity like a mindfulness coloring page, a sharing & listening meeting with each other, or someone from the community to offer mental health exercises. Be sure to NAME the stressor and recognize the hard work of your team.
- Does your 'C-suite' know what you are trying to achieve? Sometimes by sharing your vision (and needs!) with the people in power at your organization, you can find a shared vision and **new avenues for support and funding.**

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### **ARTICLE REVIEW**

"It Takes a Village to Implement Family-Centered Care in the Neonatal Intensive Care Unit" by Nesibe S. Kutahyalioglu, PhD, RN, et al. (2023) (link)

Nurses are critical for the successful implementation of FCC. NICU nurses may be aware of the benefits of parental participation in the care of the neonate, but they may hesitate to fully engage the family over concerns about giving up some of their power, control, and responsibilities. This study aimed to understand how NICU nurses can implement the FCC model into practice. The mixed-methods study began with an online survey of NICU nurses, followed by video-based dyadic interviews that were conducted with a subsample of 20 NICU nurses. Analysis of the interviews of the nurses revealed six main areas which help to facilitate FCC in the NICU. Each of the six areas aligned well with the 'it takes a village' metaphor and are listed below:

- Equitable Relationships- The care of a neonate in an FCC model requires a care team that includes nurses, parents, physicians, educators, and administrators. Each "village" member has a role to play with specific responsibilities; no individual is solely responsible for the infant's care.
- **Bond of Trust-** Individual FCC team members need trusted relationships, believing each provides the best possible care.
- **Knowledge Sharing-** Knowledge about best practices and FCC should be provided through institutional training. Several nurses noted the importance of institutional "buy-in" for continuing education.
- **Empowerment in the Workplace-** Members should share knowledge, engender trust, and guide others. Empowering others is not dictating what to do, instead the village may be more likely to achieve its goals when each member (e.g., parents and nurses) is empowered to engage.
- Environment and Culture- To successfully implement FCC, the NICU environment benefits from a no-fault policy. For example, if something goes awry, it is not seen as the fault of an individual but rather considered to be a systemic problem. The members of the village work together to ensure that similar issues do not occur in the future.
- Regulations- Variations within—and across—groups may prevent the accomplishment
  of goals. Most respondents noted a need to establish policies, protocols, and
  guidelines.

This study shows how many NICU nurses believe that FCC implementation is not an initiative for any specific group of personnel in the NICU. On the contrary, all staff have to participate. In other words, 'it takes a village' to achieve successful practice of FCC because of the complex interrelationships between care team members.

Reviewed by Malathi Balasundaram, MD & Vargabi Ghei, MD

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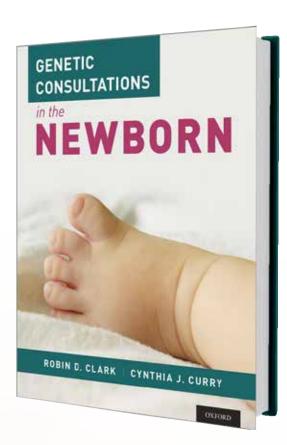


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# The Management of Meconium-Staining of the Amniotic Fluid (MSAF)

Joseph Hageman, MD, Mitchell Goldstein, MD, MBA, CML, Walid Hussein, MD

"The management of meconium-staining of the amniotic fluid in newborns in the delivery room has evolved significantly over the years."

The management of meconium-staining of the amniotic fluid (MSAF) in newborns in the delivery room has evolved significantly over the years. In the past, the approach was relatively straightforward, with neonatologists, neonatal fellows, and pediatric residents frequently performing endotracheal intubation, especially in cases where the meconium was thick and quick suctioning was deemed necessary (1,2). It was commonly believed that meconium aspiration occurred during the intrapartum period before the obstetrician and neonatology team could intervene with suctioning and delivery (see figure) (1,2).

"No longer is oropharyngeal or nasopharyngeal suctioning routinely performed before the delivery of the shoulders, nor is amnioinfusion commonly used to dilute the meconium."

Interestingly, examining the literature spanning the last 50 years reveals substantial changes in management practices on the obstetrical side. No longer is oropharyngeal or nasopharyngeal suctioning routinely performed before the delivery of the shoulders, nor is amnioinfusion commonly used to dilute the meconium (1-5). This shift underscores the dynamic nature of medical practices in response to evolving evidence and advancements.

On the neonatal side, recent updates from the American Academy of Pediatrics (AAP) Neonatal Resuscitation Program (NRP) textbook, along with insights from prospective randomized studies involving both vigorous and non-vigorous newborns with MSAF, have led to changes in recommendations. Tracheal suctioning is no longer the default approach unless there is a clear indication of airway obstruction due to thick meconium (3-5). It is important to note that while this approach is recommended, the level of certainty attached to the recommendation is considered low, supported by some available data (3).

Conversations with practicing obstetricians and neonatologists corroborate this changing landscape. Obstetricians now tend to avoid suctioning before the delivery of the shoulders, and the neonatology team rarely resorts to intubation for tracheal suctioning. This transformation in clinical practice highlights the impact of research, collaboration, and evolving guidelines on the ground level of medical care (WH).

