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Peer Reviewed Research, News and Information  
in Neonatal and Perinatal Medicine



Volume 16 / Issue 6 | June 2021

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**NEONATOLOGY TODAY**  
© 2006-2021 by Neonatology Today  
Published monthly. All rights reserved.  
ISSN: 1932-7137 (Online), 1932-7129 (Print)  
All editions of the Journal and associated manuscripts are available on-line:  
[www.NeonatologyToday.net](http://www.NeonatologyToday.net)  
[www.Twitter.com/NeoToday](http://www.Twitter.com/NeoToday)



Loma Linda Publishing Company  
A Delaware "not for profit" 501(c) 3 Corporation.  
c/o Mitchell Goldstein, MD  
11175 Campus Street, Suite #11121  
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# Prevention of Shaken Baby Syndrome Among High-Risk Neonates: Program Implementation and Evaluation

Rebecca Tortolano, DNP, MS, RN, Michelle E. Neuman, DNP, RN, APN, PPCNP-BC, Shannon D. Simonovich, PhD, RN

## Abstract:

**Background:** Studies suggest that the implementation of high-quality education and support services for caregivers may reduce the incidence of unplanned harm to infants and young children under high-stress circumstances.

**Purpose:** This pilot study evaluates the usefulness of the Period of PURPLE Crying program in a high-acuity NICU at The University of Chicago Comer Children's Hospital based on six measurable objectives.

**Methods:** The pilot study utilized a Likert-style pretest-posttest survey design to evaluate how NICU nurses perceived the Period of PURPLE Crying program. Nurses were educated on the program content during an in-service to teach participants how to utilize the Period of PURPLE Crying program materials to support and educate families about Shaken Baby Syndrome (SBS).

**Results:** The intervention effectively increased nursing confidence in delivering the SBS and Abusive Head Trauma (AHT) education and increased accessibility to available resources pertaining to SBS and AHT. Questions pertaining specifically to the Period of PURPLE Crying presented exclusively on the post-test were met with an overwhelmingly positive response, with the majority ( $n=33$ , 97%) of respondents agreeing that the intervention was useful in standardizing SBS education, providing meaningful, effective information on this topic area, and delivering SBS and AHT information promptly.

**“The Centers for Disease Control and Prevention (CDC) reports previously describe how “excessive frustration and exhaustion can lead individuals to a breaking point,” leading to Shaken Baby Syndrome (SBS) and Abusive Head Trauma (AHT) in infants (n.d., p. 4) (1).”**

## Introduction

The Centers for Disease Control and Prevention (CDC) reports previously describe how “excessive frustration and exhaustion can lead individuals to a breaking point,” leading to Shaken Baby Syndrome (SBS) and Abusive Head Trauma (AHT) in infants (n.d., p. 4) (1). Implementing high-quality education related to SBS and AHT coupled with support services for caregivers may reduce the

incidence of unplanned harm to infants and young children under high-stress circumstances.

## Incidence

Shaken baby syndrome (SBS) is the leading cause of child abuse-related deaths in the United States (U.S.) and most often occurs in infants less than six months of age (National Center on Shaken Baby Syndrome, 2020) (2). Approximately 1,300 cases are reported each year in the U.S., with nearly 80% of survivors suffer long-term disabilities, and it proves fatal for one out of four victims (National Center on Shaken Baby Syndrome, 2020) (2). Unfortunately, data on this problem is likely underestimated as many cases remain unreported and undiagnosed (National Center on Shaken Baby Syndrome, 2020) (2). Abuse of this nature occurs when an infant's caregiver becomes excessively frustrated, with a higher incidence among those with disproportionate hardships or relationship problems that challenge coping methods (New York State Department of Health, 2010) (3). Other risk factors include those with unrealistic expectations related to normal infant behaviors, individuals that were abused or neglected as a child, domestic violence victims, single parents, preterm infants, children with disabilities, multiples, infants less than six months old, and infants

**“The Period of PURPLE Crying program referred to throughout this publication, and much of the literature to date as the PURPLE program is an education program aimed to reduce the incidence of SBS and AHT through education and caregiver support during the period of increased infant crying (National Center on Shaken Baby Syndrome, 2020) (2).”**

that cry inconsolably frequently (CDC, n.d.) (1).

## Prevention

The Period of PURPLE Crying program referred to throughout this publication, and much of the literature to date as the PURPLE program is an education program aimed to reduce the incidence of SBS and AHT through education and caregiver support during the period of increased infant crying (National Center on Shaken Baby Syndrome, 2020) (2). A study in British Columbia evaluated a sample of 354,477 parents and concluded that the PURPLE program effectively reduced hospital admissions related to SBS and AHT by 35% for children ages two years and under over an eight-year period (Barr et al., 2019) (4). This hallmark study emphasizes the value of widespread adoption of standardized, preventative education related to SBS and AHT. Another large-scale study conducted in North Carolina across 86 healthcare entities found that 90% of parents receiving the PURPLE program materials recalled the main constructs two months after having received the intervention and reported an increase in behaviors such as walking away when the infant is inconsolable (Nocera et al., 2016)

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Despite these findings, just eighteen states across the U.S. have adopted the program statewide; see figure 1 in Appendix C (National Center on Shaken Baby Syndrome, 2021) (2). The universal adoption of this program among healthcare and community settings across the nation may improve coping methods for parents and caregivers, offer ongoing support, and reduce the incidence of SBS and AHT.

#### **Cost Implications:**

The cost of SBS and AHT per case accounts for millions in healthcare spending (National Center on Shaken Baby Syndrome, 2020) (2). Visits to the emergency department are one of the key drivers of cost for SBS and AHT. Barr et al. (2015) (6) found that the implementation of the PURPLE program in British Columbia decreased E.D. visits related to crying episodes for well babies by 29.5%. This program contributes to better health outcomes for families and reduces the overall cost of such visits for the healthcare system.

#### **Study Purpose:**

The purpose of this project was to evaluate the usefulness of the PURPLE program in a high-acuity Neonatal Intensive Care Unit (NICU) at The University of Chicago Comer Children's Hospital. Before implementing this pilot study, SBS and AHT were routinely discussed as a part of patient education; however, this practice was carried out with minimal guidance, standardization, or clearly defined objectives.

#### **Methods**

##### **Study Design:**

The study utilized a Likert-style pretest-posttest survey design to evaluate how the PURPLE program was perceived by NICU nurses who agreed to utilize the PURPLE program content to educate parents and caregivers. The Likert scale ranged from one (strongly disagree) to seven (strongly agree). See Appendix A for complete survey content. Surveys were developed for this study and distributed using the Qualtrics software. The proposal was approved by the University of Chicago Institutional Review Board (IRB) as well as DePaul University's IRB. The University of Chicago's IRB served as the lead site for overseeing this project. IBM SPSS statistics software was used to analyze data.

##### **Implementation:**

Recruitment was completed by following a script asking nurses to partake in an in-service education aimed to teach participants how to utilize the PURPLE program materials to educate families about SBS. At the start of the in-service presentation, participants completed a confidential, Likert-style pre-intervention survey on an iPad or personal smartphone device that evaluated their perception of SBS, knowledge surrounding this topic area, and demographics. The in-service education reviewed the most common cause of SBS and AHT, timeframes of increased infant crying, and data on the incidence of such trauma in correlation with periods of increased infant crying. Nurses were asked to give parents and caregivers the PURPLE program pamphlet, review the education and direct them to the smartphone application to watch the program's video content. After delivering the intervention for approximately four to six weeks, participants received the post-intervention survey link via email or text message with the same six Likert-style questions on the pre-intervention survey plus an additional three questions specific to the PURPLE program content. Participants were given a link to a free CEU related to the program content after completion of the study as an appreciation for participating in this project.

##### **Resources:**

The purchase of the PURPLE program materials was required to deliver this project. The cost of these materials was \$2.00 per pamphlet and app code couplet. Five hundred copies of these materials were purchased for a total cost of \$1,000.

#### **Measures:**

Measurable objectives for this project included: (1) nursing knowledge about SBS and AHT (*pretest-posttest question one*), (2) nursing confidence in delivering SBS and AHT education (*pretest-posttest question two*), (3) accessibility to resources related to SBS and AHT (*pretest-posttest question six*), (4) functionality and efficacy of SBS/AHT education (*pretest-posttest question four, post-test questions eight and nine*), (5) perception of the value of SBS and AHT education in the NICU (*pretest-posttest questions three and five*), and (6) message consistency when delivering education about SBS and AHT (*post-test question seven*). See Appendix A for complete survey content used to measure these

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***“ After delivering the intervention for approximately four to six weeks, participants received the post-intervention survey link via email or text message with the same six Likert-style questions on the pre-intervention survey plus an additional three questions specific to the PURPLE program content.”***

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objectives.

#### **Results**

The study results are summarized in this section. Each participant did not respond to every question on the pre-test and post-test surveys. See Appendix B for all frequencies and means.

##### **Study Sample & Setting:**

Data were collected from February to April 2021. Among the participants in this study, 47 individuals responded to the pre-test survey, but only 34 participants responded to the post-test for a response rate of 72%. The demographic data of participants are detailed in Appendix B, Table 1.

##### **Nursing Knowledge:**

The majority (n=44, 93.6%) of respondents on the pre-test answered positively to “I feel knowledgeable when it comes to shaken baby syndrome,” with a mean score of 5.70. Similarly, the majority (n=33, 97%) of post-test respondents agreed to a slightly higher degree, with a calculated mean score of 6.0. Despite this increase in the mean score, comparative analysis using the Wilcoxon matched-pairs test determined this change was not statistically significant (p=.792).

##### **Nursing Confidence:**

The majority (n=40, 86.9%) of pre-test respondents answered, “I feel comfortable discussing SBS with parents and caregivers of NICU infants,” with an overall agreeable response and a mean score of 5.61. The majority (n=33, 97.1%) of post-test respondents reported an increase in confidence, with a calculated mean score of 6.24. Comparative analysis using the Wilcoxon matched-pairs test confirmed this change to be statistically significant (p=.016),

## Appendix A

### Survey

Age: 20-30                      31-40                      41-50                      51-60                      61-70                      71-80

Gender:                      Male                      Female                      Other                      Prefer not to answer

Education Level: Associates Degree    Bachelor's Degree    Master's Degree    Doctoral Degree

Years of experience as an RN: 0-5    6-10    11-15    16-20    21-25    26-30    30+

Years of Experience in the NICU: 0-5    6-10    11-15    16-20    21-25    26-30    30+

Shift: 7a-7p    7p-7a    other \_\_\_\_\_

How often do you complete discharge teaching: Never                      Seldom                      Sometimes                      Often

\*\*Included on post-test only

	(1) Strongly Disagree	(2) Disagree	(3) Somewhat Disagree	(4) Neutral	(5) Somewhat Agree	(6) Agree	(7) Strongly Agree
1. I feel knowledgeable when it comes to shaken baby syndrome							
2. I feel comfortable discussing shaken baby syndrome with parents and caregivers of NICU infants							
3. NICU nurses should be providing shaken baby syndrome education during discharge teaching							
4. Time constraints during discharge are a major barrier to discussing shaken baby syndrome (i.e., too much other education to provide, not enough time, too many other tasks to accomplish)							
5. Providing education about shaken baby syndrome in the NICU is useful in preventing unplanned harm to an infant							
6. I am aware of available resources for families and caregivers about shaken baby syndrome							
7. The Period of PURPLE Crying program was helpful in standardizing shaken baby syndrome education on our unit**							
8. The Period of PURPLE Crying program provides effective, meaningful education about shaken baby syndrome**							
9. The Period of PURPLE Crying program provides education about shaken baby syndrome in a timely manner** (i.e., able to provide SBS education in a reasonable amount of time within discharge teaching)							

concluding that the intervention effectively increased nursing confidence in discussing SBS and AHT with families and caregivers.

#### Resource Accessibility:

In response to “I am aware of available resource for families and caregivers about shaken baby syndrome,” pre-test responses were largely mixed with a mean score of 3.85 and only a 42.6% agreeable response. Posttest responses reflected a significant change, with a mean score of 5.97. Wilcoxon matched-pairs confirmed that this change was statically significant ( $p < .001$ ), concluding that intervention effectively increased SBS and AHT resource awareness for nurses in the study.

#### Functionality and Efficacy of SBS/AHT Education:

Just over half ( $n=32$ , 68%) of pre-test respondents agreed that “time constraints during discharge are a major barrier to discussing shaken baby syndrome,” with a calculated mean score of 4.83. Posttest responses found that nurses felt more strongly about time constraints as a barrier to SBS education post-intervention, with 76.4% of respondents reporting agree or strongly agree and a mean score of 5.18. Analysis using Wilcoxon matched pairs confirmed that this result was not statically significant ( $p=.775$ ). Despite this finding ( $n=33$ ), 97% of post-test respondents agreed with the statement that the PURPLE program “provides education about shaken baby syndrome in a timely manner,” demonstrating a mean score of 6.44. Paralleling this outcome, ( $n=33$ , 97%) of post-test respondents agreed that the PURPLE program “provides effective, meaningful education about shaken baby syndrome,” with a mean score of 6.52. See Appendix B, Table 2 for frequency data.

#### Perception of Educational Value:

The majority ( $n=44$ , 95.7%) of pre-test respondents answered positively to “NICU Nurses should be providing shaken baby syndrome education during discharge teaching,” with a mean score of 6.28. Similarly, the majority ( $n=33$ , 97%) of post-test respondents agreed with a calculated mean score of 6.56. Despite an increase in the mean score, comparative analysis using the Wilcoxon matched-pairs test determined this change was not statically significant ( $p=.731$ ).

Similarly, the majority ( $n=42$ , 91.3%) of respondents on the pre-test answered positively to “Providing education about shaken baby syndrome in the NICU is useful in preventing unplanned harm to an infant,” with a mean score of 6.43. All post-test respondents ( $n=34$ , 100%) agreed or strongly agreed, with a calculated mean score of 6.56. Despite an increase in the mean score, comparative analysis using the Wilcoxon matched-pairs test deter-

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***“The majority ( $n=33$ , 97%) responded on the post-test with some degree of positivity, with responses indicating that the PURPLE program “was helpful in standardizing shaken baby syndrome education on our unit,” with a mean score of 6.35.”***

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mined this change was not statically significant ( $p=.705$ ).

#### Consistency of Educational Messages:

The majority ( $n=33$ , 97%) responded on the post-test with some

degree of positivity, with responses indicating that the PURPLE program “was helpful in standardizing shaken baby syndrome education on our unit,” with a mean score of 6.35.

