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Romiplostim Administration to a Preterm Neonate with Severe Acquired Thrombocytopenia Michael D. Kamitsuka, MD, Shrena Patel, MD,	Prolonged	I CA Am
Richy T. Lee, MD, Robert D. Christensen, MD	.Page 3	The Kell
27th Cool Topics in Neonatology Conference A Virtual Educational Conference Clara H. Song, MD		 The
	.Page 11	Dav
Developing a Shiny WebApp User Interface Fu-Sheng Chou, MD, PhD	Domo 22	Nec Spe
Fellow Column: Comparing Transcutaneous Bilirubin Level Serum Bilirubin Levels to Screen for Neonatal Jaundice Kaivan Dadachanji, DO	ls with	Rot Meo Cor
On Adapting to Remote Learning for Healthcare Professionals Barb Himes, IBCLC	.Page 28	The Dele
Section on Neonatal-Perinatal Medicine Update – Raising our Voic Lily J. Lou, MD, FAAP	es	Nive Hur
Interpreting Umbilical Cord Blood Gases Cord Occlusion with Ter Bradycardia: Part IV Jeffrey Pomerance, MD, MPH	.Page 35 minal Fetal	Heid Clir A T
Neonatology Solutions Redesigned Interfaces Scott Snyder, MD		Pati Lett
Conversations About COVID Vaccines with Latino Immigrant Co Julia Koehler MD		Mito Erra
Medical Legal Forum: Case Debrief: J.S. v. The United States of J Jonathan Fanaroff, MD, JD, Robert Turbow, MD, JD, Gilbert Marti	America in, MD	Aca
Surfactant Rob Graham, R.R.T./N.R.C.P.		Upc Sub
Abstracts from National Perinatal Association 2020 Conference, 2-4, 2020: New Framework for Multidisciplinary Care in the 4 th Tri Jerasimos (Jerry) Ballas, MD, MPH, FACOG	December mester	Edit
Jerasimos (Jerry) Ballas, MD, MPH, FACOG Featured Conference: Agenda for the Virtual 37 th Annual Advances peutics and Technology: Critical Care of Neonates, Children, and Ad Donald Null, MD, Mitchell Goldstein, MD, Arun Pramanick, MD	in Thera- dults	Nec
New Congress Takes Aim at Maternal Health Inequities Michelle Winokur, DrPH, and the AfPA Governmental Affairs T	Ŭ	Sta

I CAN Digitally Involved (iCANDI) Amy Ohmer Page 81
The Next Generation of NICU Staff Kelly Welton, RRT-NPS
Page 84 The Nature of Neonatal Experience during Pandemic COVID-19 Daved van Stralen, MD, FAAP, Thomas A. Mercer, RAdm, USN
Page 87 Neonatal Clinical Nurse Specialist (CNS): The Importance of Specialized Nursing Care for NICU Patients and Families Robin Koeppel, DNP, CPNP, CNS, RNC-NIC, C-ELBW, C-NNIC Page 99
Medical News, Products & Information Compiled and Reviewed by Mitchell Goldstein, MD Editor in Chief
The Genetics Corner: The Positive Predictive Value of NIPT for 22q11 Deletion Syndrome Varies with the Indication Nivedita Rajakumar, Subhadra Ramanathan, Robin D. Clark, MD
Human Milk: The Best Medicine for Vulnerable Babies
Heidi E. Karpen, MD Page 129
Clinical Pearl: A Thoughtful Approach to Neonatal End-of-life Discussions Patricia Stevens, MS, NNP-BC
Letters to the Editor: Truth in Monitoring Mitchell Goldstein, MD responds to Hernando Baquero Latorre, MD
Erratum
Academic True Open Model (ATOM)
Upcoming Meetings Page 148
Subscriptions and Contact Information Page 148
Editorial Board
Page 151 Neonatology Today: Policy on Animal and Human Research
Page 153 Neonatology Today: Instructions for Manuscript Submission
Page 153 Neonatology and the Arts - Herbert Vasquez, MD
Page 153 Stargazer Lily - Paula Whiteman, MD
Mallard Duck in Hiding - Larry Tinsley, MD
Page 155

.Page 79



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Romiplostim Administration to a Preterm Neonate with Severe Prolonged Acquired Thrombocytopenia

Michael D. Kamitsuka, MD, Shrena Patel, MD, Richy T. Lee, MD, Robert D. Christensen, MD

Abstract

Platelet transfusions can be lifesaving for neonates with thrombocytopenic hemorrhage. However, multiple transfusions themselves convey risks and hazards. We cared for a preterm neonate with severe/prolonged acquired thrombocytopenia who received 61 platelet transfusions. Her platelet counts stabilized, and further transfusions were not needed, following three escalating doses of romiplostim.

Abbreviations

Tpo: thrombopoietin

DOL: day of life

NEC: necrotizing enterocolitis

SQ: subcutaneously

IPF: immature platelet fraction

Keywords: thrombopoietin; immature platelet fraction; platelet transfusion

Established Facts

- Thrombocytopenia is a common problem and may affect up to 70% of extremely low birth weight neonates
- Platelet transfusion is the current treatment option for neonates with severe symptomatic thrombocytopenia
- Mortality and risk for sepsis is increased in those requiring multiple platelet transfusions so other options need to be explored

Novel Insights

• Thrombopoietic stimulators like romiplostim may reduce the need for multiple platelet transfusions in neonates with symptomatic and persistent thrombocytopenia.

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Introduction

The purpose of this report is to describe a case in which an extremely premature, low birth weight neonate, developed a prolonged course of thrombocytopenia requiring multiple platelet transfusions but subsequently stopped requiring platelet transfusions following a short course of the Tpo-mimetic, romiplostim.

In 1994 the principal physiological regulator of thrombopoiesis, thrombopoietin (Tpo), was cloned (1). Two recombinant forms were created: a full-length Tpo and a pegylated form containing only the receptor-binding domain. In early clinical trials, a few subjects receiving these molecules developed cross-reactive neutralizing antibodies against their endogenous Tpo, resulting in severe hypo-regenerative thrombocytopenia and aplastic anemia (2).

Second-generation Tpo-mimetics were developed, which do not share any sequence homology with endogenous Tpo, but stimulate thrombopoiesis by binding and activating the Tpo receptor (3). In 2018, the FDA approved romiplostim for use in children >1 year of age with immune thrombocytopenic purpura of > 6 months (3). Although romiplostim has been used in cases of refractory thrombocytopenia in children, published use in neonates is limited (4). We would like to describe our experience of using romiplostim in a neonate with protracted thrombocytopenia.

"The purpose of this report is to describe a case in which an extremely premature, low birth weight neonate, developed a prolonged course of thrombocytopenia requiring multiple platelet transfusions but subsequently stopped requiring platelet transfusions following a short course of the Tpo-mimetic, romiplostim."

Case Report

A 540 gram, 23-week female was admitted to the neonatal intensive care unit with an initial platelet count of 201 x $10^3/\mu$ L. The mother had been visiting Seattle from the East Coast when she delivered. Her prenatal laboratory values included non-reactive rapid plasma regain and human immunodeficiency virus titer, immune Rubella titer, normal cell-free DNA screen. Her platelet count was 151 x $10^3/\mu$ L

On day of life (DOL) 10, the infant's abdomen became dusky and distended. No pneumatosis or free air was detected on her abdominal radiographs. Fluconazole was started after Candida albicans grew from a blood culture. Platelets were transfused four days later for a platelet count of $91 \times 10^3/\mu$ L; because she was a septic 23-week infant with a germinal matrix hemorrhage, we

were trying to prevent further extension.

On DOL 30, her abdomen became distended and firm. Despite serial abdominal radiographs without pneumatosis or free air, necrotizing enterocolitis (NEC) was suspected. She was severely ill, requiring platelets and fresh frozen plasma transfusions for disseminated intravascular coagulation. Due to pancytopenia and extreme instability, exploratory surgery was deferred. During this time, she required 1-2 platelet transfusions daily to keep her platelet count > 100 x $10^3/\mu$ L. Post transfusion platelet counts were rarely > 100 x $10^3/\mu$ L (Figure); therefore, starting on DOL 47, all aliquots were plasma reduced. Subsequent, immediate post-transfusion platelet counts were frequently > 200 x $10^3/\mu$ L but by 48 hours would invariably fall to < 100 x $10^3/\mu$ L, as low as 9 x $10^3/\mu$ L.

Three weeks later, she was stable enough to go to surgery for a bowel obstruction. No intra-abdominal abscess, candidiasis, or necrotic bowel was identified. Her bowel was matted and friable. Handling the bowel trying to find the area of obstruction left her with multiple enterotomies. A diversion was not possible, so the abdomen was left open, and the baby was brought back to the NICU with the peritoneum open and the bowel exteriorized. She continued to require platelet transfusions, assumed to be consumptive related to her abdomen. The previous work-up for other possible causes for thrombocytopenia were negative, including urine polymerase chain reaction testing for cytomegalovirus and heparin-induced antibody testing (done due to the prolonged presence of a central line infusing heparinized solution). Laboratory values for liver failure, including coagulation factors, liver function tests, urine organic acids, and serum amino acid screen, were normal. Mother had a normal platelet count. The infant's platelet count was > 104 x $10^{3}/\mu$ L for the 10 first days of life, making alloimmune or autoimmune thrombocytopenia less likely. Her platelet count did not fall until she became septic.

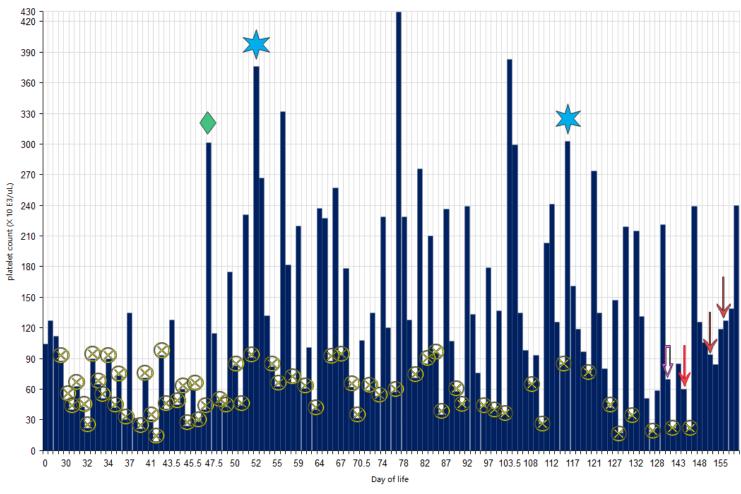
Her clinical condition improved following her surgery, such that by DOL 87, she was transfused only for platelet counts < 50 x $10^{3/}$ µL. She returned to surgery eight weeks later, where a primary end-to-end anastomosis was performed. The bowel, but not the liver, could be reduced into the peritoneal cavity. The closure was accomplished with a vicryl mesh.

She received 61 platelet transfusions from DOL 14 to 145. The last three weeks of her hospital stay showing the platelet count in relation to platelet transfusions, dexamethasone start, and romiplostim are seen in the table. Dexamethasone was started for worsening bronchopulmonary dysplasia. Her last transfusion for a platelet count of 20 x 10³/µL was the day after the initial romiplostim. Before her first dose of romiplostim (2 mcg/kg/dose) subcutaneously (SQ), her immature platelet fraction (IPF) was 3.2% (NL 1.1-7.1%). The platelet count continued to decrease, so a second dose (4 mcg/kg/dose) SQ was given after one week. The platelet count nadir was two days later. The first rise in the platelet count was four days after the second dose. After receiving her 3rd dose, her IPF was 11.6%. The mean platelet volume was 10.2 fL with a platelet count of 70 x $10^{3}/\mu$ L One day after her third dose, she was transferred across the country to a NICU closer to her mother's home. A follow-up call to the hospital caring for this infant reported the platelet count was 240 x 10³/µL on DOL 200, and she had not received any platelet transfusions follow her transfer. No complications that we could attribute to romiplostim occurred prior to her transfer, and we did not have access to follow-up data to evaluate for complications after the transfer.

Discussion

This was an unusual case of chronic thrombocytopenia associated with a platelet count as low as $22 \times 10^3/\mu$ L from DOL32 to as

	• •			•
DOL	Platelet (x 10 ³ /µL)	transfusion	medication	Dose (mcg/kg)
136	18	yes		
140	70			
141			dexamethasone	
142	22	yes		
143	85			
144	60		Romiplostim	2.4
145	20	yes		
146	239			
148	126			
150	106			
151			Romiplostim	4
152	94			
153	84			
155	119			
156	127			
158			Romiplostim	4
159	139			
200	240			



FIGURE

Shows platelet count in response to platelet transfusion and romiplostim

↓ Romiplostim; ⊗ platelet transfusion;

late as DOL 145. Following three doses of romiplostim, the baby never received another platelet transfusion.

"In a survey of United States and Canadian neonatologists, Josephson found 30% - 45% of the neonatologists would transfuse platelets in a sick preterm infants with platelet counts of > 50 x 103/µL (5), a threshold of < 20 x 103/µL was selected by < 5%; and 50% selected 50 x 103/µL as the "transfusion" trigger for extremely low-birthweight neonates despite the absence of apparent bleeding (5)."

plasma reduced platelets; \star surgery \Downarrow dexamethasone

We have no unit standard when to transfuse platelets, and nationally, there are no universally accepted guidelines for platelet transfusion in neonates. In a survey of United States and Canadian neonatologists, Josephson found 30% - 45% of the neonatologists would transfuse platelets in a sick preterm infants with platelet counts of > 50 x $10^{3}/\mu$ L (5), a threshold of < 20 x $10^{3}/\mu$ L was selected by < 5%; and 50% selected 50 x 10^{3} /µL as the "transfusion" trigger for extremely low-birthweight neonates despite the absence of apparent bleeding (5). More recently, Curley showed a platelet count threshold of 50 x 10³/µL had a significantly higher rate of death or major bleeding than those transfused at a platelet count threshold of 25 x 103/µL (6). Their study included infants who were older, up to 34 weeks and did not include in their analysis any infants born at 23 weeks and no mention of how many were included who underwent major surgery as in our this case. The platelet count was < 50 x $10^{3}/\mu$ L 24 times and < 25 x $10^{3}/\mu$ L 6 times as late as DOL 145. There were days when there as a rapid decrease in the platelet count to 26-50 x 10³/µL. We suspect by waiting, the platelet count would have eventually decreased to < 25×10^{3} /µL, and the baby would have needed to be transfused. The number of transfusions may have been reduced if the lower threshold of 25 x 10³/µL was followed, but in this sick, extremely premature infant, we were concerned the risk for significant bleed-

ing complications would be too great using such a low threshold.

We don't have a clear understanding of why the platelet count would continue to fall to < 25 10^{3} /µL at five months of age. We assumed the chronic thrombocytopenia resulted from prolonged gut inflammation resulting from infection or NEC. Thrombocytopenia can be categorized kinetically as hyporegenerative, consumptive, or a mixed mechanism. The great majority of neonates who receive >20 platelet transfusions have a consumptive or mixed mechanism (7). The mortality rate has been reported to be 50% for infants receiving ≥ 20 platelet transfusions. Though some of this correlation may be related to the degree of illness, platelet transfusions themselves may also be responsible for the increased mortality rate. The risk of sepsis from platelet bacterial contamination increases in those receiving >10 transfusions (8), so other treatment options need to be explored.

In certain thrombocytopenic conditions, corticosteroids can increase platelet counts. Bourchier and Weston reported that dexamethasone increased platelet counts, which was speculated to be on the basis of reduced inflammation and diminished platelet consumption (9). In contrast, Peng did not find dexamethasone increased platelet counts (10). Dexamethasone may have contributed to the increase in the platelet count in our case. However, the IPF was low at the time dexamethasone was started, suggesting the thrombocytopenia might have a hypoproliferative component. The platelet count continued to fall for 12 days, and she still required two platelet transfusions after starting dexamethasone.

"In certain problematic cases, thrombopoietic stimulators like romiplostim might be considered to reduce or eliminate platelet transfusions (3). Early in her hospital course, the rapid decrease in the platelet count suggested a consumptive process."

In certain problematic cases, thrombopoietic stimulators like romiplostim might be considered to reduce or eliminate platelet transfusions (3). Early in her hospital course, the rapid decrease in the platelet count suggested a consumptive process. Following sepsis and possible NEC, thrombocytopenia normally resolves in 1-2 weeks, but in some, thrombocytopenia may persist for several weeks. Before initiating romiplostim, the lower IPF indicated impaired capacity to increase platelet production, suggesting hyporegenerative thrombocytopenia (11). Sepsis or NEC can result in an insufficient compensatory increase in thrombopoiesis (12), which may explain why she responded to romiplostim. We also cannot know what effect the increased number of transfusions had on bone marrow hyporegeneration linked to transfusion inhibition of endogenous thrombopoietin as in this case. However, the platelet count rise and the IPF following romiplostim may suggest a possible boost from the exogenous thrombopoietin agonist.

The starting dose in neonates is unknown. Data from the ITP Consortium of North America ICON2 found the median starting dose was 2 mcg/kg with a maximum 10 mg/kg/dose (2). The only study in a neonate started with 1 mcg/kg/dose and increased up to 3 mcg/kg/dose. Four doses were given over a 35 day period. (4). After discussion with our hematology, co-author consultant, we elected to start with 2 mcg/kg SQ and increase the dose weekly until we had a sustained result. We doubled the dose to 4 mcg/kg after the first dose since the platelet count continued to fall. After the second dose, the platelet count began to increase four days later.

Possible complications following romiplostim have been reported to be rebound thrombocytopenia, bone marrow fibrosis, and thrombocytosis (13). Non-hematopoietic effects of romiplostim have not yet been well characterized, but recent data suggests that Tpo may result in proapoptotic and differentiating–blocking effects on neuronal cells (14), so the effects on subsequent neonatal neurodevelopment are unknown. In the first pediatric studies, the most frequent non-bleeding adverse events were headache, upper respiratory tract infections, vomiting, and oropharyngeal pain (15). No thrombotic or embolic events were noted in this baby prior to transfer, and her records were not available for review after her transfer.

This anecdotal use does not constitute a cause-and-effect relationship, nor does it establish the success of this treatment. It may have been a coincidence that the platelet count increased after the romiplostim. We would consider the cautious use of romiplostim in cases of severe and persistent thrombocytopenia in an attempt to reduce the number of platelet transfusions needed to control bleeding. We hope this case may encourage the study of romiplostim in neonates to define which platelet disorders would make this an appropriate drug for use.

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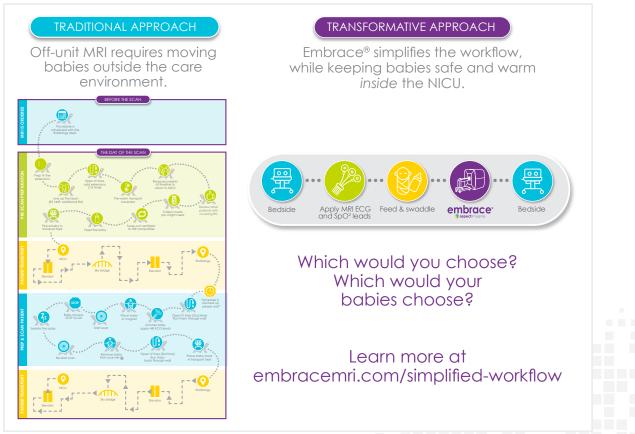
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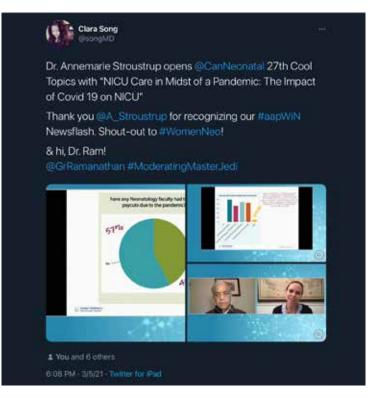
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"The California Association of Neonatologists (CAN) and AAP District IX Section on Neonatal-Perinatal Medicine (SONPM) bring us Cool Topics in Neonatology year after year on Coronado Island in sunny Southern California."





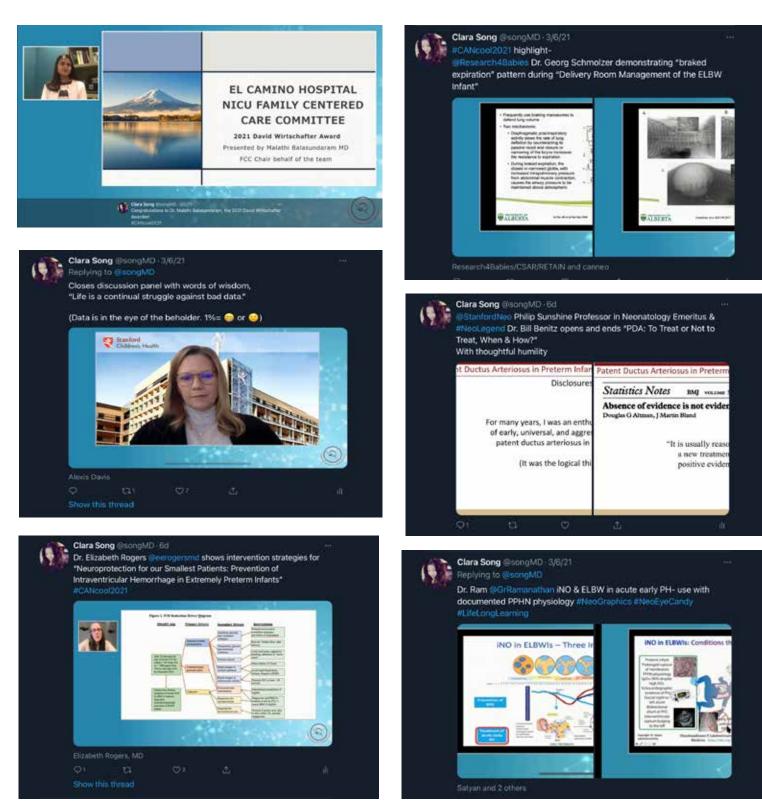
The California Association of Neonatologists (CAN) and AAP District IX Section on Neonatal-Perinatal Medicine (SONPM) bring us Cool Topics in Neonatology year after year on Coronado Island in sunny Southern California. The 27th annual meeting for 2021 was a virtual gathering, in tune with all the other meetings of the past year.



I was lucky enough to catch this three-day event for the first time since my fellowship over a decade ago. Much has changed, and much of the great stuff has stayed the same. Trainees and early career neonatal intensivists within two years of graduation are still welcome to the "Life After Fellowship: Exploring Career Opportunities and Practical Considerations for New Neonatologists," the pre-conference event organized by Dr. Rangasamy Ramanathan. This unique set-up allows intensivists in the TECaN stage to interact with a panel of MidCaN (Mid-Career Neonatologists) and WECaN (Well-Established Career Neonatologists) of various career trajectories and backgrounds. A great addition- that is new for me- is the CPQCC collaboration. The 2021 CPQCC Improvement Palooza, moderated by Dr. Elizabeth Rogers, focused this year on "Advancing Anti-Racism in the NICU Through Teamwork and Family Centeredness." An annual update from CAN leadership accompanied the lunch break- Chair Dr. Bob Kahle Secretary Dr. Meena Sankar, and AAP SONPM executive committee members. Highlighted within this hour was an update from Past SONPM

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Chair Dr. Mark Hudak on the National Perinatal COVID-19 Registry, which has captured nearly 8000 thousand mother-baby dyads.

The 2021 Cool Topics meeting officially kicked off with an evening keynote lecture from Dr. Annemarie Stroustrup, from Cohen Children's Medical Center, on "NICU Care in the Midst of a Pandemic: The Impact of Covid 19 on the NICU: Staff, Patient and Family Perspectives". Opening night also recognized all 2021 accepted abstracts in the Virtual Poster Session, a trailblazing QI champion and an early career neonatal intensivist for outstanding scholarly

work. The 2021 David Wirtschafter Awardee was Dr. Malathi Balasundaram for her QI leadership, presented by Dr. Wirtschafter himself this year. Dr. Rangasamy Ramanathan presented the Bhatt-Ramanathan Award to rising star Dr. Elizabeth Couch from UCSF.

The weekend meeting continued with a focus on this year's meeting star- the extremely low birth weight infant born at the limits of viability. The following one-and-a-half-day conference was filled with early management strategies to optimize this fragile population's outcomes. Day one included a discussion on fetal management from Maternal-Fetal Medicine Specialist, Dr. Andrew Combs, of the MEDNAX Center for Research, Education, Quality & Safety, with "Management of the High-Risk Pregnancy at the Threshold of Viability: PPROM, IUGR, PIH," the first in the preemie alphabet soup. Dr. Alexis Davis from Stanford University carried on the conversation torch to discuss "The Prenatal Consult at the Threshold of Viability: Clinical and Parental Perspective." Dr. Georg Schmolzer, the Director of the Center for the Studies of Asphyxia and Resuscitation (CSAR), presenting from Edmonton, Alberta, reviewed "Delivery Room Management of the ELBW infant." Dr. Jonathan Klein of the University of Iowa dove into "Respiratory Management from Birth to Discharge fo the Periviable Infant at 22 to 23 weeks Gestation: First Intention High-Frequency Jet Ventilation". Also from Iowa, Dr. Patrick McNamara spoke on the "Cardiovascular Support of the ELBW: BP Management, Assessing Cardiac Function, Targeted Neonatal Echocardiography." The Philip Sunshine Professor in Neonatology from Stanford University and the 2020 AAP Section on Neonatal-Perinatal Medicine Avroy Fanaroff Education Awardee took a microscope to the ageold question, "PDA: To Treat or Not to Treat: When and How?" Dr. Rangasamy Ramanathan from University of Southern California (USC) presented "Pulmonary Hypoplasia and Pulmonary Hypertension: iNO in the ELBW Infant," using the brilliant and mesmerizing illustrations of Dr. Satyan Lakshminrusimha of University of California, Davis. The day concluded with Dr. Ishminder Kaur of UCLA discussing "Early and Late-Onset Neonatal Sepsis: Opportunities for Antibiotic Stewardship."



Day two highlighted prevention and outcomes. Dr. Elizabeth Rogers returned to examine "Neuroprotection: Prevention of Intraventricular Hemorrhage in the ELBW Infant." Dr. Bobbi Pineda from USC took over the presentation baton to describe "Optimizing the NICU Environment for the ELBW Infant." Dr. Talkad S. Raghuveer from the University of Kansas reviewed "Strategies for the Prevention of Retinopathy of Prematurity." Dr. Brenda Poindexter from Emory University detailed the "Fluid and Nutrition Management of the ELBW Infant" in her early days to set-up for future success. This half-day concluded with a rundown of "NEC/SIP: the NEST Trial" from pediatric surgeon Dr. Marty Blakely from Vanderbilt University. The fun continued for the lucky ones that grabbed a coveted seat at the Neonatal Point-of-Care Ultrasound (POCUS) Virtual Workshop, chaired by Dr. Jae Kim of Cincinnati Children's and Dr. Jennifer Shepherd from Children's Hospital Los Angeles.

My memory of the annual CAN meeting years back is heartily associated with catching up with old friends on Coronado Island and the opportunity to meet new ones in District IX. This was a great educational getaway weekend. The virtual transition maintained the educational integrity and incorporated a central digital station to view the pre-recorded and live sessions, which was a major advantage for those viewing at various times. The chat function for many virtual meetings is disabled for logistical reasons and helps maintain control over time. Inadvertently, it also mutes conversation and networking, which are some of the best things about our neonatal meet-ups, particularly CAN Cool Topics. This is a tricky decision to make when coordinating a virtual meeting- do we focus on delivering content at the expense of interaction? Or do we set-up opportunities for interaction and communication and levy a time limit on lectures? Hybrid meeting options are in the foreseeable future and may be a great compromise to pull the best of both worlds.

Until then, in case you missed it, catch all the #CANcool2021 highlights here:

https://wke.lt/w/s/vGb2Ge

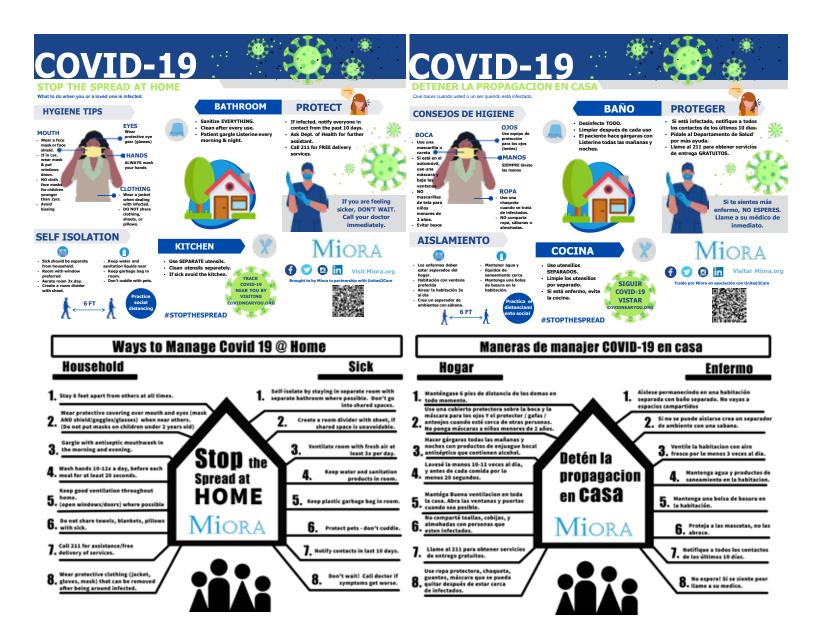
Disclosure Statement: The author has no relevant conflicts of interest to declare.

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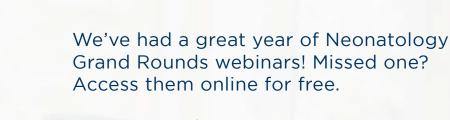


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I am not an addict.

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).



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NAS is a temporary and treatable condition.

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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 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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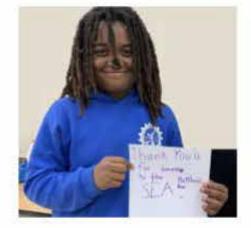


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1 month	\$120
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1 year	\$1,080
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Developing a Shiny WebApp User Interface

Fu-Sheng Chou, MD, PhD

Last month, we introduced different basic layouts available for choosing when designing a Shiny WebApp. The plain layout is easy to start. It is useful when you are developing simple WebApps for routine tasks. I used the plain layout to develop the NAS scoring WebApp (https://lluchnicu.org/NICU_Manual/NAS_scoring/). Because of its simplicity, the plain layout also works very well on mobile browsers. When the sidebar layout is used, it is typical to have all the input widgets on the sidebar panel and the output for display on the main panel, although it is just a general guide. On the other hand, the dashboard layout has more complete functions and appears more like typical websites we see and use routinely. It has a sidebar panel that hides when not in use. It also allows the construction of a header toolbar for notification. message, and task menus. In the main panel, the dashboard layout allows the use of "boxes" to group information for display. There are basic boxes, tabbed boxes, and infoboxes. (1) The dashboard layout uses AdminLTE (2), a fully responsive administrative template based on the Bootstrap 3 framework(3). All this means is that, for professional web developers, the potential is limitless.

"There are basic boxes, tabbed boxes, and infoboxes. (1) The dashboard layout uses AdminLTE (2), a fully responsive administrative template based on the Bootstrap 3 framework(3). All this means is that, for professional web developers, the potential is limitless."

1. HTML Tags

HTML, or HyperText Markup Language, is the standard programming language for webpages. It is the most basic building block of the websites. Here, we will discuss how the *Shiny* package turns R codes into HTML. We will use the NAS scoring WebApp as an example. If you click on the above link to go to the NAS scoring WebApp, and open up the code webpage (<u>https://neonatologytoday.org/datascience/NAS.html</u>) side by side to compare, we can see that the first argument in the ui <- fluidPage() is title=" LLUCH NICU NAS Scoring WebApp". This argument will place the strings in the tab title of the webpage (Figure 1). The second argument is a sub-function titlePanel("Modified Finnegan Scoring System"). Now, if you type down the same codes in the console:

> titlePanel("Modified Finnegan Scoring System")

<h2>test</h2>

You see that the return is an HTML string. The basic HTML uses <xxx></xxx> to flank the content for display in a web browser. h2 is a header tag: a standard HTML element used to define page headings. You can think of h2 as the Heading 2 style in Microsoft Words® (Figure 2). The header tags go from h1 to h6, with h1 being the largest and h6 being the smallest. So, what does this mean, and why do we care? This means that the Shiny package's functions turn the R codes into HTML codes, so people who know the R language do not have to re-learn a new programming language from the beginning before creating WebApps that are based on HTML. These Shiny functions also helped me learn HTML. Moreover, one can replace titlePanel("Modified Finnegan Scoring System") with HTML("<h2>Modified Finnegan Scoring System</h2>"), and still get the same result because they both result in the same output. The implication from this example is that people who know HTML well can further fine-tune the user interface with HTML. The possibility is enormous.

"The implication from this example is that people who know HTML well can further fine-tune the user interface with HTML. The possibility is enormous."

Similarly, going down to the sixth argument, h4("Central Nervous System Disturbances") gives the output of <h4>Central Nervous System Disturbances</h4>. Because h4() aims to translate R codes into HTML codes, rules applicable to HTML codes will be applicable to the corresponding R codes. For example, <h4 style="color:red;>Central Nervous System Disturbances</h4> will turn the flanked words into red font color. The corresponding R code writes h4("Central Nervous System Disturbances", style=" color:red;"). You can even add an align=" right" argument to align the words to the right border of the web browser. Try it for yourself if you will. In R, h4() is called a function; in HTML, <h4></ h4> is called a tag. The Shiny package has prepared numerous useful functions that will translate into corresponding HTML tags, available here: https://shiny.rstudio.com/articles/tag-glossary.html. I found that some functions require the prefix of tags\$, others don't. A safe approach is always to add the prefix.

2. Widget Arrangement

As mentioned before, webpages are divided into twelve invisible stripes of equal size. If not specified, the widgets are lined up horizontally (by row) unless a line break of indicated. <h4></h4> (or h4() in R) automatically adds to line break at the end, so as <hr/>(or hr() in R, which is used to draw a horizontal line).Other don't, especially widgets. The function fluidRow() is used to force the arrangement of widgets or other items by column. The first and only argument I typically use inside fluidRow() function is a sub-function called column(), inside which the first argument



\odot	LLUCH NICU NAS Scoring	×	+
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Modified Finnegan Scoring System

Total Score: 0

Central Nervous System Disturbances

High-Pitched Cry

None

4

Excessive high-pitched (or other) cry (2 points)

Continuous high-pitched (or other) cry (3 points)

Sleeps

is used to define the number of stripes this "column" will occupy. Here I put 12 so it occupies the entire webpage. By doing this, it is guaranteed no widgets or items will be placed side by side. The arrangement can only be done vertically. column() takes an optional argument of offset=n. It should be straightforward to the readers that the items will be placed on the n+1 stripe. For example, fluidRow(column(5, offset=3)) will place the widgets/items on stripes 4-8.

"Last month, we introduced that a Shiny WebApp has two parts, the user interface, and the server function. Practically, this means that designing the user interface is uncoupled from the backend computation."