"Obstetricians now tend to avoid suctioning before the delivery of the shoulders, and the neonatology team rarely resorts to intubation for tracheal suctioning. This transformation in clinical practice highlights the impact of research, collaboration, and evolving guidelines on the ground level of medical care."

The references provided offer further insight into this evolution, such as the combined obstetrical and pediatric approach proposed by Carson et al. in 1976 (1), Cleary and Wiswell's comprehensive exploration of meconium aspiration syndrome in 1998 (2), Wiswell et al.'s pivotal collaborative trial on delivery room management of meconium-stained neonates in 2000 (4), and more recent studies like Kalra et al.'s investigation into neonatal outcomes in cases of non-vigorous neonates with MSAF (5). These references underscore the progression of medical knowledge and the adaptive nature of medical practitioners in response to emerging evidence.

In conclusion, managing meconium-stained amniotic fluid in newborns has undergone substantial changes. While the approach to obstetrical and neonatal care has evolved, these changes are rooted in ongoing research, collaborative efforts, and evidence-based updates to clinical guidelines. This dynamic process reflects the commitment of healthcare professionals to provide the best possible care to newborns and their mothers.

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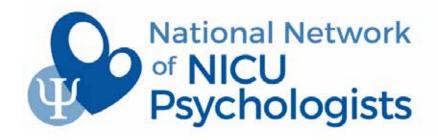
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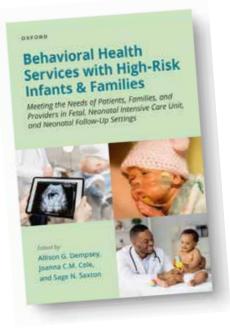


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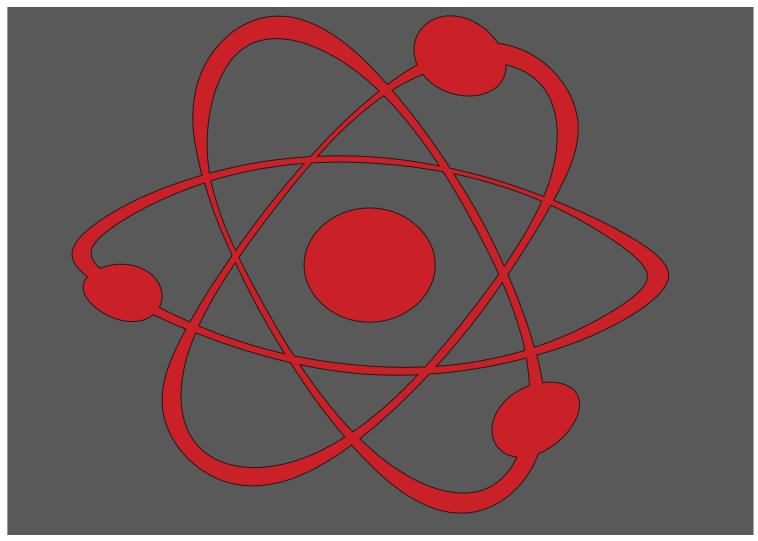
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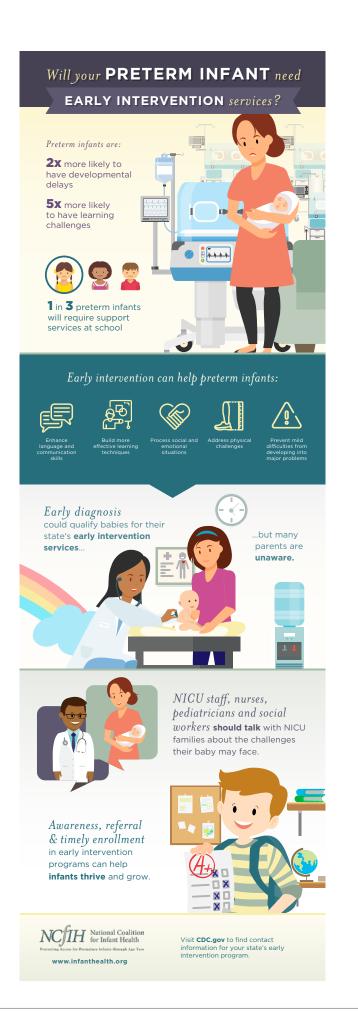
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https://www.nc3rs.org.uk/arrive-guidelines

http://www.icmje.org

https://olaw.nih.gov/policies-laws/phs-policy.htm

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#### **Neonatology and the Arts**

This section focuses on artistic work which is by those with an interest in Neonatology and Perinatology. The topics may be varied, but preference will be given to those works that focus on topics that are related to the fields of Neonatology, Pediatrics, and Perinatology. Contributions may include drawings, paintings, sketches, and other digital renderings. Photographs and video shorts may also be submitted. In order for the work to be considered, you must have the consent of any person whose photograph appears in the submission.

Works that have been published in another format are eligible for consideration as long as the contributor either owns the copyright or has secured copyright release prior to submission.