## Appendix B

**Table 1 Study Sample**

Demographics of Study Sample		n
<b>Age</b>	20-30	11
	31-40	17
	41-50	6
	51-60	12
	61-70	1
<b>Gender</b>	Male	0
	Female	46
	Other or prefer not to identify	1
<b>Education Level</b>	Bachelor’s Degree	35
	Master’s Degree	10
	Doctoral Degree	2
<b>Years of experience as R.N.</b>	0-10	27
	11-20	5
	21-30	9
	30+	6
<b>Years of NICU experience</b>	0-10	26
	11-20	8
	21-30	8
	30+	4
<b>Shift</b>	Day shift	29
	Night shift	6
<b>Discharge teaching frequency</b>	Seldom	17
	Sometimes	21
	Often	9

#### Discussion:

Among the six measurable objectives defined in this study, objectives two and three were met with statistical significance. The intervention effectively increased nursing confidence in delivering education about this sensitive topic area, evident by the statistically significant findings among pre-test and post-test responses designed to assess this parameter. The intervention also proved effective in increasing accessibility to available resources on SBS and AHT, similarly evident with statistically significant findings among comparative responses. Of note, pre-test survey responses related to the perceived value of SBS and AHT education infer participants considered education on this topic area valuable before this intervention, with post-test responses implying a heightened awareness of this value beyond these initial measures. Moreover, questions pertaining specifically to the Period of PURPLE Crying presented exclusively on the post-test were met with an overwhelmingly positive response, with the majority ( $n=33$ , 97%) of respondents agreeing that the intervention was useful in standardizing SBS education, providing meaningful, effective information on this topic area, and delivering SBS and AHT

**Table 2 Mean score and frequency summary of pre-and post-survey responses**

	Pre-test survey mean scores	Frequency (rank)	n	Posttest survey mean scores	Frequency (rank)	n
<b>I feel knowledgeable when it comes to shaken baby syndrome</b>	5.70	(1)Strongly disagree (2)Disagree (3)Somewhat Disagree (4)Neutral (5)Somewhat Agree (6)Agree (7)Strongly Agree <b>Total</b> Missing	2 0 1 0 1 3 1 9 1 2 4 7 0	6.0	(1)Strongly disagree (2)Disagree (3)Somewhat Disagree (4)Neutral (5)Somewhat Agree (6)Agree (7)Strongly Agree <b>Total</b> Missing	2 0 0 0 3 16 13 34 0
<b>I feel comfortable discussing shaken baby syndrome with parents and caregivers of NICU infants</b>	5.61	(1)Strongly disagree (2)Disagree (3)Somewhat Disagree (4)Neutral (5)Somewhat Agree (6)Agree (7)Strongly Agree <b>Total</b> Missing	1 0 3 2 9 2 2 9 4 6 1	6.24	(1)Strongly disagree (2)Disagree (3)Somewhat Disagree (4)Neutral (5)Somewhat Agree (6)Agree (7)Strongly Agree <b>Total</b> Missing	0 0 0 1 5 13 15 34 0
<b>NICU nurses should be providing shaken baby syndrome education during discharge teaching</b>	6.28	(1)Strongly disagree (2)Disagree (3)Somewhat Disagree (4)Neutral (5)Somewhat Agree (6)Agree (7)Strongly Agree <b>Total</b> Missing	1 0 0 1 3 1 8 2 3 4 6 1	6.56	(1)Strongly disagree (2)Disagree (3)Somewhat Disagree (4)Neutral (5)Somewhat Agree (6)Agree (7)Strongly Agree <b>Total</b> Missing	0 0 1 0 2 7 24 34 0
<b>Time constraints during discharge are a major barrier to discussing shaken baby syndrome (i.e., too much other education to provide, not enough time, too many other tasks to accomplish)</b>	4.83	(1)Strongly disagree (2)Disagree (3)Somewhat Disagree (4)Neutral (5)Somewhat Agree (6)Agree (7)Strongly Agree Total Missing	0 6 7 2 1 2 1 4 6 4 7 0	5.18	(1)Strongly disagree (2)Disagree (3)Somewhat Disagree (4)Neutral (5)Somewhat Agree (6)Agree (7)Strongly Agree Total Missing	3 2 2 1 6 11 9 34 0

Providing education about shaken baby syndrome in the NICU is useful in preventing unplanned harm to an infant	6.43	(1)Strongly disagree (2)Disagree (3)Somewhat Disagree (4)Neutral (5)Somewhat Agree (6)Agree (7)Strongly Agree Total Missing	0 0 0 0 4 1 8 2 4 4 6 1	6.56	(1)Strongly disagree (2)Disagree (3)Somewhat Disagree (4)Neutral (5)Somewhat Agree (6)Agree (7)Strongly Agree Total Missing	0 0 0 0 0 15 19 34 0
I am aware of available resources for families and caregivers about shaken baby syndrome	3.85	(1)Strongly disagree (2)Disagree (3)Somewhat Disagree (4)Neutral (5)Somewhat Agree (6)Agree (7)Strongly Agree Total Missing	4 8 1 0 5 1 2 5 3 4 7 0	5.97	(1)Strongly disagree (2)Disagree (3)Somewhat Disagree (4)Neutral (5)Somewhat Agree (6)Agree (7)Strongly Agree Total Missing	0 0 0 0 9 17 8 34 0
The Period of PURPLE Crying Program was helpful in standardizing shaken baby syndrome education on our unit	NA	NA		6.35	(1)Strongly disagree (2)Disagree (3)Somewhat Disagree (4)Neutral (5)Somewhat Agree (6)Agree (7)Strongly Agree Total Missing	0 0 0 1 2 15 16 34 0
The Period of PURPLE Crying Program provides effective, meaningful education about shaken baby syndrome	NA	NA		6.52	(1)Strongly disagree (2)Disagree (3)Somewhat Disagree (4)Neutral (5)Somewhat Agree (6)Agree (7)Strongly Agree Total Missing	0 0 0 0 1 14 18 33 1
The Period of PURPLE Crying Program provides education about shaken baby syndrome in a timely manner (i.e., able to provide SBS education in a reasonable amount of time within discharge teaching)	NA	NA		6.44	(1)Strongly disagree (2)Disagree (3)Somewhat Disagree (4)Neutral (5)Somewhat Agree (6)Agree (7)Strongly Agree Total Missing	0 0 0 1 0 16 17 34 0

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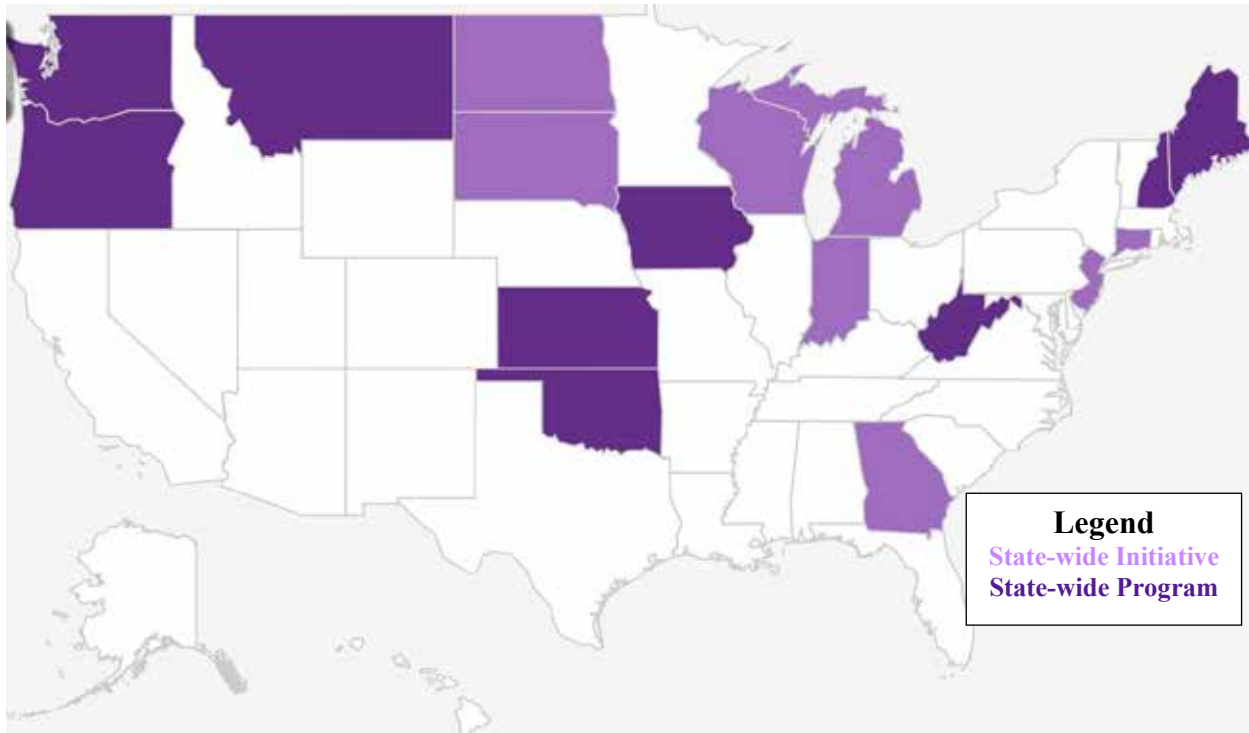


**Table 3** Wilcoxon Matched Pairs Test

	Pre-intervention Survey	Post-intervention Survey	Z	Asymp. Sig (2-tailed).	Statistical significance
I feel knowledgeable when it comes to shaken baby syndrome	5.70	6.0	-.264	.792	Retain null
I feel comfortable discussing shaken baby syndrome with parents and caregivers of NICU infants	5.61	6.24	-2.412	.016	Reject null
NICU nurses should be providing shaken baby syndrome education during discharge teaching	6.28	6.56	-.344	.731	Retain null
Time constraints during discharge are a major barrier to discussing shaken baby syndrome (i.e., too much other education to provide, not enough time, too many other tasks to accomplish)	4.83	5.18	-.286	.775	Retain null
Providing education about shaken baby syndrome in the NICU is useful in preventing unplanned harm to an infant	6.43	6.56	-.378	.705	Retain null
I am aware of available resources for families and caregivers about shaken baby syndrome	3.85	5.97	-3.438	<.001	Reject null

**Appendix C**

**Figure 1** The PURPLE program implementation map in the U.S.



information promptly. This study supports the use of high-quality, standardized education to improve the quality and functionality of SBS/AHT education in the NICU setting; however, a larger sample would be advantageous in making more definitive inferences about these objectives.

#### **Time Constraints and Patient Education:**

An increase in the mean score from 4.83 to 5.18 on the pre-test to post-test responses when considering time constraints during discharge as a major barrier to discussing shaken baby syndrome may highlight an inherent conflict in healthcare. A study published in *Clinical Nursing Studies* (2017) examined the relationship between nurses' perceived barriers and patient education, finding that despite the importance nurses placed on patient education, work overload ranked highest among the barriers to delivering education (Livne et al., 2017) (7). Paralleling this notion, the findings of this study may imply that the use of the PURPLE program may offer nurses a means of making workload at discharge more manageable by embedding SBS and AHT education throughout the infant's hospitalization rather than solely discussing this topic

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*“Paralleling this notion, the findings of this study may imply that the use of the PURPLE program may offer nurses a means of making workload at discharge more manageable by embedding SBS and AHT education throughout the infant's hospitalization rather than solely discussing this topic at discharge.”*

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at discharge. Further evaluation is necessary to make a definitive inference about this concept.

#### **Clinical Implications:**

Understanding that infants and children with risk factors such as prematurity, special needs, those under the age of six months that are often inconsolable, and multiple births place infants and young children at a higher risk for AHT and SBS and place further emphasis on the importance of utilizing this education program in the NICU setting, as many NICU graduates can be grouped into one of these aforementioned categories. This study may serve as a tool to reinforce and guide the adoption of the PURPLE program in this and other NICUs settings.

Beyond the NICU setting, considerations for how the widespread adoption of this program at the University of Chicago could impact the community should be acknowledged, as this hospital resides in an underserved community. Demographic evaluation of the medical center's surrounding area further emphasized the need for SBS and AHT education, as disparities prevalent within the community place families at high risk for unplanned infant harm.

According to the *Journal of Research on Social Work Practice*, “Low-income families are significantly more likely to have to contend with domestic violence, as poverty can act as a fueling factor in this type of conflict” (Slabbert, 2016, para. 1) (8). Data from the United States Census Bureau (2018) reported that 42.1% of households in Chicago are single-parent households, compared to 31% across Illinois and 32.7% across the U.S (Statistical Atlas, 2018 (9); U.S. Census Bureau, 2018) (10). This data also concluded that poverty affects 19.5% of households in Chicago, compared to 12.1% in Illinois and 11.8% across the U.S. (U.S. Census Bureau, 2018) (10). Understanding this data in relation to identified risk factors for AHT and SBS emphasizes the significance of incorporating high-quality, effective education into healthcare practices.

#### **Strengths and Limitations:**

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*“Given the commonality of resource challenges among hospitals coupled with the monetary challenges faced while implementing this study, barriers to the widespread use of this education program should be acknowledged and further explored.”*

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Strengths of this study included the utilization of pre-test post-test design measures for assessing the quality of this education program. Survey responses were collected anonymously, thereby encouraging authentic results. Limiting factors of this study include the small sample size (n=48) and a lower response rate on the post-test (n=34). Other limitations included user error while entering their pre and post-test I.D. numbers into the surveys; this factor made matching survey responses more challenging. Despite these limitations, the study results inferred statistical significance with two of six measures, reinforcing the validity of this intervention.

#### **Future Research:**

Although the literature largely supports implementing this program, considerations to the challenges and barriers of implementing a large-scale education program in communities and hospitals alike must be addressed. A study in 2011 utilized cross-sectional surveys to evaluate current AHT educational practices and prevention programs among all North Carolina hospitals and birthing centers to further understand barriers to the adoption of a widespread AHT prevention program. This study reported that hospitals experiencing challenges in providing education on AHT were predominantly in rural communities, smaller hospitals, and those with limited access to abundant resources (Nocera et al., 2011) (5).

During this intervention, the cost to deliver the program was a barrier that nearly disrupted this intervention and would cause this

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program to be unsustainable in the long-term without adequate funding. Throughout this project, grant funding was explored to overcome this barrier and may be a real resource for achieving large-scale adoption of this program in the future. Given the commonality of resource challenges among hospitals coupled with the monetary challenges faced while implementing this study, barriers to the widespread use of this education program should be acknowledged and further explored.

A study conducted in British Columbia reviewing 64 cases of AHT events from 2002-2014 found that subsequent costs ranged from \$1.6 to \$7.1 million in healthcare spending and a societal cost of \$354,359,080. Comparatively, the PURPLE program costs approximately \$5.00 per infant (Beaulieu et al., 2019) (11). As healthcare continues to shift toward a preventative paradigm, this data strongly emphasizes the need to conduct future research in the U.S. surrounding cost-related barriers to implementing such prevention programs. Additionally, such research offers information to facilitate support from key stakeholders such as policymakers and health care providers, emphasizing that "...investing upstream in well-developed AHT prevention programs, such as PURPLE, not only promote child safety and health but also translates into avoided costs to society" (Beaulieu et al., 2019) (11). Future research must underpin cost-benefit analysis to prevent SBS and AHT to improve health outcomes and reduce future healthcare spending.