Last month, we introduced that a Shiny WebApp has two parts, the *user interface*, and the *server function*. Practically, this means that designing the user interface is uncoupled from the backend computation. Therefore, when I start working on a new WebApp, I like to start with outlining the placement of the input widgets and other items, including the logo, text, icon, etc., and just run the App so I can appreciate it visually. I then create simple placeholders for the outputs. By doing this, I can visually assess the WebApp and write the codes for the server functions accordingly, ensuring that the WebApp is intuitive to the users and is easy to use. I don't focus

too much on making the WebApp fast and computation-efficient initially, which probably goes against the dogma that software engineers hold firmly. Having easy-to-use WebApps that allow me to be more efficient with my busy life as a clinician outweighs the importance of computational efficiency. This goal is achieved by having WebApps that are user-friendly. After all, these WebApps I develop for daily use don't contain high-level logic. I can't tell if a task takes 2 vs. 4 microseconds, even though that means doubling the computation time and may terrify engineers.

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"After all, these WebApps I develop for daily use don't contain high-level logic. I can't tell if a task takes 2 vs. 4 microseconds, even though that means doubling the computation time and may terrify engineers."

3. CSS and Javascript

It is worth mentioning that the developers can add custom cascading style sheets (CSS) to the R codes to polish up the webpages. Additionally, JavaScript can be added to improve the user experience of WebApps further. Several R packages have been developed to wrap JavaScript into R functions for easy adoption, such as *shinyjs*, *shinyBS*.(4,5) I used the *dashboard* layout for the Neonatology Today website, with the sidebar placed on the right side. The current and past issues reside in their own boxes, such as

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File Home Insert Design Layout References	Mailings Review Ξ ~ '== ~ == == Ξ == ‡= ~	View Help Styles Edi AaBbCcDc I Normal AaBbCcDc Intense E AABBCCDC	ACROBAT ACROBAT Dictate Dictate Dictate Dictate C Dictate	AaBbCcDa AaBbCcDa Subtle Em AaBbCcDa Quote	AaBbCcC Heading 2 AaBbCcDu Emphasis	×
Page 1 of 1 0 words	[Ľ] F	ocus 🗐			+	100%

the search function, leaderboard advertisement, editorial board, and authors' art. The carousals for the announcement (below today's date in the title area), the advertisement leaderboard, and the authors' art were made possible with additional CSS codes. The closing of the sidebar panel after a button is clicked and the hiding and appearance of the input widgets, for example, were made possible by using the JavaScript wrapper functions from the aforementioned packages. I have to admit that I am not all that fluent with CSS, and I don't know how to write JavaScript, but I would also say that, with some effort, you can always find example codes on the internet. Once you see an example, it's not that difficult to extrapolate and customize it to your own needs.

To summarize, in this article, we discussed how the functions in the *Shiny* package translate R codes into HTML codes. We also discussed the function used to force the alignment of the widgets. Next month, we will further discuss the *server function's reactivity*, which is why I love *Shiny* WebApps so much.

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Disclosure: The author identifies no conflict of interest

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- 4. A new section called news and views will enable the submission of commentary on publications from other journals or news sources. We anticipate that this will be available as soon as the site completes the beta phase
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A Life's Journey

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

Houchang D. Modanlou

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 The moat, or area around the syringe barrel, is difficult to clear. Medication can hide there, inadvertently increasing the delivered dose when the syringe and feeding tube are connected; patients may receive extra medication.

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WORKFLOW ISSUES

 Increased nursing workflow is seen with additional steps for clearing syringe moats, cleaning tube hubs, and using multiple connectors.

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Fellow Column: Comparing Transcutaneous Bilirubin Levels with Serum Bilirubin Levels to Screen for Neonatal Jaundice

Kaivan Dadachanji, DO

Newborn babies are frequently screened for jaundice to avoid kernicterus. The gold standard for checking for jaundice is the use of serum bilirubin levels and plotting the levels on an established nomogram (Bhutani Nomogram). (1, 2) However, unnecessary serum lab testing can be costly. Many clinics utilize a point of care transcutaneous bilirubin (TCB) to screen for jaundice. (3) Often clinics utilize a "75th percentile rule": if the TCB level is greater than 75%ile for age, total serum bilirubin (TSB) should be obtained. (4)

However, these TCB nomograms are based on old data; that do not account for updated devices. (2, 5)

The TCB nomogram our clinic utilizes is based on data from Patras, Greece, using BiliChek Device between September 2005 and December 2007, which only included healthy, full-term infants with no NICU stay and minimal diversity in ethnic/ racial backgrounds. (6, 7) All patients were less than 120 hours old. 14,864 measurements from 2,818 patients.

Materials and Methods:

Retrospective data were obtained from August 2018 to January 2021 of patients in our Riverside University Health Systems Main General Pediatrics clinic. Pts must have TCB and TSB within 4 hours of each other. Our TCB data was obtained from 2 BiliChek (B) devices (manufactured by Philips). "Newborn babies are frequently screened for jaundice to avoid kernicterus. The gold standard for checking for jaundice is the use of serum bilirubin levels and plotting the levels on an established nomogram (Bhutani Nomogram). (1, 2) However, unnecessary serum lab testing can be costly."

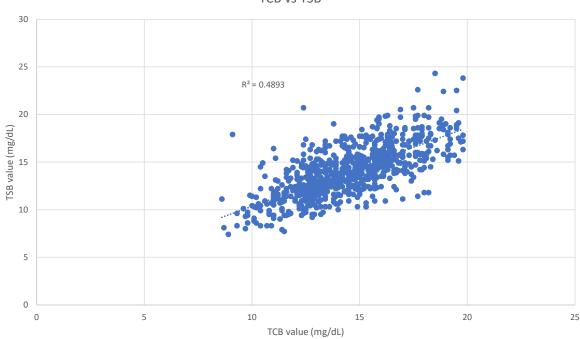
Results:

TCB, on average, is about 0.43 higher than TSB, p-value 0.0008. N = 754. We found the TCB is more accurate for babies born >92 hours of life (p-value 0.003). There is no change in variation between those born less than 92 hours of life and those greater than 92 hours of life. (Standard deviation: 1.67 vs 1.85, respectively; F Value 1.22). No correlation between Hispanic and Non-Hispanic patients was found.

Discussion:

Further research should be obtained to determine how point-ofcare transcutaneous bilirubin devices can further minimize se-

28



TCB vs TSB

rum bilirubin testing. This may be achieved by creating new algorithms/ protocols that determine which transcutaneous bilirubin values. Our clinic is considering a quality improvement project to decrease total serum bilirubin blood draws safely. (4)

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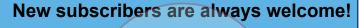


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On Adapting to Remote Learning for Healthcare Professionals

Barb Himes, IBCLC



Saving babies. Supporting families.

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

"The COVID-19 pandemic has changed and continues to change our health outlook, risk behaviors, and daily activities. For clinicians and health education professionals, it has forced us to be open to new ways of working with each other and with those we serve. "

The COVID-19 pandemic has changed and continues to change our health outlook, risk behaviors, and daily activities. For clinicians and health education professionals, it has forced us to be open to new ways of working with each other and with those we serve.

Some of these options we have had to explore have resulted in new perspectives and results we might not have realized possible before, and which can leave us with more choices than we might have thought.

A case in point for us at First Candle has been conducting our Straight Talk for Infant Safe Sleep program during the past year and into this one, which has given us some lessons learned that might be useful to other health care providers.

Our mission is to reduce the rate of infant mortality due to Sudden Unexplained Infant Death (SUID), which includes Sudden Infant Death Syndrome (SIDS) and Accidental Strangulation and Suffocation in Bed (ASSB). This can be achieved by following the American Academy of Pediatrics (AAP) set of recommendations for infant safe sleep. These guidelines, updated every five years, have been in use since the original Back to Sleep campaign, developed by a coalition including NICHD, the AAP Task Force, NHLBI, HRSA, and the SIDS Alliance (now First Candle) in 1994.

In 2017 we strengthened our educational outreach with the launch of Straight Talk for Infant Safe Sleep, a train-the-professional education workshop designed for health care providers, including nurses, doulas, social service agencies, faith-based workers, and childcare providers.

The program, under which nurses can earn CEU contact hours, follows a collaborative approach designed not only to cover the AAP guidelines but to help frame them in the context of a given family's environment, recognizing many factors that influence a parent's safe sleep decisions. These can include family and cultural norms, socio-economic factors, past experience, and the desire to bond or breastfeed (which we recommend). The program also addresses unrecognized implicit bias from healthcare providers, which through qualitative feedback to First Candle and other organizations indicated a barrier to adopting the safe sleep guidelines. The normal training format is a five-hour session of instruction, general discussion, and breakout groups.

In 2019 we were scheduled to conduct five sessions hosted by a state's hospital association with its member hospitals' staff. Then the pandemic and lockdown happened. However, working with the association, we developed a combination of in-person and online schedules that enabled us to proceed. The in-person sessions were held in training rooms or the association's classrooms and followed COVID-19 protocols regarding sanitation, distancing, and personal protective equipment.

We realized that we were naturally moving into new territory for the sessions that would have to be online and so observed these not only for their stated purpose but also to assess how the format itself performed as a training method.

We learned several things, key among them that we could accom-

To every NICU nurse who has cared for these precious babies we say..... "Thank you."

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

At First Candle we're educating parents, grandparents and caregivers about safer sleep to make sure all babies reach their first birthday. Learn more at firstcandle.org modate more participants than in person. They were more forthcoming in responses having to do with their current understanding of infant safe sleep and their perceptions about human behaviors. We attribute this in part to the association's online format; their responses were not individually identified to the group but were read aloud and shared by the trainer.

In addition, because their responses came in simultaneously, there was no opportunity for first-out responses to influence subsequent ones. In the instances where several respondents did provide the same answer, we could share it once as an acknowledged collective response, saving everyone time.

A strong component of the Straight Talk program focuses on implicit bias, including recognizing it and how to address it when working with parents and families. Some thought that this part of the course's dynamics might be affected by the remote format, but we found it was not. Participants were able to engage in constructive individual self-revelation and group discussion.

"A strong component of the Straight Talk program focuses on implicit bias, including recognizing it and how to address it when working with parents and families. Some thought that this part of the course's dynamics might be affected by the remote format, but we found it was not. "

Post-course evaluations showed that 100% of the participants reported a heightened awareness of implicit bias, and 87% reported having implemented changes in the time period subsequent to taking the course, including sharing learnings with staff, increasing their patient prenatal education in hospital, and a more sensitive approach to working with families.

However, under the hospital association's format, we did not have a breakout session option, which we are working to include as we move forward with the online version.

And we are moving forward with it during this year and will continue to do so even as things gradually begin to open up again, making it a permanent option to our Straight Talk offerings. We expect that we may gain further understanding of how people learn via online platforms (e.g., some may find they are more forthcoming in writing vs. orally, and there may be different results among sessions depending upon levels of identification, and so on.)

"Adult professional education is a different arena than online primary and secondary schooling, which involves a younger isolated population and has its own set of challenges. We look forward to learning more about this format's dynamics even as we pass learning on to our constituents." Adult professional education is a different arena than online primary and secondary schooling, which involves a younger isolated population and has its own set of challenges. We look forward to learning more about this format's dynamics even as we pass learning on to our constituents.

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

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About First Candle

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

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Section on Neonatal-Perinatal Medicine Update – Raising our Voices

Lily J. Lou, MD, FAAP

Dear All,

Your representatives on the Section Executive Committee have spent the past three months reflecting upon our Section's goals and how we should prioritize our resources and activities to best serve you and the community of neonatology.

Our previous SONPM strategic plan was formulated in 2016 and saw the introduction of advocacy and a strong emphasis on quality, with a sustained prioritization of innovative education and member value. In this update, I'd like to review our shiny **new Strategic Plan** and point out some shifts in focus and new activities that reflect our updated priorities. The full plan can be found on our website at <u>https://services.aap.org/en/community/aap-sections/</u> <u>sonpm/mission-goals-core-values-and-strategic-plan/</u>. We really appreciated all of the responses to the survey that provided insight into what matters to our members.

First of all, we have re-crafted our Mission and vision statements to try to capture more concisely what we are all about and how we hope to accomplish our goals:

To improve the health of newborns by enabling the neonatology community to provide optimal care through education, research and advocacy

Vision

Healthy newborns, universal quality care, fulfilled professionals

Our 2021-2026 Strategic Plan contains the following 6 domains:

- 1. Education
- 2. Member Value
- 3. Optimal Care
- 4. Advocacy
- 5. Health of the Subspecialty
- 6. Health of the Section

Let's take a closer look at each one.

One of the most key areas of our mission is **EDUCATION**. Our goal is to improve the knowledge, skills, and perspectives of neonatal-perinatal providers through high-quality education and stateof-the-art education delivery. We continue to value updating our educational approaches to the way neonatologists and trainees learn in today's world. This includes our support of such innovative strategies as the flipped classroom, integration of tools like Quizlet, interactive sessions, and practice question banks into NeoPREP, and conversion of many of our learning activities to effective virtual platforms, in addition to sustaining our strong support for trainee networking and research program development. We have also added "perspectives" into the goal—this is to reflect the prime importance of issues of equity, diversity, and inclusion. This was not added as a separate domain but is woven into every

aspect of our plan.

"We are now inviting leaders of our special interest groups and liaisons from partner organizations to attend the SONPM executive committee meetings to enhance leadership transparency and promote cross-talk and coordination between all sectors of our membership."

The **MEMBER VALUE** domain remains our biggest one and the area in which we most need continual input from members about where to focus our attention and resources. The goal is stated as: to identify and address the needs and interests prioritized by SONPM members. A common theme in this area is understanding the needs and member value of section membership for neonatologists practicing in primarily non-university settings. In response to this thread of concern, we are launching a working group called "All Pathways" to make sure the Section serves neonatologists pursuing all the various career trajectories open to those in our subspecialty. We will also focus on communicating on a multitude of platforms to reach members the way they like to get information. As our members develop multiple robust interest groups, we hope to tie them together through the website to make it easy to find synergy and avoid duplicated effort. We are now inviting leaders of our special interest groups and liaisons from partner organizations to attend the SONPM executive committee meetings to enhance leadership transparency and promote crosstalk and coordination between all sectors of our membership. We will also represent our members' views in discussions about the MOC-4 process with the ABP and work to streamline avenues for meeting the current requirements.

Our third domain is a combination of our previous Quality domain with a recognition of the seminal importance of research. The **OP**-**TIMAL CARE** goal is to facilitate high-quality research and quality improvement in neonatology to assure excellent clinical care. The SONPM quality Metrics Working Group is poised to submit the first of several white papers for publication so that quality is calibrated meaningfully on scales set by neonatologists rather than by external entities. There will be further work to do to refine the proposed metrics and work toward implementation. Our research mission is supported through our multiple fellows' conferences, the Klaus and Young Investigator awards, as well as travel scholarships to key neonatal conferences on a national level. One new deliverable in this domain is to elevate issues of diversity and inclusion in neonatology scholarship.

ADVOCACY was introduced as a strategic domain in 2016, and we continue to work to define an advocacy agenda for the neonate and develop the capacity of section members to achieve it. We will achieve this through our SONPM Advocacy Committee, our

advocacy listserv, which disseminates updates on neonatologyspecific issues with tools to speak up for babies, through our support of section members to attend the AAP Advocacy Conference, an upcoming workshop on advocacy at our Scottsdale Workshop, and development of toolkits like the one on coverage of donor milk that the Georgia and Ohio chapters are using to help babies get access to this essential intervention. One hot topic to watch is the potential for states to extend Medicare coverage for mothers to 12 months after delivery to avoid disruptions in care at a critical time point. Look for updates, op-eds, and podcasts from this active group.

"We want to publicize leadership opportunities widely to better engage more section members in fulfilling endeavors within the academy and thus amplify the voice of the subspecialist in our professional home."

Our new strategic plan continues to include the domain of HEALTH OF THE SUBSPECIALTY to envision, articulate and engage members in supporting the neonatal-perinatal medicine profession. This area encompasses priorities that overlap with other domains. As mentioned above, the current ABP approach to assuring continued competency in our field is a frequent topic of discussion, complicated this year by the delays in the initial certification exams imposed by the pandemic. We will foster dialogue between the SONPM and the ABP to represent the viewpoints and concerns of section members, as well as working to make existing routes to meeting the current requirements easier to navigate. We are anxious to learn more about the needs of private practice neonatologists and look forward to enhancing ways the SONPM can support their interests, per the working group mentioned above. We continue to appreciate the robust functioning of our coding committee, now chaired by Dr. Scott Duncan, in keeping up with the evolution of our practice. We will also work to ensure a diverse workforce of neonatologists in the future, so understanding our training numbers and areas of need are crucial. We want to publicize leadership opportunities widely to better engage more section members in fulfilling endeavors within the academy and thus amplify the voice of the subspecialist in our professional home.

Our final domain, to ensure the long-term sustained organizational <u>HEALTH OF THE SECTION</u>, is especially critical as budgets tighten and our traditional sources of support come under increased scrutiny. There is no other professional association in our field. We need to build strong operational security within the AAP to withstand a range of future economic landscapes. We also want to develop a skilled and diverse pipeline of future leaders who will take the helm as we work through the goals of many Strategic Plan updates to come

Please visit our website, review the SONPM Strategic Plan in detail, and always feel welcome to get in touch with ideas for where we need to turn our attention or inquiries about how you can engage with the Section. We are enthusiastic about moving the Section forward, but we need you to point us in the right direction.

In closing, I'll share this inspirational video called "Be the Change." It was produced by Kulture City, a non-profit organization that promotes sensory inclusivity, trying to make the world better for "individuals of unique abilities" such as invisible challenges like autism.

https://www.youtube.com/watch?v=Z8oJV_mBY9g

Stay well and take care,

Lily

Disclosure: There are no reported conflicts.

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Interpreting Umbilical Cord Blood Gases Cord Occlusion with Terminal Fetal Bradycardia: Part IV

Jeffrey Pomerance, MD, MPH

Case 13: Cord Occlusion with Single Cord Gas Result

The mother was a 35-year-old, gravida 2, para 0, aborta 1 with an intrauterine pregnancy at 38 4/7 weeks gestation. NSTs during the week prior to delivery were reactive. The initial FHR was 150-160 bpm with moderate beat-to-beat variability. Recurrent deeper and longer-lasting variable decelerations and prolonged decelerations ensued. Terminally, the FHR was approximately 60 bpm with poor variability. The tracing ended 13 minutes before delivery and 20 minutes after the beginning of the severe fetal bradycardia.

"Recurrent deeper and longer-lasting variable decelerations and prolonged decelerations ensued. Terminally, the FHR was approximately 60 bpm with poor variability. The tracing ended 13 minutes before delivery and 20 minutes after the beginning of the severe fetal bradycardia."

An emergency cesarean delivery under epidural and general anesthesia resulted in an infant with Apgar scores of 0 and 3 at one and five minutes, respectively. Intubation, cardiac compressions, and ETT epinephrine were provided. Birth weight was 3120 g.

An umbilical arterial cord blood gas result was as follows:

	Umbilical Vein	Umbilical Artery
рН	NA	7.26
Pco ₂ (mmHg) <i>(kPa)</i>	NA	45 6.00
Po ₂ (mmHg) <i>(kPa)</i>	NA	41 5.47
BD (mmol/L)	NA	7

Twenty cc of normal saline were given via a UVC at age 10

minutes.

A subsequent arterial blood gas at age 18 minutes was as follows:

	ABG
рН	6.84
Pco ₂ (mmHg) <i>(kPa)</i>	61
	8.13
Po ₂ (mmHg) <i>(kPa)</i>	118
	15.73
BD (mmol/L)	23

The initial hematocrit was 54%. Blood culture was negative. At age two days, a head ultrasound showed increased echogenicity in the thalami. At six days of age, an MRI of the head demonstrated thalamic injury. At age ten months, a diagnosis of hypotonic cerebral palsy was made.

Interpretation

The sample identified as arterial has a normal pH, Pco_2 and base deficit. The Po_2 is way above the upper end of normal. In a newborn with a one-minute Apgar score of 0, even an umbilical arterial Po_2 above the normal mean of 18 mmHg would be unlikely. This blood gas cannot possibly reflect the arterial blood gas status at birth of this apparently lifeless infant. If the infant is depressed at birth, a Po_2 above the arterial mean *suggests* the sample came from the umbilical vein. Therefore, the sample obtained is almost certainly venous, not arterial. To quote a famous sports personality and commentator, Charles Barkley,() (1) "I may be wrong, but I doubt it."

"The question then becomes: approximately what would the umbilical arterial sample values have been had they been obtained? It is helpful to take this in small steps. Would they have been essentially normal or abnormal? "

Corrected vessel identification appears below.

	Umbilical Vein	Umbilical Artery
рН	7.26	NA
Pco ₂ (mmHg) <i>(kPa)</i>	45 6.00	NA
Po ₂ (mmHg) <i>(kPa)</i>	41 5.47	NA
BD (mmol/L)	7	NA

The question then becomes: approximately what would the umbilical arterial sample values have been had they been obtained? It is helpful to take this in small steps. Would they have been essentially normal or abnormal? Certainly, one would not expect to find normal umbilical arterial sample results following a 20 minute severe, terminal bradycardia along with a one-minute Apgar score of 0. The next question becomes: would one expect the umbilical arterial sample to be mildly abnormal or severely abnormal? With a one-minute Apgar score of 0 and a follow-up arterial blood gas base deficit of 23 at 18 minutes of age, even with an expected acid washout, one would anticipate an umbilical cord arterial base deficit in the high teens to 20 mmol/L. This clearly suggests the etiology to be umbilical cord occlusion. A history of recurrent deep variable decelerations lasting 60-90 seconds and prolonged decelerations also suggests cord occlusion. An umbilical venous Po, at the upper end of normal suggests a brief period of time when the umbilical venous blood flow was slowed but not entirely stopped prior to a complete cessation of blood flow in this vessel. Slowed blood flow allows for a more efficient transfer of carbon dioxide to the mother and oxygen to the fetus. Since the umbilical cord was not entangled around any fetal structure, nor was a prolapsed cord identified, the most likely diagnosis becomes occult cord occlusion/prolapse.

Obtaining an umbilical cord arterial blood gas sample is always harder than obtaining a venous sample as the vein is so much larger. Spanning four years and including over 19,000 deliveries, at a center in which a routine attempt was made to obtain paired umbilical cord blood gas samples at all deliveries, paired-samples were successfully obtained about 64 percent of the time. () (2) One cause of the difficulty in obtaining arterial blood stems from the net transfer of blood into the placenta when the umbilical vein, but not the artery, is compressed. The resultant fetal/neonatal hypovolemia is likely to make obtaining an arterial umbilical cord blood gas sample even more difficult. There is less blood than normal in the umbilical arteries.

Myers (3) found that total cord occlusion resulted in an increasing base deficit of 1.1 mmol/L/minute. However, Myers's model acutely and completely shut off blood flow in both the umbilical vein and arteries. Early in the phase of cord occlusion with terminal fetal bradycardia, generally, there is a period when the vein remains occluded, but umbilical arterial blood flow resumes, resulting in fetal hypovolemia. Hypovolemia in conjunction with hypoxia likely results in a more rapid onset of poor blood flow to the heart and brain, i.e., ischemia. Therefore, increasing base deficit, or metabolic acidosis, may accumulate more rapidly than 1.1 mmol/L/minute. Ischemia is a much more potent cause of hypoxic-ischemic-encephalopathy than is hypoxia alone. () (4) This explains the surprisingly large base deficit of 27 following 20 minutes of cord occlusion. A normal hematocrit of 54%, despite likely significant net transfer of blood to the placenta during the terminal bradycardia, does not argue against this transfer as the normal range of newborn hematocrits at the time of birth is quite wide, 42%-65%.() (5) Most likely, the greater the difference between the umbilical vein and umbilical artery blood gases, the greater the degree of fetal/neonatal hypovolemia.

In many situations, although the umbilical cord blood gas sample is mislabeled and only a single sample is drawn, it may be possible to approximate at least part of the missing data.

Key Points

- Unless both umbilical venous and umbilical arterial samples are obtained, one cannot be certain that a single sample is from an umbilical artery, even if it is so labeled.
- If the infant is severely depressed at birth, a Po₂ above the arterial mean *suggests* the sample came from the umbilical vein.
- Obtaining an umbilical cord arterial blood gas sample is always harder than obtaining a venous sample as the vein is so much larger. Following a period of cord occlusion with terminal fetal bradycardia, during which there is a net transfer of blood to the placenta, the resultant fetal/ neonatal hypovolemia adds to the difficulty of obtaining an umbilical arterial cord blood gas sample. There is simply less blood than normal in the umbilical arteries.
- Metabolic acidosis may accumulate more rapidly in the presence of both hypoxia *and* hypovolemia than with hypoxia alone.
- Most likely, the greater the difference between the umbilical vein and artery blood gases, the greater the degree of fetal/neonatal hypovolemia.

Case 14: Cord Occlusion without Widened Venoarterial Cord Gas Differences

The mother was a 38-year-old, obese, gravida 2, para 0, aborta 1, with an intrauterine pregnancy of 39 1/7 weeks' gestation. Fetal movement was present; the fetal monitor demonstrated moderate variability and there were accelerations. At times, it was difficult to monitor FHR. Membranes were artificially ruptured 11 hours prior to delivery with egress of clear fluid. The cervix was completely dilated and effaced eight hours prior to delivery. The fetus was manually turned from occiput posterior (OP) to occiput anterior (OA) twice in the three hour period prior to delivery. Both times the fetus reverted to OP. Just following a decision for cesarean delivery, approximately one hour prior to delivery, there were multiple variable decelerations lasting 30-60 seconds and the FHR baseline was rising. During the final 40 minutes prior to delivery, the FHR was unmonitored. Just prior to placement

of spinal anesthesia, the FHR was auscultated at 151 bpm. The mother's recent heart rate was quite similar. At delivery, it was difficult to elevate the fetal head out of the pelvis. After 30 seconds of pushing from below, the fetal head was elevated into the uterus.

Various versions of the Apgar scores appeared in the record. There was agreement that the Apgar scores were 0 until age 10 minutes when the score was 1. There was further agreement that the score was never higher than 1 through age 25 minutes. At age 30 minutes, the Apgar score was either 1 or 4; and at 35 minutes, was again recorded as 1. At age 40 minutes, the Apgar score was recorded as 6, but there was no breakdown of the components. Resuscitation included: bag/mask ventilation, intubation, PPV with 100% oxygen, chest compressions, epinephrine via ETT and UVC, and UVC normal saline and bicarbonate. During all of the resuscitation, there was no record that the infant was ever reintubated. Therefore, the endotracheal tube was almost certainly in the trachea.

Cord blood gas re	sults were as follows:
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	Umbilical Vein	Umbilical Artery
рН	7.255	7.162
Pco ₂ (mmHg) <i>(kPa)</i>	48 6.40	67 8.93
Po ₂ (mmHg) <i>(kPa)</i>	25 3.33	9 1.20
BD (mmol/L)	6	5

A follow-up ABG at age 34 minutes was:

	Infant's ABG
рН	6.97
Pco ₂ (mmHg) <i>(kPa)</i>	27 3.60
Po ₂ (mmHg) <i>(kPa)</i>	437 58.27
BD (mmol/L)	26

A UVC hematocrit obtained at age two hours was 45%. Blood culture was negative. Head ultrasound at age three hours was

normal. An MRI of the brain at age 29 hours showed infarction in the watershed areas of both occipital lobes and in both basal ganglia. Findings were consistent with acute total asphyxia. Also observed were a small subarachnoid hemorrhage, a small subdural hematoma (without evidence of mass effect), and an occipital subgaleal hemorrhage.

The infant demonstrated early seizures, HIE, DIC, and renal, hepatic, and cardiac dysfunction. At age 16 months, this child exhibited severe developmental delay, variable muscle tone, dystonia and athetosis, and mild spasticity, more evident in the lower extremities.

Interpretation

The umbilical venous blood gas is entirely normal. The umbilical arterial blood pH is slightly low, the Pco_2 is mildly elevated, and the Po_2 and base deficit are normal, i.e., there is a mild respiratory acidosis. The difference between the umbilical venous and arterial pH is at the upper end of normal (6,7) (7.255 - 7.162 = 0.093; the pH values were reported to a third decimal place so that this calculation would be clearer). Therefore, this in and of itself is not suggestive of cord occlusion. However, there are considerable associated data that do suggest cord occlusion with terminal bradycardia.

First, the fetus was twice rotated from OP to OA. This requires elevating the head out of the pelvis, thus providing an opportunity for the cord to migrate to a position alongside the head. (8,9) Second, just prior to the end of FHR monitoring, moderate variable decelerations were present, suggesting that the umbilical cord was in a vulnerable position. Third, there was a 40 minute period of no fetal monitoring. Fourth, a heart rate of 151 bpm was auscultated just prior to placement of spinal anesthesia (a rate very close to the maternal heart rate). And finally, and perhaps most importantly, at birth, the infant had no signs of life. And yet, the cord gases were near normal. Which should one believe ... the near-normal umbilical cord blood gases or one's own lying eyes? One should believe both! Clearly, one must believe that this infant had no heart rate at birth. A normal set of cord gases associated with a severely depressed newborn infant suggests cord occlusion with terminal fetal bradycardia. Considerable umbilical venoarterial pH differences almost always accompany cord occlusion with terminal bradycardia, but if there is little or no resumption of umbilical arterial blood flow, the pH difference will not be widened.

Because the resuscitation was so difficult, it is unlikely that the fetal heart rate dropped to near-zero in the preceding few minutes. On the other hand, it is also unlikely that the FHR stopped 40 minutes earlier because if this were so, this infant would have been dead. As it was, this infant was very nearly unresuscitable. In all likelihood, therefore, there was severe fetal bradycardia for *at least* 20 minutes prior to delivery.

Optimally, to confidently establish a diagnosis of cord compression as the etiology of severe neonatal depression without associated widened pH differences, one would like to see a regularly improving condition of the newborn beginning at birth, followed by documentation of severe metabolic acidosis within the first hour (as soon as possible) following birth. As there is almost always a widening of the normal venoarterial pH difference associated with cord occlusion and terminal bradycardia, when there is not, other findings must be carefully sought (see Table below). In this case, the great difficulty in the initial resuscitation undoubtedly contributed to the very severe metabolic acidosis found at 34 minutes of age. Because of the results of the ABG at that time (low Pco_2 and very high Po_2), it would appear that an Apgar score of 4 at age 30 minutes was more likely than an Apgar score of 1.

This was only the second case in which I thought there was cord compression with terminal fetal bradycardia as the etiology of neonatal depression in the absence of widened umbilical venoarterial pH differences. I have seen about half a dozen more since. However, as is pointed out in Case 9 (virtual cord occlusion), theoretically, umbilical pH differences do not have to be widened. This case suggests that the umbilical vein and arteries were all permanently occluded simultaneously, or almost simultaneously, at the onset of the terminal fetal bradycardia. This infant's head was tightly wedged into the pelvis and was difficult to extract, making it likely that the umbilical cord was also forcefully occluded. Therefore, one would not expect neonatal hypovolemia in this infant. The initial hematocrit was at the lower end of normal(4) (4), but there was some blood loss into the head as documented by the small subarachnoid, subdural, and subgaleal hemorrhages.

Discontinuing resuscitative efforts might have been considered during the very long and difficult resuscitative effort in this infant. A future case will discuss this issue further.

Cord Occlusion with Terminal Fetal

Bradycardia and Normal or Near Normal Cord Gases in the absence of Widened Umbilical

Venoarterial Differences

Findings	1 min Apgar Score ≥1
Moderate or Severe Variable Decelerations and/or	Yes
Cord Tightly Around Fetal Body Part or	Yes
Occult or Overt Cord Prolapse or	Yes
Shoulder Dystocia or	Yes
Breech with Trapped Head and	Yes
Regularly Improving Neonatal Condition and	Yes*
Post-resuscitation Blood Gases with Substantial Base Deficit	Yes

Table

Minimal criteria were necessary to establish cord occlusion with terminal fetal bradycardia as likely etiology of neonatal depression with normal or near-normal cord gases in the absence of widened umbilical venoarterial pH difference.

* If 1 minute Apgar score is 0, regularly improving neonatal condition may not occur.

- Cord occlusion with terminal fetal bradycardia may occur in the absence of widened umbilical venoarterial pH difference, albeit this finding is unusual.
- A normal set of cord gases associated with a severely depressed newborn infant suggests cord occlusion with terminal fetal bradycardia.
- In order to establish cord compression with terminal fetal bradycardia as the likely etiology of neonatal depression, in the absence of a marked venoarterial pH difference, one must rigorously demonstrate:
 - o preceding evidence of a vulnerable cord
 - o the presence of normal or near-normal venous and arterial cord gases, and
 - o a post-resuscitation blood gas that has a much worse base deficit

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Key Points



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41 **NEONATOLOGY TODAY** www.NeonatologyToday.net March 2021

Neonatology Solutions Redesigned Interfaces

Scott Snyder, MD



Based on feedback from colleagues and site users, <u>Neonatology</u> <u>Solutions</u> recently redesigned interfaces for both the NICU and Job Directories on the site. The new filter-based search engines have been reengineered to improve search speed, responsiveness, and overall user experience. The entire <u>NICU Directory</u> provides data on 1,386 Level II, III, and IV NICUs in the U.S., regardless of hiring status. The regularly updated <u>Job Directory</u> focuses on just those NICUs with active open positions, with filters to drill down to your ideal practice parameters, such as type of practice, number of hospitals covered, and geographic location.

Sites are encouraged to submit information about open Neonatologist positions via this <u>submission form</u>. There is no cost to post or view these submissions, and NNP and NICU Hospitalist positions will be coming soon! At present, there are more than 180 NICUs with open positions. "The regularly updated Job Directory focuses on just those NICUs with active open positions, with filters to drill down to your ideal practice parameters, such as type of practice, number of hospitals covered, and geographic location."

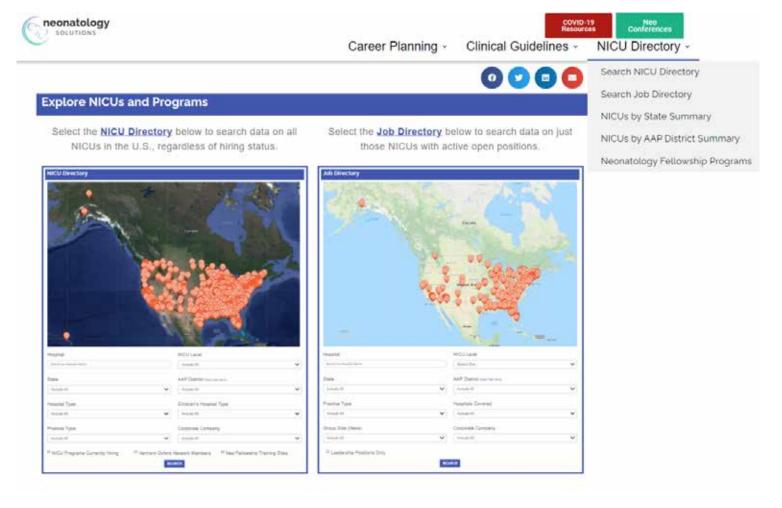
Both Directories are accessible via the following link: <u>https://neo-natologysolutions.com/explore-nicus-and-programs/</u>

As usual, we always welcome feedback on improving the site to make it the most valuable and helpful free resource on the web for neonatology trainees, Neonatologists, APPs, and NICU staff!