Logos and trademarks will usually not qualify for publication.

This month we continue to feature artistic works created by our readers on the next to last page as well as photographs of birds on rear cover.. For this edition, our art was graciously provided by Colleen Kraft, MD. It is a work done by her son Tim. This is "Downtown" .Our Bird is an Owl from Scotland from my collection.



Mita Shah, MD, Neonatal Intensive Care Medical Director 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, SVG, or pdf) for each figure. Preferred formats are ai, SVG, psd, or pdf. tif and jpg images with sufficient resolution so as not to have visible pixilation for the intended dimension. In general, if acceptable for publication, submissions will be published within 3 months.

- 3. There is no charge for submission, publication (regardless of number of graphics and charts), use of color, or length. Published content will be freely available after publication. There is no charge for your manuscript to be published. NT does maintain a copyright of your published manuscript.
- 4. The title page should contain a brief title and full names of all authors, their professional degrees, their institutional affiliations, and any conflict of interest relevant to the manuscript. The principal author should be identified as the first author. Contact information for the principal author including phone number, fax number, e-mail address, and mailing address should be included.
- 5. A brief biographical sketch (very short paragraph) of the principal author including current position and academic titles as well as fellowship status in professional societies should be included. A picture of the principal (corresponding) author and supporting authors should be submitted if available.
- 6. An abstract may be submitted.
- 7. The main text of the article should be written in formal style using correct English. The length may be up to 10,000 words. Abbreviations which are commonplace in neonatology or in the lay literature may be
- 8. References should be included in standard "NLM" format (APA  $7^{\text{th}}$  is no longer acceptable). Bibliography Software should be used to facilitate formatting and to ensure that the correct formatting and abbreviations are used for references.
- 9. Figures should be submitted separately as individual separate electronic files. Numbered figure captions should be included in the main file after the references. Captions should be brief.
- 10. Only manuscripts that have not been published previously will be considered for publication except under special circumstances. Prior publication must be disclosed on submission. Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.
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NEONATOLOGY TODAY is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.

Please submit your manuscript to: LomaLindaPublishingCompany@gmail.com



#### 1- THE RIGHT TO ADVOCACY

My parents know me well. They are my voice and my best advocates. They need to be knowledgeable about my progress, medical records, and prognosis, so they celebrate my achievements and support me when things get challenging.

#### 2- THE RIGHT TO MY PARENTS' CARE

In order to meet my unique needs, my parents need to learn about my developmental needs. Be patient with them and teach them well. Make sure hospital policies and protocols, including visiting hours and rounding, are as inclusive as possible.

#### 3- THE RIGHT TO BOND WITH MY FAMILY

Bonding is crucial for my sleep and neuroprotection. Encourage my parents to practice skin-to-skin contact as soon as and as often as possible and to read, sing, and talk to me each time they visit.

#### 4- THE RIGHT TO NEUROPROTECTIVE CARE

Protect me from things that startle, stress, or overwhelm me and my brain. Support things that calm me. Ensure I get as much sleep as possible. My brain is developing for the first time and faster than it ever will again. The way I am cared for today will help my brain when I grow up. Connect me with my parents for the best opportunities to help my brain develop.

#### 5- The Right to be Nourished

Encourage my parents to feed me at the breast or by bottle, whichever way works for us both. Also, let my parents know that donor milk may be an option for me.

#### **6-** The Right to Personhood

Address me by my name when possible, communicate with me before touching me, and if I or one of my siblings pass away while in the NICU, continue referring to us as multiples (twin/triplets/quads, and more). It is important to acknowledge our lives.

#### 7- THE RIGHT TO CONFIDENT AND COMPETENT CARE GIVING

The NICU may be a traumatic place for my parents. Ensure that they receive tender loving care, information, education, and as many resources as possible to help educate them about my unique needs, development, diagnoses, and more.

#### 8- THE RIGHT TO FAMILY-CENTERED CARE

Help me feel that I am a part of my own family. Teach my parents, grandparents, and siblings how to read my cues, how to care for me, and how to meet my needs. Encourage them to participate in or perform my daily care activities, such as bathing and diaper changes.

#### 9- THE RIGHT TO HEALTHY AND SUPPORTED PARENTS

My parents may be experiencing a range of new and challenging emotions. Be patient, listen to them, and lend your support. Share information with my parents about resources such as peer-to-peer support programs, support groups, and counseling, which can help reduce PMAD, PPD, PTSD, anxiety and depression, and more.

#### 10- THE RIGHT TO INCLUSION AND BELONGING

Celebrate my family's diversity and mine; including our religion, race, and culture. Ensure that my parents, grandparents, and siblings feel accepted and welcomed in the NICU, and respected and valued in all forms of engagement and communication.

Presented by:



# NICU Parent Network

NICU PARENT NETWORK Visit nicuparentnetwork.org to identify national, state, and local NICU family support programs.

\* The information provided on the NICU Baby's Bill of Rights does not, and is not intended to, constitute legal or medical advice.

Always consult with your NICU care team for all matters concerning the care of your baby.