### Conclusion:

The PURPLE program has been well-studied, with evidence suggesting that ongoing support for parents and caregivers can reduce hospital admissions associated with SBS and AHT and significantly impact the incidence of SBS and unplanned infant harm (Barr et al., 2019) (4). The purpose of this pilot study aimed to evaluate the nursing perception of the PURPLE program in a high-acuity NICU setting based on six measurable objectives. Two of the six Periods of PURPLE Crying objectives showed statistical significance supporting the important goals of this program. To continue improving upon the content and outcomes of the PURPLE program, ongoing evaluation across multivariate settings to further examine the multifaceted nature of unplanned infant harm is critical in the fight against this tragedy and to truly make a meaningful impact on this preventable, dynamic public health issue.

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**Disclosures:** The authors have no disclosures:

### Acknowledgments:

The money for this project was gifted as a donation by Dr. Veena Ramaiah to promote research on this topic area. We thank Dr. Ramaiah for making this contribution and this research project possible.

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Randall Bell, Ph.D.

# SHARED DECISION-MAKING PROTECTS MOTHERS + INFANTS

DURING COVID-19

## KEEPING MOTHERS + INFANTS TOGETHER

Means balancing  
the risks of...

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



## EVIDENCE

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

## PARTNERSHIP

What is the best  
for this unique dyad?

### SHARED DECISION-MAKING

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



## TRAUMA-INFORMED

Both parents and providers  
are confronting significant...

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

## LONGITUDINAL DATA

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

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



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# Epigenetics Explains the Imperative for Extended, Intimate Human Contact in Every Newborn, Especially Those at the Highest Risk

Robert D. White, MD

*“In this discussion, I will explore these challenges to persuade the reader that there is now strong evidence for the value of extended, intimate human contact for newborns, especially those at high risk and that this concept should be fully implemented in all NICUs regardless of the resources available or demographic served.”*

“Developmental Care,” a term often used to encompass both sensory protection and targeted sensory stimulation in high-risk newborns, has faced two serious challenges since its inception:

- It has been difficult to prove its value.
- It has not been easy to incorporate into a NICU culture.

In this discussion, I will explore these challenges to persuade the reader that there is now strong evidence for the value of extended, intimate human contact for newborns, especially those at high risk and that this concept should be fully implemented in all NICUs regardless of the resources available or demographic served.

## **It has been difficult to prove the value of developmental care:**

The primary tenets of developmental care - that newborns should be protected from noxious stimuli and provided with age-appropriate nurturing stimuli by their parents whenever possible - were established in extensive studies decades ago. In the 1950s, John Bowlby (in humans) and Harry Harlow (in monkeys) showed that separating newborns from their mothers led to immediate and lasting psychological changes. Even so, this separation continued to be practiced in newborn nurseries until it was successfully challenged by Marshall Klaus and John Kennell in the 1970s. Their work led to a radical change in maternity services in the newborn nursery but a much lesser degree in the NICU.

As parents continued to be excluded from the NICU or, at best, allowed to “visit” their infants, efforts to enrich the sensory environment in the absence of parental caregiving were introduced, of which the Newborn Individualized Developmental Care and

Assessment Program (NIDCAP) is the most notable example. A highly structured, labor-intensive, specialist-based program, NIDCAP became well-established in some NICUs, supported by several trials that suggested efficacy (1), but has not been adopted by a large majority of NICUs because of its cost, complexity, and absence of evidence of a compelling benefit(2). However, several other developmental care-based programs have been introduced, some of which, such as the SENSE program, are actively being studied (3).

*“The importance of family participation is emphasized in NIDCAP, SENSE, and similar programs, but the value of simple skin-to-skin care, even without a structured developmental care program, has also been demonstrated.”*

Concurrent with these efforts, families have been granted increased access to their infants as both structural and operational barriers are removed. The importance of family participation is emphasized in NIDCAP, SENSE, and similar programs, but the value of simple skin-to-skin care, even without a structured developmental care program, has also been demonstrated. While numerous trials suggest efficacy, meta-analysis has yet to confirm the benefit of skin-to-skin care in high-risk premature infants except in resource-limited settings (4).

Perhaps the chief challenge with these efforts has been that neuronal development in the premature infant is still largely a “black box.” The impact of a ventilator change, a dose of surfactant, or most other NICU interventions can be easily demonstrated - if not immediately, then at least within a short time and almost always by the time an infant is discharged. However, there is no such obvious positive response to developmental care that a clinician can appreciate by making rounds. A NIDCAP therapist can detect responses to interventions, as can a nurse when an infant is being held skin-to-skin, but these do not show up on the datasheets or outcome measures that drive decision-making in the NICU. It may well be that more long-term brain deficits are secondary to inadequate developmental care in the NICU than to intraventricular hemorrhage, but we have no real-time markers available to us to study this.

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## Developmental Care Has Not Been Easy to Incorporate into a NICU's Culture:

Providing the optimal sensory environment for high-risk newborns throughout their NICU stay is challenging for multiple reasons:

- Parental interaction is often restricted by operational rules or by parental absence.
- Nursing provision of developmental support is seen as secondary and optional in many NICUs. Nurses obtain vital signs, provide feedings, and change diapers in even the most stable infants; they understand there will be consequences if they do not do this. But all these tasks can be accomplished without providing any nurturing stimuli and neglecting this aspect of care rarely brings any consequences to the provider.
- Developmental specialists are costly in that their services generally do not generate revenue.

If developmental care provided immediate evidence of its value or generated revenue, it would be much easier to incorporate into the fabric of NICU care.

### Is There a Way Forward?

It is unlikely that strong data to support developmental care or skin-to-skin care in high-risk infants will appear in the near future, given that large, multi-center trials are not currently in progress and are unlikely to be launched due to their cost and complexity.

Fortunately, in an ironic twist that Harry Harlow would best appreciate, we have been able to return to studies in primates to find compelling evidence of the lifelong impact of sensory deprivation caused by the separation of babies from their mothers at birth, expressed in a language that modern-day scientists understand: DNA methylation. In a fascinating TED talk (5), Moshe Szyf describes how early life experience, especially maternal-infant interaction, influences the long-term expression of many genes. Monkey newborns who are separated from their mothers appear healthy, but an examination of DNA methylation of their genome reveals dramatic differences from siblings who remained with the mother. As in Harlow's studies, the monkeys who provided surrogate care suffered long-term psychological and physical differences that could not be explained by genetic differences or health in infancy. Instead, the lack of normal sensory input early in life led to a permanent change in gene expression that persisted into adulthood. These trials provide evidence that cannot ethically be obtained in humans but is certainly relevant to the NICU environment of care. It requires little imagination to draw a line connecting these findings to the continued high burden of neuropsychological disability seen in NICU graduates.

Epigenetics, then, explains how early life experiences influence the expression of the genetic code, even for neurons yet to form. Changes in DNA methylation that occur early in infancy can have a lifelong impact on health and behavior. Neuronal growth, syn-

aptic formation, and DNA methylation are not put "on hold" while the infant is in the NICU; therefore, developmentally supportive care, centered around parents whenever possible, is an essential component of state-of-the-art NICU care.

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Disclosures: The author has no relevant disclosures

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# COVID-19

## STOP THE SPREAD AT HOME

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

### HYGIENE TIPS

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

### BATHROOM

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

### PROTECT

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

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

### SELF ISOLATION

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

### KITCHEN

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



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# COVID-19

## DETENER LA PROPAGACION EN CASA

Qué hacer cuando usted o un ser querido está infectado.

### CONSEJOS DE HIGIENE

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

### BAÑO

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

### PROTEGER

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

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

### ASLAMIENTO

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

### COCINA

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



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## Ways to Manage Covid 19 @ Home

### Household

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

### Sick

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

Stop the Spread at HOME Miora



## Maneras de manejar COVID-19 en casa

### Hogar

- Manténgase 6 pies de distancia de los demás en todo momento. Use una cubierta protectora sobre la boca y la máscara para los ojos y el protector / gafas / anteojos cuando esté cerca de otras personas. No ponga máscaras a niños menores de 2 años.
- Hacer gárgaras todas las mañanas y noches con productos de enjuague bucal antiséptico que contienen alcohol.
- Lavé la manos 10-12 veces al día, y antes de cada comida por lo menos 20 segundos.
- Mantenga Buena ventilación en toda la casa. Abra las ventanas y puertas cuando sea posible.
- No compartá toallas, cobijas, y almohadas con personas que estén infectados.
- Llame al 211 para obtener servicios de entrega gratuitos.
- Use ropa protectora, chaqueta, guantes, máscara que se pueda quitar después de estar cerca de infectados.

### Enfermo

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

Detén la propagacion en Casa Miora



## SHARED DECISION-MAKING

PROTECTS PARENTS + BABIES

COVID-19

### INFORMED PROVIDERS

- Seek participation
- Help explore options
- Assess preferences
- Reach a decision
- Evaluate the decision



### CARE DELIVERY REQUIRES PARTNERSHIP



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# CORONAVIRUS

COVID-19

### RELIABLE RESOURCES:

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

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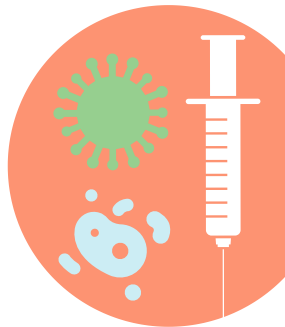
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# PROTECT YOUR FAMILY FROM RESPIRATORY VIRUSES

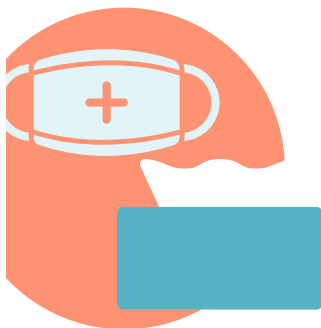
flu coronavirus  
pertussis RSV



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



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



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



**USE A HAND SANITIZER THAT IS 60%+ ALCOHOL.**



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



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

## KEEPING MOTHERS + INFANTS TOGETHER

Means balancing...



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## TRAUMA-INFORMED

Both parents and providers are confronting significant...

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### GET CLEAN WASH YOUR HANDS, ARMS, and CHEST

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



### PUT ON FRESH CLOTHES

change into a clean gown or shirt.

### IF COVID-19 + WEAR A MASK

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



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# Tracheal Agenesis: A Case Report Emphasizing the Use of a Laryngeal Mask Airway

Richelle M. Reinhart, MD, Morarji R. Peesay, MD, Nitin R. Mehta, MD

***“Here we present a case where a preterm infant with severe Tracheal Agenesis (TA) was successfully intubated with LMA during resuscitation at birth and ultimately transferred to a Level IV NICU for a tracheostomy.”***

## Introduction:

A significant amount has been learned in the past few decades about the basics of using Laryngeal Mask Airway (LMA) intuba-

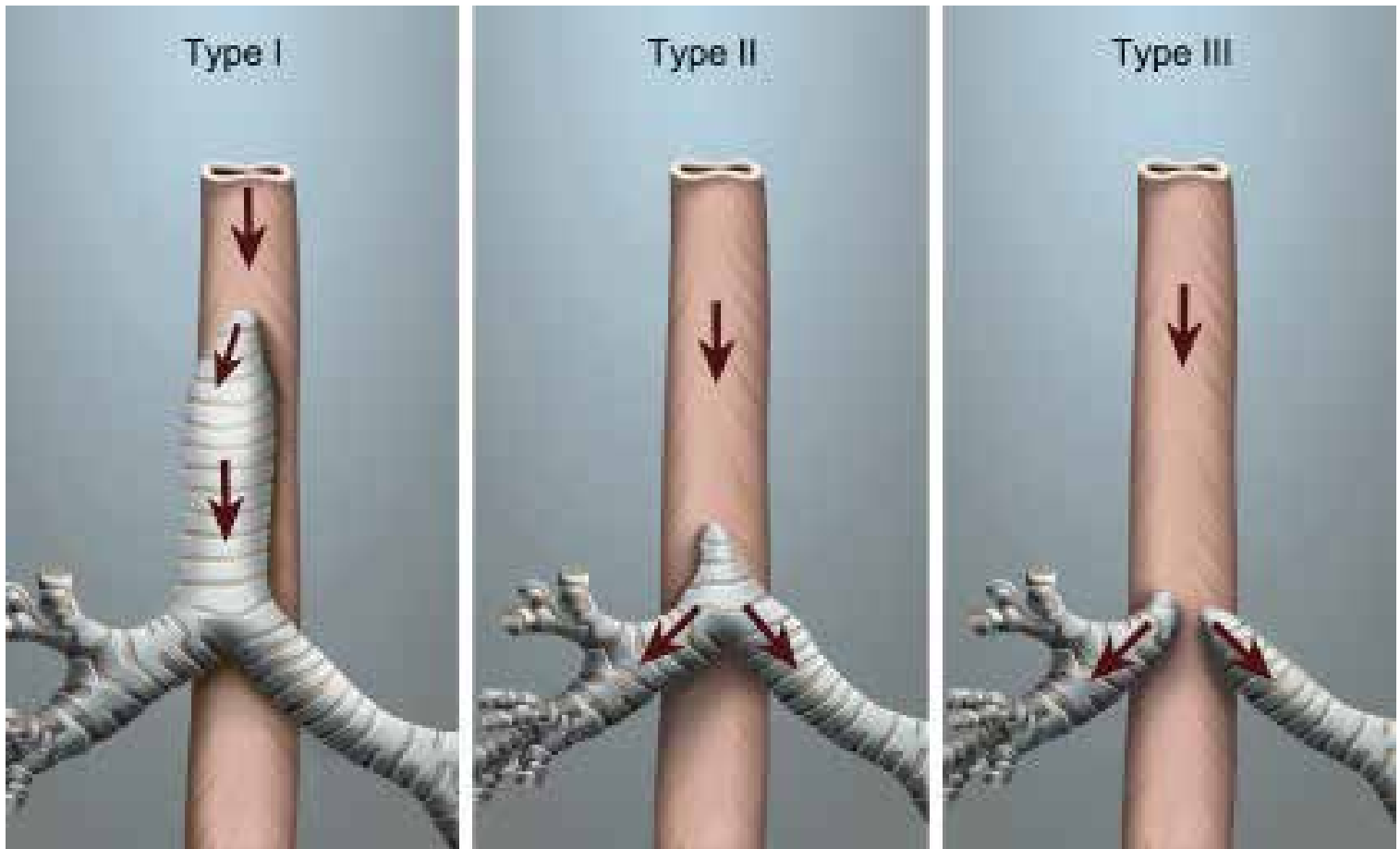
tion, but much remains to be determined about its practical use. Recently, renewed interest in its usage was supported by the Neonatal Resuscitation Program (NRP) course, and, thus, there is increased awareness of managing an airway via LMA. Here we present a case where a preterm infant with severe Tracheal Agenesis (TA) was successfully intubated with LMA during resuscitation at birth and ultimately transferred to a Level IV NICU for a tracheostomy. TA is rare and usually fatal. Few survivors with concomitant Tracheoesophageal Fistula (TEF) who underwent ligation of the distal esophagus with the creation of a spit-fistula and neo-trachea from the proximal esophagus exist. To our knowledge, this case of Tracheal Agenesis is the first of its kind to be reported as successfully managed via LMA.