Scott A. Snyder, MD

References:

1. <u>https://neonatologysolutions.com/explore-nicus-and-pro-grams/</u>



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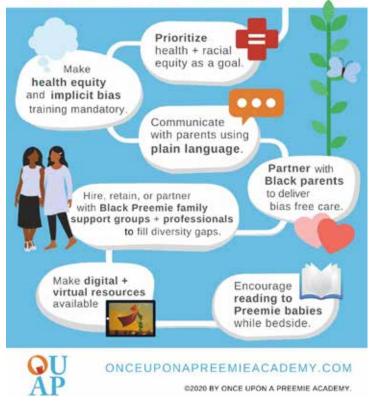
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Conversations About COVID Vaccines with Latino Immigrant Communities

Julia Koehler MD

The following Do's and Don'ts come from my trial and error process while doing COVID info sessions over Facebook live with immigrant organizations since February 2020. The metrics of my trial and error process are whether there were many questions or more questions than time. These sessions have about 15,000 - 20,000 views at this point; that is why I have the confidence to write down my conclusions on how to do a better job. People have been accepting and kind about my limited language skills; we do not have to be flawless in conducting an info session. Sessions can also be interpreted into the preferred language(s) of participants and still work well.

"Even with native English speakers, it is good to assume no more than elementary school literacy unless the patient indicates otherwise. It is good to assume no numeracy, no statistics, no probabilities, no percent efficacy."

Studies show that physicians often slip into medical jargon even in conversations with native English speakers and are not intelligible to their patients. Even with native English speakers, it is good to assume no more than elementary school literacy unless the patient indicates otherwise. It is good to assume no numeracy, no statistics, no probabilities, no percent efficacy.

Of note: most people for whom we are holding sessions came to this country because the opportunity to sustain their families at home was not available to them in their place of origin; land, labor, and resources were forcibly taken from their ancestors or themselves. Hence, most had to leave school early, e.g., before the fourth or fifth grade, to help their family survive. Education level in Latin America, like in this country, corresponds most closely to their parent's income. Our conversation partners are smart – they just never had the chance to study biology, chemistry, or math.

These points are for zoom sessions, but many of them can be applied to direct in-person conversations as well.

Do –

- Engage a dialog partner of the organization hosting the event to diminish the lecture-like format that an info session easily turns into.

- Begin with a courteous self-introduction and acknowledgment of the honor and pleasure of being there.

- Speak personally, from the heart.

- Try to look into the camera – on zoom, it then appears like we are looking at the dialog partner or the viewer. It can be very hard to do! – best not to read from a script but to force ourselves to look up

at where the camera is. Placing the camera at eye level is perfect. Looking up at it is fine too, looking down at it works less well.

- Speak simply and with understandable metaphors.

- Acknowledge and address people's questions and concerns upfront, before they are explicitly asked. At the same time, every question that gets asked is a good sign for the session going well...

- Be honest about knowns and unknowns and do not try to affirm more certainty than we have. Can say, e.g., Scientists are still studying how much the vaccine protects us from infecting others after we are vaccinated, and right now, we do not know the answer yet exactly. Scientists think that we are less contagious after getting the vaccine, but we are not sure how strong that protection is.

- Frame the decision for or against becoming vaccinated as one that affects not only me personally, but also that I protect my family, my neighbors, my community, and the people I work with by becoming vaccinated because though studies are not complete, it looks like vaccinated people are not going to spread the virus as much as non-vaccinated people, even if they do become infected.

- Highlight that this is everyone's own decision and that no one, including no employer at this time, can force or pressure me to take a vaccine.

"Frame the decision for or against becoming vaccinated as one that affects not only me personally, but also that I protect my family, my neighbors, my community, and the people I work with by becoming vaccinated because though studies are not complete, it looks like vaccinated people are not going to spread the virus as much as non-vaccinated people, even if they do become infected."

- Start with talking about what a vaccine is. E.g., a vaccine is a way for our body's immune system to go to school and take a lesson. Just like for us, it is good if we had the chance to learn how to make additions in school before we need to add up the prices of what we are buying in a store, it helps our immune system if it has had a chance to have a lesson about a deadly germ before it runs into that deadly germ in real life. A vaccine teaches our immune system by giving it a piece of the germ to study or by giving it a weak or a dead version of the germ. The COVID vaccine contains instructions for our body to make one important piece of the virus, and then our immune system can study that. Just like in school, where we need to study something for a while before we know it



well, the immune system also needs time. That is why we are not protected until weeks after we get a vaccine. Furthermore, just like in school, where we often need to repeat lessons before we know a subject well, the immune system can often create a better memory of a deadly germ if it gets that lesson more than once. That is why the current COVID vaccines need to be gi

- Talk to the people from the same communities you encounter at work about COVID and vaccines, like security staff, janitors, valets – this provides direct experience with their questions and concerns, and it is good regardless of the pandemic! (It is good to disregard the implicit expectation of intense segregation in this country, where doctors are expected to chat only with doctors and not with janitors. That implicit expectation does not exist in other parts of the globe.)

"Does the vaccine contain a chip by which ICE can localize me? A: no, definitely not; you can look at the syringe with the fluid and see there is no chip in it. Bar codes identify packages with vaccine doses to make theirisposition easy to track; that is the only tracking mechanism."

- Frequent questions are:

~Does the vaccine contain a chip by which ICE can localize me? A: no, definitely not; you can look at the syringe with the fluid and see there is no chip in it. Bar codes identify packages with vaccine doses to make their disposition easy to track; that is the only tracking mechanism.

~What kind of allergies may make it dangerous to take the vaccine – hay fever, allergy to crabs or peanuts, penicillin allergy? A: The risk of a dangerous reaction to the vaccine depends on the kind of allergic reaction we have had in the past. If you have previously had an acute, severe reaction called anaphylaxis that requires you to carry an epi-pen, which is a little pistol that can inject a critical medicine fast, that people carry who have had very dangerous allergic reactions, it is safer to get your vaccine at a health center or hospital where there are doctors who can attend to you if you have a reaction. But everyone is observed for 15 minutes after the injection to watch for allergic reactions.

~ How safe can these vaccines be after being developed so quickly? A: The technology for mRNA vaccines has been researched for 15 years, so it is not completely new. All of the usual steps were taken, but many were taken at the same time instead of one after the other, in order to speed up the process, given the urgent need in the pandemic. This was possible because lots of money was made available by the government.

 \sim Is there a guarantee that there will not be side effects later? A: No, there is no guarantee. Side effects of vaccines usually appear within weeks to months. Millions of people have already received these vaccines, and no common side effects have appeared within the eight weeks they have been given. But we can weigh the risk of later side effects against the risk of contracting COVID. CO-VID is a dangerous disease that has killed people of all ages, and that has left about a fifth of all who had it struggling with long-term effects like tiredness, body pains, shortness of breath, and damage to the heart, lungs, or kidneys. My risk of contracting COVID in Massachusetts is extremely high. I have to weigh this serious risk of long-term illness and death against my very small risk of experiencing an unknown side effect at some later time. This is the balance I need to consider.

~ Were cells from aborted fetuses used to make these vaccines? A: No, these vaccines were made synthetically without the use of any human cells. Aborted fetuses' cells played no role in any part of these vaccines. Pope Francis has been vaccinated and has spoken out in favor of receiving these vaccines (<u>https://www. ncronline.org/news/vatican/pope-francis-suggests-people-havemoral-obligation-take-coronavirus-vaccine</u>).

~ Will these vaccines change my genes, and will I become genetically modified? A: No, because mRNA in the vaccines is instructions for our body that generally *come from* genes. It is not instructions that *go into* genes. When you dump color into a stream, that color will show up downstream from where you stand but not upstream. There is no way that the material in vaccines turns into genetic modification.

~ What is in the vaccines? A: The vaccines contain a piece of instructions for our body to make one little piece of the virus. This piece of instruction for the body is called mRNA. When our body makes this little piece of the virus – never a whole virus – our immune system learns to recognize that piece and starts studying how to defend our body against it. This little piece of instruction, the mRNA, is wrapped into tiny bubbles of fatty material that can enter our body most effectively. These tiny bubbles that have instructions for our body (mRNA) inside of them are in a salt solution like fat in a soup. When we get the vaccine injection, the instruction material enters our system, and our body starts making a tiny, important piece of the virus, but never the whole virus.

~ Can I get COVID from the vaccines? No, because the vaccines do not contain the virus. However, we might get COVID after becoming vaccinated because we were exposed a few days after we got the vaccine, and our body's immune system did not have time to study the virus before the virus started growing in our body.

~ My uncle got sick after getting a vaccine. I'm worried I will get sick the same way if I take the vaccine. A: Before the pandemic, many people in Massachusetts got sick and had to go to the hospital. They might have had a stroke, a heart attack, a seizure, a bad infection, or any other number of diseases that had nothing to do with COVID. People will still get these diseases now, during the pandemic. Some people will get them right after being vaccinated because the diseases like heart attacks were already forming in their bodies before they got vaccinated. We cannot blame the vaccines for all these diseases that, unfortunately, people are getting for other reasons. Maybe someone with asthma lives in a polluted area and was going to get an asthma attack anyway, and when they happened to get the vaccine that same day. Or maybe someone smoked for many years and was going to get a heart attack anyway, and they happened to get it the week after they got the vaccine. Still, scientists are carefully studying whether any diseases occur more often after people get vaccinated than they occur in people who have not been vaccinated.

~ Can I stop wearing a mask after I have been vaccinated? A: No, because we only know how well these vaccines work when everyone is wearing a mask. We do not know how well they work for people who are not wearing masks, distancing, making sure of good ventilation or air filtration, and keeping their hands clean. Vaccines are just one of the tools that can keep us safe from the virus. But they can be an important tool.

~ Can undocumented people get a vaccine, and if so, will their information be passed on to ICE? A: Undocumented people can get vaccinated like everyone else. Personal information on vaccinated people will be stored to ensure that everyone gets not just one but two doses. That information will not get passed along to ICE. It is safe for undocumented people to get vaccinated.

~ Will getting the vaccine involve the "Public Charge" rule that was recently changed by the Trump administration, by which accepting specific benefits from the government makes it more difficult to get a green card or citizenship? A: No, getting vaccinated for free, or using our health insurance card to get vaccinated, will not affect anyone's status under the "Public Charge" rule.

~ Can I get a vaccine if I have no health insurance? A: Yes. If you have health insurance, bring your insurance information or card to the vaccination site. If you have no insurance, you can get vaccinated without payment.

~ Should a pregnant woman get vaccinated? A: Pregnant women can get sicker from COVID than if they were not pregnant, and they more often give birth prematurely, which is very bad for the baby. So some experts say pregnant women should get vaccinated. Other experts say they should not because the current vaccines have not yet been tested in pregnant women. So far, no problems were seen for the mother or the baby when the woman got the vaccine before knowing she was pregnant. So this is a decision every mother has to make for herself and talk with her own doctor.

~ Can a mother who is breastfeeding get vaccinated? A: Yes, because the vaccine contains no virus. It just contains instructions for our body to make a small piece of the virus to train our immune system. So she is not putting the baby at risk of catching the virus when she gets the vaccine.

~ Can I get the vaccine if I have diabetes, or autoimmune diseases like lupus, or an organ transplant? A: Yes, because the vaccine does not contain any virus. There is no risk of becoming infected from the vaccine. So it is very important actually, if you have any of those conditions, to get the vaccine as soon as possible because it will help train your immune system that may need extra help.

~ Will a COVID vaccine make me infertile? A: No. No vaccine makes anyone infertile. There is an injectable contraceptive, but it is not a vaccine and does not protect against any infection. If you get the COVID vaccine before you become pregnant, we think you will be better protected against COVID during and after your pregnancy, and your baby will also receive some immunity from you.

Do not –

- Use medical or statistics terms that your grandfather or a relative with no medical or biology knowledge does not understand.

- Sound technical – instead, express medical information in personal terms. E.g., do use "I," "we," "you," to explain a concept.

References:

1. <u>https://www.ncronline.org/news/vatican/pope-francis-sug-gests-people-have-moral-obligation-take-coronavirus-vac-cine</u>

The author has no conflicts to disclose

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Raising Global Awareness of RSV

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

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

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







Medical Legal Forum: Case Debrief: J.S. v. The United States of America

Jonathan Fanaroff, MD, JD, Robert Turbow, MD, JD Gilbert Martin, MD

"This is about to change with the implementation of a rule from the Federal Office of the National Coordinator for Health IT requiring health systems to provide greater access to patient health records."

The majority of medical malpractice lawsuits in the United States claim that the physician was negligent. The states generally regulate medical malpractice, so exact definitions vary, but in general, a negligence claim is a charge that the physician failed to meet the "standard of care," defined as how a reasonably prudent physician in the same or similar circumstances would act. In order to prevail, the plaintiff must show that the physician had a *duty* to the patient that was breached (by not practicing to the standard of care) and in turn caused measurable damages. All four elements must meet a certain burden of proof, which is usually "more likely than not," a much lower burden than the criminal prosecution's burden of proving guilt "beyond a reasonable doubt." Consequently, it is not enough to show that the standard of care was breached, but the breach must also be the cause of the poor outcome in question. This was illustrated in a recent decision in the United States District Court, Western District of Texas, San Antonio Division, the case of J.S. v. The United States of America (SA-18-CV-00605-JKP).

Facts: [All facts are derived from the legal opinion]

J.S. was born on December 2, 2015, in San Antonio. His mother is deaf and requires a sign language interpreter for communication with others. His father has retinoblastoma and lost an eye to the disease. During pregnancy, the mother was referred to a geneticist but declined amniocentesis to test for the R.B. gene. The pediatrician, Dr. S, saw J.S. on December 3. He did not have access to the prenatal chart. Dr. S saw J.S. for multiple subsequent well-child visits, and the mother requested an interpreter, but one was not provided, and the father interpreted at these visits. At the April 15, 2016 visit (4 $\frac{1}{2}$ months) a different physician, Dr. J, saw

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J.S. and, based on the physical exam and written communication with the mother, referred the baby to a retinoblastoma specialist where he was diagnosed with bilateral retinoblastoma. He has subsequently received chemotherapy, cryotherapy, and laser therapy treatments with an "outstanding" response to treatment. Due to the tumor's location, however, J.S. has permanent damage to central vision in his left eye as well as a significant blind spot in his right eye, the impact of which will not be fully understood until he is older.

"An important second aspect of the rule is penalties for anti-competitive behavior and information blocking that impedes the exchange of medical information. For example, some health IT vendors had a "gag clause" prohibiting the sharing of screenshots. These non-disclosure clauses hinder efforts to improve safety and openly discuss safety concerns. "

The Lawsuit

The family sued J.S.'s treating physicians stating that the damage to his vision was exacerbated by their failure to:

- 1. Provide an interpreter
- 2. Take a family history
- 3. Timely refer to a retinoblastoma specialist

Both sides had expert witnesses. Neither expert could predict to a reasonable degree of medical probability when the tumor formed or how long it had been growing. The plaintiff's expert testified that it was difficult to determine whether J.S. will have a recurrence. The defense expert felt that the retinoblastoma had been successfully treated and had a recurrence risk of under two percent.

The Judge's Decision

The judge ruled that Dr. S breached the standard of care by failing to obtain an adequate history and immediately refer J.S. to a pediatric ophthalmologist. The second pediatrician, Dr. J, immediately referred J.S. and did not breach the standard of care, although the judge noted it would have been "prudent" to provide an interpreter.

While the standard of care was breached, the judge ruled that the plaintiff did not establish a reasonable degree of medical probability, either the timing of the development of the retinoblastoma or how rapidly the tumors grew. As a result, there was insufficient evidence to show that the delay in diagnosis exacerbated the damage to J.S.'s vision. The defense prevailed, and there was no liability or payment to the plaintiff.

Discussion

In this case, the physicians were not held liable, although, as the judge noted, "it is possible J.S. might have had a better outcome if he had been referred to a pediatric ophthalmologist sooner." The case provides an opportunity for learning and reflection on what could have been done differently. The Institute of Medicine defines a learning health care system as one

in which science, informatics, incentives, and culture are aligned for continuous improvement and innovation, with best practices seamlessly embedded in the care process, patients and families active participants in all elements, and new knowledge captured as an integral by-product of the care experience.(1)

Medical malpractice lawsuits can provide learning opportunities to improve future patient care. What can be learned from this case that may help improve care for future patients? For one, this case highlights the importance of communication, both between obstetric and pediatric colleagues as well as with families. Family history can provide a wealth of information, and properly trained medical interpreters should be provided, especially when requested. And while rare, a baby with a parent who has retinoblastoma will have a 50% chance of developing tumors and requires timely referral and follow-up.

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1. Roundtable on Value & Science-Driven Health Care. The Roundtable. Washington, DC: Institute of Medicine; 2012.

The authors have no conflicts of interests to disclose.





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Disclaimer:

This column does not give specific legal advice, but rather is intended to provide general information on medicolegal issues. As always, it is important to recognize that laws vary state-to-state and legal decisions are dependent on the particular facts at hand. It is important to consult a qualified attorney for legal issues affecting your practice.

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The Survey says RSV



What you need to know about RSV



Really Serious Virus

WHEN IS RSV SEASON?

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

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Educate Yourself

Did you know that more than half of the babies admitted to NICUs were not born prematurely? See our fact sheets.



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Surfactant

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.

"Adverse events such as spontaneous airway obstruction, pneumothorax, pulmonary hemorrhage, changes in cerebral perfusion, bradycardia, and desaturations have been reported (1)."

Despite being used routinely for over 30 years, controversies remain regarding the method of administration and surfactant formulations themselves. Adverse events such as spontaneous airway obstruction, pneumothorax, pulmonary hemorrhage, changes in cerebral perfusion, bradycardia, and desaturations have been reported (1). There is also great variation in the delivery methods and positioning of infants during surfactant administration.

Controversy also remains regarding the safety and effectiveness of various surfactant formulations and animal-derived vs. synthetic products, with some studies indicating no difference and others favouring animal-derived formulations. I have personal experience with three formulations: bovine lipid extracted surfactant (bLES, a bovine extract available in Canada), beractant (Survanta), and poractant alpha (Curosurf). In my limited experience with Curosurf, I have found the need for second dosing higher than with bLES. Units in Canada used Survanta for approximately one year due to temporary closure of the facility that manufactures bLES. Anecdotally, I found the incidence of pneumothorax greater with Survanta (an observation shared informally between colleagues from other units). Survanta also has a slower onset of action and seemed to require a second dose more frequently than bLES. These observations are not consistent with some published literature (2). There are no studies comparing bLES to other formulations to the best of my knowledge, although calfactant appears to be more beneficial initially (3). That being said, another Toronto NICU was trading two vials of Survanta for one of our vials of bLES still in stock during that "year without bLES."

The lower volume dose of poractant compared to bLES, calfactant, and beractant (2.5 ml/kg vs. 5 ml/kg) may be beneficial in extremely small babies and may be preferred with minimally invasive surfactant administration. In the unit in which I practice, a recent trial of poractant using both invasive and minimally invasive administration was inconclusive. We did, however, find the need for a second dose was greater with poractant than with calfactant. This is at odds with published studies which indicate a decrease in both mortality and second dosing with poractant compared to calfactant or beractant (4). (bLES was not studied).

"Some studies have shown an increased mortality rate in the sub-600-gram population with calfactant (5). This may be atypical, and the reason is unclear."

Some studies have shown an increased mortality rate in the sub-600-gram population with calfactant (5). This may be atypical, and the reason is unclear. Several possibilities come to mind. Calfactant (and bLES) has a very rapid onset of action. This results in an immediate increase in compliance and a concurrent drop in pulmonary vascular resistance (PVR). If ventilation is not adjusted immediately to compensate, there is a risk of pneumothorax. If a large patent ductus arteriosus is present, the rapid drop in PVR may precipitate a pulmonary hemorrhage. Caution is in order if left to right shunting is suspected. In my personal experience using bLES exclusively, these complications are very rare. Another factor may be spontaneous blockage of the endotracheal tube. I have not experienced this, but colleagues have. This may be related to the viscosity of the surfactant. After 15 minutes at 37 degrees Celsius, the viscosity of calfactant increases exponentially, and at 30 minutes is 20 times higher than after ten minutes(6). Thus calfactant (and beractant) should be given as soon as possible after thawing/warming and within 15 minutes. (This fact was unknown to me before writing this column). There is no reason to believe bLES is any different in this regard.

Synthetic surfactants have been on the market for many years, although early studies demonstrated the superiority of animalbased products. There is a theoretical concern of infectious and antigenic complications with animal-derived products, although there is no evidence of this to date (7). First-generation synthetic

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products lacked key proteins that are essential to success and are generally no longer in use. There are also pro-inflammatory mediators present in animal-derived products (perhaps this is one reason why chronic lung disease (CLD) rates have not decreased with surfactant use) that are not present in synthetic formulations (8). Lucinactant is a relatively new second-generation synthetic surfactant formulated with proteins and peptides that mimic natural surfactant proteins. Trials have shown Lucinactant to be superior to colfosceril (a first-generation synthetic surfactant) and beractant. Calfactant was not studied. Another trial comparing Lucinactant to poractant failed to enroll sufficient infants to draw conclusions but showed no difference between the two products (7). The dosing volume of Lucinactant is higher than any other formulation at 5.8 ml/kg, which has implications for adverse effects during instillation.

"The dosing volume of Lucinactant is higher than any other formulation at 5.8 ml/kg, which has implications for adverse effects during instillation."

Changes in cerebral blood flow following surfactant administration are likely secondary to hyper or hypoventilation with resulting extremes in CO_2 . Hypoventilation can be minimized by carefully monitoring ventilation during instillation, and hyperventilation can be avoided by prudent adjustments to ventilator settings following instillation.

When I first started administering surfactant, the procedure was to deliver it in 3 aliquots; 1/3 with the baby on the right side, 1/3 with the baby supine, and 1/3 with the baby on the left side. Evidence does not support this regimen, instead favouring bolus administration and supine positioning (6).

"My approach is to give surfactant while on the ventilator with the flow sensor inline using a multi-access catheter inserted through the side suction port."

We know that manual ventilation with a resuscitation bag is associated with lung injury. At present, it is very common to "bag in" surfactant. This practice seems counter-intuitive to me, and I cannot help but wonder if the practice contributes to chronic lung disease. My approach is to give surfactant while on the ventilator with the flow sensor inline using a multi-access catheter inserted through the side suction port. One must note that the higher viscosity of surfactant requires both more time and pressure to get down the ETT. In conventional ventilation (CV) using assistcontrol with targeted volume, this can be achieved by increasing inspiratory time and maximum peak pressure while maintaining targeted volume during the procedure.

High-frequency oscillation (HFO) with volume targeting is the standard first intention in the unit in which I practice, and I give

surfactant in HFO mode. First, I increase the pressure setting on the manual (sigh) breath, then instill surfactant as above until the flow graphic on the ventilator indicates obstruction. I then use the manual inspiration button to drive the surfactant down the ETT until the flow is evident on the graphics screen. This process is repeated until all surfactant has been given. Doing this affords a degree of lung protection over manual ventilation, and volume targeting helps reduce over and under ventilating. Care must be taken to hold the flow sensor up and vertical to prevent surfactant from entering the flow sensor. I have had good results using this technique and credit Dr. Jane Pillow of Perth, Australia, for introducing it to me.

"Whether using CV or HFO, volumetargeted ventilation may mitigate inadvertent increases or decreases in ventilation and subsequent hypo/ hypercarbia."

Whether using CV or HFO, volume-targeted ventilation may mitigate inadvertent increases or decreases in ventilation and subsequent hypo/hypercarbia. The risk of pneumothorax through overexpansion of the lung as compliance increases is also decreased as the machine will automatically increase peak inspiratory pressure during instillation and reduce it as compliance improves.

Another important consideration is lung recruitment prior to surfactant administration. Failure to recruit may result in surfactant preferentially going to recruited areas with subsequent over-distention of these areas. Recruitment maneuvers and generous PEEP prior to administration may reduce the potential for lung injury secondary to surfactant administration from non-uniform distribution (6).

No analysis is complete without considering the cost. In Canada, the cost of bLES is far less than any other preparation. One indepth analysis comparing calfactant and poractant showed a significantly higher cost with poractant. Interestingly there was also a significant increase in the need for second dosing with poractant (9). This is consistent with personal experience. Another analysis comparing poractant and beractant showed a significantly higher cost associated with beractant as well as a significantly higher mortality rate with beractant in infants <32 weeks gestation. Beractant was also more likely to require a second dosing (10), again consistent with personal experience. The surfactant cost listed from least to most expensive is bLES, calfactant, poractant, Lucinactant, and finally beractant. The cost comparison between Lucinactant and beractant considered total NICU costs associated with each product's use, including the length of stay(11). Lucinactant, however, must be used once prepared or discarded.

In conclusion, regardless of the product used, administration and positioning methods are important, as is follow up with lung-protective ventilation strategies.



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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 riskbenefit ratio must be carefully considered before they are initiated.

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Abstracts from National Perinatal Association 2020 Conference, December 2-4, 2020: New Framework for Multidisciplinary Care in the 4th Trimester

Jerasimos (Jerry) Ballas, MD, MPH, FACOG

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

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



"This year the chosen theme focused on the 4th Trimester and the various areas of vulnerability for parents and infants during this time, as well as the resources available for support."

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NPA2020-1

Standards, Competencies and Recommended Best Practices for Infant and Family Centered Developmental Care (IFCDC) in the Intensive Care Unit Poster proposal for the National Perinatal Association Meeting

Joy V. Browne, Ph.D., PCNS, IMH-E (IV) and Carol Jaeger, DNP, RN, NNP-BC for the Gravens Interprofessional Consensus Panel

Background: Evidence for the benefits of developmental care for infants and families has expanded in the past two decades and there is now a strong body of evidence to support its implementation. There is no standardization of the education and application of developmental care by the interprofessionals and the parents that augment the holistic care for babies and families in intensive care nurseries. The interdisciplinary consensus panel, composed of professional leaders and parents, was established to identify and evaluate credible evidence to support the drafting of standards and competencies of infant and family centered developmental care to be practiced consistently and make a positive difference in the outcome of the baby and the family.

Content/Action: The consensus panel has met for five years to develop a model of empirically supported infant and family centered developmental cornerstones, that include systems thinking, individualized care of the baby and family, family integration with the interprofessional team members and practice, environmental protection that diminishes adverse responses from the baby and increases the opportunity for intimate interaction with the parents, neuroprotection of the developing brain of the baby, and recognizes the baby as a competent interactor. The quality of the evidence was evaluated by level, and the strength of the evidence was graded. Six areas of developmental practice were identified to apply the cornerstones to practice, and articulate standards and competencies from which to standardize the practice of all members of the interprofessional collaborative team in the intensive care units. The six areas include systems thinking, positioning and touch for the newborn, sleep and arousal interventions for the newborn, skin-to-skin contact with intimate family members, reducing and managing pain and stress in newborns and families, and the management of feeding, eating and nutrition delivery of the baby. Professional and parent participants attending three Gravens meetings provided feedback to the consensus committee and an expert panel of interprofessionals also provided recommendations. An overview of this work has been published, and the standards and competencies are available on line.

Lessons learned: Currently there is no available standardization of developmental, family centered care for interprofessional use. The panel of leaders in the field worked collaboratively to examine the literature and produce well documented standards and competencies for practice in intensive care. Further work needs to support the implementation of the standards, competencies and best practices of IFCDC by the interprofessional collaborative health team in the hospital setting.

Implications for practice: The publication of these standards and competencies will be the first available empirically based interprofessional expectations for developmental care. To the extent that they can be readily implemented they will provide a national impact on developmental outcomes for babies and their families. Recommendations for inclusion of families, and transition of the baby and family from the hospital to communities, are infused throughout the document and should provide continuity for service provision from hospital to home.

NPA2020-2

Comprehensive postpartum care: Assessment

of varying provider practices and patient experiences.

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Introduction: Women experience challenges that affect their health and their ability to care for their infant during the postpartum period. Up to 40% of women do not attend the initial postpartum visit. We investigated how different types of providers manage postpartum education and assess current patients' concerns and challenges of the postpartum period. A prenatal assessment that identifies postpartum concerns could help providers develop individualized care plans that improve postpartum care.

Methods: Patients at a major urban OB/GYN clinic were recruited for an IRB-waived voluntary survey. Descriptive statistics, chi-squared tests, and odds ratios were used for analysis.

Results: Among the 250 women in their 3rd trimester, there were high levels of concern regarding breastfeeding (59.2%), experiencing "baby blues" (50.0%), losing pregnancy weight (50%), tiredness (64.0%), and pain after birth (60.0%). However, only 52.4% reported discussing plans to feed their baby postpartum with even less discussion on other important postpartum topics such as challenges they might experience (30.0%), physical activity (20.4%), and losing pregnancy weight (12.0%). Reported discussions regarding postpartum care by type of provider were statistically significant, with midwives less likely to discuss a postpartum care plan than medical doctors (OR .10; 95% CI 0.05-0.20; P<.001). However, patients reported midwives were as likely to discuss postpartum challenges (P= .9565).

Conclusion: Patients expressed postpartum concerns but less than half report discussions with providers on aforementioned topics. The

likelihood of reported discussions regarding postpartum care varied by type of medical provider, which highlights the potential benefits of multidisciplinary collaboration. We suggest that a standard 3rd trimester survey might improve postpartum care plans.

NPA2020-3

Helping Parents When the $4^{\rm th}$ Trimester is in the NICU- An Integrated Training Model for NICU Physicians

INNOVATIVE MODELS OF CARE

Background: Nearly all parents whose babies require NICU care experience some level of distress, with up to 20-60% developing postpartum depression, anxiety, or posttraumatic stress disorder. These conditions adversely impact parent-infant attachment and overall parenting behaviors, leading to higher risks of worse physical and developmental outcomes in the babies. Research suggests that providing psychosocial support to NICU parents can reduce their distress, depression, anxiety, and increase the possibility of the parent-infant bonding and attachment. Therefore, providing psychological care to families in the NICU may lead to overall healthier infant outcomes. However, it has been noted that many pediatric and neonatology trainees, and neonatologists, feel they do not have the self-efficacy care for distressed and anxious parents. In 2014, the American Board of Pediatrics Strategic Planning Committee identified the areas of behavioral and mental health as the highest priorities for education of pediatric trainees. This led to the development of the Roadmap Project, which advocates supporting "the resilience, emotional, and mental health of pediatric patients with chronic conditions and their families." While some neonatology fellowship programs teach communication skills for high stress situations, no comprehensive program exists in psychosocial care of NICU families. We have created the first such course for this purpose, in alignment with the Roadmap's Key Drivers. This poster will discuss the development and piloting process of this training program.

Action: This is a prospective an educational intervention on neonatology fellows in the United States. All accredited neonatology fellowship programs have been contacted for possible enrollment of their fellows in the study. Consenting fellows complete, at a minimum, all portions of the online program including both assessments of self-efficacy and knowledge at all time points. Fellowship programs have the option to have their fellows participate in the evaluation of clinical fellow skill via parent evaluation. Fellows who are local to the children's hospital that holds the institutional review board approval for this study have been offered participation in simulated parent conversations that require practical application of the concepts found in the course. There are 27 available fellows considering participation in the simulation.

Enrolled fellows are given access to a 4-module online course covering the topics of Recognizing and Mitigating Parental Emotional Distress, Infant Distress, Communication, and Developmental Care. This course was modified specifically for education of neonatal fellows from a course already offered to NICU staff, called "Caring for Babies and Their Families: Providing Psychosocial Support in the NICU". The course has its foundation in the "Interdisciplinary Recommendations for Psychosocial Support of NICU Parents," as well as in the concepts of trauma-informed care. It is available at www.mynicunetwork.com.

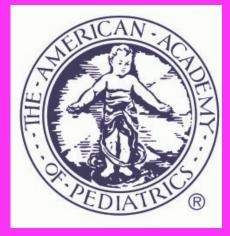
A subgroup of fellows will go through a simulation session at an immersive learning center that has extensive experience in physician training via simulation, including simulations of emotional distress in the medical setting. The center will provide training of our selected simulated patients in conjunction with study team to ensure alignment with study goals. Simulated patients/parents will go through a minimum of 2 days of training on study scenarios. The fellows will each interact with a simulated patient representing a NICU parent confronting an "everyday" situation, as opposed to a situation requiring delivery of "bad news." Scenarios will be videotaped for later review. Fellows participate in these sessions for a half-day, personally perform in one scenario and watch scenarios of 2 other fellows. Groups of 3 fellows will participate in debriefings using video tape after each scenario.

Lessons Learned: This poster will discuss lessons learned from the development of the training program and provide highlights of program content. Additionally, through meetings with the identified field representatives during interdisciplinary collaborations between parents, neonatology, psychiatry, and psychology the authors will share topical insights regarding the teaching of mitigating both parental and infant distress for trainees. Topics include providing culturally sensitive care in the NICU, psychological impact of trauma on babies and their families, and effective communication strategies in the NICU.

Implications for Practice: The time is now to focus our efforts heavily on the fourth trimester. For parents who have an infant in the NICU, the fourth trimester comes way too soon and increases the potential for needed psychological support. Our project hopes to address a high priority educational need as identified by the American Board of Pediatrics and the Accreditation Council for Graduate Medical Education. A new core program requirement became active July 1, 2019 for pediatric training programs to develop curricula to train residents and fellows on screening for mental health issues in their patients and in the case of infants, in their parents. No national programs



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Presenters: Lily Lou, MD, FAAP; Mark Hudak, MD, FAAP; David Stevenson, MD, FAAP; Bill OH, MD, FAAP

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exist for addressing this important topic, leaving programs to find local resources and craft individual and less comprehensive training. Our project could provide an example to other pediatric training programs. If found to be effective, our course, or elements of our course, could be adapted for the training of residents and fellows in other pediatric subspecialties.

Our project has the potential to impact thousands of NICU families at a crucial time for the development of their foundational relationships with their infants. High rates of distress have been documented in NICU families making the impact of trainee understanding, efficacy and skill at caring for them particularly important. Distress experienced by both parents and their infant(s) in the NICU may impair both the emotional and physical health of each, as well as the family's relationships throughout childhood, creating unseen negative impacts in both populations. Finally, our training program has the ability to address a known educational deficit, possibly impact thousands of parents and their infants, and provide a model for other pediatric training programs to adapt for their specific patient populations and needs.

NPA2020-4

A Critical Analysis of Intimate Partner Violence During Pregnancy in The United States

Elizabeth Filipovich, MPH

Abstract

Introduction: Intimate partner violence during pregnancy is a significant public health problem with several associated adverse maternal and fetal outcomes, including preterm labor, low birthweight and maternal mortality. This critical analysis will explore factors that contribute to the high incidence of IPV in pregnancy, current prevention best practices, and

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interventions suited to reduce the incidence of IPV among pregnant women.

Methods: A literature review was performed using PubMed and George Washington University's Himmelfarb Health Sciences Library.

Results: Pregnancy is an optimal time to screen for IPV due to repeated contact with a care provider throughout a woman's pregnancy. Barriers to screening for IPV, inadequate provider education, lack of appropriate resources, and a lack of consensus regarding screening strategies and tactics contribute to lack of intervention for women who are experiencing IPV in pregnancy.