## Case description:

A preterm infant of 34-weeks gestational age was delivered to a 36-year-old Black mother. This was an in vitro fertilization pregnancy with appropriate prenatal care, complicated only by polyhydramnios. She had been found to have a 2-vessel umbilical cord with a subsequent normal fetal echocardiogram. The mother was admitted in spontaneous labor without evidence of chorioamnio-



**Figure 1.** Infant described in the case report with LMA securely in place for transport.



**Figure 2.** Floyd's classification of tracheal agenesis.(6)

nititis and received one dose of betamethasone prior to delivery. Prenatal labs negative for HBsAg, HIV, RPR, GC, Chlamydia; GBS was unknown. The infant was delivered by cesarean section for breech positioning with difficult extraction secondary to footling presentation. At birth, the infant was apneic and hypotensive with a low heart rate. Despite visualization of cords, intubation was unsuccessful with an inability to advance the tube with 3.0, 2.5, and 2.0 endotracheal tubes. Ultimately, a premature infant size LMA was placed and secured with subsequent improvement in her heart rate, oxygen saturation, and color. The LMA was secured, and she stabilized on the ventilator. On exam, she had no significant anomalies other than the previously known 2-vessel cord. Her birth weight was 2200 grams, and APGAR scores were as follows: 1, 4, 2, 7, and 8 at 1, 5, 10, 15, and 20 minutes, respectively. The infant was then transferred to a tertiary care center on LMA ventilation (Figure 1). On arrival to the NICU, she was taken to emergent explorative surgery and found to have tracheal agenesis, Floyd Type 1. She required extracorporeal membranous oxygenation (ECMO) but was ultimately provided with a neo-trachea via a novel approach by ENT and pediatric surgery. (1) She was discharged home after ten months in the NICU, status-post trachealization of her esophagus with a tracheostomy and gastric tube in place. She initially did well after discharge with normal neurological development until she passed away from accidental

decannulation at 16 months.

#### **Discussion:**

It is unclear how aerodynamics worked out in this case of Tracheal Agenesis with TEF. Based on exploration by ENT, the patient's cervical trachea was missing. There seemed to be TEF (Floyd Type I) with the remaining short distal trachea that could potentially be ventilated via the fistula. The three Floyd classifications of TA are as follows: I (20%) – atresia of the proximal trachea with a short distal trachea, normal bronchi, and a TEF; II (60%) – complete tracheal atresia with normal carina and bifurcation of the bronchi; III (20%) – complete tracheal atresia with bronchi arising directly from the esophagus (Figure 2). (2) In such situations where TEF is suspected, LMA intubation (or accidental esophageal intubation) may improve the respiratory status temporarily. TA should be at the top of a differential for any patient who is either having difficulty being intubated or experiencing severe cyanosis with respiratory distress immediately after birth without an audible cry. As with our patient, about half of patients with TA have abnormal prenatal ultrasounds, with polyhydramnios reported most commonly. (3) Many are born prematurely, and most patients have another associated anomaly. (4) There is a known high mortality rate in infants with this rare malformation, with only a 3-month-survival of less than 10%. (3) Tracheotomy is often attempted after birth once

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the diagnosis is suspected; however, for many newborns, survival until surgery is not possible. Airway management is the most critical part of care in any infants who survive. In one large systematic review of patients with TA, airway management occurred most often via esophageal intubation (38%), with some version of surgical airway placement (cervical exploration, gastrostomy, cervical esophagostomy, etc.) occurring with the majority of the remaining patients. (5)

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**“This report encourages the use of LMA not only in situations where there is a concern for airway obstruction but also whenever there is difficult intubation, or alternative modes of management are needed, per NRP.”**

---

### Conclusion:

This report describes a successful airway management case in Tracheal Agenesis with LMA intubation and transport on LMA ventilation. This report encourages the use of LMA not only in situations where there is a concern for airway obstruction but also whenever there is difficult intubation, or alternative modes of management are needed, per NRP. Proactive thinking of the use of LMA is emphasized in place of Bag and Mask Ventilation as primary resuscitation equipment in difficult-to-manage airways.

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*Disclosures: The authors have no disclosures or conflicts of interest relevant to this case report.*

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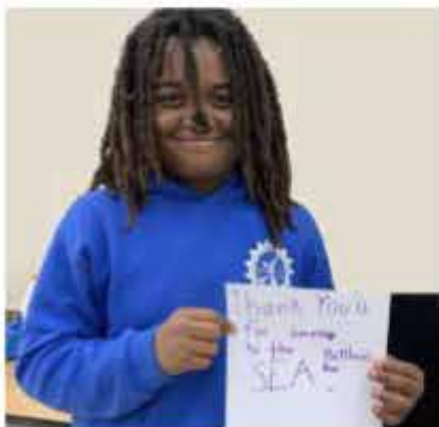
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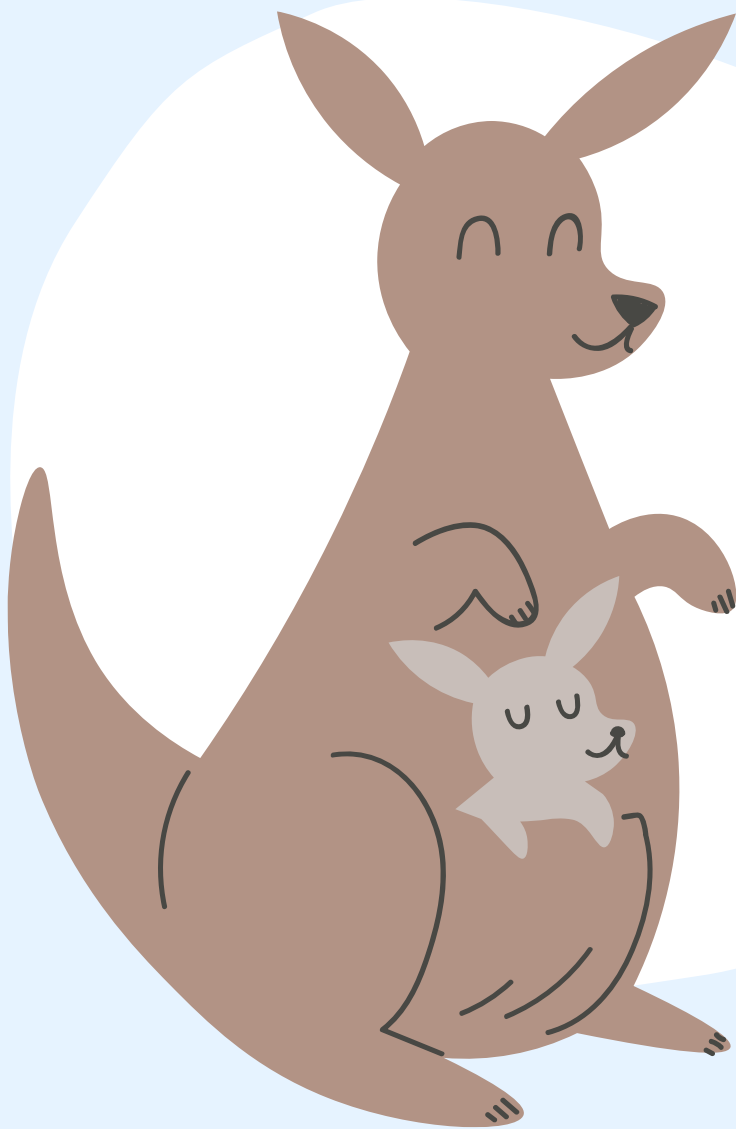


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# How Are Machine Learning Algorithms Different from Statistical Methods?

Fu-Sheng Chou, MD, PhD

Last month, we kicked off a new series of articles to introduce machine learning to the readers of Neonatology Today. The goal was to take a stepwise approach to deliver key terminology and concepts of this branch of artificial intelligence to the audience. This methodology is finding its way into neonatal and perinatal research. The hope is that when the readers come across manuscripts that involve this methodology for data analysis, there will already be a basic understanding of machine learning and what this term entails. In this issue, the objective is to provide a more in-depth discussion about the fundamental differences between statistical modeling and machine learning algorithms.

*“The hope is that when the readers come across manuscripts that involve this methodology for data analysis, there will already be a basic understanding of machine learning and what this term entails. In this issue, the objective is to provide a more in-depth discussion about the fundamental differences between statistical modeling and machine learning algorithms.”*

## The bottom-up approach in statistical modeling

In statistical modeling, a statistical approach is chosen based on the clinical question or, more often, based on the comfort level of the clinical researchers in the statistical approach selected for the analysis. Linear regression and logistic regression analyses are probably the most commonly utilized methods for the variable association. It usually starts with a “simple” regression analysis where one independent variable is attempted at a time to assess its correlation with the outcome (the dependent variable). As shown in Equation 1, the goal is to calculate “a.” Based on our data, it is straightforward to calculate “a,” but does our data represent the population? This is where statistics come in – to solve this uncertainty (of whether our data represents the universe) and provide an estimate for “a” to infer the population. A predefined p-value cutoff is used to determine whether “a” can be zero or would always be a non-zero value, in which case the association between  $x$  and  $y$  can be considered as present or “statistically significant.” Those variables ( $x$ ) that show significant associations individually with  $y$  are then incorporated in a “multivariable” regression analysis, where selected variables (e.g.,  $x_1$ ,  $x_2$ , and  $x_3$  in Equation 2) are added together on the right side of the equation. In contrast, the outcome variable remains on the left side. Statistics are then carried out again to assess whether  $a_1$ ,  $a_2$ , and  $a_3$  are likely non-zero. After the analysis, if  $a_2$  is determined to be non-zero, we will then say, after adjusting for  $x_1$  and  $x_3$ , that  $x_2$  is independently associated with  $y$ .

$$y = ax + b \quad (\text{Equation 1})$$

$$y = a_1x_1 + a_2x_2 + a_3x_3 \quad (\text{Equation 2})$$

Most of our readers have experienced this analytic method numerous times. I am not trying to provide a statistics review here. Also, this is not the only way to build a statistical model; it is just an example. As one can see, humans select  $x_1$ ,  $x_2$ , and  $x_3$  for the multivariable analysis. One may have another equation used to estimate coefficients for  $x_1$  and  $x_2$  only and yet another equation that incorporates  $x_1$ ,  $x_2$ ,  $x_3$ , and  $x_4$ . Certain additional “goodness of fit” analyses are then performed to determine which equation fits the data and provides the best inference to the population. The final model is then born, and a manuscript is written up -- hoping to get published somewhere.

The statistical approach is a bottom-up approach, like building a house brick by brick, step by step, to assess the likely variables associated with the outcome. It is based on rational deduction according to clinical observations and hypotheses. We usually use it to study risk factors: for example, is high-grade intraventricular hemorrhage associated with worse neurodevelopmental outcomes after adjusting other risk factors?

*“The statistical approach is a bottom-up approach, like building a house brick by brick, step by step, to assess the likely variables associated with the outcome. It is based on rational deduction according to clinical observations and hypotheses.”*

## The top-down approach in machine learning modeling

The difference between statistics and machine learning is the “learning” part by the machines. Let us build upon the linear regression model to demonstrate how the machines “learn” from the data.

Here, two methods that have been applied on top of linear regression models allowing the machine to “learn” are 1) least absolute shrinkage and selection operator (LASSO) and 2) Ridge regression. It is commonly called “variable regularization.” Without going into the formulas and mathematical details, and generally speaking, LASSO regression allows the machine to determine whether to “shrink” a coefficient for a variable down, even to 0. When a coefficient approaches 0, that variable is essentially negligible in the equation. In other words, when a coefficient is 0, the machine has learned that this specific variable does not play a role in outcome prediction. The Ridge regression also shrinks the coefficients but, unlike LASSO, does not eliminate any variable. One can think of LASSO and Ridge as putting relative weights on each of the variables being tested. The goal is to minimize the difference between the predictive and actual outcomes and improve statistical inference.

There is an additional advantage for doing regularization. In lin-

ear modeling, the researchers are most concerned about multicollinearity, where two or more independent variables are highly correlated. It leads to variable inflation and inaccurate estimation of the coefficients. LASSO and Ridge may take care of that. By adding additional terms, these methods put weights on each variable to reduce the impact of multicollinearity.

What does it mean by putting weights on each variable and reducing the impact of multicollinearity? It means that one does not have to hand-pick variables like the deductive approach in statistical model development. By learning from the data, the machine weighs the variables and determines which ones are important and which ones not as much. This is a top-down approach. We provide the predictors and the outcomes. The machines figure out the in-between.

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***“By learning from the data, the machine weighs the variables and determines which ones are important and which ones not as much. This is a top-down approach. We provide the predictors and the outcomes. The machines figure out the in-between.”***

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### **Hyperparameter**

How much LASSO and Ridge will attempt to shrink the variables is determined before data is fed into the algorithms. What controls how much to shrink is called a “hyperparameter.” The coefficient for the penalty term that constrains the coefficients for the variables, called  $\lambda$ , is a hyperparameter. A hyperparameter always has to be pre-determined by humans before the machine starts to learn from the data. Feels good here, right? Humans control the hyperparameters, not the machines, so do not worry. At least in machine learning, machines are not taking over yet!

### **The black-box fear**

In straightforward linear regression with manageable variable numbers, it is not too tricky to figure out the “in-between” by assessing how much weight each variable receives and rationalizing the why *post hoc*. In cases where there is an enormous number of observations and numerous variables for each observation, the “in-between” may start to overwhelm humans. This process is probably the fear clinicians have when talking about using machine learning-based models for augmenting clinical decision-making: how does the machine conclude that this baby will respond to indomethacin but not that one? Should one trust an educated guess, should one listen to the machine, or should one dig up that PDA treatment guideline that was developed ten years ago? And by the way, in this parallel world where individual prediction is available with sophisticated models, the flowchart-based protocol for PDA treatment is probably obsolete. After all, flowcharts cannot handle more than a handful of variables in their decision tree.

### **Do NOT throw everything into the algorithm**

Before we conclude this topic, there is a key message that is very important for our readers. Machine learning is such a novel approach to neonatal research; researchers and clinicians may have the temptation to throw all variables they have collected over

the years in a myriad of Excel files into the algorithms to see if these potential variables predict any outcome. Even though the researchers will not receive formal complaints from the machines because the machines cannot and will not complain, this is a dangerous approach and should not be encouraged in the literature. The reason is simple: humans develop machine learning because humans cannot handle excessive data. If humans put all the data they cannot handle together and feed this data into the machines, humans will soon be drowned, knowingly or unknowingly, by the data the engines put out on the other end of the algorithm. Machines “augment” the decision-making process owned by humans; they do not take over the process. Indiscriminate data entry leads to indeterminate results. Please do not assume that one can input all the available data, and the machine will deliver a guidebook or a policy statement to solve clinical questions. Machine learning-based predictive model development should follow the well-established steps developed by experts in the field, just like statistical models should be developed. The steps may be different, but the core spirit is the same.

### **Ask the machine to develop clinically relevant models**

It is also important to be mindful about what outcomes to predict. Are they clinically relevant? During this COVID-19 pandemic, many chest x-rays and chest CT scans were performed on patients to determine the severity and monitor radiographic response. With access to these image data, researchers hoped to use a branch of machine learning called deep learning to investigate whether image studies can be used to replace or augment COVID-19 diagnosis. In other words, can a machine learning model be developed to distinguish between pneumonia caused by COVID-19 or by other etiologies? This seemingly plausible idea goes against the definition of pneumonia in the first place and makes no sense in clinical management. As we learned in medical school, pneumonia is a clinical diagnosis, not a radiographic diagnosis. It is diagnosed by history and physical exam. We should never start a machine learning project just because we have the data.

---

***“Machine learning-based predictive model development should follow the well-established steps developed by experts in the field, just like statistical models should be developed. The steps may be different, but the core spirit is the same.”***

---

### **Conclusion**

Unlike rigorous hypothesis-driven research, machine learning-based research is more about outcome prediction, exploration of novel variables, and comparing the performance of different algorithms. The predictors are usually already known to have a potential association with the outcome, albeit can be assumed loosely and anecdotally, or are tested for hypothesis generation. These two goals are sometimes combined with learning about novel variables and then using these novel variables to predict the outcomes. Going back to the point that was made earlier, do *not* throw every variable into the algorithm and wish that magic will show. It will not, unfortunately.

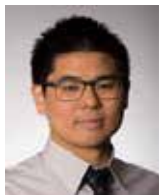
I hope readers new to machine learning feel a little bit relieved by this brief comparison between statistics and machine learning. Machine learning is still mathematics and statistics. It incorporates

additional steps to optimize outcome association systemically. These extra steps are what is perceived as "learning." There are different algorithms in machine learning, many of which are based on non-linear approaches. We will talk more about these other algorithms next month.

*Disclosure: The author identifies no conflict of interest*

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

1. An online submission portal: Submitting a manuscript online will be easier than before. Rather than submitting by email, we will have a devoted online submission portal that will have the ability to handle any size manuscript and any number of graphics and other support files. We will have an online tracking system that will make it easier to track manuscripts in terms of where they are in the review process.
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with soap and water for 20+ seconds. Dry well.



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# Telehealth in the NICU

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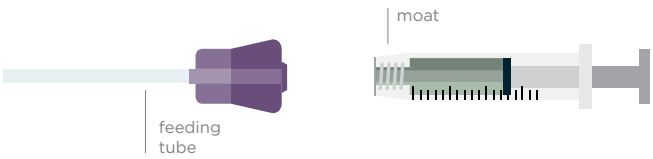
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# Prenatal Exposure to Cannabis: Adverse Neonatal and Childhood Outcomes

Japmeet Sandhu OMS III, Arun Sengupta OMS III

Since 2012, 16 states have legalized the use of cannabis, and 36 states have legalized medical marijuana. This means that the majority of Americans have access to marijuana. With increased legalization, there are trends of increased usage and the idea of cannabis being a relatively safe drug. Cannabis is the most common recreational drug used in pregnancy. 2016 data from the National Survey on Drug Use and Health revealed that 4.9% of pregnant women aged 15 to 44 reported marijuana use in the past month. In 2015, this percentage was 3.4%. However, the use of marijuana is also underreported. THC, the substance responsible for the psychoactive effects of marijuana, was found in 13.25% of meconium samples of neonates born to mothers who self-reported no marijuana usage. (1) Bayrampour et al. evaluated cannabis use in pregnant women before and after legalization in British Columbia (May 2018 and May 2020). They found that self-reported cannabis use preconception increased significantly after legalization, from 11.74% to 19.38%. Rates of cannabis use during pregnancy also increased from 3.64% to 4.63% after legalization. (2) Despite this increasing usage, scientific literature on the effects of marijuana use while pregnant is limited and mixed. Many early studies were retrospective or did not address confounding variables such as the use of tobacco or other drugs of abuse, mental health, and socioeconomic factors. This results in confusion among practitioners as to how to counsel women about risks of use.

***“Many early studies were retrospective or did not address confounding variables such as the use of tobacco or other drugs of abuse, mental health, and socioeconomic factors. This results in confusion among practitioners as to how to counsel women about risks of use.”***

Biologically, cannabis can affect the fetus. The endocannabinoid system (ECS) is made up of cannabinoid receptors and neurochemical cannabinoids. This system is how cannabinoids mediate their effects. The ECS is detectable as early as five weeks gestation and plays an essential role in the early stages of neuronal development and cell survival through processes such as cell proliferation, migration, and differentiation. Thus cannabinoid exposure during this early developmental stage can cause long-term neurobehavioral consequences, which will be discussed later in this article. (3) Cannabis affects the normal transport functions of the placenta throughout pregnancy. THC is highly lipophilic and readily crosses the placenta. It is distributed rapidly to the brain and fat of the fetus after ingestion or inhalation by pregnant women—the concentrations of THC in the fetal blood range from 1/3 to 1/10 of maternal concentrations. (1) THC also can pass into breastmilk, demonstrating that cannabis affects not only the fetus but the neonate as well. (4) Cannabidiol, the non-psychoactive substance found in marijuana, can enhance placental barrier permeability to

pharmacologic agents and recreational substances. (1) Fetuses who were prenatally exposed to marijuana had significantly reduced levels of molecular substances needed for neuronal cell axonal elongation. These substances are essential for the development of normal neuronal circuitry during early brain growth. This was caused by THC binding to cannabinoid receptors and disrupting the normal ECS signaling and sequencing functions. These cannabinoid receptors are widely distributed in the adult brain; however, in the fetus, these receptors are only found in mesocorticolimbic structures—areas that are important for emotional regulation, cognition, and memory. (3) Rats who were exposed to cannabis prenatally showed cognitive impairments with long-term memory impairment and motor hyperactivity during infancy and adolescence. These rats also had long-lasting changes in emotional reactivity—less social interaction and less social play during adolescence. (5)

***“Rats who were exposed to cannabis prenatally showed cognitive impairments with long-term memory impairment and motor hyperactivity during infancy and adolescence.”***

In addition to its effects on neonates, cannabis can also affect the pregnant woman. Maternal cannabis use results in an increased resistance and pulsatility index of the uterine artery. This affects uterine blood flow and can lead to increased placental resistance and reduced placental circulation. (1) The occurrence of premature labor and placental abruption increased with a higher frequency of marijuana use. When marijuana is consistently used during pregnancy along with tobacco, there is a higher risk of maternal asthma and preeclampsia. (3) Regarding maternal use, only 39% of women reported using it for recreational reasons. The rest used it to help with nausea, vomiting, depression, anxiety, or pain. 92% of women who used marijuana for nausea and vomiting reported relief of symptoms. Studies found that up to 60% of marijuana users report continuous use of it during pregnancy as they believe it to be safer than tobacco. (1) There are demographic trends amongst maternal marijuana users. These women tend to be younger (<25 years), come from households with lower income, and have less than a college education. Many also are unemployed, lack adequate prenatal care, and report having experienced a significant stressor (traumatic, financial, or partner-related) before or during the pregnancy. (6) Women who had a higher level of education were more likely only to use cannabis before pregnancy. These women, who stopped use once pregnant, also had a higher percentage of planned pregnancies. (7)

It is known that women who smoke cigarettes during pregnancy deliver on average an infant whose birth weight is 150–250 grams lower and have a 1–2 day lower mean duration of gestation than nonsmoking women. (8) However, few studies have examined the effects of maternal marijuana use on fetal development while controlling for potential confounding. Conner et al. is one study that adjusts for these confounders. They found that women who smoked marijuana had a higher risk for preterm delivery. If women smoked both tobacco and marijuana, the risk was much higher.

These women were also more likely to deliver infants with lower mean birth weights, lower APGAR scores, or experience stillbirth. When marijuana use began at the beginning of pregnancy and was continuous, lower birth weight can be seen starting in the second trimester. However, if neonates were exposed to marijuana in the third trimester, this lower birth weight was not seen. (9) Again, if marijuana and tobacco were both used consistently, infants had even lower birth weights (< 25<sup>th</sup> percentile) along with decreased head circumferences (< 25<sup>th</sup> percentile). The National Academy of Sciences reported that fetuses exposed to marijuana in early pregnancy grew 11.2g less per week than those not exposed. Those with ongoing marijuana exposure grew 14.4g less per week. (5) Data from the 2017 Pregnancy Risk Assessment Monitoring System found associations of maternal marijuana use with small for gestational age and low birth weight infants. In pregnant women who used cannabis, the prevalence of delivering an SGA infant was 18.9% and 12.9% for high frequency (> once/week) and low-frequency use (< once/week) respectively. This percent is only 8.6% in women with no cannabis use. The prevalence of delivering a low birth weight infant was 12.1% for high-frequency use and 7.4% for low-frequency use. It is only 5.2% in women with no cannabis use. (10)

Neurological effects can also be seen. Neonates exposed to marijuana in utero show altered arousal patterns, excitability, increased tremors, and exaggerated startle reflexes as measured by the NICU Network Neurobehavioral Scale and Neonatal Behavioral Assessment Scale. These neonates have poor habituation and responses to visual stimuli, but not auditory stimuli. They also have abnormal sleep patterns with decreased quiet sleep and increased sleep motility. These were all observed within the first week of life and persisted from 9 to 30 days. (3) Some of these behaviors are similar to those seen in neonatal abstinence syndrome; however, there is not enough data to support a marijuana withdrawal syndrome. Nonetheless, marijuana use is significantly associated with neonatal morbidity, with an emphasis on neonatal infection morbidity. This is biologically plausible as animal studies have shown immune suppression and T-cell dysfunction with cannabis exposure. (11) Bao reported a case of an 11-day infant born at 36.5 weeks who was found unresponsive with no evidence of suffocation or trauma. The autopsy revealed that she died of extensive necrosis and hemorrhage of both adrenals and the liver due to acute marijuana toxicity and maternal marijuana use. (12)

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***“The Ottawa Prenatal Prospective Study (OPPS) and the Maternal Health Practices and Child Development Study (MHPCD) are two longitudinal studies assessing the long-term adverse neurodevelopmental effects caused by prenatal marijuana exposure.”***

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The Ottawa Prenatal Prospective Study (OPPS) and the Maternal Health Practices and Child Development Study (MHPCD) are two longitudinal studies assessing the long-term adverse neurodevelopmental effects caused by prenatal marijuana exposure. OPPS has observed 84 pregnant women and their children since 1978, and MHPCD has observed infants since 1982. These studies demonstrate that marijuana exposure has significant effects noticeable in a child beginning at age 4 and continuing into young adulthood when compared to tobacco. At age 4, children had

deficits in executive function tasks with poor memory and verbal reasoning. At 6, children had deficits in language comprehension, memory, and reading tasks that required sustained attention. Children exposed to higher amounts of marijuana starting in the first trimester showed increased impulsivity and hyperactivity. At age 9 through 12, there were no more deficits in global intelligence or verbal subscales on intelligence testing. However, children had deficits in executive function tasks, including impulse control and visual problem-solving. While OPPS did not show a decreased intellectual ability, the MHPCD study found lower reading and spelling scores in children whose mothers reported first-trimester use of at least one joint per day. These lower scores were also seen at age 14 but then included reading, spelling, and math. At ages 13 through 16, there were deficits in attention, problem-solving, visual integration, and analytical tasks requiring sustained attention. Both studies demonstrated higher rates of substance use, including marijuana and tobacco, starting at age 16. These adolescents had an increased risk for addiction and psychiatric disorders later in life. A proposed mechanism for this risk is that early fetal marijuana exposure decreases gene expression for dopamine receptors in areas of the brain important for reward recognition. THC also significantly changes the gene expression levels of the opioid, glutamate, and  $\gamma$ -aminobutyric acid systems. (1) These findings on neurodevelopmental and behavioral outcomes suggest that marijuana use during pregnancy might not be as harmless as one thinks. Moreover, when these studies started, the marijuana available had a much lower potency than what is available today, raising concern that these adverse consequences may be much greater today.

The AAP, ACOG, and American Society of Addiction Medicine recommend all women considering or currently pregnant to be routinely screen for alcohol and drug use, including marijuana. They recommend intervention techniques and counseling abstinence. A study conducted in 2016 found that out of the women who reported marijuana use during pregnancy, only half received counseling on the medical or health effects of marijuana. It was found that women seeking information about prenatal marijuana use were unlikely to get that information from their health care providers. Instead, they relied on anecdotal experiences, advice from family and friends, and even sought advice from dispensary employees. This indicates the importance of educating health professionals on the effects of marijuana while pregnant. A factor to address in future studies would be information on the potency and dose of cannabis being used. It is also important to address that in a majority of these studies, marijuana use is self-reported; thus, the percentage of pregnant women using marijuana can be much higher. Nonetheless, pregnant women should be advised to decrease their cannabis use as it is the option with the least risk and highest safety for both mom and baby.

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Disclosures: The authors have indicated no conflicts of interest.

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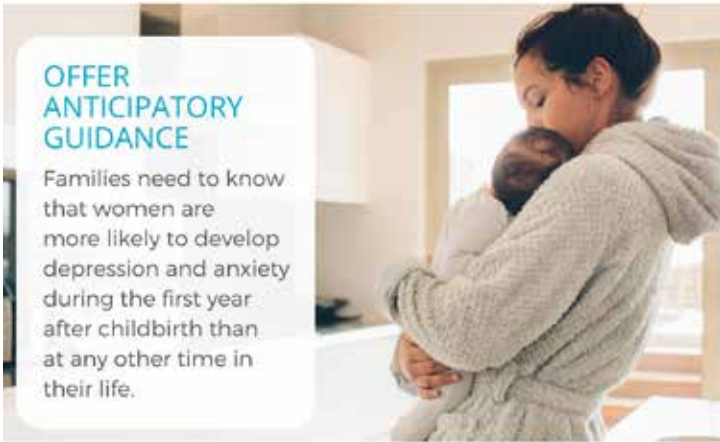
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# Understanding Paternal Grief at the Loss of a Child

Barb Himes, IBCLC, Kelly D. Farley

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June brings us Father's Day, which can be a difficult time for fathers who have lost a child. First Candle's bereavement support services have been there for fathers as well as mothers and other family members, and we have come to know Kelly D. Farley, the author of *Grieving Dads: To the Brink and Back*. Kelly and his wife Christine lost their daughter Katie in 2004 and their son Noah in 2006, both stillborn. It changed his life, leading him to seek help

for his grief and become involved in helping other grieving fathers.