Conclusions: Progress in addressing IPV requires further research, including broad based controlled trials of intervention methods applied in diverse populations. In particular, studies comparing effectiveness of IPV intervention among various pregnant populations have the potential to determine whether the period of pregnancy presents a greater opportunity for success in reducing IPV than intervention at other times in a woman's life. Further research into the impact of IPV intervention on birth outcomes may provide critical information on which to base specialized programs of care for populations most at risk for low birth weight and preterm birth. Model programs have demonstrated effectiveness in reducing harm related to IPV using a combination of interventions. Testing these models can further the evidence base on which to build standard practices for effectively addressing this public health problem.

NPA2020-5

"Babywearing" as a Tool to Decrease Pain Associated with Neonatal Abstinence Syndrome

Introduction: Prescription opioid sales in the U.S. has almost quadrupled from

1999 to 2014; correspondingly, infants diagnosed with Neonatal Abstinence Syndrome (NAS) has increased more than fivefold. NAS is commonly associated with maternal opioid use and includes symptoms such as high-pitched crying, tremors, and poor feeding. Infants with NAS are accustomed to drug exposure in utero; consequently, when the drug is no longer present, the absence of the stimuli is painful. Elevated heart rate (HR) is synonymous with increased infant pain and stress in adults. Research on skin-to-skin or kangaroo care has found decreased perceptions of pain (i.e., HR) during heel prick procedures. The purpose of the study is to examine whether infant carrying or "babywearing" (i.e. holding an infant on one's body using cloth) can reduce stress and symptoms associated with NAS.

Methods: This repeated-measure study took place in a Neonatal Intensive Care Unit (NICU) in the Southwest USA. Starting when infants were four days old, physiological readings (N=97 readings; N=15 infants; 53% White, 20% Hispanic, 13% African American; 53% female) were assessed daily. Heart rates of infants and individuals wearing the infant (e.g. parents, nurses) were taken every 15-seconds before- (no touching), during- (20 minutes into being worn in a carrier) and post-babywearing (five to ten minutes later), approximately a forty-five minute procedure from start to finish. A finger plethysmograph, also known as a pulse oximeter, measured heart rate for the adults wearing the infants. Infants were continuously monitored by cardiopulmonary machines using a pulse oximeter wrapped around their foot.

Results: A 3-Level Hierarchical Linear Model (HLM) was used in order to account for the nested data (HRs nested within readings, nested within infant-adult dyads) at three time points (before, during, and after babywearing). We found that

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based on the "Interdisciplinary Recommendations for Psychosocial Support for NICU Parents."

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babywearing decreased infant and caregiver heart rates. Approximately, across a 30-minute period, infants worn by parents decreased 15 beats per minute (bpm) compared to 5.5 bpm for infants worn by an unfamiliar adult, and adults decreased by 7 bpm (parents) and nearly 3 bpm (unfamiliar adult).

Discussion: Findings from this study suggest that babywearing is a non-invasive and accessible intervention that can decrease symptoms in infants diagnosed with NAS. Babywearing is cost-effective, culturally relevant, and can be done by noncaregivers (e.g., nurses, family members, friends). Results suggest that babywearing is especially calming when parents are the ones wearing the infants. Babywearing supports parenting by including the parent in the treatment and empowering them in caring for their infant. This intervention can be used outside of the NICU and provide additional support to parents and caregivers once infants are discharged. Close physical contact, by way of babywearing, can improve infant outcomes in NICUs as an alternative to pharmacological treatment.

NPA2020-6

Caring for Women and Their Families: Providing Psychosocial Support During Maternity Care

Authors: S Hall, A White, L Baker, A Brown, S Detlefs, ML Martin, C Milford, S Wolf, K Saxer, J Ballas, K Sorrells, MA Davids, B Boet, E Thatcher, C Duffy, and T Pella.

Background: The Accreditation Council for Graduate Medical Education (AC-GME) has outlined numerous milestones that residents in obstetrics/gynecology must achieve during their training. These include development of: 1-compassion, integrity, and respect for others, 2- respect for patient privacy, autonomy, patient-physician relationship, 3- interpersonal and communication skills necessary for communication with patients and families, and 4- interpersonal and communication skills necessary to provide informed consent and shared decision-making (ACGME, 2019).

We created an innovative online educational program focused on these oftenneglected areas of training for all providers of maternity care, including physicians in training (residents and fellows), practicing physicians, nurses, and other practitioners at the bedside. A key principle of our program development was that it was both interdisciplinary and interprofessional, including contributions by patients. We applied the concepts of trauma-informed care in the setting of providing maternity care as our foundation for training. We used as our exemplar an educational program we previously developed for all staff providing care in Neonatal Intensive Care Units. This program has been found to be effective at improving nurses' (the primary study population) knowledge and confidence in providing psychosocial support to NICU parents (Hall, 2019). Additionally, we wanted to satisfy the mandate passed by several states requiring that physicians who provide maternity care receive training in perinatal mental health issues.

Content/Action: A multidisciplinary and interprofessional team consisting of obstetricians, specialists in neonatal and perinatal medicine, nurse midwives, obstetric nurses, psychologists, and patients developed a 6-course online learning program that contains the following topics: 1- Using Trauma-informed Care as a Basis for Communication in Maternity Care, 2-Perinatal Mood and Anxiety Disorders: Providing Emotional Support During Maternity Care, 3- Providing Support During the Antepartum Period of Maternity Care; 4- Providing Support During the Intrapartum Period of Maternity Care, 5- Providing Support During the Postpartum (Fourth Trimester) Period of Maternity Care, and 6-Supporting Maternity Care Staff as they Support Patients. Patients contributed personal narratives to demonstrate learning points, collected resources they felt would be helpful to clinicians, and helped to review and edit all content. Each course describes how trauma-informed care can be integrated into obstetric care to ensure patients feel safe, and invested as partners in their own care at every step along the way. High risk social and emotional factors, and how to identify and respond to them, are enumerated. There are also multiple links to other sites on the internet that reinforce the content being presented, as well as downloadable documents that further enhance learning by demonstrating best practices. Courses have interactive cases to reinforce clinician learning. Each course has an extensive bibliography, and all content is firmly grounded in evidencebased literature.

Lessons Learned: An interdisciplinary and interprofessional model can be successfully used to create educational content for providers that speaks to their patients' needs. This model affords providers the opportunity to understand the patient experience from a deeper, more personal, and more meaningful perspective.

Implications for Practice: An innovative online learning program has the potential to widely disseminate educational content on providing psychosocial support, which is required in obstetric training but is not often a specific part of training curricula. Enhancing provider understanding of the patient experience can lead to increased sensitivity to patient needs and improvement in both compassion and in communication skills. Attention to staff's own needs for emotional well-being is a critical part of the curriculum, as quality care can best be delivered by providers who can avoid burnout.

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NPA-2020-7

Universal Maternal Home Visiting: A Public Health Cross-Jurisdictional Model

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Background: The North Shore Mother Visiting Partnership (NS MVP) was launched by Public Health Nurses (PHNs) from five communities on the North Shore of Massachusetts in January 2018 with a belief that all postpartum women in Massachusetts deserve to benefit from a maternal home visit after birth regardless of income, insurance status, age, health, or number of children. NS MVP nurses support families by performing perinatal mood disorder screenings, provide brief interventions, make referrals to support services, improve access to healthcare, address parental concerns, provide safe sleep education and connect families to their communities. Due to dwindling healthcare reimbursements on a federal and local level and lack of universal maternal home visiting program in the region, PHNs are working in a cross-jurisdictional capacity to deliver an evidence-based model of care to families.

Content/Action: NS MVP uses a public health approach to mobilize community partnerships to identify and solve health problems, link families to needed health services and evaluate effectiveness, accessibility, and quality of personal and population-based health services. Creating a durable cross-jurisdictional mother home visiting model, resources such as, nursing staff, financial contributions, and program supplies become shared enabling NS MVP to maintain and expand the program into additional communities. Through the work of NS MVP, the participating PHNs have engaged with senior community leaders. Boards of Health, area health providers, State Department of Public Health (DPH), and Massachusetts legislators to advocate and raise awareness of prioritizing maternal and infant health in their communities.

Lessons Learned: NS MVP works in partnership with UMass Medical School's Center for Healthcare Financing and DPH's Welcome Family to identify insurance billing codes and explore reimbursement options to address sustainability of maternal home visiting in the Commonwealth. Additionally, NS MVP collaborates with Metropolitan Area Planning Council (MAPC) to develop a cross-jurisdictional model to formalize the participating communities' relationship as a North Shore Nursing Program. Currently, participating communities have signed a Memorandum of Understanding to capture current roles and responsibilities. The goal is to create an inter-municipal agreement by developing a robust governance and shared staffing, as well as a sustainable financial model that will enable the program to maintain and expand nursing services beyond home visits.

Implications for Practice: The formal collaboration of PHNs across municipal lines is a new and unique model designed to deliver vital Public Health services to a vulnerable population. While collaboration between PHNs in other areas such as disease investigation and staffing vaccination clinics is common practice, NS MVP is an innovative addition to local Public Health services. The numerous implications for practice include increased workforce efficiency and capacity, a strength based approach with a focus on wellness, and expanded nursing services aimed at decreasing numerous Health People 2020 maternal health goals. By having strong community partners, it is possible to provide families with a sense of well-being in their own community. All NS MVP nurses complete additional education in home visiting, infant development and nutrition and maternal health. NS MVP nurses continually update their knowledge of evidencebased practices in the field of maternalchild health by attending conferences and seminars. Quantitative and qualitative data collected at each visit is evaluated and discussed at monthly planning meetings to guide the home visiting practice.

NPA-2020-8

Early Postpartum Contact: A Quality Improvement Project

Authors: Genevieve Hofmann, DNP, WH-NP-BC and Amy Nacht, DNP, CNM, MPH

Innovative Models of Care

Background: Postpartum care in the United States (US) is inconsistent and fragmented. Nationally 40% of women forgo postpartum follow up (ACOG, 2018). At the University of Colorado School Of Medicine OB/GYN resident practice, over 60% of low-risk postpartum patients forgo postpartum follow-up. Low rates of postpartum follow-up lead to low rates of recommended screenings. In Colorado, 10% percent of postpartum women report symptoms of postpartum depression (PPD), and self-harm is the most common cause of pregnancy related mortality (Metz, Rovner, Hoffman, Allshouse, Beckwith, & Binswanger, 2016). Gestational diabetes, a pre-cursor to Type 2 diabetes, is on the rise (CDC, 2017). The American College of Obstetrics and Gynecology (ACOG) revised committee Opinion, Optimizing Postpartum Care, calls for a paradigm shift in postpartum care advocating for more patient-provider contact, ideally, within 3-weeks postpartum (ACOG, 2018). Proactive telephone support during the early postpartum period can bridge this gap in care (Lavender, Richens, Milan, Smyth, & Dowswell, 2013); (Danbjorg, Wagner, Kristensen, & Clemensen, 2015).

Content/Action: An early contact, proactive, phone call intervention was initiated. Eligible low-risk postpartum patients delivering at the University of Colorado Hospital in Aurora, Colorado received a nurse initiated phone call approximately 1-week after discharge.

Lessons Learned:

 Early contact did not significantly improve postpartum follow up (p = 0.78).

- Sixty-seven percent of patients were successfully contacted.
- Almost 50% of successfully contacted patients attended their appointment (p = 0.13).
- Average call time was 6.7 minutes (SD 4.2); non-English 9.4 minutes (SD 4.3).
- Women who attended their postpartum appointment received screenings and referrals.
- Patient experience with the early contact intervention was overwhelmingly positive.
- One hundred percent of the nurses providing the intervention stated it was "non-burdensome" to workflow.

Implications for Practice: Early postpartum contact is best practice. Early contact is feasible and acceptable as demonstrated by successful contact rates, brief call duration, and positive patient and nurse surveys. Continued evaluation of alternative means of patient contact during the postpartum period, including text messaging, utilizing patient portals, and telehealth are next steps to improving contact and care during the postpartum period.

> *Process maps, charts, tables, and other visuals are available to build a poster*

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NPA-2020-9

Mindful Mood Balance for Moms: A Scalable Digital Intervention to Prevent Relapse of Depression in the Perinatal Period

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Introduction: Depressive relapse during pregnancy is highly prevalent particularly among women with recurrent depression. Maternal psychiatric morbidity associated with depressive relapse during pregnancy is a concern as is the deleterious impact of untreated mood disorder during pregnancy and the postpartum period on child development. Although maintenance antidepressant treatment is the standard of care for women with recurrent depression, concerns exist regarding known and unknown effects of fetal exposure to these agents. Due to this, many women seek non-pharmacologic alternatives to treatment during pregnancy. Mindfulness-based cognitive therapy (MBCT) is an efficacious intervention that prevents depressive relapse among pregnant women as compared to usual care. Despite MBCT's effectiveness, there are barriers to dissemination, including availability of trained therapists, cost, time, transportation and stigma. We will describe an innovative digital program based on MBCT that is specifically designed for women during pregnancy and the postpartum period, Mindful Mood Balance for Moms (MMB for Moms). We also will highlight lessons learned in its development and how it may be used in practice.

Content: The MMB for Moms program is an 8-session self-guided digital program that is specifically tailored for pregnant women who have a history of depression but are currently euthymic or have residual depressive symptoms. In addition to the digital program, women are supported by a mindfulness coach who engages them at regular intervals throughout the program. We will explain an overview of the content of the program and the role of coaching. We also will share first person experiences of the program among pregnant and postpartum women via video recordings. We will describe research that has examined the clinical benefits of this program and its evidence base.

Lessons Learned: We propose to share information about the importance of the coaching role and key mindfulness practices for the perinatal period. We will share lessons learned about engagement with the program and how to increase uptake.

Implications of Practice: MMB for Moms is a novel, scalable program that is designed to support women during pregnancy and the postpartum period who are at elevated risk of depressive relapse. This approach is in alignment with the US Prevention Task Force's statement in support of offering preventative programs during pregnancy. Additionally, this program can be scalable and has the potential to reach women who experience barriers to receiving care.

NPA-2020-10

Evaluation of YouTube videos as a resource for improving health literacy in pregnant women with Opioid Use Disorder

Authors: Elizabeth Kravitz (BSA), Natalie Close (BS)

Introduction: In the setting of the opioid epidemic, the significant perinatal morbidity and mortality of opioid use disorder during pregnancy is well established (1). The increasing prevalence of associated complications is exacerbated by the poor health literacy in this country, inhibiting diagnosis and treatment (2). Around the world people of diverse backgrounds are looking to YouTube for their medical education (3). The purpose of our project was to evaluate the utility of YouTube videos as a source of education on opioid use disorder during pregnancy.

Figure 2: Data on videos with targeted audience of patient (total 86 videos)

videosj		
Characteristic of Video	<u>Result</u>	Percentage (86 videos total)
Views (aver- age)	2 0 , 4 5 6 views	
Average score	4.03	
Define Opioids	45 videos	52%
Defines Opioid Use Disorder	43 videos	50%

Includes con- sequences of OUD during prenatal period	23 videos	27%
Neonatal ab- stinence Syn- drome	61 videos	71%
Ability to breastfeed	2 videos	2%
Mentions treat- ment	55 videos	64%
Includes how to get help	22 videos	26%
Source type: Professional Personal News Webinar	36 videos 17 videos 31 videos 2 videos	4 2 % 2 0 % 3 6 % 2%

Methods: A YouTube search was conducted on October 26th, 2019 with the following search terms: "How to quit opi-oids during pregnancy", "opioid addiction treatment during pregnancy", and "opioid detox during pregnancy". The first 100 videos for each search term were sorted by relevance and videos were excluded if they were duplicates, silent videos, in a language other than English, or if they had no mention of opioid use disorder or pregnancy. A 12-point scale was developed matching the American College of Obstetrics and Gynecology patient education resource (figure 1). This scale was applied to each video in order to evaluate its utility for a patient population. Videos were sorted based on how many of the 12 points were included. Less than 4 points were deemed poor utility, 4 to 6, mild utility, 7 to 9, moderate utility, 10 to 12, excellent utility.

Results: Of the total 300 videos, 113 remained after exclusion criteria were applied, 86 of those had a targeted audience of a patient or the general public. Of the videos targeted to the patient or general public, the average utility score was 4.02. Only one of these videos qualified as excellent utility, 17 were moderate utility, 38 were mild utility, and 39 were poor utility. Other salient results from the scoring of the videos with an audience of patients/ public can be seen in figure 2.

Discussion: YouTube videos offer a platform for health education that can address people with a spectrum education levels regardless of their geographic location. Yet, our results show a strikingly limited availability of adequate, comprehensive education for this patient population. Perhaps most remarkable, only 52% of videos defined opioids, and only 50% defined opioid use disorder, highlighting the striking deficiency in this selection of videos. These resources failed to promote the mother-baby dyad, with a particular focus (71% of videos) on Neonatal Abstinence Syndrome, but only 26% offering information to mothers on how to find help. Additionally, there was minimal acknowledgement of the prenatal risks of opioid use during pregnancy, with only 27% of videos addressing any risk at all. This study not only highlights the initial shortcomings of YouTube videos regarding this topic, but also emphasizes the need for further resource investment by the medical community utilizing YouTube as a resource for improving health literacy.

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		Proposed	scale	to	measure	
utility o	f vi	deos				

Key Areas of Content	Points
Defines opioids	1
Defines opioid use disor- der/abuse?	1
Prescription opioids can lead to abuse	1
What are the risks dur- ing a pregnancy?	
Placental abruption	0.5
Prenatal complica- tions	0.5
Preterm birth/labor	0.5
Stillbirth	0.5
Neonatal Abstinence Syndrome	1
How is it treated during pregnancy?	
Methadone	0.5
Buprenorphine	0.5
Explanation of access/ administration of meds	1
Benefits of Treatment	1
Risks of Treatment	1
Breastfeeding on Metha- done/Buprenorphine	1
How to get help	1

NPA2020-11

Innovative Models of Care:

Neonatal Social Work Care Coordination in the NICU and NICU Follow-up Programs

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Background: According to the Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee, "Care Coordination is an essential element of a transformed American health care delivery system that emphasizes optimal quality and cost outcomes, addresses family-centered care, and calls for partnerships across various settings and communities." The NICU Follow-up Program at Nationwide Children's Hospital monitors the developmental progress of eligible NICU graduates until the age of 3 years, but retention rates have been variable. The need for education and guidance to NICU families regarding recommendations for their child's follow-up and a process to identify and problem-solve barriers to care was much needed. This led to the development of Neonatal Social Work Care Coordination Services (NEO-SWCCS). This specialized social work program specifically addresses the transition from hospital to home and provides partnership with families to help them better understand the goals of developmental surveillance and intervention as well as problem solve practical barriers to care which may interfere with program retention.

Content/Action: The poster will showcase this specialized program, Neonatal Social Work Care Coordination Services (NEO-SWCCS), which was initiated in October of 2016. Patients discharged from the NICU are eligible for NEOSWCCS if they meet specific criteria potentially associated with non-adherence (e.g. parents with cognitive limitations, mental health issues, language barriers) or if the child's healthcare needs are especially complex. Once a patient is identified as eligible for NEOSWCCS, attempts are made by the Neonatal Social Work Care Coordinator (Neo SWCC) to meet families referred to the NICU Followup Program prior to their discharge from the NICU. The Neo SWCC provides parent education about the clinic their child will be attending and the importance of developmental monitoring and intervention. Barriers to follow-up care are also explored during this initial face-to-face intake and the Neo SWCC then links families with available resources to mitigate these barriers. In addition, the Neo SWCC completes a phone call approximately one week after discharge to asses for post-discharge needs and during the week prior to the initial developmental evaluation (typically at 3-4 months corrected age) to provide information regarding what to expect for the evaluation and explore barriers to care. The Neo SWCC has also led an initiative developing systems to follow up on noncompliance in the clinics which includes a triage process for high risk patients. This has been a multidisciplinary effort rolled into standard operating procedures for the clinics.

Lessons Learned: Developing clear criteria for patient eligibility and having pre-existing clinical relationships with the multidisciplinary team in the NICU was essential. Both helped to identify patients, facilitate communication with the families, and for identification of barriers to care. Challenges during the implementation of this program include slower or missed identification of eligible families for NEO-SWCCS during planned and unplanned absences of the Neo SWCC as well as an insufficient tracking system to evaluate circumstances affecting data.

Implications of Practice: The implementation of NEOSWCCS allows for targeted interventions specific to helping families transition from their NICU care to outpatient follow-up thus increasing the retention rates and developmental follow-up. The NICU Follow-up Program at Nationwide Children's Hospital averages 5,000 completed visits each year. Average completion rate of the D1 developmental evaluation (3-4 months corrected age) in the NICU Follow-up Program in 2016 was 52%. In 2018, the rate increased to 89% (for completion of initial developmental evaluation) for patients eligible for NEO-SWCCS. Results will be illustrated through tables and will include data from 2019.

NPA2020-12

Family Infant Neurodevelopmental Education (FINE)

Poster proposal for the National Perinatal Association Meeting

Author: Debra Paul, BS, OTR/L (parent) and Joy V. Browne, Ph.D., PCNS, IMH-E (IV),

Background: Developmental care is a globally accepted and evidence based approach to optimizing outcomes for babies and their families. Through the work of Dr. Heidelise Als, Beverly Johnson and others, and now with recommended standards and competencies in Europe, Canada and the United States, developmental, family

centered care is becoming the expected norm. The gold standard for education and implementation of this approach is the Newborn Individualized Developmental Care and Assessment Program (NI-DCAP; www.nidcap.org) which has 22 training centers worldwide. However. training in the NIDCAP program is complex and has not been well accepted as a model in the US. In the past decade a foundational program, referred to as Family Infant Neurodevelopmental Education (FINE) program was developed in Europe to meet the needs of NICU professionals who wish to have more empirically supported strategies for implementing basic practice in neurodevelopmental care. There are two levels of the FINE program, a two day foundational education program for all NICU professionals (FINE 1) and a 12 week individualized program for those who wish to have a more in depth mentored experience incorporated into their practice (FINE 2). Both are intended to be foundational for those who wish to become NIDCAP Professionals.

Content/Action: In 2019 the two day FINE 1 program was implemented in US locations with over 320 interdisciplinary professionals. At the conclusion of FINE 1 training, attendees identified a variety of areas where they want to implement infant and family supportive strategies into their NICU caregiving. Themes included: enhanced integration of families in infant care, more consistent kangaroo mother care, pain prevention and alleviation, avoidance of sleep disruption, better positioning and alignment for babies, and demand feeding practices. An overview of the components of FINE training that are most salient for NICU professionals as well as specific data regarding how attendees plan to utilize the information from the FINE 1 program will be provided. One year follow up data are currently being obtained to determine long term follow through on how attendees have implemented evidence based family centered and developmental care practices.

Lessons learned: The FINE program appears to be well accepted and has implications for evidence based developmental care. It has been developed to be consistent with the Gravens Standards and Competencies for Infant and Family Centered Developmental Care (see abstract by Browne and Jaeger) and the European Foundation for the Care of Newborn Infants (EFCNI) standards for newborn health in Europe.

Implications for practice: Neurodevelopmental care practices are evidence based with standards for implementation in all NICUs. FINE 1 training provides foundational training that is consistent with best practice and provides rationale for optimizing infant and family support during hospitalization. With data now being accumulated, we will have a better understanding of what practices are consistently implemented and utilized as a result of attending the FINE 1 training.

NPA2020-13

The impact of sociodemographic characteristics on postpartum depression in Hispanic women Authors: Sneha Rajendran, BS,BA, Mary S. Dietrich, PhD, MS, Melanie Lutenbacher, PhD, MSN, RN, FAAN

INTRODUCTION: Hispanic people living in the United States "bear a disproportionate burden of disease, injury, death, and disability" when compared to non-Hispanic white people(1). Postpartum depression falls into this category. Despite similar rates of postpartum depression in women of differing ethnicities, among low-income women, the odds of starting and continuing treatment for postpartum depression following delivery are significantly lower for Hispanic women compared to white women(2). Barriers to care has been hypothesized as a potential explanation, but has not been supported(3). Other possible factors that may contribute to the healthcare disparity Hispanic women with postpartum depression face must be examined. Evidence suggests that various sociodemographic characteristics and maternal factors such as age(4), breastfeeding duration(5), and intimate partner violence(6) may be associated with postpartum depression. This study further examines these and other maternal factors and their potential relationship with reliable change in the levels of depressive symptoms from late pregnancy to two months and six months postpartum in a sample of Hispanic women living in Davidson County, TN.

METHODS: Data for this secondary analysis were collected in an RCT conducted from July 2014 to September 2016 which assessed the efficacy of the Maternal Infant Health Outreach Worker (MIHOW) program (www.mihow.org), a peer mentoring home visitation program, in a sample of 188 Hispanic women(7). A prospective, longitudinal experimental design with two study groups: comparison (printed educational material) and intervention (MIHOW home visits plus printed educational material) was used. Eligibility criteria included: age \geq 18, self-identification as Hispanic, confirmation of pregnancy \leq 26 weeks gestation, and residence within 30 miles of study offices. Data was collected at five time points (prenatal through six months postpartum) using validated measures and questions from national surveys. The study was approved by the Vanderbilt University Institutional Review Board. The sample for the secondary analysis included the 178 participants who completed the parent study and their de-identified data related to: levels of depressive symptoms, acculturation, health literacy, parenting stress, and education, breastfeeding intent, duration, and self-efficacy, time living in the US, maternal age, presence of a medical provider, health insurance, and presence of infant NICU stay. Multivariate logistic regression was used to analyze the significance of each of these demographic variables in explaining variance in reliable change in level of depressive symptoms. The following three variables were used as co-variates to control for changes in the outcome variable: 1) gestational age at study enrollment, 2) level of depressive symptoms at baseline, and 3) parent study group assignment.

RESULTS: The average maternal age at enrollment was 29.6 years (SD= 6.5). The median gestational age was 17.5 weeks. The median time lived in the USA was 9 years (IQR= 3-13). Mexico had the largest representation of home country (66.9%). followed by Honduras (15.7%) and El Salvador (9.6%). 19.3% of the subjects had graduated high school or completed a GED. 68.5% of the subjects earned less than \$10,000 yearly in family income, and 28.1% earned between \$10,0001-\$15,000. Of the factors examined, the presence of health care coverage at two months postpartum was associated with a statistically significant decrease in level of depressive symptoms (p = 0.017, 95%CI 1.279 - 12.763) and a higher parental stress score at six months postpartum was associated with a statistically significant increase in level of depressive symptoms (p = 0.02, 95% CI 0.842 - 0.986).

DISCUSSION: The findings have clinical and research implications. Helping patients access available health care coverage and resources that may help lower their parenting stress are important factors to consider when caring for Hispanic women, particularly those with postpartum depression. Future research related to postpartum depression should include these variables and potential evaluation of interventions that may impact change. Further research into this healthcare disparity will increase our understanding of characteristics and maternal factors that may contribute to variability of depressive symptoms in Hispanic women and serve as the underpinnings for targeted culturally competent interventions and policies for a growing minority in the United States.

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NPA2020-14

NPA ABTRACT SUBMISSION (for poster presentation)

TITLE OF ABSTRACT Family Celebrations: A NICU Perspective Navy Spiecker, BA, Pamela A. Geller, PhD, Chavis A. Patterson, PhD

Background:For many parents, celebrations can be a joyful time; however, for those with an infant in the NICU, holidays can cause conflicting emotions. Parents face difficulties integrating celebration with the anxiety they may be simultaneously experiencing. Additionally, parents may feel isolated as they manage their infant's illness or bereavement while other families participate in celebratory activities. This project seeks to offer a greater understanding of the complex emotions families face with regard to child illness during holidays. The goal is to summarize the literature and offer recommendations to NICU providers on how to best assist families around celebratory events.

Content/Action: Existent literature on family experiences in the NICU during holidays was examined, including: review of academic articles, qualitative examination of personal stories from families, and input from NICU providers.

Lessons Learned: Recommendations are made towards financial/transportation support available to families, the utilization of parent support and activity groups, integrating volunteer assistance from previous graduate families of the NICU, and utilizing a family-centered approach to care with regard to celebrations and holidays. Additionally, emphasis is placed on the provider's knowledge of outside resources/nonprofits dedicated to supporting families in the NICU.

Implications for Practice: A thorough understanding of the family's experience in the NICU during celebrations will help providers address challenges with effective evidence-based care. Provision of open dialogue, celebratory programs for parents within the NICU, and knowledge of outside resources can improve coping among parents. Current literature and resources in this area are limited.

Providers should consider the role of outside factors that further complicate the NICU experience, such as time divided between home and the bedside.

NPA2020-15

Innovative Models of Care

TITLE OF ABSTRACT A Provider Education Model for Supporting Caregivers and Vulnerable Infants in the Fourth Trimester

Petora Spratt, P.T., D.P.T., IMH-E (III)Emily McNeil, L.C.S.W, IMH-E (IV), Debra Paul, OTR (parent), and Joy Browne, Ph.D., PCNS, IMH-E (IV).

Background: Infants and their families who transition from NICU to their communities are typically followed by early intervention and/or public health nurses. Medical complications, invasive procedures and many unknowns during hospitalization for both infants and their families result in physical, mental and behavioral health issues that require appropriately informed mental health supports. Currently there is little mental health information and/or approaches in basic educational programs for providers that address the develop-

OPIOIDS and NAS When reporting on mothers, babies, and substance use LANGUAGE MATTERS

I am not an addict.



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

I was exposed to opioids.



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



NAS is a temporary and treatable condition.

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

My mother may have a SUD.



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

My potential is limitless.



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

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



mental and mental health issues of newborns and young infants. The BABIES and PreSTEPS model has been developed to provide providers in the community with appropriate education to address mental, physical and developmental health issues of this vulnerable population and their families.

Content: Data will be provided from surveys of providers in four states (AK, CO, IN and AZ) indicating a lack of specific training for physical, developmental and mental health assessment and intervention for fragile newborns and their families. Description of the BABIES (Biophysiologic, Arousal and Sleep, Body Movement, Interaction with others, Eating and Soothing) and PreSTEPS (Predictability and continuity, Sleep and arousal supports, Timing and pacing, Environmental modification and Soothing strategies) model will be presented to include assessment and intervention guidance for supporting fragile newborns and their parents in the fourth trimester. Infant Mental health Diversity Tenets and Reflective Practice best prac-



tices are used in the year long learning collaborative. Descriptions of state wide provider practice outcomes as a result of engaging in the educational program will be provided.

Lessons learned: A mental health informed practice including reflective opportunities are essential to best support fragile newborns and young infants and their families in the fourth trimester. Although essential to the recovery of infants and parents after hospitalization, providers do not have the educational background to incorporate mental health approaches into their currently utilized intervention strategies. Parents are the best supporters of regulation in the fourth trimester, an essential developmental task of newborns. Support for both providers and families during this vulnerable time is essential.

Implications for practice:

NPA2020-16

NPA Innovative Model of Care Proposal

Title: Baby Attachment and Comfort Interventions (BACI): A multidisciplinary intervention to support parents and neonates in a cardiac neonatal intensive care unit in the first weeks after birth

Authors: Rochelle Steinwurtzel, Katharine Press Callahan, Elvira Parravicini

Background: Parents with babies in the Neonatal Intensive Care Unit (NICU) due to congenital heart disease (CHD) are at high risk for stress in the context of longlasting emotional, familial and financial costs associated with diagnosis, hospitalizations, and ongoing treatment. Babies hospitalized in the NICU for CHD often experience multiple traumas related to physically stressful medical procedures while experiencing a loss of other developmentally appropriate sensory inputs. Simultaneously, they experience the additional stressor of separation from their parents whose role is to facilitate a sense of security through a constant, loving and responsive relationship.

It is essential for parents to buffer infants' stress levels. If parents are overwhelmed by their own stress levels associated with the NICU experience, their capacity to effectively regulate the baby's stress becomes compromised. Trauma-informed care in the NICU empowers staff to support parents and in turn neonates. Similarly, palliative care principles focus on improving quality of life and reduce suffering while enhancing families' decision-making capabilities through early integration of interdisciplinary interventions.

Content/Actions: The Baby Attachment

Comfort Interventions (BACI) is an innovative method of early palliative care developed and validated by the Neonatal Comfort Care Program at NewYork Presbyterian, Columbia University Irving Medical Center in an effort to support parents and enhance comfort of all hospitalized neonates, regardless of prognosis (Callahan, K., Steinwurtzel, R., Brumarie, L., Schechter, S., & Parravicini, E. Early palliative care reduces stress in parents of neonates with congenital heart disease: validation of the "Baby, Attachments, Comfort Interventions. J Perinatology. 2019; 39(12):1640-1647). BACI utilizes palliative care and trauma-informed care concepts with a focus on supporting parents so they can more effectively co-regulate their hospitalized babies. BACI focuses on four domains: bonding, feeding, memories, and emotional, psychological, and spiritual support. The intervention is provided by the interdisciplinary BACI team, which includes the Neonatal Comfort Care Program core team (a neonatologist/medical director, nurse, and social worker) and other NICU professionals including a psychologist, speech pathologist, Child Life specialist, and chaplain. Overall, BACI team members meet with parents an average of 4 times per week and offer a variety of services that are tailored to the individual family and the neonate's medical condition. Services include opportunities for skin-to-skin. developmentally-appropriate touch and positioning, non-nutritive suck or colostrum care, memory-making, and psychological and spiritual support. Additionally, BACI helps support bedside staff and foster opportunities for parental involvement in pleasurable dyadic experiences between parent and baby.

Lessons Learned: Based on previously published findings (Callahan et al., 2019), the BACI program significantly reduces stress in parents of infants with CHD. The BACI program requires the focused attention and availability of the BACI team, in addition to their regular job roles.

Implications: This program requires dedicated time and resources to provide the consistent, multidisciplinary care parents need to feel psychologically safe in the cardiac NICU. Future research could assess whether effects on parental stress persist long-term or how this program impacts the stress of staff.

NPA2020-17

Redefining the Postpartum Care Rotation for OB/Gyn Interns

Authors: Julia Switzer, MD; Aref Senno, MD; Kavisha Khanuja, MD; Abigail Wolf, MD Background: Increased recognition of the importance of the 'fourth trimester' and the pressing need to reduce maternal morbidity and mortality, has led many professional organizations, including ACOG, to encourage a renewed focus on postpartum care. Changing the culture of practice requires changing the way we teach our trainees. Resident training in OB/Gyn is rigorous and historically has not allowed for focused study of the postpartum period. Postpartum rounding is typically done early, quickly, and as an afterthought to other responsibilities such as managing patients on Labor and Delivery and in Triage. The ACGME Milestones Project helps to define the developmental steps necessary for a resident to move towards independent practice. Advanced milestones for The Care of the Postpartum Patient include ability to effectively counsel patients on antenatal, intrapartum and postpartum complications, collaboration with other members of the health care team in postpartum care and application of innovative approaches to the management of patients in the postpartum period. There is currently no literature regarding how to teach OB/Gyn residents about comprehensive postpartum care.

Action: In order to emphasize the importance of the fourth trimester, we created a postpartum care rotation to allow time for the resident to provide culturally sensitive and individualized care, be directly observed and receive feedback in the postpartum care environment, and to learn about the complications of the postpartum period. Under the guidance of their attending, the resident independently manages the care of the postpartum service. Care coordination is a large part of the rotation. The resident works with hospital social workers, case management, lactation consultants, medical consultants and outpatient practice members to individualize the outpatient follow up needs of all patients while learning to manage an inpatient service. During this block the resident also staffs a dedicated outpatient postpartum clinic two afternoons per week. Assigned learning tasks of this rotation include: completion of a breastfeeding training course; direct observation of the informed consent process, implicit bias training with reflection and discussion of perinatal mood disorders.