Today he provides individual and group counseling for fathers and continues to write extensively on facing and living with paternal grief. In honor of Father's Day, we share some of his work, which may offer health care providers insights into this side of bereavement when an infant is lost to Sudden Unexpected Infant Death (SUID) or a child is lost due to other causes.

## Father's Day Void

I spent two years interviewing men that have experienced the death of a child. As you can imagine, I heard a lot of heartbreaking stories. All were different, and all were bad. I also learned a lot about my own pain and suffering caused by the aftermath of burying two children. Those interviews, and my own hard lessons, are captured in my book *Grieving Dads: To the Brink and Back*.

*"I have tried to become an advocate of sorts for grieving dads. My goal is to make sure these men feel like they have the permission to grieve, to feel the impact, and express their pain without society trying to hush them because the topic of a child's death is uncomfortable for those who have not experienced it."*

I have tried to become an advocate of sorts for grieving dads. My goal is to make sure these men feel like they have the permission to grieve, to feel the impact, and express their pain without society trying to hush them because the topic of a child's death is uncomfortable for those who have not experienced it.

Because of my book and my advocacy, I receive a lot of requests to write Father's Day articles about the dark side of the day from the perspective of the guys who have had to bury a child. Is the day harder than most? Yes, but to us grieving dads, it is not much different from the holidays, birthdays, and death anniversaries. They are all difficult to navigate, and each one stirs similar but different emotions.



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There is not a day that goes by that we do not think about our absent child. Regardless of the circumstance of their deaths, we miss them deeply. However, there are days where we feel this pain more acutely than other days. Days like Father's Day remind us that they are not here. We are keenly aware of their absence every single day, and on days like Father's Day, the hole they left grows a little bigger.

We feel a sense of emptiness on Father's Day because there is an obvious void that tends to suck the air out of the day, creating a difficult space that we do not know how to navigate. We try our best, but it is hard to explain our feelings to those that haven't lost a child. It is not fair for us to expect you to understand; you're one of the lucky ones that have never had to walk in these shoes.

---

***“Most of us will try to keep our minds occupied with other living children or by filling the day with busy, mindless tasks. It's a defense mechanism that helps us to hide from the harsh reality that lurks in the darkness, seeking our whereabouts.”***

---

Most of us will try to keep our minds occupied with other living children or by filling the day with busy, mindless tasks. It's a defense mechanism that helps us to hide from the harsh reality that lurks in the darkness, seeking our whereabouts. It's a constant battle that we often lose in the early years. Yes, I said years.

This isn't something that goes away after a year. It's a burden that weighs heavy on our souls for the rest of our lives. However, the weight lightens dramatically as time moves forward, and we continue to process our loss. The death of a child becomes who we are. It does not define us, but it certainly changes the course of our lives and destroys the naivety we once had.

Regardless of the day, most people will not bring up the fact that your child died because it is too awkward for them. They are not sure if they should acknowledge this day. Let me resolve this confusion: you should acknowledge Father's Day.

It certainly isn't a "Happy" Father's Day. So, what should people say or do?

Try saying something like, "I know this must be a difficult day, but know I am thinking about you." This statement, or a variation of it, goes a long way with the men that are on the receiving end of it. It might trigger a visible emotion, but know the emotion constantly lurks just below the surface regardless. Though you just don't see it, it's just waiting for an opportunity to escape.

I wish all fellow grieving dads a peaceful Father's Day. If you know a grieving dad, pay them a visit, or make that phone call to tell them that you are thinking about them and their child. - KDF

*Disclosure: The authors declared no conflict of interest related to work presented in this manuscript.*

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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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 PEDNOTES

# Psychosocial Aspects of Neonatal Care: Compassionate Care of Infants and their Families

Kelly Welton, RRT-NPS

*“Every prospective parent wants and hopes for a healthy baby. They plan for it, and a lot of thought goes into that preparation and planning. They may have already put together the baby’s new room with the bassinet and crib.”*

Every prospective parent wants and hopes for a healthy baby. They plan for it, and a lot of thought goes into that preparation and planning. They may have already put together the baby’s new room with the bassinet and crib. They may have gone to great lengths to redecorate it with baby furniture and rearrange things to get ready for the new little one.

They may have even already had a baby shower with lots of people coming and well-wishers bringing them gifts anticipating that day. But instead, they end up with a very tiny, very ill infant. What happens when a mom gives birth to either a premature baby or possibly a term baby who’s very ill? Firstly, the normal bonding process gets interrupted. Usually, a baby is born and placed on Mom’s chest, and the bonding process starts immediately. When the baby is ill, or premature, or needs resuscitation, we whisk that baby away, and the parents often don’t get to see that baby until much later.

From the parents’ perspective, the baby that they believed would be just perfect is not. The baby may be small, and not even look like a baby if it is a VLBW or ELBW. Or the baby may be deformed. When the parents get to see the baby again, the baby has all kinds of tubes and probes attached. This is very stressful for parents who had planned all along for a perfect pregnancy, had a perfect baby shower, and now there will not be a perfect homecoming.

Parents of babies in NICU go through similar feelings as outlined by Elizabeth Kubler Ross in her famous book “On Death and Dying.” (1) Things to remember about this is that these feelings may not happen in order, AND you have two parents who may each be in a different phase of these feelings. One parent may be in shock while the other one is angry. Then the first parent enters the anger phase, and the other parent is now at a different phase. It can be challenging to deal with the parents when you don’t know where they are emotionally. Parents don’t walk into the NICU with a label on their forehead saying what they’re feeling for that day.

Often shock is the underlying current beneath all the other feelings for a long time. The parents don’t know what’s going to happen. They may have feelings of disbelief – “This isn’t really hap-

pening. The baby’s not that sick, right?” They may fall into a deep depression that their baby is not perfect. They may just be numb and can’t feel anything. They walk in and out of the baby’s room and don’t even know what they’re looking at or what to think about it. With all these feelings and all these phases, parents frequently don’t remember much of anything that the hospital staff said to them initially. What they do remember is whether or not the hospital staff was kind and caring. We spend a lot of time educating these parents. They have a lot of questions, we explain things over and over again, and in the end, if you ask them what they remember, they likely will say, “I don’t remember anything anybody said that first week. I was just completely out of it, in addition to being exhausted. I couldn’t believe this was happening. I had so much going on. And, I had to call family and friends and explain what was happening. I don’t remember much, except I do remember two people that were very nice to us”.

Parents have different levels of ability to understand what’s going on, not so much referring to their education level, but to absorb everything that’s happening.

*“Parents have different levels of ability to understand what’s going on, not so much referring to their education level, but to absorb everything that’s happening.”*

There may be anxiety or fear. There may be a language barrier. We’re speaking in English, and they do not understand enough, considering how critically ill their baby is. What about their education level? Is their education level 6th grade, is it high school, is it college? Do they have an engineering degree? Without knowing, it’s just as easy to insult them as it is to talk way over their head.

How can we help these parents cope with everything that’s going on? Things in the NICU with their baby could change in a second. Do they have a support system that will help them with that? If they are equipped to deal with the changes, do they have community support, family, friends, and neighbors that will do things like take their other kids to school or pick them up so they can spend more time with their baby? Do they have religious or spiritual support? And if they don’t, would they like to? We can offer them licensed clinical social workers to help and to direct them to people who can be a source of support for them.

Some parents have very unhealthy coping mechanisms. These are the parents that deny that there are any issues or any problems. They are happy all the time, they are cheerful, everything’s great, they’re very reluctant to receive or seek any help. They may believe that since their baby is just 8 weeks early, that in eight weeks, the baby will be ready to go home, and all will be well. It is also very stressful to take care of babies with parents with that

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attitude as a hospital RT or Nurse, or Doctor. It's imperative **not** to disengage from these parents.

Some other thoughts that run through a NICU parent's mind are the feelings of failure. Facing feelings of, "my parents and my spouse's parents really wanted this grandchild, we planned, we did all the 'right things, and now we failed." This is not true; the parents are not failures.

When the baby has made it past a certain critical point, other considerations for parents are they've got to learn how to care for that baby in the NICU and at home. We start involving the parents in the baby's care in the NICU with small tasks such as changing a diaper or helping us turn the baby, and they've got to learn other care tasks in preparation for discharge to home. Discharge anxiety can happen when the baby's been in the NICU for a long time, and the realization hits the parents: The staff taking care of their baby is there 24 hours a day, seven days a week. And there are many of us -- Respiratory Therapists, Nurses, Doctors, Occupational Therapists, Physical Therapists, and more. And they realize: "Oh -when we get home, it's just going to be my spouse and me, maybe my Mom if I'm lucky." And that's a daunting task to think about, "How am I going to do everything that seven people do 24 hours a day by myself with only one other person who's probably going back to work?" That's a significant source of anxiety.

What about the parents of babies that have serious congenital defects? We must be truthful with the parents, even if the outcome is uncertain. If you don't have an answer to their question, find someone that does. Please don't sidestep the parents and tell them to speak to the doctor every time. We can confirm, "yes, your baby has gastroschisis, and we're going to determine when your baby will go to surgery." Kindness, at this point of their journey, will be remembered for years. Sometimes when we have a baby that's really sick, we do our best just to float into the room, do what we need to do, and float out. We don't even acknowledge that the parents are sitting right there. It's important to say, "Hello, how are you today, my name is Kelly, and I am your RT today." All that courtesy will be remembered. And be patient with these parents. Put yourself in their place. These people are entirely stressed, they've had no sleep, they are utterly helpless in terms of the outcome of this baby, and they may ask the same questions repeatedly. They're not dumb; they just want to make sure they understand as best they can. And with their baby's status changing every day, it makes it even more difficult. You can expect the reactions of shock, anger, fear, guilt, and depression with each new setback, update, or new event.

It's not uncommon for a very premature baby to spend 3 months in the NICU. After surviving the long NICU stay, now the parents may be performing many of the duties that healthcare personnel did. These parents may be slowly learning how to care for a chronically ill child at home. They may not feel fully prepared for this and may seem manipulative in getting us to do tasks they need to practice and master. Parents need reinforcement of skills

and encouragement to do even more. If we do everything for the parents up to the day of discharge, these babies will only return to the hospital when the parents feel uncomfortable doing things like changing a trach or a regulator on an oxygen cylinder. Saying things like, "you're really good at suctioning. Now let's practice a tank change!" will help them recognize their learned skills and hopefully encourage them to do more. The parents may express complete overwhelm. Saying things like, "Oh my gosh, you didn't expect any of this, and look at how much you've learned!" can go a long way.

Some of these babies may go home on monitors, they may go home with therapy, breathing treatments, they may go home on oxygen, some of them may even go home on a home ventilator. When the parents realize that the beautiful baby room they set up and decorated will look like a hospital room, it is important to reassure them that it's OK to feel overwhelmed and just to take one step at a time.

What can we do for parents of dying children? Staff may anticipate a baby's death long before the parents fully grasp the reality. If the baby takes a turn for the worst, we don't give up, but we may know where this is heading. We need to figure out the best way to let the parents know that things aren't going really well, but we are not giving up, and we will do everything that we can. Sometimes because of the impending death, staff may withdraw. We don't want to answer all their questions anymore. We want to deal with them as little as possible. When the parents are trying to ask us serious questions about their child, and we do everything we can not to engage with the parents, they perceive the staff as being cold or uncaring.

What about the staff when we have a baby that's dying? The staff RT's, nurses, doctors, and others may feel anger or guilt about our inability to save the baby. We worked our tail feathers off to do everything we could. We've had this baby on CPAP, high flow, ventilator after ventilator, oscillator, everything we know to save this baby, and now the baby is dying. We may feel angry or guilty and ask, "Did we do everything right?" We play it over and over in our minds. Did we do everything possible? Maybe we should have done this instead of that..... Staff need ways to vent these feelings and not internalize them. Many NICUs hold debriefings when they lose a baby. Depending on the disease state and degree of prematurity, the average premature infant survival rate can be 80 to 90% or lower. Are we prepared for that? After the baby dies, is it OK to attend their funeral? If the parents invite you, it's absolutely OK. The family may not even have a funeral for a very long time because they're still in shock that their baby was sick, and it's going to take a while before they can get to the point of being able to plan something like that. Remember, for months, these parents have gone home every day to an empty baby room. They go home every day to many presents and gifts that people gave them at the baby shower that might not get used. They go home every day to a scene that they don't want to look at unless there's a baby in the picture. Now they have to change course again, and they have a lot on their minds. They also have a lot on their plate in terms of paperwork, insurance, financial things to deal with. And they have to plan a funeral in addition to all this, something that they really didn't want to think about.

As if having a baby in the NICU isn't stressful enough, staff often forget about the parents' other obligations such as jobs and other children, or even parents at home to take care of. Parents under stress may lash out at staff or make inappropriate comments. Please do not take these comments personally. Sometimes the grandparents get involved, and the stress takes a toll on them, too. Things come out directed at you. Keep your professional hat pinned in place, carry on and just know they may not have the necessary coping skills for all that is going on. Parents also need time balancing support. Parents may both have jobs; they

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may have grandparents who can only visit for a limited amount of time. Two weeks go by, baby's still in NICU, and now the baby's grandparents have to go back wherever they came from, so now the parents are left by themselves again, and the baby is still in the NICU. They have other kids at home, nobody there to watch those other kids, and they've got to go back to work, and how are they going to manage time with everybody that needs their attention?

When the parents are coping as best they can, what do they need? Parents do need emotional help, and they need support. They may not think they need it, or they may say that they don't want it, but honestly, they need as much help and support as we can give. Parents' biggest request is for continuity of care, something out of our control unless we as RT's, RN's, and MDs push for it. Could we do our best to have the same babies three days in a row for continuity of care? Because of staffing rules or union rules, some hospitals require everybody to rotate a certain number of days fairly and squarely through a certain number of units. The patient loses out in that scenario because a baby has one RT one day, a different one the next day, and so on. In addition, they've got one nurse one day a different one the next because we all have 12-hour shifts. We all work very different schedules, and the parents just don't know who's who anymore. You may walk into a baby's room, and the parents will ask for the RT or the RN there yesterday. Don't take it personally. It's not that they don't want you. They just want someone familiar and consistent. We need to have some empathy for these parents and just let them know that we acknowledge their feelings and that it's OK to cry and that it's OK if they're not sure they can cope with this today. Let them know that we understand what they're feeling even though we can't fix it.

Parents need to be able to trust the NICU staff. They need to know that we know what we're doing and do the best we can. One thing that will really undermine the parents' trust is every time a new Doctor comes on shift, everything changes. Or, every time a new nurse comes on or every time a new respiratory therapist comes on, more changes get made. In many hospitals, the doctors change shifts every eight hours or 12 hours. You may have a doctor that works for three days straight, but then that doctor goes home, and the next doctor comes in and says, "OK, everybody that's on PRVC mode is now going to go on pressure control mode. And everybody that's on high flow is now going to go on SiPap". Parents may ask, "why is it that one doctor uses this and another doctor comes on, and then everything gets changed?" How can we as nurses and RT reassure the parents? Often we just shrug our shoulders and say, "Well, that's what the doctor wanted," but that's not really an answer. We need the family to trust all of the NICU staff that we're doing our very best and know what we're doing. Sometimes we think we're doing the right thing, and we believe we're being kindest when we just slip in the room and ninja slip out when actually what the parents would really like is an acknowledgment that they exist, an acknowledgment that we as the staff are there for them, and acknowledgment that they're not bad parents, they're not failures, they're not all of the things that they're feeling. And continual reassurance that we are doing all we can.

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Disclosures: The authors have no relevant disclosures.

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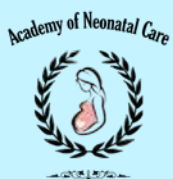
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# A Case Report of Hyperleukocytosis in An Extremely Low Birthweight Neonate

Mehwish S. Sheikh, MD

## Abstract:

*Hyperleukocytosis is elevation of WBC >100,000/uL. The condition can lead to significant morbidities and can be associated with neonatal sepsis, myeloproliferative disorders of Trisomy 21, Neonatal leukemia, or leukocyte adhesion defect. The diagnosis is challenging in extremely low birth weight premature neonate, and limited literature is found for the preterm population. We present a case of hyperleukocytosis in extremely preterm neonate managed conservatively with a good outcome.*

***“Physiological leukocytosis, white blood cell (WBC) up to 30,000/uL in the neonatal period is well reported. Leukemoid reaction is when WBC >50,000/uL and not because of the myeloproliferative disorder. Hyperleukocytosis (WBC > 100,000/uL) is not as well reported in extremely premature neonates. ”***

## Introduction:

Physiological leukocytosis, white blood cell (WBC) up to 30,000/uL in the neonatal period is well reported. Leukemoid reaction is when WBC >50,000/uL and not because of the myeloproliferative disorder. Hyperleukocytosis (WBC > 100,000/uL) is not as well reported in extremely premature neonates. The condition may be associated with myeloproliferative disorder or LAD, requiring extensive workup and extended days of antibiotic therapy. Some literature supports the watchful waiting in the extremely premature neonate. We present a case of an extremely preterm neonate with hyperleukocytosis, managed conservatively.

## Case report

An extremely preterm (~25 weeks gestation age) female born to a multigravida via vaginal delivery in breech presentation. Mother was admitted >7 days for PPRM (Preterm premature rupture of membrane). She had routine antenatal care and was doing well until her admission to the hospital with leakage of clear fluid. She received Mg SO<sub>4</sub> per our protocol and antenatal steroids on admission (>7 days before delivery). Mother was Rh-negative, otherwise serology negative and GBS negative.

The NB was admitted with a birthweight of 700 grams. On admission, the baby had respiratory acidosis with a pH of 6.9 and a pCO<sub>2</sub> of 108. The baby was switched to HFJV at the time with improving gases.

Further labs revealed the WBC to be 87,000/uL peripheral smear showed 2% bands, 4% promyelocyte, 1% myelocyte, 62% seg-

mented neutrophil, 21% lymphocytes. Hb was 11.4 g/dl and platelet 350,000/ uL.

The baby was started on antibiotics, Fluconazole, adequate hydration through IVF. Repeat CBC at 12 hours of life reported WBC to be 102,000/uL. Peripheral smear showed 6% bands, 4% promyelocyte, 4% myelocyte, 68% segmented neutrophil, 4% lymphocytes. Hb was 12.4 g/dl and platelet 350,000/ uL. CRP <0.1. Arterial blood gas continued to improve. Clinically, the newborn did not show other signs of sepsis. Lactic acid was 1.84. LDH was 726 U/L.

Pathology review reported Nucleated red blood cell (RBC) within range for age; the left shift was suggestive of a reactive, infectious, or therapeutic process.

The newborn was managed for possible complications of hyperleukocytosis with hyperhydration.

The baby received 36 hours of antibiotics with two doses of Fluconazole. Blood culture was negative.

Placental pathology was reported as placental vasculitis and fetal membranes with chorioamnionitis.

As this was deemed to be most likely a Leukemoid reaction, no further workup was done to investigate the etiology.

The baby was extubated on ~ day of life (DOL) 21 and required DART therapy. The baby was Discharged home on RA with Mild bronchopulmonary dysplasia (BPD) at ~40 weeks of gestation. Stable grade 1 intracranial hemorrhage was present at discharge.

This is an interesting case of an EPT neonate presenting with hyperleukocytosis in the first three days of life without further significant signs of infection, managed conservatively, with a short duration of antibiotic therapy. The WBC trended down to normal range without further investigation within seven days.

## Discussion:

Physiologic elevation of leukocytes (<30,000/ uL) in the neonate is well known and is usually associated with a physiological surge of granulocyte colony-stimulating factor. It has been reported to be a predictor of survival in some premature newborns (1). Leukemoid reaction is defined as a WBC count of more than 50,000/ uL when associated with etiology other than malignancy. Hyperleukocytosis is defined as a WBC count of more than 100,000/ uL and is seen in neonatal leukemia, Leukocyte adhesion defect, and Trisomy 21; management can be challenging in an EPT infant. A literature search is limited for hyperleukocytosis in (extremely low birth weight) ELBW population. We present a case of an

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extremely preterm (EPT) ELBW infant with hyperleukocytosis at birth (early onset) with resolution within seven days while following a conservative management approach.

Antepartum factors such as steroid use, chorioamnionitis, funisitis, preterm rupture of the membrane are associated with hyperleukocytosis (2). Our patient was born with extreme prematurity. There was an administration of antenatal steroids >7 days before birth and evidence of histological chorioamnionitis.

Neonatal leukemia is extremely rare (3). Our patient did not have abnormalities of the blood cell lines (no thrombocytopenia or anemia), no significant findings on the exam such as hepatosplenomegaly, leukemia cutis suggestive of leukemia (3); hence we did not proceed with bone marrow biopsy. Close monitoring with daily a CBC was recommended per consultation with Hematology.

The transient myeloproliferative disorder has a 10% incidence in Trisomy 21 (4). It manifests in the neonatal period as hyperleukocytosis and hepatomegaly with increasing circulating blast cells (5). Our patient did not have physical features attributable to Trisomy 21, which sometimes is difficult to assess in EPT. Also, only a few blast cells were seen on pathology review.

Leukocyte adhesion deficiency is described with an incidence of 1 in 1 million (6). LAD 1 is a severe form and can present as hyperleukocytosis, delayed cord separation, and poor wound healing. This defect is most often a diagnosis of infancy, and only two cases in the neonatal period are found in the literature (7).

The diagnosis for the above possible etiologies requires a considerable amount of blood draw, which is challenging in ELBW neonates. We chose to follow the newborn conservatively without

further diagnostics.

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***“We followed the American Committee of Fetus and Newborn 2014 recommendation (12). We treated the baby with 36-hour empiric therapy with extended-spectrum antibiotics. Blood culture was negative, as were inflammatory markers. There was no clinical progression.”***

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Infectious disease is the second leading cause of neonatal mortality worldwide, preceded only by complications related to preterm birth. Hyperleukocytosis can be a finding in neonatal sepsis. The overall incidence of neonatal sepsis ranges from one to five cases per 1000 live births (8). At the same time, antibiotic stewardship is encouraged to avoid unnecessary exposure to antibiotics in this fragile population. Prolonged use of broad-spectrum antimicrobials in NICU increases the risk of *Candida* colonization and invasive infection, necrotizing enterocolitis, late-onset neonatal sepsis, and death (9,10,11). We followed the American Committee of Fetus and Newborn 2014 recommendation (12). We treated the baby with 36-hour empiric therapy with extended-spectrum antibiotics. Blood culture was negative, as were inflammatory markers. There was no clinical progression.

While following the trend of WBC, we continued to provide hydration to our patient in the first three days of life of up to 120

Table 1

	DOL 1	DoL 2	DOL 3	DOL 4	DOL 6	DOL 9
WBC	87.3	102.3	84.2	44.6	35.2	23.1
Neutrophils, segmented	62	68	70	75	72	68
Bands	2	6	5	2	1	1
Metamyelocytes	0	2	4	0	0	0
Promyelocyte	4	4	1	0	0	0
Myelocyte	1	4	1	0	0	0
Lymphocyte	21	4	8	14	12	21
Reactive lymphocyte	0	0	0	0	4	3
Basophils	0	0	0	0	0	0
Eosinophils	0	0	0	1	1	0
Monocyte	5	11	10	8	10	7

ml/kg/day while keeping close monitoring of fluid balance. Our patient did not require exchange transfusion, as can be performed for extreme cases (3).

Hyperleukocytosis is associated with significant short- and long-term morbidities such as IVH, pulmonary hemorrhage, respiratory failure, RDS, BPD, renal failure, and DIC (13, 14). Our patient did not have IVH at 7 and 28 days of life on screening US, no AKI, was extubated at 21 DOL after requiring DART therapy. The patient did require high-frequency ventilator support in the first seven days of life. These findings have a strong association with prematurity itself. It is hard to associate this even partially with hyperleukocytosis.

Our patient did require pharmacological therapy for clinically significant PDA. This situation may have been attributable to higher fluid intake in the first week of life; however, there is no clear association of clinically significant PDA for TFI of < 150 ml/kg/day in the first weeks of life.

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Disclosure: The author has no disclosures.

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# Consultation or Counseling?

Scott D. Duncan, MD, MHA

***“A consultation is an evaluation and management (E/M) service provided at the request of another physician or qualified healthcare provider (QHP) to recommend care, diagnostic or therapeutic services for a specific condition or problem. (1)”***

Requests for outpatient antenatal or perinatal counseling or consultations are a common scenario in neonatology. Many times, the consultation request will originate from obstetrical services. On rare occasions, the family may request the consultation. A consultation is an evaluation and management (E/M) service provided at the request of another physician or qualified healthcare provider (QHP) to recommend care, diagnostic or therapeutic services for a specific condition or problem. (1) Outpatient consultation codes correspond to Current Procedural Terminology (CPT®) codes **99241-99245**.

When providing time-based services for consultation, these CPT® codes are defined as follows<sup>1</sup>:

**99241** typically 15 minutes,

**99242** typically 30 minutes,

**99243** typically 40 minutes,

**99244** typically 60 minutes,

**99245** typically 80 minutes.

However, the Centers for Medicare & Medicaid Services (CMS) eliminated the use of all consultation codes, inpatient and outpatient, effective January 1, 2010. (2) In doing so, CMS increased the work relative value units for office visits, initial hospital visits, and global surgical codes. Many payors have followed suit, and recommendations may vary on the use of office-based based E/M codes to substitute for the consultation codes. Nevertheless, documentation should include the requesting physician, reason for the consultation, recommendation, and reporting. (3) The physician groups should reexamine the current state Medicaid physician fee schedule to determine whether consultation codes have been published and valued.

If substituting office-based CPT® E/M codes, the provider should be aware of other changes that occurred on January 1, 2021. **99201** (office visit for the E/M of a new patient up to 15 minutes) was eliminated, and the guidelines for selecting a code changed, focused on medical decision making and time. (4) Current CPT® codes for new patient office visits include:(1)

**99202** straightforward medical decision making, 15-29 minutes,

**99203** low-level medical decision making, 30-44 minutes,

**99204** moderate level of medical decision making, 45-59 minutes,

**99205** high level of medical decision making, 60-74 minutes.

In neonatology, preventive medicine counseling CPT® codes **99401–99404** are used to report risk factor reduction services and include counseling, anticipatory guidance, and/or risk-factor reduction interventions.(3) For example, these services might provide prenatal counseling to a family to reduce the risk of a problem or complication. If another physician or QHP referred the family, office-based consultation codes or other payor-recommended E/M codes might apply.

Preventative medicine counseling CPT® codes are time-based codes and do not differentiate between new and established patients. These codes include: (1)

**99401** Preventive medicine counseling and/or risk factor reduction intervention(s) provided to an individual (separate procedure); approximately 15 minutes,

**99402** approximately 30 minutes,

**99403** approximately 45 minutes,

**99404** approximately 60 minutes.

## Scenario

**Mr. and Mrs. Smith have recently moved from out of state to your community. The mother’s previous pregnancy was complicated by gestational diabetes, requiring insulin. That pregnancy resulted in a large for gestational age baby with hypoglycemia, a brachial plexus injury, and muscular ventricular septal defect. In addition, the mother has a sister who had a small VSD as a child. The family asked to consult with you in your neonatal office as they are now expecting their second child and want to explore using a Mediterranean diet to reduce the risk of complications. You spend 30 minutes of face-to-face time counseling the family.**

The correct code is:

- A. 99252
- B. 99242
- C. 99402
- D. 99203



**The correct answer is C.**

**99402** is a preventive medicine counseling and/or risk factor reduction intervention provided to an individual for approximately 30 minutes. This preventive medicine counseling code may be reported if the family seeks consultation either self-referred or sent by another provider to discuss risk reduction interventions. A risk reduction intervention is defined as seeking advice when there is no present problem but rather to avoid a further problem or complication. These codes are reported based upon the time spent face-to-face providing counseling.

**99242** is an office consultation for a new or established patient, which requires these three key components: an expanded problem-focused history, an expanded problem-focused examination, and straightforward medical decision making; typically, 30 minutes.

**99252** is an inpatient consultation for a new or established patient, which requires three key components: an expanded problem-focused history and expanded problem-focused examination and straightforward medical decision making; typically, 40 minutes.

**99203** is an office visit for evaluating and managing a new patient, which requires a medically appropriate history and/or examination and a low level of medical decision making; typically, 30-44 minutes.

Note that 99401-99404 are not included in the CMS list of expanded telehealth services throughout the national public health emergency, as directed by the CARES act.

Preventative services provided to the mother prior to the delivery are reported using the mother's insurance. As with other time-based counseling codes, the medical record must include documentation of the total time spent on providing face-to-face consultation and the issues discussed. In the above scenario, there are no current health conditions and the use of ICD-10 Z codes, denoting the reason for the encounter, such as circumstances that may impact one's health. The appropriate ICD-10 codes would include the following:

- Z76.81 – An expectant parent(s) pre-birth pediatrician visit
- Z82.79 – Family history of congenital malformations, deformations, and chromosomal abnormalities
- Z86.32 – Personal history of gestational diabetes

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Disclosure: The author has no disclosures.

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### Keeping Your Baby Safe during the COVID-19 pandemic

#### How to protect your little one from germs and viruses

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

Here's what you can do...