Lessons Learned: Feedback regarding this rotation was collected through resident interviews. Recognized benefits of the rota-



tion include: perception of appropriate time for counseling specifically around contraceptive choices in medically complex patients, understanding of lactation and feeding concerns, decreased stress regarding the time spent on the postpartum unit (and therefore away from Labor and Delivery or other responsibilities) while counseling patients, increased utilization of video interpreter services, and generation of ideas for quality improvement projects. Residents have the opportunity for continuity in that they can schedule and see patients in the outpatient setting whom they have cared for while inpatient. One-on-one rounding with the attending provides more opportunity for direct observation of patient care, patient handoffs, discharge planning and patient counseling. Patients are also invited to provide feedback on the resident's professionalism, communication skills and medical care. Concerns about the rotation included an increased burden of administrative paperwork on the resident and a sense of highly repetitive work. Faculty development is needed in order to change the approach to the postpartum rounding and allow for direct teaching with the resident.

Implications for Practice: By creating a dedicated postpartum rotation with specific learning goals and objectives, we are demonstrating to our trainees that this aspect of care is critically important to development as an Ob/Gyn physician. Participation in a focused postpartum rotation may therefore improve attention to this aspect of care once the resident enters independent practice. In addition, the postpartum unit is an optimal environment to promote interprofessional education and teamwork. Direct observation in this environment allows for timely feedback on performance which aligns with the ACGME milestones for OB/Gyn Residency Training.

NPA2020-18

Innovative Models of Care: Essential Knowledge and Competencies for Psychologists Working in Neonatal Intensive Care Units (POSTER) **Authors:** Willis, T., Saxton, S., Dempsey, A., Baughcum, A., Chavis, L., Hoffman, C., Fulco, C., Milford, C., & Stenberg, Z

Background: The role of the neonatal psychologist is multifaceted, with psychologists embedded in inpatient NICUs, outpatient NICU follow-up developmental clinics, and fetal care centers. Consistent with efforts of other sub-specializations to delineate training and competency guidelines to prepare psychologists in subspecialty fields (e.g., Jerson, Cardona, Lewallen, Coleman, & Goyette-Ewing, 2015; Mc-Daniel et al., 2014; Palermo et al., 2014), the proposed poster will present an aspirational model that begins to define competency in the sub-specialization of neonatal psychology. Our general framework was adapted from a paper on training and competency standards for psychologists in primary care (McDaniel et al., 2014), which was based on competency models in psychology that focus on achievement of measurable, behavioral learning objectives rather than a focus on curriculum (Kaslow, 2004). The model includes six clusters: Science, Systems, Professionalism, Relationships, Application, and Education. Each of these clusters is subdivided into associated competency groups, and each of which has its own table with specific knowledge/skills.

Content/Action: To identify the key knowledge and abilities to be included within each competency table, the workgroup evaluated literature of behavioral health issues that present in NICUs and consulted a number of different groups that included NICU psychologists, physicians, clinicians, therapists, and parents. Over a 2-year period (2017-2019), the workgroup generated a list of key knowledge and abilities for each competency group. Once all tables were populated, each workgroup member reviewed all material contained across the competency tables and identified areas of overlap within and across tables, added additional items they felt were omitted, and indicated the six to ten over-arching themes that summarized the items within each competency group.

Lessons Learned: It is important to note

that the identified areas of knowledge and abilities are provided as a general reference and are not intended to be prescriptive. Psychologists pursuing this area of subspecialty are not expected to have expertise in all of these areas. The utility of each competency and specific knowledge area will vary depending on the psychologist's role, setting, time dedicated to NICU work, and/or service level of the NICU.

Implications for Practice: Given the array of expectations for neonatal psychologists, specialized training that goes beyond the basic competencies of a psychologist in general practice and includes a wide range of learning across multiple domains is needed. For both trainees and practicing psychologists who seek to work as a neonatal psychologist, we strongly recommend seeking education and training in (1) infant mental health, focusing on the dyadic relationship; (2) identification and treatment of perinatal mood and anxiety disorders and trauma; (3) family systems practice and impact of pediatric medical condition on coping/adjustment, and (4) provision of integrated mental health services in a medical setting. Additionally, the neonatal psychologist's role may vary greatly across NICUs; the ability to conduct a needs assessment and develop and evaluate programs is critical, particularly when establishing new psychological services. Achieving competency will enable the novice neonatal psychologist a more successful transition into a highly complex, fast-paced, often changing medical environment, and ultimately, provide the best care for the infants and their families.

NPA2020-19

Revisiting the Postpartum Home Visit: A Call to Action

Author: Yeman, Jodi

Background: Postpartum health care has been reduced to a 48-96 hour hospital stay depending on the type of delivery, followed by a 6 week postpartum clinic visit that marks the end of the postpartum period by all conventional standards. The United

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States maternal mortality rate continues to climb with a 26.6% increase from 2000 to 2014. Approximately 15-20 % of postpartum women will develop postpartum depression within the first year of after delivery which has generated much discussion surrounding the most effective way to identify those at risk and provide adequate support and management. In light of these statistics the conversation surrounding how to best meet the postpartum needs of women and newborns has been renewed.

In 2018 the American College of Obstetricians and Gynecologists (ACOG) proposed redesigning postpartum care with the goal of providing a more holistic approach to what is known as the 4th trimester, addressing areas such as mood and emotional well-being, maternal infection, infant care and feeding along with addressing sleep and fatigue issues to name a few.

A successful postpartum home visit program addressing the 4th trimester already exists that encompasses many of ACOG's goals. The Duke Family Connects model has been studied in two randomized controlled trials demonstrating improved mother mental health, reduced emergency care for participating infants of 59%, enhanced home environments and greater community connections to programs like Nurse-Family Partnership for continued long-term continuity of care. The Family Connects program studied demonstrated that for each program \$1 spent, a savings of \$3.04 in emergency care costs was produced.

Content/Action: Postpartum home visits should be incorporated as the standard of care for pregnant women and considered part of the multidisciplinary team that supports and cares for new families during this critical life transition using the Duke Family Connects as a model. Current evidence supports the benefits of providing home nurse visits in reducing readmission rates for both newborns and mothers as well as promoting family bonding.

Lessons Learned: Successful postpartum home visit programs should begin before the family is discharged home. The home visit nurse needs an opportunity to establish rapport with the family and time to assess and evaluate their unique needs prior to delivery. Many women find it challenging and burdensome to make multiple doctors visits once the baby arrives. Home visits are patient centered and scheduled around convenience for the family. A postpartum home visit program can facilitate individualized transition of care plans to community resources for those families that need continued care beyond the 4^{th} trimester.

Implications for Practice: With the Postpartum home visit model as the standard of care, women will have access to quality care that is timely and holistic. Postpartum home visit studies to date reflect improved outcomes for both mom and newborn as well as reduction in cost related to decreased readmissions. Successful programs already exist and include interactions with and assessment of the family prior to delivery. Ultimately, if implemented as part of the standard of care for childbearing families, postpartum home visits could bridge the gap in care during the 4th trimester and reduce maternal and infant morbidity and mortality in the United States.



Respiratory Syncytial Virus:

How you can advocate for babies this RSV season



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

NT



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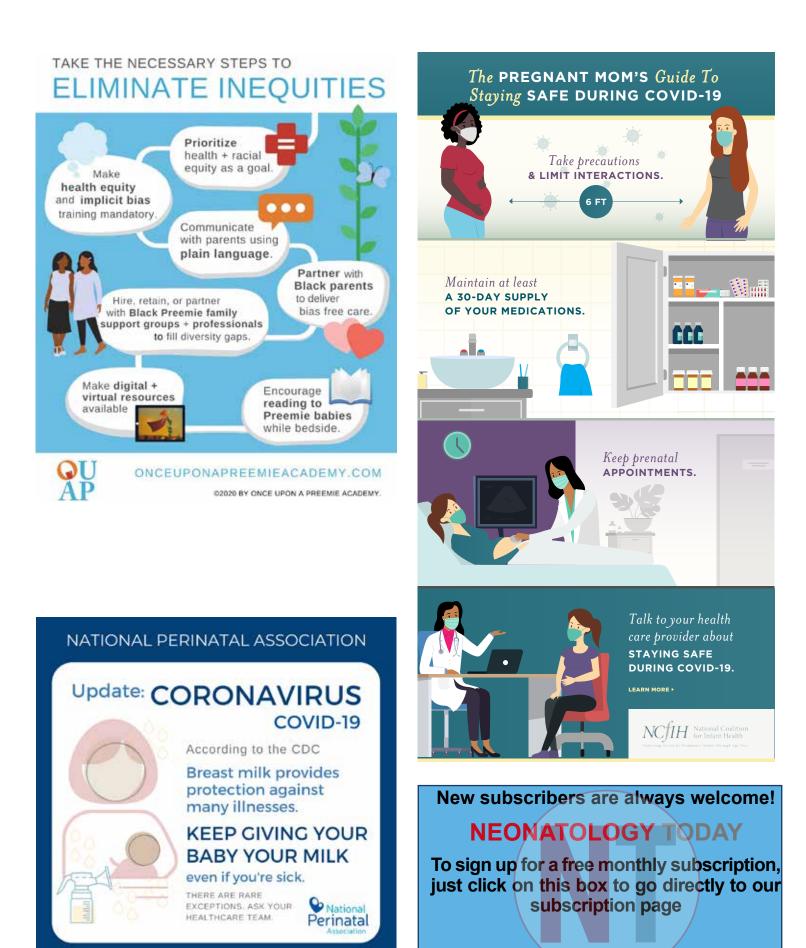


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NICU Awareness



Educate. Advocate. Integrate.

Did You Know?

Most NICU babies have special needs that last longer than their NICU stay. Many will have special health and developmental needs that last a lifetime. But support is available.

Learn about the programs in your community. Seek out other families like yours. Then ask for help. Working together we can create a community where our children will grow and thrive.

Special Health Needs

Babies who have had a NICU stay are more likely to need specialized care after they go home. **Timely follow-up care is important.**

NICU babies have a higher risk for re-hospitalization. So every medical appointment is important. Especially during cold and flu season when these babies are especially vulnerable to respiratory infections.

Who Can Help

- pediatricians
- neonatal therapists
- pulmonologists
- neurologists
- gastroenterologists
- cardiologists
- nutritionists
- CSHCN Programs for Children with Special Health Care Needs

Special Developmental Needs

Any NICU stay can interrupt a baby's growth and development.

Needing specialized medical care often means that they are separated from their parents and from normal nurturing.

While most NICU graduates will meet all their milestones in the expected developmental progression, It is typical for them to be delayed. This is especially true for preterm infants who are still "catching up" and should be understood to be developing at their "adjusted age."

Who Can Help

- IBCLCs and lactation consultants
- Early Childhood Interventionists
- developmental pediatricians
- occupational therapists (OTs)
- physical therapists (PTs)
- speech therapists (SLPs)
- WIC Special Supplemental Nutrition Program for Women, Infants, and Children
- social workers and case managers

Special Educational Needs

Every child has their own unique developmental needs and **every student has their own unique and special educational needs**.

Take advantage of the services and support that can meet your child where that are and help them reach their future educational goals.

Call your local school district to request a free educational evaluation. Learn about all the available programs and support.

Who Can Help

- Preschool Program for Children with Disabilities (PPCD)
- Special Education programs under the Individuals with Disabilities Education Act (IDEA)
- educational psychologists
- speech therapists (SLPs)
- occupational therapists (OTs)
- reading specialists





Virtual 37th Annual Conference Advances In Therapeutics And Technology: Critical Care Of Neonates, Children And Adults

March 24, 2021-March 26, 2021 At 8:00am

Registration Link: <u>Https://Www.Eventbrite.Com/E/Virtual-37th-</u> <u>Annual-Conference-Advances-In-Therapeutics-And-Technology-</u> <u>Cri-Tickets-132360811751</u>

For More Details And Accommodation Information, Please Go To <u>Www.Paclac.Org/Advances-In-Care-Conference/</u>.

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Featured Conference: Agenda for the Virtual 37th Annual Advances in Therapeutics and Technology: Critical Care of Neonates, Children, and Adults

Donald Null, MD, Mitchell Goldstein, MD, Arun Pramanick, MD

Wednesday, MARCH 24, 2021

Time	Title	Speaker
8:00am	Opening remarks	Arun Pramanik, MD
		Professor of Pediatrics, Louisi- ana State University School of Medicine
8:15am	Special Lecture	Mitchell Goldstein, MD
	Respiratory Syncytial Virus: What is New and Where are we Going	Director, Neonatal ECMO Profes- sor of Pediatrics, Division of Neonatology, Loma Linda University Children's Hospital
9:10am	Neonatal Resuscitation Workshop: Scenarios with	Anup Katheria, MD
	Development of Check Lists with Pre-briefs and De-briefs	
10:10am	Break	
10:30am	Abstract Presentation	Mitchell Goldstein, MD
	Inadvertent High-Frequency Ventilation Associated with High Flow Nasal Cannula and Temperature Variation	
10:50am	Abstract Presentation	Venkatakrishna Kakkilaya, MD
	Decreasing CPAP Failure in Preterm Infants by Optimizing CPAP and Less invasive Surfactant Administration (LISA)	
11:10am	Electrical Impedance Tomography: Benefits and Limitations	Karel Roubik, PhD
12-1pm	Break: Exhibit Hall Zoom Link:	
	https://zoom.us/j/92004155267?pwd=Y2ZtanZVa3p2VHJQMXJjbFZCTGZEZz09	
1:00pm	Special Lecture	
	Long Term Health Outcomes of Oxygen Exposure in Preterm Infants from a Mouse's Perspective	Michael O'Reilly, Ph.D.
2:00pm	Case Scenarios of Special Newborns. How to tell when your evidence based proto- col is not likely to work	Donald Null MD, Professor of Pediatrics
		Director NICU and Neonatal Transport
		UC Davis Children's Hospital
3:00pm	Break	
3:15pm	Update on transcatheter occlusion of the PDA in very low birth weight infants	Frank Ing, MD
4:05pm	Metabolomics in a Clinical Care Environment:	
	Perioperative environmental exposure to cyclohexanone during neonatal congenital cardiac surgery is associated with decreased	David Graham, M.Sc., Ph.D
	Neurodevelopmental outcome	
4:30- 5:20pm	Technology and how it could address health disparities in children	Colleen Kraft, MD

Thursday, MARCH 25, 2021

Time	Title	Speaker
8:00am	Diaphragmatic Hernia Strategy to improve survival and reduce the need for ECMO	
		Bradley Yoder, MD
9:00am	Assessment of Cardiac function in the ECMO patient both Pre-ECMO and while on ECMO	
		Donald McCurnin, MD
10:00am	Break	
10:20am	Implementation of a High Frequency Jet Ventilation	Brian Simmons, B,Sc, (Hons),
	Program Over the Years	BM, MMEd, FRCPC.
11:15am	Special Lecture	
	Adult Cardiopulmonary Sequelae of Preterm Birth	Stephen Derdak, DO
12-1pm	Break: Exhibit Hall Zoom Link:	
	https://zoom.us/j/92004155267?pwd=Y2ZtanZVa3p2VHJQMXJjbFZCTGZEZz09	
1:00pm	Special Lecture	Shinjiro Hirose, MD
	Fetal Surgery Risks and Benefits	Vice Chair Dept of Surgery
		Chief Div. of Pediatric Surgery
		UC Davis Medical Center
2:00pm	Abstract	Mitchell Goldstein, MD
	Can Bubble CPAP Enhance High-Frequency Jet Ventilation?	
2:20pm	Abstract	
	20 Impact of timing of Polymyxin B-immobilized Fiber Column Direct Hemoperfu- sion on Outcome in Patients with Septic Shock	Tomoki Tanaka MD
2:40pm	Abstract	Antoine Persello
	A new rat model of extracorporeal life support developing early multiple organ dys- function is relevant for preclinical studies and comparable to clinic	PhD student
3:00pm	Break	
3:15pm	Special Lecture	Stephen Minton, MD, FFAP
	DeLemos Memorial Lecture	Chief Neonatology Utah Valley
	Telemedicine A Neonatologist's Perspective and Use	Hospital
		Medical Director Intermountain Healthcare Newborn Services
4:10pm	Abstract	
	Neurobehavioral Outcomes of Former Preterm Lambs are Better when Respiratory Management is Noninvasive compared to Invasive	E. Dawson
4:30pm	Abstract	
	Noninvasive Resuscitation and Continuing Respiratory Support of Preterm Lambs Leads to Appropriate Alveolar Capillary Growth	A. Rebentisch
4:50pm	Abstract Intensive Care on the Go: Practical Evaluation of the Simplified Auto- mated Ventilator II as Adjunct to Mobile Extracorporeal Life Support in Management of Trauma-Induced Respiratory Failure	Brendan Beely, RRT



Friday, MARCH 26, 2021

Time	Title	Speaker
8:00am	<i>Special Lecture</i> Genomic testing approaches in the critically ill neonate	Lisa A. Schimmenti, MD Department of Clinical Genomics, Professor of Pediatrics, Co-Director, Medical Scientist Training Pro- gram (MD/PhD), Consultant, Departments of Clinical Genomics, Otorhinolaryngology, Head and Neck Surgery, and Biochemistry and Molecular Biology, Mayo Clinic School of Medicine
9:00am	Special Lecture	
	Advances in microfluidic organ support technology	Jeffrey Borenstein, PhD
10:00am	Break	
	Abstract Presentation	
10:15am	Diagnosis of inhalation injury severity using optical coherence tomogra- phy	Jae Choi
10:50am	Abstract Presentation	Lidia Park, MD, PhD
	Asymmetric vertical transmission of SARS-COVD-19	Department of Pediatrics, UC Davis Chil- dren's Hospital
		Joseph A. Bocchini, Jr., MD, FAAP
11:10am	Covid-19 Multisystem Inflammatory Syndrome in Children	Vice Chairman, Department of Pediatrics, Tulane University
11:45am	COVID-19 Vaccines: Update	Joseph A. Bocchini, Jr., MD, FAAP
	Break: Exhibit Hall Zoom Link:	
12-1pm	https://zoom.us/j/92004155267?pwd=Y2ZtanZVa3p2VHJQMXJjbFZCTG ZEZz09	
1:00pm	Covid-19 in NYC: The Epicenter (Safety & New Approaches)	Felix Khusid, RRT
2:00pm	Innovation in Antithrombogenic Coatings for Extracorporeal Life Support	Teryn Roberts, PhD
3:00pm	Break	
3:15pm	Protecting the Lung: Ventilator Optimization during VV ECMO	Steve Conrad, MD, PhD
4:10pm	ECMO for the Covid-19 Patient	Steve Derdak, DO
5:45pm	Conference summary Closing remarks Plan for 2022	Donald Null, MD

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Arun Pramanik, MD Professor of Pediatrics Division of Neonatology Department of Pediatrics Louisiana State University

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New Congress Takes Aim at Maternal Health Inequities

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

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



The 117th United States Congress, which first convened in January, is the most racially and ethnically diverse Congress to date. (1) Nearly a quarter of voting members are people of color. More than a quarter are women.(2) It should not come as a surprise then that this Congress quickly proposed multiple bills on health inequities affecting women in underserved and rural communities.

Pregnancy-related mortality is one of those issues. Native American moms are dying at more than twice the rate of their white counterparts. Black moms are three times more likely to die than white moms. (3)

The Black Maternal Health Momnibus Act of 2021

In February, the Black Maternal Health Caucus of the U.S. House of Representatives introduced the Black Maternal Health Momnibus Act of 2021. (4) The package includes 12 bills that collectively "address every dimension of the maternal health crisis in the United States." Vaccines, social determinants of health, mental health care, and the perinatal workforce are among the topics of individual bills.

More than 190 organizations have declared their support for the legislative Mominibus. Proponents include the Association of Women's Health, Obstetric and Neonatal Nurses, among others.

"These bills align with our agenda of reducing maternal morbidity

"Nearly a quarter of voting members are people of color. More than a quarter are women.(2) It should not come as a surprise then that this Congress quickly proposed multiple bills on health inequities affecting women in underserved and rural communities."

and mortality, improving the health status of women, addressing racial health disparities and structural and social determinants of health, and resolving health inequities contributing to these issues," declared Cyndy Krening, MS, the association's president.

The Rural Maternal and Obstetric Modernization of Services Act

Also, in February, Representatives Dan Newhouse (R-WA) and Cindy Axne (D-IA) led another group of lawmakers in refiling the Rural Maternal and Obstetric Modernization of Services Act.(5) The legislation extends support to rural moms, who are experiencing inequitable maternal mortality rates, too.

"Rural areas have a maternal mortality rate that is 38% higher than urban area," according to a one-pager from the bill's sponsors.(6) It also noted that maternal health care's disappearance in rural America disproportionately affects people of color. (7)

These outcomes are driven, in part, by the shortage of health care providers and the lack of access to labor and delivery hospital services in remote areas. (8) Financial strain has forced many rural hospitals to close their labor and delivery units or shutter their entire facility. This forces expectant and new moms to travel great distances to get quality maternal health care. Ten to 40% do not keep a postpartum appointment in part because of geographic isolation or limited transportation. (9)

The Rural MOMS Act aims to address these access challenges by expanding existing federal telehealth grant programs to include birth and postpartum services. It will also establish a rural maternal and obstetric care training demonstration to provide maternal care services in rural community-based settings.

The United States posts the highest maternal mortality rates in the developed world. (10) It is even more disturbing that the vast majority of these deaths are preventable. Now, an enthusiastic new Congress appears committed to addressing the drivers of this unfortunate and rising trend. As Representative Alma Adams (D-NC) declared, "Black mamas can't afford to wait."

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- <u>https://www.pewresearch.org/fact-tank/2021/01/15/a-record-number-of-women-are-serving-in-the-117th-congress/</u>
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80



I CAN Digitally Involved (iCANDI)

Amy Ohmer



International Children's Advisory Network

"Founded in 2014 by Dr. Charlie Thompson, iCAN, a registered 501(c)3, has grown to represent children ages 8-18 on four continents in over 29 (including one virtual) chapters. This unprecedented growth results from the strong partnerships between the American Academy of Pediatrics, Georgia Tech, other academic institutions, and a large number of hospitals and other committed stakeholders."

At the International Children's Advisory Network, Inc. (iCAN), we are committed to offering many wonderful and exciting opportunities to ensure that the pediatric patient voice is infused throughout all facets of science, research, medicine, and advocacy. This month, in order to reach our community members from around the world, iCAN invites everyone to check out the robust and comprehensive website at <u>www.icanresearch.org</u>. As always, iCAN content is made freely available to those interested in supporting our youth members. To work with us directly by engaging with our kids, contact iCAN today through <u>info@icanresearch.org</u>.



The 34th Annual Gravens Conference on the Environment of Care for High Risk Infants March 3, 4, 10, and 17, 2021: Virtual live March 24 – September 30, 2021: On-demand

www.thegravensconference.com Early Bird Registration through Dec. 31, 2020

This month, iCAN is pleased to announce new partnerships with Synchrogenix, MedEvoke, and PRA HealthSciences. These three organizations are a wonderful addition to our existing iCAN community of dedicated partners. By engaging with iCAN, the commitment to providing youth with the highest level of pediatric care is at the forefront of every decision they make. Watch for more information at the upcoming iCAN 2021 Summit as we create special activities designed just for kids. Speaking of the iCAN 2021 Summit... registration will open on March 15th, 2021, and we invite everyone to join in.

"Watch for more information at the upcoming iCAN 2021 Summit as we create special activities designed just for kids. Speaking of the iCAN 2021 Summit... registration will open on March 15th, 2021, and we invite everyone to join in."

In addition, iCAN completed projects with Hope for Henry and The Beauty Bus in which kids ages 13 and up shared their feedback for products designed to support in-patient recovery. This fun virtual event was hosted through Zoom, and kids were given a firsthand look at supporting their peers in long-term care. By the end of the evening, there was additional awareness of what helps kids along with a great learning session of what can be improved - plus a lot of fun had by all.

Next, iCAN collaborated with Astellas, SHIP-MD, the Pediatric Trials Network (PTN), AIMED, and a new start-up called KIDSx to ensure that the patient voice continued to the forefront. Through a series of opportunities using technology, kids created videos, took



Provided by: USF HEALTH

For more information, contact the meeting planner at nrose@usf.edu

surveys, wrote scripts, and participated in virtual reality games to share their expertise. Each project provided researchers, providers, and scientists with up and close learning opportunities of what "kids really think." By involving kids from the beginning, each project had a terrific outcome in creating innovative new materials and processes for children living with rare, chronic, and complicated conditions.

iCAN is featured in the digital copy of the Global Genes' Young Adult Financial Advocacy Resource Guide. This online guide provides information and tools to help you have purposeful conversations with your family and care providers about care transitions. Whether you are heading to college, into the workforce, or living at home with your parents, this guide provides information on how to get health insurance coverage, find healthcare providers who understand your needs, and advocate for yourself when you need care. <u>https://globalgenes.happyfox.com/kb/article/270-financialadvocacy-in-rare-navigating-the-u-s-health-system-for-youngadults/</u>

Several survey opportunities remain open through the collaboration of EPTRi as well as on Assent.

Looking ahead, we invite Summit participants (to be virtually held from July 12-16, 2021) participants to send in a Chapter Poster - a culmination of work done throughout the year to support their local chapters. The Summit Poster Session is also open to other interested community members that might like to showcase their original abstracts to the iCAN Community. The Poster Session and all other open projects are available on the 'FOR KIDS' tab on the homepage. As a reminder, if any interested kids are not involved in an iCAN chapter but would like to participate, iCAN offers a Virtual Chapter to accommodate any child, anywhere in the world.

For more information on iCAN, email <u>info@icanresearch.org</u> or visit <u>www.icanresearch.org</u>

#iCANMakeADifference #iCAN #iCANDigitallyInvolved #Global-Genes #CareAboutRARE

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Amy Ohmer Director, International Children's Advisory Network Email:. <u>amyohmer@icanresearch.org</u> Website: <u>www.icanresearch.org</u> Phone: (+1)7345452831 OPIOIDS and NAS When reporting on mothers, babies, and substance use LANGUAGE MATTERS



I am not an addict.

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

I was exposed to opioids.

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



NAS is a temporary and treatable condition.

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



My mother may have a SUD.

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

My potential is limitless.

82

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

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



Respiratory Syncytial Virus is a

Really Serious Virus

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



www.nationalperinatal.org/rsv

PROTECT YOUR FAMILY FROM RESPIRATORY VIRUSES

flu 🛔

coronavirus







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

1.



The Next Generation of NICU Staff

Kelly Welton, RRT-NPS

2020 wreaked havoc on all of us. Life's rhythm as we knew it in 2019 got transformed as we learned a new way to do almost everything in 2020. Although Zoom and Amazon saved many people from unnecessary trips to the office and the store, one thing remained unchangeable: healthcare, specifically patient care, is a hands-on business.

Since patient care is a hands-on profession, training requires a mentor to show us the how-tos. It is one thing to learn how to set up a ventilator or an IV pump; another thing entirely to trouble-shoot one that's not doing what you set it to do.

Thanks to SARS-Covid-19 [CoVid], many respiratory therapy and nursing school programs closed. First, clinical sites closed their doors so as not to expose students to this new virus that was spreading fast. Then schools closed their doors to in-person instruction. Forced to learn online, recent graduating classes will only get their 'hands-on 'experience once hired.

" In Southern California, there were two programs available that provided in-depth NICU classes and clinical training. Both programs have subsequently closed, leaving nowhere for therapists to get basic NICU training."

In the hospitals, current staff who want to be trained to work in NICU often need approval from their manager. In Southern California, there were two programs available that provided in-depth NICU classes and clinical training. Both programs have subsequently closed, leaving nowhere for therapists to get basic NICU training. Managers are also tasked with being chronically short-staffed, unable to let a staff member shadow a NICU RT for a day because they are desperately needed in the other hospital areas. This situation has been true for decades; however, CoVid demanded all-hands-on-deck, and there was no time for any RT not to carry a workload.

As an RT Educator, my role has been to find the areas in which staff need additional training. Whether it is low-use equipment or training in a new area, competency in not just knowledge. Critical thinking and troubleshooting are also 'musts.' Although the NICU was not left untouched by Covid, when the CoVid dust settles, many RT's and RN's will either leave the field or seek solace in a place that is not calling a code every hour and losing 3-4 patients per shift. When these seasoned therapists retire, who will be left to care for patients? For these reasons, the Academy of Neonatal Care was formed. Initially, AoNC was designed to be a hands-on workshop. Participants learn the foundation of neonatal respiratory care and participate in workshops practicing correct fitting of nasal prongs, changing Oscillator circuits, surfactant instillation, and more. Covid has now challenged AoNC as well to translate learning to an online format. Clinical competency software and the ability to present live online courses where students can ask questions in real-time help AoNC fill the void.

"As a non-profit 501 (c) 3, the Academy of Neonatal Care's goal is to teach the highest level of care to beginners in NICU and seasoned therapists. RN's are welcome to join, as are physicians."

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As a non-profit, the Academy of Neonatal Care's goal is to teach the highest level of care to beginners in NICU and seasoned therapists. RN's are welcome to join us, as are physicians.

Our secondary goal is to reach out to NICU babies' parents and family to support them while their baby is in our care. Lastly, as a non-profit, we will give back by contributing to community outreach and support healthy pregnancy and healthy baby efforts across the world.

With the release of a CoVid vaccine, we look forward to presenting live and in -person. AoNC's platform continues to change with the times, but our 'base camp' remains the same. We built day one for beginner RT's and RN's who have wanted to learn NICU but have never been given a chance to get into a NICU with a preceptor.

Day 2 is designed for the RT that floats to NICU occasionally and wants a refresher to reinforce skills and knowledge.

Day 3 is designed for current NICU staff who want to expand their knowledge on subjects such as Jet ventilation, iNO, Transports,

84

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and more. The way we are going, we may soon have a full 5-day course!

"That certificate carries significant weight with the participant's employer or director, enough so that the manager would feel confidant pairing the RT with a mentor to help them assimilate into NICU."

Academy of Neonatal Care's vision is that when the first three days are completed, the RT has a certificate from AoNC that says, "I finished the entire AoNC course, and am now ready to work with a preceptor." That certificate carries significant weight with the participant's employer or director, enough so that the manager would feel confidant pairing the RT with a mentor to help them assimilate into NICU.

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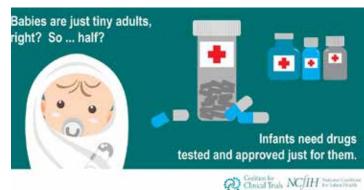
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Education. Anytime, Anywhere.



The Academy of Neonatal Care serves to educate Respiratory Therapists, Nurses, and Doctors in current and best practices in Neonatal ICU care. We prepare RTs new to NICU to fully function as a bedside NICU RT. Our goal is to enrich NICU care at all levels. Beginner to Advanced Practice, there is something for you at:

www.AcademyofNeonatalCare.org.

Peer Reviewed

The Nature of Neonatal Experience during Pandemic COVID-19

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

Abstract

Life abruptly becomes chaotic. This is much like crossing a threshold into a room where we don't belong. The chaotic situation entrains energy and resources, forming a trajectory to cascading failure. The HRO accepts this trajectory and members of the HRO engage in events even as they do not know how to bring it to an end. This is the liminal period, across the threshold and away from our routines. While it appears daunting, if not dangerous, this approach builds on experiences we have had throughout life. HRO methods uniquely shape the engagement that moves through and out of a liminal period. HRO is a trajectory of engagement that fuses now with the experience of then into simultaneous inquiry and redescription. In these states of engagement, the HRO supports using all our mind.

"Experience is more than an encounter or an event. Our presence alone affects the environment, our actions change the environment, and the environment's response changes us."

The Nature of Experience

Experiences happen to an individual. We "have" experiences in that they happen with "a minimum of regulation, with little foresight, preparation, and intent" (1). Experience is more than an encounter or an event. Our presence alone affects the environment, our actions change the environment, and the environment's response changes us. Reflection gives meaning and salience to our experience. Experience has a form of intimacy in that we don't share the totality of our experience with anyone, how we interpret experience (meaning), nor how we keep and use experience (value). From the Latin root, *experiential*, "a trial, proof, experiment; knowledge gained by repeated trials," experience contributes to wisdom and identity. A person's experiences become an extension of themselves into the group and help develop new work areas.

When encountering an abrupt change in circumstances, we draw upon experience until we develop the necessary information to use concepts. It is only afterward that we process our experience through concepts for better understanding. When we discuss such an experience, we use concepts that constrain our message.

> During a crisis, there is no time to think about each specific bit of knowledge or experience that we depend on to make sense of imperfect information and ambiguity. But having those resources immediately accessible in our minds, we use them in a conceptual decision-making process to frame the decision. We essentially quickly come up with a paradigm of how to solve the problem. It is after the fact that we retrospectively begin to attribute specific reasons for the decisions that we made.

> Capt. Chesley "Sully" Sullenberger (personal communication)

"Conscious experience is the awareness of a person's environment as it is perceived. In risky situations, what helps us also hurts us. Such imbalance is continuous while our rules and concepts are fixed and discrete. Experience is what we bring to maintain this balance."

Conscious experience is the awareness of a person's environment as it is perceived. In risky situations, what helps us also hurts us. Such imbalance is continuous while our rules and concepts are fixed and discrete. Experience is what we bring to maintain this balance.

Perhaps the characterization of experience in this article will demonstrate how experiencing the trajectory of events amidst the flux and flow can serve as a foundation for understanding High-Reliability Organizing. We differentiate the use of experience *during* a crisis from the conceptual clarity that comes *after*, as described by Capt. Sullenberger.

> The essence of life is its continuously changing character, but our concepts are all discontinuous and fixed, and the only mode of making them coincide with life is by arbitrarily supposing positions of arrest therein. With such arrests, our concepts may be made congruent. But these

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concepts are not parts of reality, not real positions taken by it, but suppositions rather, notes taken by ourselves, and you can no more dip up the substance of reality with them than you can dip up water with a net, however finely meshed. William James (2)

William James (2) describes thought as dealing solely with surfaces while experience can delve into the "thickness" of reality. James (1842 – 1910) (3) and Charles Sanders Pierce established pragmatism as the philosophical study to counter the Kantian view that concepts distort rather than reveal reality. He established Harvard University's psychology department and the first experimental psychology demonstration laboratory. The James-Lange Theory of Emotion describes how the human experience of emotion arises from physiological changes in response to external events. James initially trained in painting, an experiential observation activity that contributes to the Art of Knowledge (4).

Experience is the particulars and relations which have meaning, values, and intention (5). This explains why each of us will have a different experience during the same incident. Thinking is ongoing (6), contextual, and how we experience the environment, how we reach into the environment (7).

We learn about the environment through experience, which provides a way into life's true shape, unconfined by concepts. "The tiniest feeling that we can possibly have comes with an earlier and a later part and with a sense of their continuous procession" (2). Everything is in an environment as an open system subject to the flow of elements and energy. Everything experiences friction and support from other parts of the environment. Each element can be described by both its intrinsic qualities and its external relations with its environment. The traits of a situation include the openness if the system and these extrinsic elements. For example, a seriously ill neonate's care in a rural community hospital differs from the care for an identical, seriously ill neonate in the labor and delivery unit of a university medical center. Each person present in the same situation has a different experience.

Direct acquaintance through experience and conceptual knowledge complement each other, filling in the gaps natural to each. This experience that reveals the nature of things is critical to support the validity of intellectual knowledge. Experience as direct, unmediated awareness of events is knowledge by acquaintance (8), a foundational principle of HRO.

We cannot know how someone individually experiences an event, even when we are adjacent to them. Sensations are experienced singly, together, fluctuating as attention fluctuates, items in memory entering or dropping out (2). To have "knowledge by acquaintance," we must have a cognitive relation with the person, direct and unmediated awareness of what they are experiencing (8), including their cognition. This is not a trite statement. When we accept others' experiences, we gain a more reasonable idea of the sum of experiences in the event and a better appreciation of life.

Introducing students in training to a basic truck driving maneuver, which is the same worldwide, the instructor must be aware of each student's experiences and motivations, how they react to instructions, and how they react to the truck's movement. The real teaching and learning event occurs when the student synthesizes a new experience from their previous experience (Errol van Stralen, polymath, educator). In this manner, *instructional* learning becomes a preparation for *experiential* learning. "Maybe, HRO is a trajectory of engagement that fuses now with the experience of then into simultaneous inquiry and redescription," Karl Weick (personal communication).

While the leader may have developed close relationships with subordinates, the cognitive and affective responses to an emotionally charged event can be indirect, delayed, or become dormant (9, 10). The leader can become familiar with the cognitive styles experienced individuals may use, such as model- or concept-based, pragmatism, stress- or fear-based, or allostatic challenge.

We also cannot experience the sum-total of events around us because the experience is disseminated, distributed, and incompletely unified. The belief that one's experience is shared by or subordinate to others risks negating their experience. This absolutist view happens in healthcare when a physician or surgeon negates others' experience, removing their experience from consideration. It then becomes the dominant account, driving other views to become hidden voices with loss of the expertise the leader could have deferred to (11).

"Considering the world as rational, coherent, and predictable removes the sense of experience, contributing to reliance on discrete concepts and introducing expectations into operations. Through irrationality, a constituent of experience, and our reluctance to simplify, the 'actual world' reveals discontinuities, discrepancies, and disruptions."

Considering the world as rational, coherent, and predictable removes the sense of experience, contributing to reliance on discrete concepts and introducing expectations into operations. Through irrationality, a constituent of experience, and our reluctance to simplify, the 'actual world' reveals discontinuities, discrepancies, and disruptions. Thus, our irrationality becomes the conduit necessary for the identification and engagement of early heralds of failure. At worse, the charge of irrationality is used to gain conformance from others.

Experience has its own internal rationality that appears irrational to the outsider. Everyone acts in a way that makes sense to them. Some will apply external rationality to a situation, for example, "What were they thinking?" This phrase diminishes the efforts of others and prevents learning from the experience of others, a necessary step in generating safety. One author reframed the situation, "What the person did was correct. It was what I would have done." Then, the question, "What made the person think it was the right thing to do?" reveals information otherwise unattainable and produces interventions to generate greater reliability and safety.

88

The drive to conjure a satisfactory reason for an irrational act comes from our need for self-preservation. If the person acted or thought in a way "I wouldn't," and since "I don't do that," then "I am safe." This becomes striking in the NICU when well-meaning family and friends ask the mother if she did "X" during her pregnancy. They are searching for anything that makes them feel safe; anything the mother did that they wouldn't do, means they are safe.

"Experience is how we transform reality, how we transition the actual world to a possible world. Regardless of role or status, the individual has the experience and transforms reality. One's presence constitutes experience. "

Experience is how we transform reality, how we transition the actual world to a possible world. Regardless of role or status, the individual has the experience and transforms reality. One's presence constitutes experience. When one author (DvS) exited the fire rescue ambulance as one of two on the unit, his presence changed the scene - countenance, stance, or walk. It didn't matter if the crowd was angry, apprehensive, or frightened. We could direct their feelings or leave them uncontrolled to continue cascading toward an uncertain result. The simple process and content of questions changed their experience. Asking what the person did could make them feel responsible, as described above, impeding information flow. Concepts assumed to be necessary for evaluation and management could misdirect or mislead our inquiry. "Vital or direct experience, as man's experience, is more valuable; and is truer in the sense of worth more for other interpretations, for the construction of other objects and the basing of projects upon them" (12).

John Dewey (1859–1952) was a psychologist who criticized the reflex-arc for animal behavior as simplistic because animals *continuously interact* with the environment in cumulative and modifying ways; educator, initiating the University of Chicago Laboratory Schools; and philosopher, identifying the importance of experience in "cultural pragmatism."

Concepts and Concreteness

Concepts provide the elements for comparison, standardization, and quantification. Immanuel Kant (1724–1804) presented concepts from specified delimited categories and argued against scientists' efforts to transcend thought and experience. He posited that knowledge is accessible and contained within the limits of these categories. Therefore, it is possible to know the world and its phenomena. He argued against the value of experience. Today we readily reject the details of his ideas without realizing his work formed science as concepts and logic.

His influence spans the 18th Century to today in the physical sciences, the life sciences, modern mathematics, mathematical logic (13), and social sciences (14). Our use of "spatio-temporal relations" comes from his idea of space and time as entities that structure experience distinct from objects themselves. The formulation

of "social knowledge" is how Kant mediated between the facts and thought of reason and morality's values and action (14). *Kant's Critique of Pure Reason* (15) is one of the most influential works in philosophy.

Kant developed the idea that knowledge as facts and concepts are included in preformed (a priori) categories and linked rigorously by laws of formal logic (16, 17). Something cannot exist except for its inclusion in a category, therefore placing a limit on knowledge. Kant's influence on the definitions of knowledge and the validity of science directly influences how we experience science and, by extension, how we experience emergencies in the NICU.

One view of Kant is that living in an environment of chaos simplified thinking for us, separating the objective from the subjective and delimiting knowledge to specified categories connected by scientific logic. Kant responded to an environment of chaos, particularly in response to the 1755 Lisbon, Portugal earthquake that killed 40,000 people, by creating metaphysical order for knowledge and behavior (18, 19). Kant also argued earthquakes were a natural phenomenon and not punishments from God and may have started a humanitarian approach to disasters (20). Perhaps Kant separated belief from reason because of concurrent disasters. HRO, through experience, unites belief and experience.

With modifications, the Kantian view of concepts continues into the sciences with a priority of beliefs developed from concepts over beliefs derived from experience. James, Dewey, and Whitehead argued against the primacy of concepts when applied to actions. Today, we encounter healthcare professionals who, standing at the bedside with us, refuse to believe what is happening because it is not in a concept known to them or will not accept the experience because it does not fit a known concept. However, in a liminal state or High-Reliability Situation, the gap between structured theories and an unstructured situation makes it difficult to rely on reasoning. In our discussions with Karl Weick, we believe that HRO shrinks the size of that gap.

Dewey and James contested Kant's emphasis of concepts over experience, that knowledge did not exist beyond concepts and his categories (19, 21, 22). The theory provides unity of experience by general laws and the constitution of experience. For Kant, this determines the completeness (unity) of knowledge (13).

We do not experience concepts; rather, concepts emerge from experience. Concepts are representations of reality; we must not mistake them for reality. "What really exists is not things made but things in the making" (2).

> When we conceptualize, we cut out and fix, and exclude everything except what we have fixed. A concept means a "that-and-no-other"... In the real concrete sensible flux of life experiences compenetrate each other so that it is not easy to know just what is excluded and what is not... Past and future, for example, conceptually separated by the cut to which we give the name of present and defined as being the opposite sides of that cut, are to some extent, however brief, co-present with each other throughout experience. The literally present moment is a purely verbal supposition, not a position; the only present ever realized concretely being the 'passing moment' in which

the dying rearward of time and its dawning future forever mix their lights. Say 'now', and it was even while you say it.

William James (2)

"Concepts can be 'counterfeit abstractions' that imitate some, but not all, of the differentiated flux produced by attentive HRO practitioners, (Karl Weick, personal communication). That is the trouble with experience, when is a concept useful, when it is a counterfeit abstraction, and when is it misplaced concreteness? Alfred North Whitehead (23) describes "the accidental error of mistaking the abstract for the concrete. It is an example of what might be called the 'Fallacy of Misplaced Concreteness.'" But concepts can be intentionally used as concreteness. James (24) described how one could identify a salient or important feature to use it as the group's classifier, negating other attributes in favor of this single trait. "Abstraction, functioning in this way, becomes a means of arrest far more than a means of advance in thought." It becomes too easy to substitute a virtual world from concepts for the actual world is by way of the fallacy of abstraction.

"HROs operate within the flux and flow of not only operations but the environment. Rather than a direction, operations do operate in a direction, such as a premature infant is admitted, the mechanical ventilator is managed, the lungs heal, the infant can be discharged home. "

HROs operate within the flux and flow of not only operations but the environment. Rather than a direction, operations do operate in a direction, such as a premature infant is admitted, the mechanical ventilator is managed, the lungs heal, the infant can be discharged home. But disruptions change the arc, something the neonatologist engages intending to redirect the new trajectory. Using abstractions for concreteness is a fallacy more likely relied on at a distance; the moving trajectory of events reduces this severe concreteness (Karl Weick, personal communication).

> The misplacing and fixing of abstractions is a big issue. Misplaced concreteness is the problem. and your emphasis on moving, flow, trajectory, reduces (severe concreteness.) I'm studying a disaster that sank the container ship El Faro. As they are entering the eyewall of hurricane Joaquin, without knowledge of winds and at 4 AM in darkness, the captain says, 'this is a typical winter day in Alaska.' and sticks to his route straight toward the eye. Ship (790 feet long) capsizes 3 1/2 hours later drowning all 33 crew. Typical day is a severe abstraction. Karl Weick (personal communication)

<u>The problem with models</u>. Experts do not use systematic patterns yet tend to detect errors faster and with greater accuracy than students (25). "There is a leap, a discontinuity, between the competent level and the proficient and expert levels. If experts are

made to attend to the particulars or to a formal model or rule, their performance actually deteriorates" (26, 27). To become truly proficient, we must drop rules, which are the tools of professionals. This is similar to Weick's adage to firefighters to know when to drop their tools (28). It is the experience that gives the wisdom when to drop them. In the Mann Gulch wildland fire disaster, fire foreman Wagner Dodge says, "Drop your tools." His crew held onto their tools. Thirteen men died. Using experience as the frame of reference, experiencing a fire burning up a steep slope on a hot day and you are near the ridgeline, what would you be experiencing? What is the experience of holding a fire tool? When does the tool protect you, and when does it kill you? Is there a sharp line? Experience that when you stand next to the isolette with a dying baby. Experience decompresses decisions even as alternatives gain gravity while you work to gain life. At times, we can only communicate through experience.

"Experience decompresses decisions even as alternatives gain gravity while you work to gain life. At times, we can only communicate through experience."

Experience has purpose

Our experiences in the moment contain story arcs that connect us to our past to others and form extensions into our future. For John Dewey(29), when we perceive our work as aesthetically pleasing, we create experiences in which the subject is new. Our work then becomes an endeavor with those around us. This is the art of neonatology as experienced (4). Dewey contrasts this with inchoate experience in which we are distracted and do not complete our course of action. "For Dewey, life is a collection of histories, each with their own plots, inceptions, conclusions, movements and rhythms" (29). Each has a unique pervading quality. Our experience becomes our identity and is the source of our pride.

Experience as an endeavor. Dewey holds that someone who aesthetically perceives a work will create an experience in which the subject is new material. Experiences are processes of doing or making. Experiences are the assets people bring to a program. Experiences are also their identity and source of pride in their own accomplishment rather than in the team or organization. This goes to the aesthetic from Dewey: Art and experience (4) are what makes an experience an experience by uniting them in the same relation. When the experience runs its course and problem solved, or we have a resolution, it is more a consummation than a cessation. This carries a quality of self-sufficiency, and our experience gives meaning to our life (29).

Our experiences in the moment contain story arcs that connect us to our past, to others and that form extensions into our future. For John Dewey (29), when we perceive our work as aesthetically pleasing, we create experiences in which the subject is new. Our work then becomes an endeavor with those around us. This is the art of neonatology as experienced (4)]. Dewey contrasts this with inchoate experience in which we are distracted and do not complete our course of action. "For Dewey, life is a collection of his-



tories, each with their own plots, inceptions, conclusions, movements, and rhythms. Each has a unique pervading quality. Our experience becomes our identity and is the source of our pride.

"Through the Art of Neonatology, neonatologists care for their patients and gain life."

Experience as inquiry. "Inquiry is the behavioral response of a reflective organism to its environing conditions, taking place in the world, not just within the mind," John Dewey (30). Truth is related to experience rather than extrinsic to experience. Truth, then, is a process of inquiry (29). Whereas in science, truth is objective and can be settled to be available for the use of others. One of the five values is honesty (DvS book), described by one of the authors (TAM), where what a person says represents what is happening. In the HRO process, knowledge and truth never become settled.

John Dewey believed in keeping continuity between everyday experience and art (29). In fact, the art of neonatology extends the experience of life into the NICU and the methods of cognition into everyday experience. This develops at a deeper level than acting as healthcare professionals in public. Rather than maladaptive responses to the stress vectors novelty, uncertainty, uncontrollability, or a fear vector (31), individuals more readily adopt allostatic or prosocial responses. Discrepancies and disruptions then become early heralds of failure that trigger engagement.

During a routine state review where one author (DvS) was an attending, the auditor asked facility leaders a question about the mechanical ventilators. Observing the discomfort as the leaders called for a senior administrator, a bedside respiratory care practitioner (RCP) hurried to the room and announced, "Hi! I'm an RCP. Can I help?" The RCP correctly answered the question. This is not a story of a bedside caregiver besting leaders. The RCP joined the group with a sincere desire to help. Rather, the RCP had incorporated into experience the *extensional traits* of HRO regarding the ecology of fear and the art of medical care (4, 32).

Experience as meaning. Experiences are the assets people bring to a program. Experiences are also their identity. Our experiences in the moment contain story arcs that connect us to our past, to others and that form extensions into our future. Consummating an experience or solving a problem gives us meaning (Letty) and a sense of self-sufficiency. For John Dewey (29), when we perceive our work as aesthetically pleasing, we create experiences in which the subject is new. Our work then becomes an endeavor with those around us. This is the "art of neonatology" (4) as experienced. Our experience then becomes our identity and is the source of our pride.

Theories can isolate the organization from the environment in the manner that appreciation of the *theory* of HRO supersedes the appreciation of the *experience* of HRO. Experiences are the source of pride for the individual in their own accomplishments rather than the team or organization's accomplishments. We give meaning to our personal efforts through experience. Experience as learning. Our experiences are developing series and circuits of activities rather than disconnected sequences. Learning builds on complementary experiences and prepares us for expected experiences. This is the affective domain (33) of how learning will help the individual. One of the authors (DvS) held that "what is taught today should explain yesterday or be used tomorrow." For Dewey (Letty), "inquirers" move from the phase of dissatisfying doubt toward satisfaction of resolving a problem and gaining meaning.

Experience as support. "You can do it." These words, said in person, provide a deep, intimate level of support that carries in memory for decades. One author (TAM) heard it from his captain before his first combat mission over North Vietnam. The other author (DvS) heard it from his fire station commander, Bill Corr, during a difficult period of rescue calls working with a novice firefighter. A paramedic (who dropped out of medical school for the fire department) responded to his first cardiac arrest patient, who was his father. He looked to his captain, also the surgeon who trained him, and his captain said, "You can do it." His father survived. One author (DvS), as medical student body co-president, sat on the stage to welcome the first-year medical students. As the last speaker, he

"Negative space is the space in a painting intentionally left empty to bring attention to the subject, the subject being the positive space."

heard all the speakers express how difficult the first year is. Standing up to speak, he discarded his talk and said, "You can do it." A student came to him one year later and said those words helped him through the first year.

Experience as success. The CEO of a pediatric nursing home wanted to improve the facility in terms of patient care and increased census. Jeff Lewis, the new administrator of 18 months and knowledgeable about HRO, met with staff to identify areas of improvement. Bedside staff did not know what to do or how to do it. Managers believed it was a trick to make them look bad. The only role Lewis assumed was approving projects. The subsequent state survey found no deficiencies; a record kept for five years. US News and World Report recognized the facility as one of 27 out of 15,500 nursing home facilities in the nation having zero deficiencies, recognition the facility sustained for five years. Experience as inquiry generated organizational learning and developed meaning within the experience of subordinates, from management to the bedside caregiver. Lewis, without additional funding, had used HRO as engagement and self-organizing improvisation to initiate his program, which culminated in national recognition.

<u>The need for experience</u>. One author (DvS) has attended conference lectures that demonstrated the effects of inexperience on the part of the speaker. Several lecturers introducing themselves with "I've seen everything" (having seen a lot, neither author uses this phrase). Lecturers on safety presenting scenarios where the operators or patients were severely injured or killed, followed by "What were they thinking?" (Standing at the scene in the presence of family, friends, and colleagues, one can understand, DvS.) Lecturers using movie or television comedies with large families to describe the home conditions of ethnic multi-generational families. (Inside the house looks crowded but does not feel crowded; only love and affection, DvS.) Lecturers used notorious criminals or incarcerated family members who claim they are innocent as foils as a reason to deny home care (criminals show love for their families, and wrongful convictions and false confessions are overrepresented with people of color, DvS). In every lecture, the entertained audience laughed.

"Perception may seem dependent on definitions, but definitions come up short in the turmoil of the liminal space. Descriptions of how something is used, an action performed, or a situation experienced all carry meaning. "

These situations describe inexperience on the part of the professional rather than malicious beliefs. It is difficult to learn as cognitive information lends itself to these views while affective information counteracts them. The fallacy of abstractions impairs reflection about the experience as the abstraction takes precedence over the actual world. Abstraction too easily changes a possible world to become considered a real world. The inexperienced person then believes that is how the world is. Neonatology, on the other hand, has taken a different approach and gained life through engagement.

But there are times our experience and concepts seem to fail us. We are in a place we are not supposed to be. We don't know how to get out. Like tarrying in a hallway, an elevator with a jammed door, or standing alone in the middle of a large reception. These are meant to be places of a threshold meant to pass through to another, better place. Sometimes we cannot. For parents, this is the NICU.

Liminal Zones, Liminal Experiences, and Liminal People

The present moment is our passing from the past to the future. Some rooms in buildings such as hallways, stairwells, and elevators serve as passages and are not designed for people to remain any length of time. Liminal zones describe the time when the future hasn't arrived before you pass to the next room. These are episodes, seemingly motionless, between what was and what will be.

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Sometimes these are "thresholds" (liminal from the Latin, *limin*, threshold) to a new beginning. Graduations, full recovery from major illness or injury, and major accomplishments all mark a change in our lives. From our knowledge and experience, we have a repertoire of actions necessary to move through these transitions and reach our goals. This is about good planning and preparation.

Liminal times and liminal spaces are concepts from anthropology, described as "rites of passage" when the initiate has entered a new space, leaving behind the characteristics of a previous status and not yet moving on to the new status's characteristics. The old rules do not apply, and moving to the new rules is not assured. There are three phases, each with its own meaning, but the middle passage describes the sense of not belonging with the inability to act.

- A rite of separation is characterized as a metaphorical "death."
- Remove norms from the previous status without receiving the new status's norms; the passage is in doubt, making it the apparent potentially dangerous part of the ceremony.
- Rejoin the community in the new status.

However, when structure and activity become random, we lose context. Unfamiliarity and loss of context become disorienting or overwhelming. At other times, the context or structure is too complex or disordered for us to proceed. Prudence and an abundance of caution may overtake reasoning, and we hold back. Time compression or self-protection may overtake reasoning, and we strike outward using forceful action – verbal or physical. Though this may feel like a failure and even appear like a failure to outsiders, it is not a failure. We have entered a liminal space, a common if unrecognized experience in routine life and a characteristic of nonroutine life. The ecology of fear (32, 34) creates widespread and unrecognized liminality. The fear of error, litigation, failure, etc., creates the liminal space, and, similar to liminality described in this article, there is no assured means to escape and no way out.

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"Experience *is* the rite of passage. All certainties are removed. The certainty of past behaviors and treatments are permanently gone. Acceptance and any new behaviors and treatments are not present and may not be. There are no standard behaviors and treatments during the experience. This creates the delicate uncer-



tainty and malleable state of the individual. Anything that happens can change the person's core being" (21).

These characteristics align with the NICU events from an abrupt change when learned behaviors no longer operate and grave, possibly hidden threat is present. This second stage, the verge of the threshold or "limin," gives liminality its name. This area of liminality, whether it is space or time, we call the "liminal zone."

Liminality is in-between BECAUSE you leave the familiar and enter an environment with no solution. The solution you generate creates your next actual world from the possible worlds that existed as you entered. So, it is in-between your actual world and the next actual world that you generate from the possible worlds. If there were no possible worlds, you would not be in-between, and if both worlds are actual worlds, you would not be in-between.

Liminal spaces are like areas of a building that are meant for transit or storage. Dwelling in a strange room for any length of time is uncomfortable, especially if you are alone. Liminal spaces can also be social spaces like a party or any gathering where you are unfamiliar with the people. Try standing in the middle of a social gathering without anything in your hands. The social isolation becomes palpable. (Though one of the authors (DvS) did this at a military special operations medical conference. Rather quickly, individual army medics approached to talk. One invited the author to join his table for the conference dinner.)

"We question if plans and planning, the commonly accepted methods, are the most effective approach to enter or exit a liminal space. It appears the hallmark of liminal space is the uncertainty of what actions will be successful. This is what makes planning difficult."

We question if plans and planning, the commonly accepted methods, are the most effective approach to enter or exit a liminal space. It appears the hallmark of liminal space is the uncertainty of what actions will be successful. This is what makes planning difficult. *Engagement*, we define, is the act of approaching and entering liminal spaces. In these situations, sometimes, all we have are observation and action (4). Engagement describes actions taken without certainty that they will succeed. These are reasoned actions that generate information while building structure and controlling energy. This is "learning-by-doing" and not "trial-and-error." In a situation fraught with ambiguity and equipoise, the only error occurs when one stops acting, and the only failure that occurs is withdrawal. A movement toward the best achievable end-state is the goal.

In extreme forms, this becomes a rebirth as a reciprocal change to the individual is significant. At the milder level, it is substantive learning. That is, we have changed our way of thinking.

Liminality is Experience

"If your body is moving faster than your brain can think, then slow down. If you feel your eyes glaze over, slow down," William J. Corr, Captain of the Los Angeles Fire Department (personal communication). Corr was describing the shift from engagement to the disengaged thought that can occur in the liminal zone. We describe engagement below as experience entering the liminal space. Corr, acknowledging that events can overcome us, advises one to slow down to regain the senses.

Severe concreteness or reliance on abstractions signifies when someone has mentally entered a liminal zone. Severe concreteness arises when abstract thought becomes impaired from the loss of executive functions in the prefrontal cortex function. This is a primary stress response (31, 35).

Kant's response to the energy of chaos was to bring calm, separating the subjective from the objective with concepts (19) and separating science (practical reason) from belief (pure reason) (14). But concepts are a technical system independent of the situation and experience. They are used with intention from outside the liminal space to give organized commands to form a structure in the chaos. The rigidity and wishful thinking fail in open systems faced with entropy. Rather experience as engagement by entering the liminal space with nonlinear interactions with local effects builds structure. This is the self-organizing improvisation of HRO (36, 37). It can be difficult working in an emergency with someone who pursues concepts. Methods are described elsewhere (31, 35).

Abstractions are more than abstract thoughts, and the future is an abstract thought relative to the time scale. Abstractions include rules, cliches, maxims, principles, models, concepts, and theories. Concepts are representations of reality. They must not be mistaken for reality. "Concepts can be 'counterfeit abstractions' that imitate SOME but not all of the differentiated flux produced by attentive HRO practitioners," Karl Weick (personal communication).

Liminal people. Those who have sustained liminal experiences find that their values and characteristics have changed (38). They are often marginalized from the dominant account, for example, combat veterans. Combat veterans are reluctant to use and share their experiences, particularly those from the Vietnam era, because of their liminal wisdom (38). Reasoning from past experience to apply to present experience seems irrational since the situations are not identical. The combat veteran learned that experience is a process and engagement that relies on constant reciprocal feedback to learn what works through action. Mastery of concepts, a Kantian approach, becomes the dominant account, suppressing interpretations of those constructing the reality. Liminality nor experience, as arts (4), cannot be mastered.

Engagement

Passage through the liminal space is active rather than passive. From the "concept stance," one would expect planning to prepare a person and plans to guide actions. Sean McKay (37) answered the criticism of improvised plans regarding the fire department response to a terrorist shooting. The department moved 14 patients from the triage site in 18 minutes with no deaths. "They didn't improvise a plan. Their plan was improvisation." Despite the emphasis on evidence-based approaches in numerous fields, there has been no controlled experimentation for best practices to engage an unstructured situation in flux. One area that relies on HRO, high angle rescue, requires all rescuers to be secured by rope, plans for engagement in liminal spaces, adapting equipment, and training for situations where equipment and training are not sufficient (39). They follow Karl Weick's dictum (personal communication): "If it's liminal (which it often is), engage with all your mind."

"Engagement describes the approach and experience with a situation when the operator does not know what will work. "I don't know what is happening, but I know what to do." – a Los Angeles Fire Department firefighter."

Engagement describes the approach and experience with a situation when the operator does not know what will work. "I don't know what is happening, but I know what to do." – a Los Angeles Fire Department firefighter. "HRO uniquely shapes the engagement that moves through and out of a liminal period," Karl Weick (personal communication).

Engagement reduces certitude. Certitude is an early herald of failure. Engagement at the point of contact, where line workers operate, is nearly always a liminal space. Neonatal physiology, parents, families, and the local circumstances are never the same. While creating a PICU, Ron Perkin would tell staff he didn't care what they did...they just had to stay at the bedside (DvS, personal communication). That is, engagement continued past the point of action, continuing through observation for complications, effectiveness, and sustainability. The further away one moves, the consequences of certitude decrease. In some sense, certitude can be a hazard from limited experience in the field or with higher status.

Previously, we (40) described how engagement bridges the gap between theory and practice (40) and between discrete concepts and continuous perceptions (41). Engagement also bridges the gap between abstractions and details (Karl Weick, personal communication). Engagement makes use of details, nuance, and the subtle. Details can herald early response to therapy or be an early herald of failure. Yet, focus on details without context is the definition of micromanagement details (Karl Weick, personal communication).

Bag-valve-mask (BVM) ventilation for the unprotected airway in a breathing patient is fraught with complications. One author (DvS) altered the methods used for BVM based on details from his field experience providing mouth-to-mouth ventilation to a breathing infant, adolescent, and adult. The feedback felt in the mouth guides when to stop the breath and start the next breath. That is why mouth-to-mouth ventilation rarely, if ever, causes emesis. Using detailed sensing with BVM, this method is used in a pediatric subacute facility and by special groups in the Special Operations Command (SOCOM) in the US and several NATO countries (42).

HRO is "Knowledge by acquaintance"

"To say that I am acquainted with an object when I have a direct cognitive relation to that object. When I speak of a cognitive relation here, I do not mean the sort of relation which constitutes judgment, but the sort which constitutes presentation (8). Acquaintance is *not* judgment. Therefore, the experience is *not* judgment. Experience is what happens to you, it changes you, but it is not you.

This is critical for engagement. Acceptance is the absence of judgment. Acceptance is also a critical element of comedy improvisation and is the gate for HRO improvisation. When we self-organize under intention, we are improvising. Otherwise, our responses are random at worse and trial-and-error at best; neither leads to learning. Also, in Dewey's pragmatism, acceptance intercedes between causation and action. In fact, acceptance is *why* you don't need causation.

"HRO is a trajectory with flux and flow that continuously engages our experience. Too easily, we can plan and review for comparison from some fixed point where the vantage lets us see causation, real or putative."

HRO is a trajectory with flux and flow that continuously engages our experience. Too easily, we can plan and review for comparison from some fixed point where the vantage lets us see causation, real or putative.

Experience by description: The illusion of experience. Experience is to interact with the environment without mediation. Some linger under the fallacy of experience when they are in close proximity or are well-read. It is the intimate give-and-take of corrective measures outsiders would call an error that creates the experience. Giving priority to the first thing a person thinks of, the availability construct, can lead to grave danger during the engagement. This problem is most clearly experienced with consulting physicians whose frame of reference comes from a medical specialty rather than the flux and mix-up from direct actions with a patient. A more subtle and treacherous illusion of experience occurs when an individual's identity forms from their perceived experience. These individuals do not entertain the questioning that a veteran of engagements actively seeks.

Conclusion

In the HRO, we engage with all our mind; any space could be liminal, unidentified as such, only because we are missing something. This is not nervousness but mental preparation for the early herald. When does early engagement of an outlier become pre-



An HRO utilizes experience, beliefs, and concepts.

- There is continuity of experience.
 - Every experience takes up from those that have gone before and modifies those that come after.
 Experience helps with memory and recall.
 - Experience helps with memory and recall.
 Experience is in the affective domain of knowledge.
- Beliefs are confirmed, disconfirmed, and modified by experience.
 - Experience has a central role in fostering and supporting our beliefs.
 - Concepts aid the interpretation of our experience.
 - But it is the experience we call upon for how to use concepts.

"We operate in open systems. The liminal incident entrains energy and resources. Entering the liminal state initiates the self-organizing that will form structure. Engagement starts the self-organization necessary to reach a preferred end-state."

We operate in open systems. The liminal incident entrains energy and resources. Entering the liminal state initiates the self-organizing that will form structure. Engagement starts the self-organization necessary to reach a preferred end-state. Engagement need not be active involvement. Notification, monitoring, isolating are all forms of engagement.

We have what Karl Weick (personal communication) calls the "involuntary memory of protocols and routines, continuities with previous experience (we know with what we've known), and the past." We do *not* treat the past "in a temporal sense but in a figural sense in which it frames and categories and narrates a present liminal cue." This is our anchor to initiate engagement.

Acceptance of the situation and information is key. Doubt is necessary, but in the extreme of skepticism, we reject nearly everything in front of us. Doubt leads us to recheck and re-evaluate, remembering that our best facts and most reliable information are what we immediately generated.

HRO acts like a trajectory, moving in form and energy as the liminal event. "HRO is a trajectory of engagement that fuses now with the experience of then into simultaneous inquiry and redescription," Karl Weick (personal communication).

The HRO uniquely shapes engagement to move through and out of a liminal period. If it's liminal (which it often is), we engage with all our minds. In these events, our most reliable resources are our capabilities and our reasoning.

For a short time scale, HRO gives the reliability to conserve the organization's core functions. For longer time scales, HRO supports evolvability; the organization becomes new as the environment becomes new.

HRO accepts the actual world in its liminal state while constantly engaging toward a preferred world. We cannot substitute a virtual world or the desired world with the actual world. An HRO accepts the world as it is. Our experience supports our engagement. We make the world better.

"HRO accepts the actual world in its liminal state while constantly engaging toward a preferred world. We cannot substitute a virtual world or the desired world with the actual world. An HRO accepts the world as it is. Our experience supports our engagement. We make the world better."

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96

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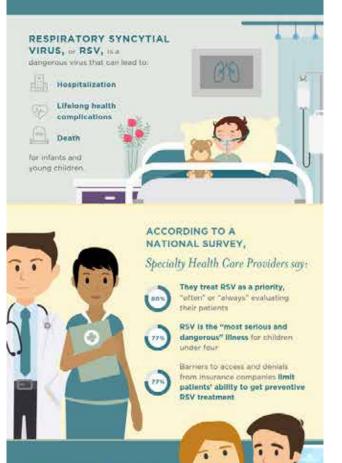
nationalperinatal.org/psychologists

Respiratory Syncytial Virus:

How you can advocate for babies this RSV season



Survey Says: RSV



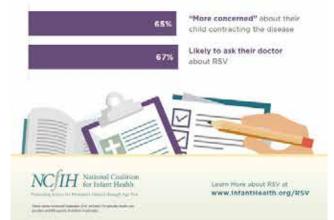
But Parents are Unprepared.

Only 18% know "a lot" about RSV

themselves "very well" prepared to prevent RSV

RSV EDUCATION & AWARENESS CAN HELP

After parents learned more about RSV, they were:



98

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

Peer Reviewed

Neonatal Clinical Nurse Specialist (CNS): The Importance of Specialized Nursing Care for NICU Patients and Families

Robin Koeppel, DNP, CPNP, CNS, RNC-NIC, C-ELBW, C-NNIC

"Decades ago, NICU CCS Standards required a neonatal Clinical Nurse Specialist (CNS). Visionary and innovative authors of these previous NICU CCS standards identified the importance of specialized nursing care for NICU patients and families and tasked the NICU CNS to serve as the nursing care expert and consultant for complex patient care needs."

Decades ago, NICU CCS Standards required a neonatal Clinical Nurse Specialist (CNS). Visionary and innovative authors of these previous NICU CCS standards identified the importance of specialized nursing care for NICU patients and families and tasked the NICU CNS to serve as the nursing care expert and consultant for complex patient care needs. With the changing complexity of nursing care in the NICU, additional technology used to care for NICU patients and families, and the increasing scope of the Registered Nurse (RN) at the bedside, the NICU CNS is needed now more than ever to assure quality nursing care is delivered consistently and reliably.

The Neonatal Nurse Practitioner (NNP) and Clinical Nurse Educator (CNE) are also vital and important, and each provides unique and distinct services to NICU patients and families, nursing and nursing staff, and the healthcare system. However, these roles are not interchangeable, and the skills, knowledge, and academic preparation are unique and distinct. Together, all three roles collaborate with the interdisciplinary team to enhance the quality of care delivered at the NICU bedside.

Recently, CCS distributed an updated draft of NICU standards for review and comment. Proposed modifications within the CCS NICU standards are to remove the NICU CNS role and replace



it with a new title, "Neonatal Clinical Nurse Educator" (NCNE), which may be filled by a NICU CNS, NNP, or CNE. The responsibilities of the new NCNE are the same as the NICU CNS. This proposed modification demonstrates a lack of understanding of the skills and knowledge that each role (NICU CNS, NNP, and CNE) brings to the NICU. The California Neonatal CNS group drafted a response to the proposed CCS changes in an effort to clarify the differences between the NICU CNS, NNP, and CNE in both academic preparation and skills, focus, and scope of practice.

To all of our colleagues in the NICU, we respectfully share our response in hopes it will be informative and bring an understanding of and clarity to the CNS role in the NICU.

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Dear California Children Services,

The California Neonatal Nurse Specialist Group recently reviewed the proposed modifications to the California Children Services (CCS) Neonatal Intensive Care Unit (NICU) standards. The proposed "Neonatal Clinical Nurse Educator" (NCNE) and the grouping of Clinical Nurse Specialist (CNS), Neonatal Nurse Practitioner (NNP), or Certified Nurse Educator (CNE) to fulfill this category in the Regional, Community, and Intermediate facilities is inappropriate and would be a great disservice to NICU patients and families, nursing and nursing practice and healthcare systems. The NICU CNS has a nationally recognized, state-specific scope of practice that cannot be replaced by the scope of practice of other Advanced Practice Registered Nurses (APRN) or nurse educators (AACN, 2019). Additionally, this proposed change, allowing the fulfillment of the CNS role with non-CNS personnel, violates the Nurse Practice Act (Business and professions Code Division 2, Chapter 6, Article 9, Section 2838.2)

https://leginfo.legislature.ca.gov/faces/codes_displayText.xhtml? lawCode=BPC&division=2.&title=&part=&chapter=6.&article=9.

We are committed to ensuring that all NICU infants, including those cared for in CCS-approved facilities, benefit from the full range of nursing services and competencies characteristic of CNS practice.

The purpose of this letter, and our recommended CCS NICU standard revisions (attached), is to share information and serve as a resource in understanding the differences between and among roles and, ultimately, to better serve the NICUs across California.

The NICU CNS is the clinical nursing care expert whose overarching goal is to improve neonatal patient outcomes and promote the health of neonatal communities and populations. The CNS and NNP, both APRNs, have distinct and separate practice characteristics with specific and unique academic preparation, skills, and knowledge. The primary role of the CNS is to continuously improve the nursing care of patients, resulting in improved patient outcomes (ANA, 2010). The CNS has a broader focus, directly impacting the delivery of neonatal patient care by impacting nurses and nursing staff, families, and organizational systems. The CNS provides both direct and indirect patient care and serves as an interprofessional liaison between administration, medicine, nursing, and other disciplines in a system's context. Utilizing each CNS sub role and the standards developed by CCS, the CNS provides not only nursing education but also consults on complex nursing care issues, participates in developing and providing family education, assists in maintaining the clinical development of the nursing staff, and ensures a coordinated and effective discharge planning program. Additionally, the CNS conducts and participates in clinical research studies and utilizes research findings to make changes in nursing practice. Increasingly, the CNS leads the interprofessional team in Quality Improvement (QI) projects improving NICU patient and family outcomes. Multiple examples of CNS-led QI projects exist on both the CMQCC and CPQCC QI Collaborative sites, as well as other quality of care networks committed to improving the health of neonates and their families.

In contrast, the primary role of the NNP is to provide acute care management of ill infants and their families at the point of care. The NNP's academic preparation, skills, and knowledge do not include teaching or developing an educational curriculum, nor are they trained in organizational systems and change management. The NNP collaborates with other members of the team to assure expert neonatal care delivery. Although very skilled in the medical management of sick newborns, the priority of NNP role is not to provide consultation to the nursing staff on complex patient care nursing management. Her focus is direct patient care assessment and treatment.

The primary role of the CNE is as an expert in education, designing, developing, and executing educational programs based on adult learning theory utilizing the latest, evidence-based educational methodologies. The CNE is not an APRN, and the academic preparation, skills, and knowledge are centered on curriculum development and teaching. The CNE is not a nursing care expert, cannot consult on NICU patients with complex nursing care issues. The CNS, not the CNE, is prepared in advanced patient care and can consistently utilize these expert skills within a framework of an advanced direct patient care perspective. It is this distinctive combination that distinguishes CNS practice from that of a CNE. Although the CNE may have some skill and expertise, it is the CNS that is uniquely prepared by higher education and experience to function at an advanced level of nursing practice (NACNS, 2019). Rather, it would be appropriate to support close collaboration between the CNS and CNE as the CNS provides the evidenced-based practice, quality control, and policy development to help the CNE build comprehensive educational components for the staff.

As a state-wide group of NICU CNSs working in Intermediate, Community, and Regional NICUs, we emphatically oppose the proposed interchangeability of these roles in meeting the responsibilities outlined within the proposed CCS standards. The CNS is the only APRN who possesses the skills, knowledge, and academic preparation to serve as the nursing care expert (over 500 supervised hours by a NICU CNS is required prior to certification as a CNS by the Board of Registered Nursing) and consult on complex critical care nursing issues, not only in the NICU but interdepartmentally where any neonate may be in the hospital. Additionally, with the expanding scope of the Registered Nurse (RN) in the NICU, increased use of technology for patient care monitoring and treatment, and increased focus on quality outcomes, the CNS is the most appropriately prepared role to meet the needs of the changing RN patient care environment.

"As a state-wide group of NICU CNSs working in Intermediate, Community, and Regional NICUs, we emphatically oppose the proposed interchangeability of these roles in meeting the responsibilities outlined within the proposed CCS standards."

We understand the lack of available neonatal CNSs in California in the past may have posed a hardship for NICUs hiring a CNS for this role. This may have been the impetus in proposing different nursing roles to fulfill the necessary and vital responsibilities under "NICU Professional Resources and Requirements" in all three CCS standards. We respectfully inform CCS and all stakeholders that there are now two public Neonatal CNS programs in California (University of California, San Francisco and California State University, Dominguez Hills), both actively preparing and graduating NICU CNSs. The functions and responsibilities noted within the Standards have been and will always be best served by a NICU CNS, who has the scope, academic preparation, expertise, and knowledge to meet the needs of the specialized infant and family population in the NICU.

In summary, we respectfully recommend:

- The title "Neonatal Clinical Nurse Educator (NCNE)" be abandoned, and the Neonatal Clinical Nurse Specialist be the role and title that meets the responsibilities outlined under "NICU Professional Resources and Requirements" in all three CCS Standards for Regional, Community, and Intermediate NICUs.
- 2. The CNS be one full-time equivalent for both Regional and Community level NICUs
- 3. A CNE be recommended in addition to, but not in place of the CNS for both Regional and Community level NICU

Thank you in advance for your consideration. We are happy to discuss further the CNS role in the NICU. Sincerely,

CA Neonatal CNS Group

References:

 https://leginfo.legislature.ca.gov/faces/codes_display-Text.xhtml?lawCode=BPC&division=2.&title=&part=&ch apter=6.&article=9.

Disclosures: The author does not have any relevant disclosures.

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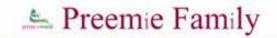
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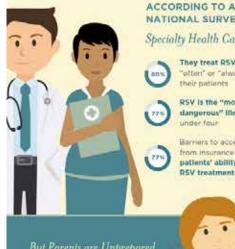




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Survey Says: RSV





NATIONAL SURVEY,

Specialty Health Care Providers say:

They treat RSV as a priority, often" or "always" evaluating their patients

RSV is the "most serious and dangerous" Illness for children under four

Barriers to access and denials from insurance companies limit patients' ability to get preventive **R5V** treatment

But Parents are Unprepared.



Only 18% know "a lot" about RSV

Uternsolves "very well" prepared to prevent RSV

RSV EDUCATION & AWARENESS CAN HELP

After parents learned more about RSV, they were: "More concerned" about their 65% child contracting the disease Likely to ask their doctor 679 about R5V NCIH National Costilition re about RSV at www.infantHealth.org/RSV

OPIOIDS and NAS When reporting on mothers, babies, and substance use LANGUAGE MATTERS



I am not an addict.

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

I was exposed to opioids.

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



NAS is a temporary and treatable condition.

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



My mother may have a SUD.

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

My potential is limitless.

I am so much more than my NAS diagnosis. My drug exposure will not determine my long-term outcomes. But how you treat me will. When you

invest in my family's health and wellbeing by supporting Medicaid and Early Childhood Education you can expect that I will do as well as any of my peers!

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Eunice Kennedy Shriver National Institute of Child Health and Human Development



Medical News, Products & Information

Compiled and Reviewed by Mitchell Goldstein, MD Editor in Chief

NIH leaders on the future of precision medicine, healthcare transformation

Thursday, March 18, 2021

NIH leaders on the future of precision medicine, healthcare transformation

What

COVID-19 puts renewed focus on the urgent need to put diverse health data to work to support new discoveries and bring more precise prevention and treatment strategies to communities. A new commentary in *Cell*, co-authored by Director of the National Institutes of Health Francis S. Collins, M.D., Ph.D., and Joshua C. Denny, M.D., M.S., chief executive officer of the *All of Us* Research Program, highlights seven opportunities to accelerate tailored medicine efforts and create a more equitable health landscape in the future.

The commentary covers key areas including huge cohorts, artificial intelligence, routine inclusion of genomics as part of clinical testing, deeper investigation of the role of phenomics and environment in health and disease, and returning value across diverse populations.

The authors highlight the role of large cohorts, like the *All of Us* Research Program, and the immense potential of such resources that aim to bring together diverse streams of information spanning genomics, social determinants of health, environmental exposures, electronic health record data, and wearable device data. They note that these resources offer tremendous opportunities for discovery across every area of medicine, but that an "open science" approach is needed for researchers to combine data across cohorts to maximize their impact on a global scale.

Another necessary growth area the authors discuss is improving diversity and inclusion in science. As a case in point: a *Nature Genetics* <u>paper</u> last year reported that people of African or Hispanic/Latin American genetic ancestry make up less than 3% of participants in published, genome-wide association studies. Collins and Denny contend that such underrepresentation has the potential to worsen current health disparities, while also weakening biological discovery that could benefit all populations. *All of Us* is working to change this, with more than 80% of its core participant cohort from populations that are historically underrepresented in biomedical research, including more than 50% from racial and ethnic minorities.

The COVID-19 pandemic has only heightened the need for transformative change in health research to meet the needs of communities nationwide, especially communities of color bearing the brunt of the virus's impact. With a bold plan in place — including international collaboration, engagement of diverse populations of participants and researchers, and broad access to data — the authors believe more precise medicine is possible for all.

Article

Denny and Collins, Precision medicine in 2030 — seven ways to transform healthcare, Cell (2021), https://doi.org/10.1016/j. cell.2021.01.015 (<u>link</u>)

Who

NIH Director Francis S. Collins, M.D., Ph.D.

All of Us Research Program CEO Joshua C. Denny, M.D., M.S.

About the All of Us Research Program: The mission of the All of Us Research Program is to accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care for all of us. The program will partner with one million or more people across the United States to build the most diverse biomedical data resource of its kind, to help researchers gain better insights into the biological, environmental, and behavioral factors that influence health. For more information, visit www.JoinAllofUs.org(link is external) and https://www.allofus.nih.gov.

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

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Institute/Center

All of Us Research Program

Contact

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NT

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

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

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

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- Invitation for special programming by the Section at the AAP's National Conference.
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AAP members can join SOATT for free. To activate your SOATT membership as an AAP member, please complete a short application at <u>http://membership.aap.org/Application/AddSectionChapterCouncil</u>.

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

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

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NT

Preterm birth, prolonged labor influenced by progesterone balance

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Thursday, March 11, 2021

Novel research in mice sheds light on hormone regulation needed in late pregnancy, opens door for therapy.

New research by the National Institutes of Health found that unbalanced progesterone signals may cause some pregnant women to experience preterm labor or prolonged labor. The study in mice published online in the Proceedings of the National Academy of Sciences — provides novel insights for developing treatments.

During pregnancy, the hormone progesterone helps to prevent the uterus from contracting and going into labor prematurely. This occurs through molecular signaling involving progesterone receptor types A and B, referred to as PGR-A and PGR-B. In this first-of-its-kind study, the scientists showed how unbalanced PGR-A and PGR-B signaling can affect pregnancy duration.

"We used genetically engineered mouse models to alter the ratio of PGR-A and PGR-B in the muscle compartment of the uterus, called the myometrium," said senior author Francesco DeMayo, Ph.D., head of the National Institute of Environmental Health Sciences Reproductive and Developmental Biology Laboratory. "Our team found that PGR-A promotes muscle contraction and PGR-B prevents such contraction, and we identified the biological pathways influenced by both forms."

Previous research showed that PGR-A regulates processes involved in initiating childbirth and that PGR-B affects molecular pathways related to maintaining the normal course of pregnancy. This study builds on those findings, revealing that the relative abundance of PGR-A and PGR-B may be critical in promoting healthy pregnancy. The public health implications are significant.

Preterm birth affects 10% of all pregnan-

cies and is the primary cause of neonatal morbidity and mortality worldwide, while prolonged labor increases the risks of infection, uterine rupture, and neonatal distress, according to the researchers.

The scientists pointed out that care for preterm deliveries can result in high social and economic costs, with infants born preterm at greater risk for experiencing disorders ranging from blindness to cerebral palsy. Prolonged labor can harm both mother and infant and lead to cesarean delivery.

Progesterone treatment aimed at preventing premature labor can help a subset of patients, but for other individuals, confounding factors may reduce effectiveness, noted Steve Wu, Ph.D., first author on the study and a staff scientist in DeMayo's lab. Wu said that the research team found novel molecules that control uterine muscle contraction, and they could serve as future therapeutic targets. He added that the current study also may help to advance treatment for labor dystocia — the clinical name for abnormally slow or protracted labor.

"Although labor stimulation by oxytocin infusion is an approved measure to mitigate labor dystocia, serious side effects have been associated with this treatment," said Wu. "Novel proteins that we identified as being part of progesterone signaling could serve as a key molecular switch of uterine contraction, through drug-dependent regulation of their activities," he explained.

"Hormone signaling in pregnancy is complicated and involves both the hormone levels and the types of receptors in the uterus that sense the hormones," said co-first author Mary Peavey, M.D., from the department of obstetrics and gynecology at the University of North Carolina at Chapel Hill. "This publication sheds light on how hormones influence labor and can thus be used to help women when the uterus goes into labor too soon or for a prolonged period."

This news release describes a basic research finding. Basic research increases our understanding of human behavior and biology, which is foundational to advancing new and better ways to prevent, diagnose, and treat disease. Science is an unpredictable and incremental process each research advance builds on past discoveries, often in unexpected ways. Most clinical advances would not be possible without the knowledge of fundamental basic research. To learn more about basic research, visit https://www.nih.gov/newsevents/basic-research-digital-media-kit.

About the National Institute of Environmental Health Sciences (NIEHS): NIEHS supports research to understand the effects of the environment on human health and is part of the National Institutes of Health. For more information on NIEHS or environmental health topics, visit https:// www.niehs.nih.gov/ or subscribe to a news list.

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

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1ZIAES103311 R01HD042311

Reference:

Peavey MC, Wu SP, Li R, Liu J, Emery OM, Wang Tianjuan, Zhou Lecong, Wetendorff M, Yallampalli C, Gibbons WE, Lydon JP, DeMayo FJ. 2021. Progesterone receptor isoform B regulates the Oxtr-Plcl2-Trpc3 pathway to suppress uterine contractility. Proc Natl Acad Sci USA: https://www.pnas.org/content/118/11/e2011643118(link is external).

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National Institute of Environmental Health Sciences (NIEHS)

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NT

NIH effort seeks to understand MIS-C, range of SARS-CoV-2 effects on children

Tuesday, March 2, 2021

The National Institutes of Health has launched a new research effort to understand how SARS-CoV-2. the virus that causes COVID-19, affects children. who account for roughly 13% (link is external) of the total cases of COVID-19 in the United States. The effort is called the Collaboration to Assess Risk and Identify Long-term Outcomes for Children with COVID (CARING for Children with COVID). This research program is developing and funding studies to investigate why some children are at greater risk for SARS-CoV-2 infection than others, why symptoms vary among children who are infected, and how to identify children at risk for severe illness from SARS-CoV-2 infection. Research on the latter question is focused particularly on multisystem inflammatory syndrome in children (MIS-C), a life-threatening condition marked by severe inflammation of one or more parts of the body, including the heart, lungs, kidneys, brain, skin, eyes and gastrointestinal organs.

The program is led by the National Heart, Lung, and Blood Institute (NHLBI) and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) in collaboration



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with the National Institute of Allergy and Infectious Diseases (NIAID). Research conducted through CARING for Children with COVID is supported in part by the Coronavirus Aid, Relief, and Economic Security Act.

"This effort stems from NIH's commitment to understanding the spectrum of risk that SARS-CoV-2 poses for children and to identifying interventions to improve their short- and long-term health outcomes," said NICHD Director and CARING for Children with COVID co-chair Diana Bianchi, M.D.

Based on current data, most children with SARS-CoV-2 infection do not develop serious illness. However, those who do go on to develop MIS-C can experience prolonged fever and severe abdominal pain and may progress to shock. Although most children with MIS-C survive, its cause and long-term effects remain largely unknown. There is also early evidence(link is external) that some children with asymptomatic or mild infection may go on to develop such long term symptoms as fatigue, muscle and joint pain, and respiratory problems.

"While much of the devastation wrought by COVID-19 is on older and vulnerable populations, it is affecting children in ways we are just beginning to understand," said Gary Gibbons, M.D., director of the NHLBI and co-chair of CARING for Children with COVID. "That's why this research and these networks are so critical."

Specifically, the program developed new research protocols for three clinical networks with sites across the country, to include children with SARS-CoV-2 infection and related conditions, including MIS-C:

> Long-Term Outcomes after the Multisystem Inflammatory Syndrome In Children (MUSIC)(link is external). Funded by NHLBI and leveraging the Pediatric Heart Network, this study focuses on cardiovascular complications of MIS-C, but also collects data on all aspects of childhood and adolescent health in affected participants.



114



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- Pharmacokinetics, Pharmacodynamics, and Safety Profile of Understudied Drugs Administered to Children per Standard of Care (POPS). (link is external)Funded by NICHD and leveraging the Pediatric Trials Network, this study focuses on understanding the treatment of children diagnosed with COVID-19 or MIS-C with medicines that have shown promise in adults with COVID-19.
- Pediatric Research Immune Network on SARS-CoV-2 and MIS-C (PRISM). Sponsored and funded by NIAID, this study aims to evaluate the short- and long-term health outcomes of SARS-CoV-2 infection in children, including MIS-C, and to characterize the immunologic pathways associated with different disease presentations and outcomes.

CARING for Children with COVID also includes Predicting Viral-Associated Inflammatory Disease Severity in Children with Laboratory Diagnostics and Artificial Intelligence (PreVAIL klds), a research funding program to encourage the development of approaches that identify children at high risk for developing MIS-C. PreVAIL klds is funded by NIH's <u>Rapid Acceleration of</u> <u>Diagnostics (RADx)</u> Radical (<u>RADx-rad</u>) <u>program</u> to support new, non-traditional approaches and reimagined uses of existing tools to address gaps in COVID-19 testing and surveillance.

Although the studies supported by CAR-ING for Children with COVID have slightly different goals, all will collect data on a core set of health measures that can later be analyzed across studies. Data from CARING for Children with COVID activities will be made available on multiple NIH web platforms to allow researchers to conduct additional analyses and make more discoveries.

More information on the effort is available on the CARING for Children with COVID website at <u>https://caring4kidswithcovid.</u> <u>nih.gov</u>. About the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD): NICHD leads research and training to understand human development, improve reproductive health, enhance the lives of children and adolescents, and optimize abilities for all. For more information, visit <u>https://www.</u> nichd.nih.gov.

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

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NT

Study identifies cardiovascular risk factors that may lead to pregnancy problems for first-time moms

Friday, February 26, 2021

A new study of first-time pregnant women found risk factors for heart disease, such as obesity and elevated blood sugar, can put expectant moms at higher risk for pregnancy complications and gestational diabetes and also lead to increased chances of high blood pressure, or hypertension, two to seven years after giving birth. The findings, which appear in the Journal of the American Heart Association(link is external), may assist doctors working with patients to adopt heart-healthy lifestyles or to avoid pregnancy problems, such as preeclampsia or premature birth. Severe pregnancy complications affect more than 50,000 women in the United States each year, according to the Centers for Disease Control and Prevention.

"What we know about high blood pressure is that the earlier you have it, the worse your outcomes for heart disease can be," said <u>Victoria Pemberton</u>, a study author, nurse, and researcher in the Division of Cardiovascular Sciences at the National Heart, Lung, and Blood Institute (NHLBI), part of the National Institutes of Health. "If we can change that course and intervene earlier, such as after a woman has an adverse pregnancy outcome, then we're doing her a great service."

Researchers created the <u>nuMoM2b Heart</u> <u>Health Study</u>(link is external), which is supported by the NIH, to examine factors that influence pregnancy outcomes and support the cardiovascular health of new mothers. In this sub-study, researchers followed 4,471 women who had their first child at one of eight U.S. medical centers between 2011 and 2014. About one in two women were overweight or obese at the



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start of their pregnancy. The researchers monitored the women from the early stages of their pregnancies and stayed in touch, through self-reporting surveys, phone calls, and clinical visits, for up to seven years after the women gave birth.

The researchers found that roughly 25% of the study participants, 1,102 women, had a pregnancy complication or developed gestational diabetes. Women who experienced a pregnancy complication were more likely to have developed markers for heart disease before or during their first trimester, compared to those who did not experience complications. For example, women with pregnancy complications were more likely to have higher levels of blood sugar, blood pressure, and inflammation, while women who did not develop complications had normal or lower levels.

Women in the study who had a pregnancy complication or who developed gestational diabetes were also 1.6 times as likely to develop hypertension within seven years. Their risk for stage 2 hypertension, the level at which treatment is often prescribed, doubled. "This is often why it is said that pregnancy is a window into future cardiovascular health," Pemberton said. "Typically, we think about women who are postmenopausal being at risk for heart disease. We don't think about young women who are in their reproductive years or having babies being at risk for hypertension."

The researchers suggest that screening patients for heart disease, which the American Heart Association and the American College of Cardiology recommend doing every four to six years for adults ages 20-39, could start even earlier for pregnant women. For example, screenings and support for <u>healthy lifestyle choices</u> could be integrated into prenatal or obstetric care. In the study, women who exercised three hours each week had a lower risk for later hypertension.

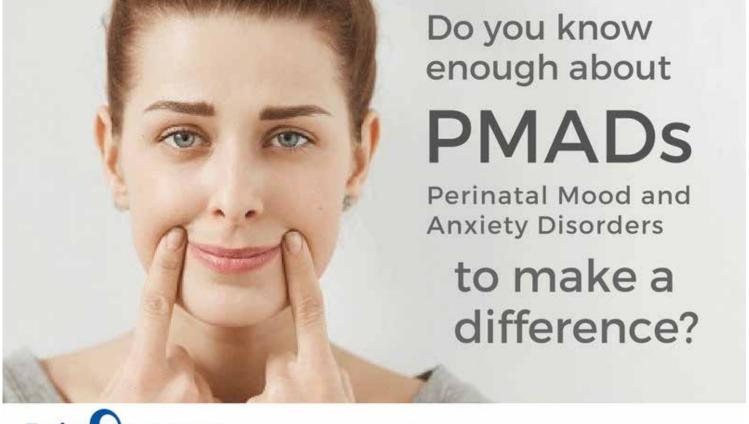
"During pregnancy women are in frequent contact with care providers and participate in multiple medical screenings," said Janet M. Catov, Ph.D., the lead study author and a researcher at the University of Pittsburgh Magee-Women's Research Institute. "A strong provider-patient partnership can be a first step in identifying potential risks for pregnancy complications, while creating strategies to support the cardiovascular health of a mother and her child for years to come."

Future <u>nuMoM2b Heart Health(link is</u> external) studies will assess how these types of cardiovascular health measures influence subsequent pregnancies and long-term health outcomes for women. The clinical trial number for this study is <u>NCT02231398</u>.

The research was shared during <u>American Heart Month</u>, which takes place in February to raise awareness about steps Americans can take to support their cardiovascular health and reduce their risk of heart disease, one of the leading causes of death worldwide.

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Study

Catov, McNeil, Marsh, et al. Early pregnancy atherogenic profile in a first pregnancy and hypertension risk 2 to 7 years after delivery. Journal of the American Heart Association. February 2021. <u>https://</u> doi.org/10.1161/JAHA.120.017216(link is external)

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NIH study finds that people with SARS-CoV-2 antibodies may have a low risk of future infection

Wednesday, February 24, 2021

A single elongated CCL-81 cell heavily in-

fected with SARS-CoV-2 virus particles. The small spherical structures in the image are SARS-CoV-2 virus particles. The string-like protrusions from the cells are cell projections or pseudopodium. Image captured at the NIAID Integrated Research Facility (IRF) in Fort Detrick, Maryland.*NI-AID*

People who have had evidence of a prior infection with <u>SARS-CoV-2</u>, the virus that causes COVID-19, appear to be well protected against being reinfected with the virus, at least for a few months, according to a newly published study from the National Cancer Institute (NCI). This finding may explain why reinfection appears to be relatively rare, and it could have important public health implications, including decisions about returning to physical workplaces, school attendance, the prioritization of vaccine distribution, and other activities.

For the study, researchers at NCI, part of the National Institutes of Health, collaborated with two health care data analytics companies (HealthVerity and Aetion, Inc.) and five commercial laboratories. The findings were published on Feb. 24 in *JAMA Internal Medicine*.

"While cancer research and cancer care remain the primary focus of NCI's work, we were eager to lend our expertise in serological sciences to help address the global COVID-19 pandemic, at the request of Congress," said NCI Director Norman E. "Ned" Sharpless, M.D., who was one of the coauthors on the study. "We hope that these results, in combination with those of other studies, will inform future public health efforts and help in setting policy."

"The data from this study suggest that people who have a positive result from a commercial <u>antibody</u> test appear to have substantial immunity to SARS-CoV-2, which means they may be at lower risk for future infection," said Lynne Penberthy, M.D., M.P.H., associate director of NCI's Surveillance Research Program, who led the study. "Additional research is needed to understand how long this protection lasts, who may have limited protection, and how patient characteristics, such as comorbid conditions, may impact protection. We are nevertheless encouraged by this early finding."

Antibody tests — also known as serology tests — detect serum antibodies, which are immune system proteins made in response to a specific foreign substance or infectious agent, such as SARS-CoV-2.

This study was launched in an effort to better understand whether, and to what degree, detectable antibodies against SARS-CoV-2 protect people from reinfection with the virus. Working with HealthVerity and Aetion, NCI aggregated and analyzed patient information collected from multiple sources, including five commercial labs (including Quest Diagnostics and Labcorp), electronic medical records, and private insurers. This was done in a way that protects the privacy of an individual's health information and is compliant with relevant patient privacy laws.

The researchers ultimately obtained antibody test results for more than 3 million people who had a SARS-CoV-2 antibody test between Jan. 1 and Aug. 23, 2020. This represented more than 50% of the commercial SARS-CoV-2 antibody tests conducted in the United States during that time. Nearly 12% of these tests were antibody positive; most of the remaining tests were negative, and less than 1% were inconclusive.

About 11% of the seropositive individuals and 9.5% of the seronegative individuals later received a nucleic acid amplification test (NAAT) - sometimes referred to as a PCR test — for SARS-CoV-2. The research team looked at what fraction of individuals in each group subsequently had a positive NAAT result, which may indicate a new infection. The study team reviewed NAAT results at several intervals: 0-30 days, 31-60 days, 61-90 days, and >90 days because some people who have recovered from a SARS-CoV-2 infection can still shed viral material (RNA) for up to three months (although they likely do not remain infectious during that entire period).

The team found that, during each interval,

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between 3% and 4% of the seronegative individuals had a positive NAAT test. But among those who had originally been seropositive, the NAAT test positivity rate declined over time. When the researchers looked at test results 90 or more days after the initial antibody test (when any coronavirus detected by NAAT is likely to reflect a new infection rather than continued virus shedding from the original infection), only about 0.3% of those who had been seropositive had a positive NAAT result about one-tenth the rate in those who had been seronegative.

Although these results support the idea that having antibodies against SARS-CoV-2 is associated with protection from future infection, the authors note important limitations to this study. In particular, the findings come from a scientific interpretation of real-world data, which are subject to biases that may be better controlled for in a clinical trial. For example, it is not known why people who had tested antibody positive went on to have a PCR test. In addition, the duration of protection is unknown; studies with longer follow-up time are needed to determine if protection wanes over time.

To continue to comprehensively address this important research question, NCI is supporting clinical studies that monitor infection rates in large populations of people whose antibody status is known. These are known as "seroprotection" studies. NCI is also sponsoring ongoing studies using real-world data to assess the longer-term effect of antibody positivity on subsequent infection rates.

This research is part of a \$306 million effort that NCI has taken on at the request of Congress to develop, validate, improve, and implement serological testing and associated technologies applicable to CO-VID-19. Through this appropriation, NCI is working with the Department of Health and Human Services; the National Institute of Allergy and Infectious Diseases, another part of NIH; and other government agencies to apply its expertise and advanced research capabilities to respond to this pandemic, including efforts to rigorously characterize the performance of serology assavs.

About the National Cancer Institute (NCI): NCI leads the National Cancer Program and NIH's efforts to dramatically reduce the prevalence of cancer and improve the lives of cancer patients and their families, through research into prevention and cancer biology, the development of new interventions, and the training and mentoring of new researchers. For more information about cancer, please visit the NCI website at <u>cancer.gov</u> or call NCI's contact center, the Cancer Information Service, at 1-800-4-CANCER (1-800-422-6237).

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New experiences enhance learning by resetting key brain circuit

Wednesday, February 24, 2021

A study of spatial learning in mice shows that exposure to new experiences dampens established representations in the brain's hippocampus and prefrontal cortex, allowing the mice to learn new navigation strategies. The study, published in *Nature*, was supported by the National Institutes of Health.

"The ability to flexibly learn in new situations makes it possible to adapt to an everchanging world," noted <u>Joshua A. Gordon</u>, <u>M.D., Ph.D.</u>, a senior author on the study and director of the <u>National Institute of</u> <u>Mental Health</u>, part of NIH. "Understanding the neural basis of this flexible learning in animals gives us insight into how this type of learning may become disrupted in humans."

Dr. Gordon co-supervised the research project with <u>Joseph A. Gogos, M.D.,</u> <u>Ph.D.(link is external)</u>, and <u>Alexander Z.</u> <u>Harris, M.D., Ph.D.(link is external)</u>, both of Columbia University, New York City.

Whenever we encounter new information, that information must be consolidated into a stable. lasting memory for us to recall it later. A key mechanism in this memory consolidation process is long-term potentiation, which is a persistent strengthening of neural connections based on recent patterns of activity. Although this strengthening of neural connections may be persistent, it can't be permanent, or we wouldn't be able to update memory representations to accommodate new information. In other words, our ability to remember new experiences and learn from them depends on information encoding that is both enduring and flexible.

To understand the specific neural mechanisms that make this plasticity possible, the research team, led by <u>Alan J. Park,</u> <u>Ph.D.(link is external)</u>, of Columbia, examined spatial learning in mice.

Spatial learning depends on a key circuit between the ventral hippocampus (a structure located in the middle of the brain) and the medial prefrontal cortex (located just behind the forehead). Connectivity between these brain structures strengthens over the course of spatial learning. If the connectivity remains at maximum strength, however, it impairs later adaptation to new tasks and rules. The researchers hypothesized that exposure to a new experience may serve as an environmental trigger that dampens established hippocampalprefrontal connectivity, enabling flexible spatial learning.

In the first task, the researchers trained mice to navigate a maze in a certain way to receive a reward. Some of the mice were then allowed to explore a space they hadn't seen before, while others explored a familiar space. The mice then engaged in a second spatial task, which required that they switch to a new navigation strategy to get a reward.

As expected, all of the mice favored their





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PAC/LAC 1010 N. Central Ave Glendale, CA 91202 original navigation strategy at first. But the mice that had explored a new space gradually overcame this bias and successfully learned the new navigation strategy about halfway through the 40-trial training session. When the researchers tested a subset of the mice on the first task again, they found that the noveltyexposed mice were able to switch back to the original strategy, indicating that they updated and chose their strategy according to the task demands.

Additional findings showed that the effects of novelty extended beyond new spaces: Encountering new mice before the second task also enhanced learning of the new reward strategy.

Changes in brain activity throughout training revealed the neuronal mechanisms that drive this novelty-enhanced learning. In rodents, there is a well-defined firing pattern in the hippocampus known as the theta wave, which is thought to play a central role in learning and memory. When Park and coauthors examined recordings from the ventral hippocampus, they found that the theta wave became stronger during exploration of the novel arena and the hour that followed; the theta wave decreased as the mice became familiar with the arena over the next two days. The researchers found that novelty exposure also disrupted encoding of the original navigation strategy, reorganizing the firing pattern of individual neurons in the ventral hippocampus to bring them in sync with the theta wave.

At the same time, neurons in the medial prefrontal cortex showed decreased theta wave synchrony, and correlations between hippocampal activity and prefrontal activity weakened. These and other findings suggest that novelty exposure dampened the synaptic connections between the ventral hippocampus and medial prefrontal cortex, resetting the circuit to allow for subsequent strengthening of connectivity associated with learning.

By triggering this reset, novelty appears to facilitate strategy updating in response to the task's specific reward structure. Machine learning analyses indicated that, following novelty exposure, ventral hippocampal neurons switched encoding from a strategy that predicted reward on the first task to one that predicted reward on the second task. The task-specific information was then relayed to the medial prefrontal neurons, which updated encoding accordingly.

On a chemical level, the neurotransmitter dopamine acts as a key mediator of this plasticity. Several experiments showed that activating dopamine D1-receptors in the ventral hippocampus led to novelty-like effects, including dampened hippocampal-prefrontal connectivity and enhanced learning. Blocking D1-receptors prevented these novelty-induced effects.

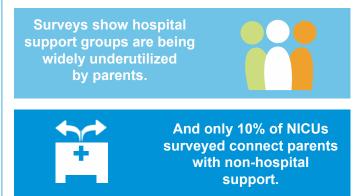
Together, these findings shed light on some of the brain mechanisms that play a role in flexible information encoding.

"Our study points to novelty as one way to trigger the circuitry reset that facilitates spatial learning in mice," said Park. "The next step is to build on these findings and explore whether novelty plays a similar role in human memory and learning."

Grants: MH096274, MH018870-29, MH117454, MH109735

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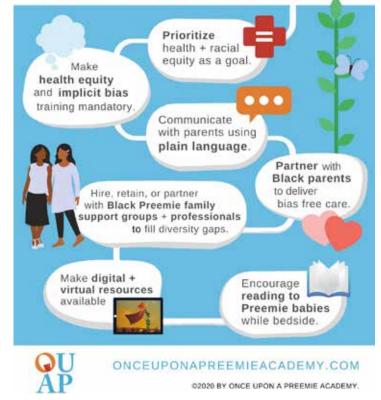
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The Genetics Corner: The Positive Predictive Value of NIPT for 22q11 Deletion Syndrome Varies with the Indication

Nivedita Rajakumar, Subhadra Ramanathan, Robin D. Clark, MD

Case Summaries

Patient 1

A 31-year-old G4 P1 female was referred for prenatal genetic counseling at 28 w 3 d gestation for a fetal cardiac anomaly. A detailed anatomy scan at 20 weeks

gestation identified a tetralogy of Fallot with pulmonary atresia, confirmed by a fetal echocardiogram. The mother chose to have a cell-free fetal DNA (cff) non-invasive prenatal test (NIPT) that included screening for microdeletion syndromes. The NIPT (genome-wide counting method, QNATAL, Quest) reported:"high risk" for 22q microdeletion syndrome (fetal fraction 19.79%; sensitivity 69-99% and PPV 75%; Guy *et al.*, 2019). The mother declined confirmatory diagnostic testing during the pregnancy. The baby boy was born at 38 weeks five days' gestation by planned induction of labor. Apgar scores were 8 and 8.

Birth weight:	3885 g (8 lb 9 oz)
Birth length:	52 cm (20.47")
Birth head circumference:	33 cm (12.99")

Postnatally, a chromosomal microarray confirmed a 2.5MB deletion at 22q11.21. Parental samples were normal, and the deletion was determined to be a *de novo* variant. He had cardiac surgery with unifocalization at nine months with plans for further cardiac surgery to repair pulmonary atresia. Other problems include bilateral hydroureteronephrosis, recurrent UTI, and an intradural arachnoid cyst of the spine. He is growing well with intact immune function, but global developmental delay affects his gross motor, fine motor, and speech.

Patient 2

A 12-month old female was referred to clinical genetics for confirmatory testing as cell-free fetal (cff) DNA screening testing during pregnancy was positive for 22q11.2 deletion syndrome. The pregnancy was detected at around 23 week's gestation, and NIPT was offered in place of routine maternal serum screening as the 25-year old mother was late to prenatal care. There were no fetal anomalies. NIPT (SNP-based method, Panorama, Natera) at 27week 1 day's gestation reported a high risk for 22q11.2 deletion syndrome (fetal fraction 8.9%, risk before test: 1/2000, risk after test: 1/5, sensitivity 90% (9/10), specificity 99.74% (389/390), false positive-rate 0.26%.; Ravi *et al.* 2018). Fetal ultrasound and echocardiogram exams were normal.

The baby was born at 39w 6d by NSVD.

 Birth weight:
 3885 g (8 lb 9 oz)

 Birth length:
 54 cm (21.25")

Birth head circumference: 34.9 cm (13.75")

There were no postnatal complications, and the baby was discharged home with her mother from the newborn nursery after a normal postnatal echocardiogram and renal ultrasound. Chromosome microarray analysis on cord blood failed due to maternal cell contamination. It was ordered again by the infant's pediatrician but was not completed. At 12 months, the patient was non-dysmorphic, growing well, and was on target developmentally. The physical exam was not consistent with 22q11.2 deletion syndrome. A chromosome microarray analysis was offered primarily for reassurance and to rule out any copy number variants, typical or atypical, at the 22q11 locus.

"The arguments for offering NIPT for microdeletion detection to low-risk women are that copy number variants are not associated with advanced maternal age and that microdeletions, as a group, are more prevalent than Down syndrome in infants born to younger mothers."

Discussion

These two infants both had a positive cff DNA screening test for 22q11.2 microdeletion during gestation, but only the baby with a prenatally detected cardiac anomaly was affected. This is not surprising as the prior risk for a 22q11.2 microdeletion is substantially higher when a fetus has a cardiac anomaly. In case 2, in spite of her normal development and lack of associated anomalies, the mother of the child with the (presumed) false-positive result was still concerned enough to seek a confirmatory test at a year of age. When an NIPT is positive for 22q11.2 deletion syndrome, a definitive diagnostic test should be offered soon after birth to resolve both the true positives and the false positives.

Chromosome anomalies significantly contribute to the etiology of congenital anomalies in both numerical (aneuploidy) and copy number variants (microdeletions and microduplications). Clinically relevant copy number variants occur in as many as 1.6% of

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pregnancies. Increasingly, NIPT, which analyzes maternal serum for fetal (primarily trophoblast) and maternal cell-free DNA, is employed to identify both types of fetal chromosome variants in highrisk and low-risk pregnancies. Although professional societies do not endorse this practice, it is widely offered in clinical practice.

The arguments for offering NIPT for microdeletion detection to low-risk women are that copy number variants are not associated with advanced maternal age and that microdeletions, as a group, are more prevalent than Down syndrome in infants born to younger mothers. Taken together, the 5 most common microdeletions (1p36 deletion, 4p [Wolf-Hirschhorn syndrome], 5p [cri du Chat syndrome], 15q11-13 deletion [Prader-Willi/Angelman syndromes], 22q11.2 deletion [DiGeorge/velocardiofacial syndrome) have an incidence of 1/1000 at birth. This means that a pregnant woman under the age of 29 is more likely to have a child with a microdeletion than a child with Down syndrome.

As with any rare condition, a screening test for microdeletion syndromes is expected to have a high false-positive rate and a low positive predictive value. However, little data has been published on the subject. As more pregnant women choose non-invasive prenatal testing, including microdeletion and standard aneuploidy screening, we can expect more false-positive than true positives. This raises many questions about the most appropriate response to a positive or negative NIPT test for a microdeletion. How worrying is a positive NIPT test? How reassuring is a negative test?

The positive predictive value (PPV) is the ratio of true positives to all positive test results.

Many factors influence the PPV for NIPT for microdeletions, including the prevalence of the disorder in the population, size of the copy number variant, sample characteristics (fetal fraction of DNA, regions of homozygosity within the target), test methodology, and laboratory protocol (SNP coverage, depth of reads). The two main testing methods used for NIPT are not equivalent in their ability to detect 22q11.2 and probably other microdeletions. Lo, *et al.* (2019) reported a fetus with a confirmed diagnosis of chromosome 22q11.2 deletion in whom two NIPT tests using different methods yielded discordant results. The pregnancy was identified as high-risk by an NIPT test that relied on an SNP-based approach and low-risk by an NIPT test that utilized the genome-wide counting method. This occurrence may be because a high depth of sequencing is required to reliably detect a small microdeletion when a whole-genome approach is used.

A rare disorder's low prevalence means that a positive screening test result is less likely to be a true positive in a low-risk population. This finding is borne out in the general population of pregnant women, in whom the PPV for a positive NIPT microdeletion screen is generally low, ranging from 9-20%. In their study of PPV for NIPT, Chen *et al.* (2019) found 20 true positives for copy number variants out of 69 with positive NIPT results for a PPV of 28.9%, which, interestingly, was higher than the PPV for

trisomy 13 in that study. Petersen *et al.* (2017) reported Baylor data in which confirmatory testing on 52 positive NIPT screens for microdeletion syndromes revealed 7/52 were true positives, PPV 13.4%. Of these, 6/28 were true positives for 22q11.2 deletion, PPV 21.4%. No indications were given for the original NIPT tests. Among a population of patients tested with NIPT from 7 different laboratories, Schwartz *et al.* (2018), found 25 confirmed microdeletions in 335 low-risk NIPT positive patients, yielding a PPV of 7.4% overall with wide confidence limits for each microdeletion type, due to small sample sizes. Of these 25 patients, 1/21 was a true positive for 1p36 deletion (PPV 4.8%), 1/6 for 4p deletion (PPV 16.7%), 6/45 for 5p deletion (PPV 13.3%), 5/80 for 15q deletion (PPV 6.3%), and 12/183 for 22q deletion (PPV 6.6%).

Among the false positives for 15q and 22q microdeletions, Schwartz and colleagues found an over-representation of homozygosity compared to controls, implying that consanguinity between the parents may be a risk factor for false positive NIPT results in these groups, especially when the NIPT test relies on a single nucleic acid polymorphism (SNP) methodology.

As the a priori risk for microdeletion increases in high-risk populations, so does the PPV for a positive NIPT microdeletion test. The presence of fetal anomalies consistent with the diagnosis should increase the PPV substantially. In Chen's report, the PPV was 100% in the group whose indication for NIPT testing was a fetal structural anomaly on ultrasound. Schwartz et al. reported 7 confirmed microdeletions in their small group of high-risk patients, with indications of a fetal ultrasound abnormality or a family history of microdeletion, yielding a PPV of 43.8%. Helgeson et al. (2015) reported a high PPV for microdeletions detected by NIPT using whole-genome sequencing in a high-risk population. They reported confirmatory studies in 53/55 cases with a positive NIPT for microdeletions. Among NIPT tests positive for a 22q11.2 deletion, 23/32 were confirmed in the mother, the fetus, or both for a PPV of 71.9%. However, the authors expected 44 affected cases with 22q11.2 deletion in this cohort, and they estimated the sensitivity of the test to be 70.5%. Among those NIPT tests that were positive for 15q, 8/9 were confirmed for a PPV of 88.9%. These authors report that in those samples found to have a microdeletion, a fetal ultrasound finding was the most common indication for the NIPT test (48.2%).

To address how reassuring a negative NIPT with microdeletion detection for 22q11.2 would be, Asoglu *et al.* (2020) examined a cohort of patients with congenital heart defects whose cytogenetic diagnosis had been established. In their retrospective analysis of 302 CHD cases with diagnostic genetic results, 98/302 had a confirmed cytogenetic abnormality. Of these, 31/98 (31.6%) or 10.3% of the total group would not have been detectable by NIPT for aneuploidy or 22q11.2 microdeletion analysis. This reinforces the need for cytogenetic studies in newborns with CHD who have had a negative NIPT that included microdeletion analysis.

The two cases above, one with a prenatally apparent cardiac



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anomaly and one without, illustrate how the likelihood of a true positive result varies with the indication for NIPT testing. Congenital heart defects (CHD) are the most common birth defect, affecting almost 1% of all live-born infants. The 22q11.2 deletion syndrome is the most common microdeletion in the newborn, with a prevalence of 1 in 4000 live births. The presence of a CHD will substantially increase the chance that a positive NIPT for 22q11.2 is a true positive. Without a fetal anomaly, the same positive test is more likely to be a false positive. As NIPT testing for microdeletions is offered to low-risk and high-risk women alike, medical providers caring for these infants should consider the indication for the NIPT test in the first place to understand its likely significance to their patient. In any event, a confirmatory test is warranted, if only for reassurance.

Practical Applications:

- 1. Cell-free fetal DNA is a screening test that should not be considered definitive or diagnostic.
- 2. A positive NIPT for a microdeletion has a higher PPV when the indication for testing was a fetal structural anomaly detected by ultrasound
- Confirm any positive NIPT test with chromosome analysis (for aneuploidy) or chromosome microarray (for copy number variants).
- Do not let a negative NIPT test dissuade you from ordering a definitive chromosome study when the phenotype suggests a microdeletion syndrome.

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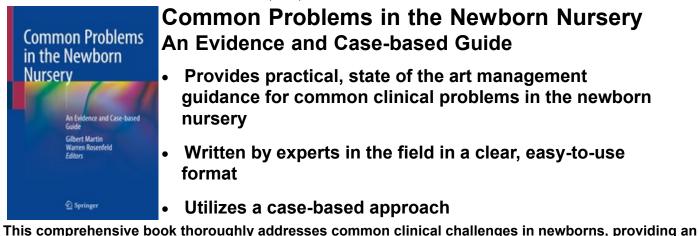


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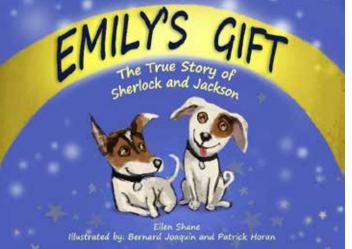
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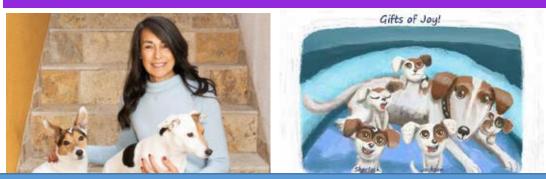
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Human Milk: The Best Medicine for Vulnerable Babies

Heidi E. Karpen, MD



The National Coalition for Infant Health is a collaborative of more than 200 professional, clinical, community health, and family support organizations focused on improving the lives of premature infants through age two and their families. NCfIH's mission is to promote lifelong clinical, health, education, and supportive services needed by premature infants and their families. NCfIH prioritizes safety of this vulnerable population and access to approved therapies.

It fosters brain development. It passes on antibodies. It lowers the risk of infection. Human milk has long been known to offer many benefits to babies, especially to those born prematurely.

My colleagues and I are now working on a <u>large, multi-hospital</u> <u>study</u> that aims to shed new light on how human milk benefits one group of infants in particular – newborns with congenital gastrointestinal disorders. (1)

The babies in this study receive exclusive human milk diets. The milk is from their own mother or pasteurized donor human milk. All babies in the study also receive a human-milk-based fortifier to provide the additional calories and protein they need. The research team is comparing the outcomes of these babies to those who received infant formula as part of their diet. The expectation?

Infants receiving exclusively human milk will require IV nutrition for a shorter period of time. We are also comparing growth between the two groups of infants.

"The babies in this study receive exclusive human milk diets. The milk is from their own mother or pasteurized donor human milk. All babies in the study also receive a human-milk-based fortifier to provide the additional calories and protein they need. "

Positive results would reinforce a growing body of research on the topic of human milk. In prior research, babies with congenital gastrointestinal disorders spent about 20 fewer days in the hospital than infants fed formula primarily did. They also had few days of intravenous nutrition, fewer feeding problems, fewer infections, and less liver damage.

Congenital gastrointestinal disorders can occur when part of the intestine doesn't form correctly or when the intestines are outside the body through a hole in the abdomen. Newborns with these birth defects experience a delay in beginning to feed because of surgeries. Feeding intolerance and frequent feeding interruptions can also force them to rely on IV nutrition for long periods of time. These delays and problems in feeding their baby can lead new moms to decide not to breastfeed or pump milk.

A parent's decision to feed her baby human milk or formula is a personal one. It can also be a sensitive subject for new moms who

129



may face unexpected challenges with milk supply, who are separated from their babies, lack support, or who are just beginning to comprehend what having a congenital gastrointestinal disorder will mean for their baby.

But data is proving that human milk might be the most effective medicine for babies with a congenital gut disorder. My goal is to help foster that education and offer support to new parents who decide that pumping and storing human milk until their baby is ready is right for them.

Human milk yields benefits to all babies, but especially those with a congenital gastrointestinal disorder.

References:

1. <u>https://clinicaltrials.gov/ct2/show/NCT02567292</u>

Heidi E. Karpen, MD, is a neonatologist at Emory University School of Medicine and a member of the National Coalition for Infant Health.

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Disclosure: The author has no relevant disclosures.



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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.

OPIOIDS and NAS When reporting on mothers, babies, and substance use LANGUAGE MATTERS



I am not an addict.

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

I was exposed to opioids.

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



NAS is a temporary and treatable condition.

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



My mother may have a SUD.

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

My potential is limitless.



I am so much more than my NAS diagnosis. My drug exposure will not determine my long-term outcomes. But how you treat me will. When you invest in my family's health

and wellbeing by supporting Medicaid and Early Childhood Education you can expect that I will do as well as any of my peers!

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





The Preemie Parent's SURVIVAL GUIDE to the NICU

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Respiratory Syncytial Virus

National Statistics

About Respiratory Syncytial Virus

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

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

National Health Plan Coverage & Access

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



"Gap" Babies Commercial Plans Denied 40% Medicaid: 25%



Medicaid: 25% **"In-Guidance" Babies** Commercial Plans Denied **25%** Medicaid: **14%** Health plans deny 40% of palivizumab prescriptions for premature infants born between 29 and 36 weeks gestation.

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

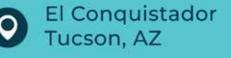
This includes severely premature infants born before 29 weeks gestation, babies born before 32 weeks gestation who have chronic lung disease, and babies born with congenital heart disease.







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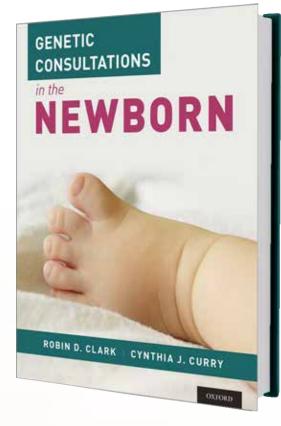
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RSV AWARENESS: A National Poll of Parents & Health Care Providers

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

Yet a national poll of parents and specialty health care providers reveals a startling divide in attitudes toward the virus. While both groups acknowledge RSV as a significant concern, the two populations vary widely in their reported ability to meet RSV's threat head-on. Health care providers vigilantly monitor for the virus, which they report seeing regularly in their practices. Parents, however, feel unequipped to protect their young children.

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

KEY FINDINGS

Preparedness

Parents of children age four and under report that understanding of RSV is lacking. That leaves them less than fully prepared to prevent their young children from catching the virus. Specialty health care providers reiterated these concerns; 70% agreed that parents of their patients have a low awareness of RSV. Meanwhile, specialty health care providers themselves actively monitor for RSV. They reported that:



SPECIALTY HEALTH CARE PROVIDERS

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

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

PARENTS

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

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



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Clinical Pearl: A Thoughtful Approach to Neonatal End-of-life Discussions

Patricia Stevens, MS, NNP-BC

Abstract:

While an infant's death is always tragic, with a review of parents' feedback, forethought, andempathy, we can help parents through this difficult time in a better way.

Since the inception of NICU to care for critically ill neonates, death before discharge has been common. As our knowledge base grows and technology advancements are made, more and more critically ill newborns now do survive in NICU, yet there are some lives; no matter how much we try, we still cannot save. So how do we counsel parents who are resistant to this discussion and/ or maintain a stance of wanting "everything done" despite being told the reality of imminent death? Do we really help the family by prolonging the inevitable, therebyprolonging pain and suffering?

Support for medical providers in this difficult situation is found in the position statement "Non-initiation or Withdrawal of Intensive Care for High-risk Neonates," which clearly states:

> The critical role of the parents in decision-making must be respected. However, the physician's first responsibility is to the patient. The physician is not obligated to provide inappropriate treatment or to withhold beneficial treatment at the parents' request. Treatment that is harmful, of no benefit, or futile and merely prolonging dying should be considered inappropriate. In his or her best medical judgment, the physician must ensure that the chosen treatment is consistent with the best interest of the infant (1).

The dichotomy of caring for more than one patient with conflicting needs is, at best, challenging. Following this recommendation is easier said than done. How do we have that difficult conversation with parents to facilitate end-of-life decisions when further care becomes futile? Needless suffering becomes unbearable to witness. Does death come after sometimes brutal resuscitations rather than a planned peaceful and meaningful experience surrounding family with support and closure?

"The dichotomy of caring for more than one patient with conflicting needs is, at best, challenging. Following this recommendation is easier said than done. How do we have that difficult conversation with parents to facilitate end-of-life decisions when further care becomes futile?" we do now. Research had reported that most deaths in the NICU were preceded by decisions agreed upon by the medical team and family to withhold or withdraw life-sustaining medical treatment (1,2). Over the pastten years, however, it seems that these numbers have reversed. Fewer deaths are peaceful, and medical teams feel that discussing redirection of care is often met with such strong family resistance that having this discussion in these cases is often feels like a waste of time.

"Fewer deaths are peaceful, and medical teams feel that discussing redirection of care is often met with such strong family resistance that having this discussion in these cases is often feels like a waste of time."

This change of trend then becomes self-perpetuating, as more physicians have become more and more uncomfortable offering transition to comfort care. Several influences may contribute to this. Some physicians do not feel they have the right, either legally, ethically, or morally, to recommend withdrawal of life-sustaining medical therapy, despite support from AAP, legislation, and ethicists (1,2,3). Yet, avoidance of having this conversation can become thepath of least resistance. Some feel their training was sparse in learning communication techniques to help families make end-of-life decisions (3), and hostility from family interactionsin failed attempts reinforces further avoidance. Some erroneously contend that the burden tomake this decision falls squarely



In the past few decades, we seemed to have done this better than



on parents alone. If they do not request redirection of care or decide once they are given "the facts" of futility, the issue is never revisited.

" Confusion from the foreign language of medical jargon even if English speaking, even more confusion if not English speaking. Mental and physical exhaustion after complicated pregnancy and delivery. Guilt, fear, and the list goes on. Society identifies childbearing as a natural process, yet often, without warning, natural very quickly can become unnatural."

In order to provide the very best end-of-life care for our patients and their families, it is important to consider the perspective of a parent entering the foreign world of NICU for the first time. Sensory overload from monitors and staff activity. Overwhelmed by the equipment. Confusion from the foreign language of medical jargon even if English speaking, even more confusion if not English speaking. Mental and physical exhaustion after complicated pregnancyand delivery. Guilt, fear, and the list goes on. Society identifies childbearing as a natural process, yet often, without warning, natural very quickly can become unnatural.

In a meta-synthesis of predominantly empirical research, Xafis and colleagues (4) explored retrospective feedback from parents, which identifies what parents found assisted or impeded them in making end-of-life decisions for their child. The findings are not surprising. However, once identified, it becomes clear how the most needed support can be easily a neglected priority in a busy intensive care environment.

According to this research, an essential aspect of care that aided parents in this situation, having never made end-of-life decisions before, was the need for a trusting relationship with the physician, which developed with time, honesty, and continuity of care long before end-of-life discussion even begins. This alone is difficult to provide in a large academic NICU, with rotating residents, attending neonatologists, nurse practitioners, nurses, social workers.

Further, we may not have the luxury of time before mortal decline presents. Alternatively, the turn of events may occur during offservice time. Creativity in carving time for establishing relationships and very clear documentation of discussions and parents' response may help inthese situations. Parents also felt that having the ability to speak with other parents who have experienced making end-of-life decisions for their child in the past is extremely helpful. Many NICUs are beginning to see the benefit of peer-to-peer support. Previous NICU parents can provide tremendous help to parents, either as a hospital-based or community-based program. Researchshows that the most successful programs are ones that connect with medical providers (5).

Things that hindered decision-making from the parents' perspective are important to acknowledge. Many felt bombarded with information from multiple providers that interact with parents daily. Many expressed difficulties in comprehending the information presented and retaining complex explanations, thus hampering their ability to make decisions. During this dreaded experience, they did best with very simple and consistent explanations given their state of mind. Better yet, many felt they were better able to process information in a written format that they could review after discussion.

Parents also acknowledge conflicting emotions between what is best for the infant as opposed to what they, as parents had wanted, were very difficult to endure. Maintaining some level of hope throughout the decision-making process was important to them. In fact, some parents expressed that trust for the medical team was hampered when no level of hope was expressed by the health care team. While we may feel that expression of any hope undermines our message of futility, parents felt that maintaining some level of hope, albeit slim, made the providers more credible and

"The truth is, there is considerable groundwork the NICU team must do long before the parent of a moribund infant is approached for this conversation."

trustworthy.

The truth is, there is considerable groundwork the NICU team must do long before the parent of a moribund infant is approached for this conversation. The American Academy of Pediatrics published "Guidance on Foregoing Life-Sustaining Medical Treatment" clearly identifies process guidance for further review, and it is a good place to use to evaluate how the process ofyour NICU compares. (3)

Two concepts must be openly discussed by the team in any institution to improve our care. First, there must be agreement among the medical team that the practice to forego painful resuscitations at the end of life and instead offer peaceful deaths is ethical in futile situations. The definition of futility may be subjective and should be up for discussion as well. Reaching this consensus

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may be difficult in both a large academic NICU or even community level III NICU.In these cases, it may be appropriate to consult with the Palliative Care team early if available or develop a subset of multidisciplinary providers within the NICU to consult and support this practice. The subset of infants can be those with severe asphyxia requiring cooling therapy, extreme prematurity less than 24 weeks, or infants requiring ECMO. Communication and establishment of working relationships with parents should begin early, usually upon prenatal diagnosis or unexpected admission to NICU in those infants at high risk for death before discharge. Written protocols may help to improve consistency among providers.

Second, this decision must be made jointly between parent and physician within a respectful working relationship. The burden of this decision cannot be left on the shoulders of the parents alone. There will be multiple caregivers interacting with the parent, and consistency in message delivery is paramount. Trust is established by providing consistent, honest, simple information that respects maintaining some element of hope. Unless circumstances arequickly dire, redirection of care should not be broached at the first meeting. Consider the development of a peer-to-peer support program for added support for parents.

In closing, while an infant's death is always tragic, with forethought and empathy, we can help parents through this difficult time in a better way.

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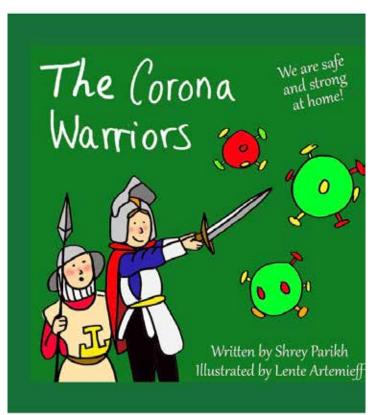
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Summarize the pearl for emphasis.

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OPIOIDS and NAS When reporting on mothers, babies, and substance use LANGUAGE MATTERS



I am not an addict.

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



I was exposed to opioids.

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



NAS is a temporary and treatable condition.

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



My mother may have a SUD.

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

My potential is limitless.

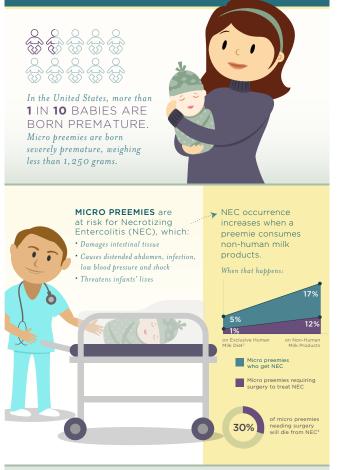


I am so much more than my NAS diagnosis. My drug exposure will not determine my long-term outcomes. But how you treat me will. When you invest in my family's health and wellbeing by supporting Medicaid and Early Childhood Education you can expect that I will do as well as any of my peers!

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142

Letters to the Editor

February 22, 2021

Dr. Mitchell Goldstein, Editor, Neonatology Today

To the Editor

I write in reference to the recently published study by Khoury R et al., which I have reviewed in detail, in which the authors compared the times taken to achieve stable heart rate readings for Masimo and Nellcor pulse oximeters in neonates immediately after delivery (1). Pulse rate stability was compared using a qualitative measure (looking at it and writing the number down).

The 60 babies studied were all healthy, and they cannot be compared to a manuscript I authored (2) and this is the basis for this letter, where I will summarize the major limitations and differences between previous publications and the current findings in Khoury's paper.

"Furthermore, I believe that the findings are of no clinical significance and could not support any changes in the current clinical guidelines of neonatal resuscitation."

The manuscript used interchangeably several aspects - "during delivery room transition," "neonatal transition," and "an uncomplicated resuscitation setting," and this has led to confusion. Furthermore, I believe that the findings are of no clinical significance and could not support any changes in the current clinical guidelines of neonatal resuscitation.

In many places of the world, there remains a significant need for education in order to improve the skill and training so that care of sick newborns after birth is improved. Adequate auscultation of the heart and palpation of the base of the umbilical cord have a more significant clinical impact than spending precious time and resources trying to apply ECG electrodes that have been shown to have reduced function in ill babies before 60 seconds of life. The scant resources in many areas should be diverted to neonates at risk due to gestational age or clinical condition to ensure the required clinical interventions are instituted in a timely manner.

This study was conducted in healthy babies born by cesarean section who did not require resuscitation with Apgar scores of 8-9 at 1 minute; 91.7% of them were born by elective Cesarean-section. None of the infants required resuscitation, and comparisons were made after the healthy babies were placed on a warmer. Pulse rate stability was compared using a qualitative measure (looking at it and writing the number down).

As mentioned by Khoury, the findings of his study cannot (and should not) be extrapolated to other groups of newborns, like those who are ill, premature, or have potentially serious conditions.

I would also like to share a concept in relation to the Masimo sensor that was used. In response to the 2015 American Academy of Pediatrics Newborn Resuscitation Protocol (NRP) to address the measurement conditions during the first few minutes after birth (3), Masimo optimized the sensor in 2016 to provide stable pulse rate readings earlier. This sensor, which upon application automatically set the Masimo oximeter settings to 2-4 second (fast) averaging time and maximal sensitivity, was not utilized in the study cohort. Matching technology is essential for performance as approved by the FDA. Additionally, many published clinical studies in preterm and term infants in the delivery room report SpO₂ nomograms in thousands of babies using Masimo SET technology (4-6). What is reported in Khoury's study cannot be extrapolated to what happens in the NICU in critically ill babies. SET technology use in thousands of babies (including many studies and all recent publications with ventilators with closed-loop technology) (7-10) led to a significant reduction in severe ROP and the need for laser therapy. Pulse oximetry selection is important in managing critically ill infants.

"What is reported in Khoury's study cannot be extrapolated to what happens in the NICU in critically ill babies. SET technology use in thousands of babies (including many studies and all recent publications with ventilators with closedloop technology) (7-10) led to a significant reduction in severe ROP and the need for laser therapy. Pulse oximetry selection is important in managing critically ill infants."

Lastly, Khoury's study mentions using the electrocardiogram (ECG) heart rate as a "gold standard" for pulse rate from pulse oximetry. Pulseless Electrical Activity (PEA, also known as Electro-Mechanical Dissociation or EMD) is not rare during the first minutes after birth, especially during asphyxia, as is clearly mentioned in NRP documents of AAP. The ECG can display heart rates far greater than the actual pulse rate in this situation. Several studies affirm this fact (11, 12). This is a possible explanation of some of the "low pulse rate" data points shown in Khoury's Figure 2 when the actual peripheral pulse rate can be significantly lower than the ECG rate.

In summary, I consider the statistically significant difference reported in this study to be clinically insignificant and do not provide any basis for the improvement of clinical care and outcomes of sick babies in the delivery room and in the NICU, and could actually distract clinicians from the first important steps that are essential during neonatal resuscitation.

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Dear Dr. Latorre:

As noted in my previous response to Dr. Barker, "comparison trials of relevant devices define usage parameters." Further, as you have noted, the populations studied must be complementary to justify conclusions. Health newborns in the delivery room are different from those who are sick in the NICU. Speed of response, notwithstanding, the technology is not just about speed alone. Accuracy, precision, and reproducibility are a sine gua non. Early pulse oximetry was neither designed to work on NICU patients nor any sick patients for that matter. The pulse oximeter was referred to as a "fair-weather friend." (1) We were taught that reliance on a pulse oximeter was problematic when a patient was moving or had low perfusion. Signal Extraction technology (SET) is an entirely different technology. Comparing SET to other technologies is like comparing a late model semiautonomous electric vehicle to a 1950s gas guzzler. However, shut down the electric grid, take away the software innovation, and provide only fossil fuel, and the 1950s gas guzzler will win every race. The innovative modes, software, sensors, and usage should have been included in the study. The fact remains that although the authors of the study have reached statistical significance, there is no clinical relevance because the Masimo devices were not used in their most optimized settings and did not have the latest software revision. (2, 3)

Pulseless Electrical Activity (PEA) is definitively an issue. Earlier AAP resuscitation guidance questioned whether pulse oximetry might "falsely" indicate that there was no pulse when there was sufficient EKG activity resulting in unnecessary resuscitation. Although there is no substitute for a full exam, the reverse is undoubtedly true and much more dangerous should a "reassuring" EKG lead to a resuscitation delay. (4-6) Arguably, the EKG is analogous to "fool's gold." It seems like the real thing (i.e., pulse), but it's not.

Your concerns are well stated and essential. Khoury et al. should have incorporated these considerations into the initial study design.

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Sincerely,

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Mitchell Goldstein, MD

Editor in Chief



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Erratum (Neonatology Today February, 2021)

Neonatology Today acknowledges that the Erratum box in the January 2021 edition referred to "2020" instead of "2021." Dr. Paula Whiteman's name was mispelled in the Table of Contents in December, January and February editions.

Corrections can be sent directly to <u>LomaLindaPublishingCom-</u> <u>pany@gmail.com</u>. The most recent edition of Neonatology Today including any previously identified erratum may be downloaded from <u>www.neonatologytoday.net</u>.

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*Source: Respirator Syncytial Virus and African Americans

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58.1%	Breastfeeding	50.2%
7.3%	Low Birth Weight	11.8%
60.1%	Siblings	71.6%
1%	Crowded Living Conditions	3%



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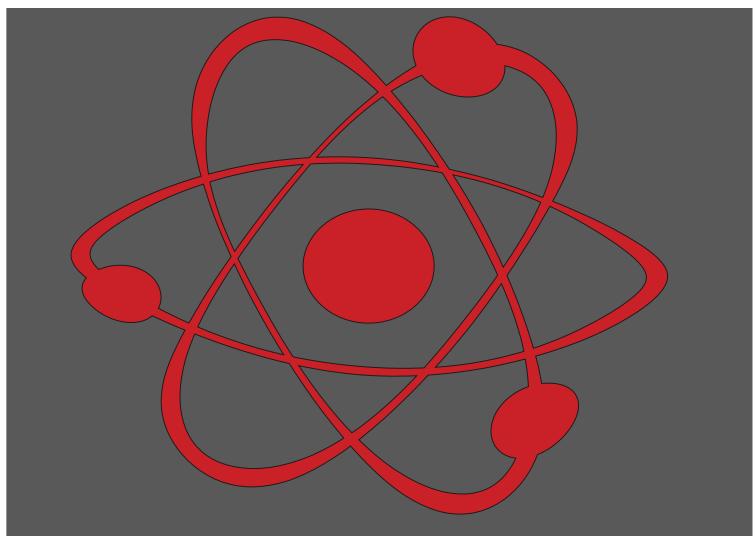


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147

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Neonatology and the Arts

This section focuses on artistic work which is by those with an interest in Neonatology and Perinatology. The topics may be varied, but preference will be given to those works that focus on topics that are related to the fields of Neonatology, Pediatrics, and Perinatology. Contributions may include drawings, paintings, sketches, and other digital renderings. Photographs and video shorts may also be submitted. In order for the work to be considered, you must have the consent of any person whose photograph appears in the submission.

Works that have been published in another format are eligible for consideration as long as the contributor either owns the copyright or has secured copyright release prior to submission.

Logos and trademarks will usually not qualify for publication.

This month we continue to feature artistic works created by our readers on one page as well as photographs of birds on another. This month's original artwork is again provided by Paula Whiteman, MD, a beautiful Stargazer Lily. Our Bird for this month is provided by NT's own Larry Tinsley, MD who provides a Mallard Duck in Hiding.



Herbert Vasquez, MD, Associate Neonatologist, Queen of the Valley Campus Emanate Health, West Covina, CA <u>VasquezH1@gmail.com</u>

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Manuscript Submission: Instructions to Authors

1. Manuscripts are solicited by members of the Editorial Board or may be submitted by readers or other interested parties. Neonatology Today welcomes the submission of all academic manuscripts including randomized control trials, case reports, guidelines, best practice analysis, QI/QA, conference abstracts, and other important works. All content is subject to peer review.

2. All material should be emailed to:

LomaLindaPublishingCompany@gmail.com in a Microsoft Word, Open Office, or XML format for the textual material and separate files (tif, eps, jpg, gif, ai, psd, or pdf) for each figure. Preferred formats are ai, psd, or pdf. tif and jpg images should have sufficient resolution so as not to have visible pixilation for the intended dimension. In general, if acceptable for publication, submissions will be published within 3 months.

3. There is no charge for submission, publication (regardless of number of graphics and charts), use of color, or length. Published content will be freely available after publication. There is no charge for your manuscript to be published. NT does maintain a copyright of your published manuscript.

4. The title page should contain a brief title and full names of all authors, their professional degrees, their institutional affiliations, and any conflict of interest relevant to the manuscript. The principal author should be identified as the first author. Contact information for the principal author including phone number, fax number, e-mail address, and mailing address should be included.

5. A brief biographical sketch (very short paragraph) of the principal author including current position and academic titles as well as fellowship status in professional societies should be included. A picture of the principal (corresponding) author and supporting authors should be submitted if available.

6. An abstract may be submitted.

7. The main text of the article should be written in formal style using correct English. The length may be up to 10,000 words. Abbreviations which are commonplace in neonatology or in the lay literature may be used.

8. References should be included in standard "NLM" format (APA 7th may also be used). Bibliography Software should be used to facilitate formatting and to ensure that the correct formatting and abbreviations are used for references.

9. Figures should be submitted separately as individual separate electronic files. Numbered figure captions should be included in the main file after the references. Captions should be brief.

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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.

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