- Wash Your Hands**
  - This is the single, most important thing you can do to stop the spread of viruses.
  - Use soap.
  - Wash for more than 20 seconds.
  - Use alcohol-based sanitizers.
- Limit Contact with Others**
  - Stay home when you can.
  - Stay 6 feet apart when out.
  - Wear a face mask when out.
  - Change your clothes when you get home.
  - Tell others what you're doing to stay safe.
- Provide Protective Immunity**
  - Hold baby skin-to-skin.
  - Give them your breast milk.
  - Stay current with your family's immunizations.
- Take Care of Yourself**
  - Stay connected with your family and friends.
  - Sleep when you can.
  - Drink more water and eat healthy foods.
  - Seek mental health support.

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

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

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

**If you are positive for COVID-19**

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

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# TOP 10

## RECOMMENDATIONS FOR THE PSYCHOSOCIAL SUPPORT OF NICU PARENTS



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

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

### 1 PROMOTE PARTICIPATION

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



### 2 LEAD IN DEVELOPMENTAL CARE

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



### 3 FACILITATE PEER SUPPORT

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



### 4 ADDRESS MENTAL HEALTH

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



### 5 SCREEN EARLY AND OFTEN

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



### 6 OFFER PALLIATIVE & BEREAVEMENT CARE

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

### 7 PLAN FOR THE TRANSITION HOME

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



### 8 FOLLOW UP

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

### 9 SUPPORT NICU CARE GIVERS

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



### 10 HELP US HEAL

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

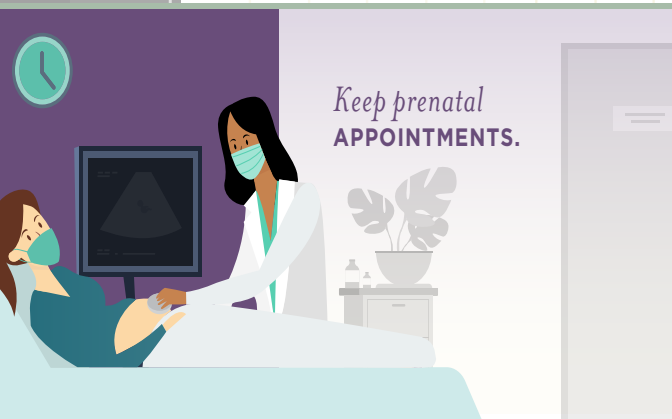
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## The PREGNANT MOM'S Guide To Staying SAFE DURING COVID-19



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SKIN-TO-SKIN CARE DURING COVID-19



GET INFORMED ABOUT THE RISKS + BENEFITS

work with your medical team to create a plan

GET CLEAN WASH YOUR HANDS, ARMS, and CHEST

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



PUT ON FRESH CLOTHES

change into a clean gown or shirt.

IF COVID-19 + WEAR A MASK

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



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# From the National Perinatal Information Center: Father's Day: Paternal Depression and the Needs of Fathers in the NICU

Elizabeth Rochin, PhD, RN, NE-BC

The National Perinatal Information Center (NPIC) is driven by data, collaboration and research to strengthen, connect and empower our shared purpose of improving patient care.

For over 30 years, NPIC has worked with hospitals, public and private entities, patient safety organizations, insurers and researchers to collect and interpret the data that drives better outcomes for mothers and newborns.



*“Maternal postpartum depression (PPD) is well studied, and significant resources have been invested in studying and treating PPD. While there continue to be significant barriers to treating PPD in many portions of the United States (US), including the availability of specialists, access, and equity of care, there is a facet of care that has been consistently overlooked: paternal postpartum depression.”*

*“I have never felt so much stress or felt so helpless in all of my life. I felt guilty for seeing our baby boy before my wife who was still recuperating from her [cesarean section]. I could not touch him and felt immediately overwhelmed. I was supposed to support my wife, support my baby, my other children, work. For a fleeting moment, I wanted to run away. Just run away. And felt overwhelmingly guilty for that vicious cycle. Over the next few weeks and*

*months, I found myself not being able to even function. As my wife fell into Postpartum Depression and during a lengthy NICU stay, I felt more and more in the shadows and even more alone. When we visited our baby in the NICU, staff consistently asked how my wife was, but no one asked me how I was. Lord knows I could not reach out to my friends or my family without ridicule or being told to “man up” or “this is normal.” I knew what I was feeling was not normal. But men are not allowed to be depressed after the birth of a baby or allowed the grace for treatment. Our insurance carrier paid for my wife’s treatment but would not pay for mine. I was truly alone”—JB, Father with Paternal Postpartum Depression*

Maternal postpartum depression (PPD) is well studied, and significant resources have been invested in studying and treating PPD. While there continue to be significant barriers to treating PPD in many portions of the United States (US), including the availability of specialists, access, and equity of care, there is a facet of care that has been consistently overlooked: **paternal** postpartum depression. In April, the National Perinatal Information Center provided data and information related to Maternal Mental Health Month and its importance in destigmatizing identification, treatment, and maternal mental health support. For Father’s Day, we turn our attention to the mental health of fathers and the important topic of paternal postpartum depression.

Meta-analyses have described paternal postpartum depression rates of approximately 10% at and around the time of birth and approaching 26% at six months after birth (1,2). Paternal postpartum depression can be exacerbated, coupled with the uncertainty of unplanned NICU admission. Several studies have supported the findings of increased stress and depression in fathers during NICU admissions (3-5). With this knowledge in hand, fathers’ emotional and psychological needs must be in mind when caring for the family unit during a NICU admission.

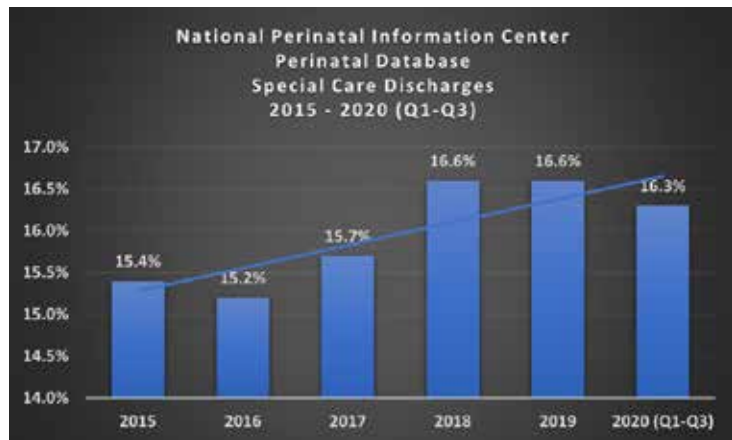
*“It is imperative to view the needs of fathers and paternal PPD through the lens of disparity. NPIC provides a Race and Ethnicity Dashboard that provides member hospitals a “deep dive” into their reporting by stratifying specific metrics by race and ethnicity.”*

The National Perinatal Information Center (NPIC) provides hospital-specific and benchmark data through the NPIC Perinatal Center Database, providing perinatal and neonatal data to members and researchers for over 35 years. National trends reveal episodic and regional variations in NICU admissions, and NPIC has found

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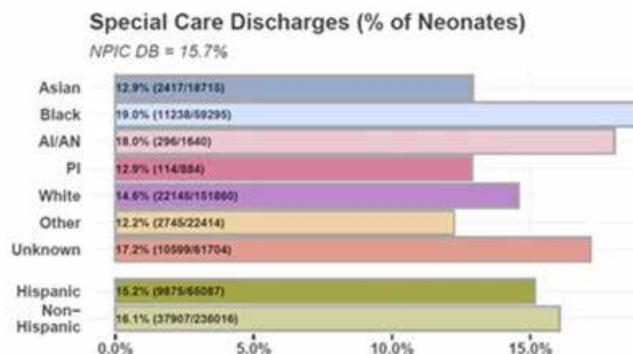
upward trends over the past five years within hospital membership. With this in mind, it is important to address the needs of the entire family unit; the vast majority of energy and effort within a NICU environment is utilized to support the baby and mother (1) with limited resources and energy spent on other family members, particularly the father. Paternal PPD is an undertreated, underdiagnosed, and under-resourced issue that warrants additional attention (6). As admissions into a NICU increase, it is reasonable to make plans for an increase in paternal PPD.



It is imperative to view the needs of fathers and paternal PPD through the lens of disparity. NPIC provides a Race and Ethnicity Dashboard that provides member hospitals a “deep dive” into their reporting by stratifying specific metrics by race and ethnicity. This dashboard has explored disparities that exist within payer sources and clinical outcomes for both mother and newborn. Within the lens of paternal PPD, there is strong evidence to suggest that racial disparities exist to identify and treat PPD. Maternal PPD within the Black and Brown communities has been studied and shown to have inequities based upon identification, access to treatment, and treatment regimens. Sidebottom and colleagues (7) described the findings of their study in which African American, Asian, and non-white women were less likely to be screened for postpartum depression than their white counterparts. In addition, this study also revealed that women insured by Medicaid and other state programs were less likely to be screened than those with private insurance. In addition, undocumented immigrants are far less likely to seek out services for fear of reporting, deportation, or social service intervention (8,9). With marginalized women already facing barriers to identifying and treating PPD, identification, and barriers to fathers’ identification and treatment of postpartum depression are essential in assuring a strong and stable environment for a baby discharged from the NICU.

Race & Ethnicity Dashboard  
Select Neonatal Measures  
Rates as a Percent of Discharges within each Race/Ethnicity Category  
NPIC ID: NPIC DB

10/1/2019 – 9/30/2020



### Discussion:

Awareness of paternal PPD is key in providing holistic, family-centered care in perinatal and neonatal settings. Developing a unit-specific or division-specific process in identifying paternal PPD, identification of resources, and treatment options can become a pillar for assuring best-in-class care for families and babies in the NICU.

- 1) Destigmatizing paternal postpartum depression: The stigma that currently exists for mental health disorders is well defined (10). Providing a safe space for fathers to describe their experiences with postpartum depression is absolute and should be a routine aspect of care when a father is at the bedside of a NICU baby. Too often, a father is asked how the mother is doing without the same courtesy of their own query or exploration of their transition into fatherhood.
- 2) Transgender men and postpartum depression: Transgender people, as a group, have faced stigma, discrimination, and bias, as well as experiencing numerous health disparities (11). Providing a neutral, compassionate environment for diverse families is key to the safe expression of depressive thoughts or experiences. Marginalized people continue to have significant challenges in accessing care and treatment for postpartum depression; early identification and support are essential.
- 3) Social Determinants of Health (SDOH): Understanding the social determinants in the communities that serve as a NICU referral base provide additional leverage in understanding the stressors and potential barriers of support and stressors to fathers. Potential barriers such as availability of transportation, food security, home environment, employment, and community safety are but some of the social determinants that should be understood by all team members providing care.
- 4) Paternal NICU Support Groups: Many NICUs around the country have established Parent Advisory Councils/Committees, Support Groups, and other resources for parents of babies admitted to the NICU. Providing space and availability of a father who has experienced paternal PPD could benefit those fathers who may be reluctant to come forward with their concerns or fears.

As families and loved ones prepare to celebrate Father’s Day, take a moment to ask the fathers in your perinatal and neonatal units how they are doing and what support they need. Children of fathers who suffer from ongoing and severe depression are at

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higher risk for emotional and behavioral problems, with boys at significantly higher risk (1). From a population health perspective, it is imperative to destigmatize paternal PPD, assure that fathers are supported during their transition into fatherhood, and support the children who depend on them.

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The author has no conflicts of interests to disclose.

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# Health Equity Column: From History to Action in Improving Maternal, Infant, and Neonatal Health Outcomes

Jenné Johns, MPH, Sheree H. Keitt, DrPH, MPH, CHES



This June, we celebrate, “June-teenth” a national holiday to commemorate the ending of slavery in the United States. As we acknowledge the ending of this traumatic lived experience for African American’s we, must also acknowledge the continued harm and injustice faced by African American’s who seek social and racial justice in healthcare.

The infant and maternal health crisis

faced by Black women and babies forces us as a healthcare community to examine the root causes and deliver equity-oriented solutions to improve the birth outcomes for historically vulnerable yet deserving birthing populations. These equity-oriented solutions expand across the perinatal and neonatal spectrum, as these solutions will save deserving lives and reduce burdens placed on families, communities, and the healthcare system.

The National Healthy Start Association is a leading nonprofit organization focusing on saving our nation’s babies by delivering nationwide equity-oriented solutions. In this interview, I am honored to share highlights of my interview with a leading policy, advocacy, community engagement leader, and Premie Mom, Dr. Sheree Keitt. Through our interview, as you learn about the equity-focused maternal health initiatives led by Dr. Keitt and the national chapters of the National Healthy Start Association, I encourage you to leverage these resources within your respective institutions and to support the closing of racial and ethnic disparities in perinatal and neonatal health outcomes based on the non-hospital maternal safety bundles framework.

*“The National Healthy Start Association is a leading nonprofit organization focusing on saving our nation’s babies by delivering nationwide equity-oriented solutions. In this interview, I am honored to share highlights of my interview with a leading policy, advocacy, community engagement leader, and Premie Mom, Dr. Sheree Keitt.”*

## What is your definition of health equity?

When I think about health equity, I use the definition provided by the American Public Health Association and World Health Organization, which states that equity is “when everyone has the opportunity to ‘attain their full health potential,’ and no one is ‘disadvantaged from achieving this potential because of their social position or other socially determined circumstance.” However, I

have learned that you cannot address health equity without first focusing on inequity at its core, which is deeply rooted in unjust practices based on race, social and economic status, demographics, and geographic status. All of which affect health, hence the social determinants of health.

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

The National Healthy Start Association (NHTSA) is the membership organization for federal Healthy Start programs. The federal Healthy Start initiative is the Health Resources and Services Administration Maternal and Child Health Bureau’s signature community-based and community-driven program focused on reducing infant mortality. Healthy Start was created as a demonstration project in 1991, primarily focused on improving pregnant women’s access to prenatal care, and has evolved to focus on improving women and men’s health starting preconception and infant health to early childhood. Healthy Start participants experience persistent health disparities, which stem from issues directly related to health equity and social justice. Healthy Start program sites are in communities where the infant mortality rate is at least 1.5 times that of the U.S. national average. In addition, the majority of communities are facing racial and ethnic disparities in birth and maternal health outcomes.

*“Healthy Start program sites are in communities where the infant mortality rate is at least 1.5 times that of the U.S. national average. In addition, the majority of communities are facing racial and ethnic disparities in birth and maternal health outcomes.”*

As part of our mission, NHTSA aims to be an effective advocate in policies and programs that improve the health status of women, men, and infants and strengthen the capacity of Healthy Start programs and community-based maternal and child organizations nationwide. Over the next three years, NHTSA will expand its mission and strengthen our brand and commitment to members. Developing strategic partnerships, engaging consumers in programmatic activities, and successfully communicating the outcomes of

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Healthy Start projects are among the goals NHTSA has put in place to become a more effective and vital organization.

Some of the work that we are doing at the association is below that directly addresses health and racial equity in neonatal care are below:

*Alliance for Innovation on Maternal Health Community Care Initiative (AIM-CCI)*

In 2019 HRSA awarded the NHTSA a cooperative agreement for a five-year project to support the development and implementation of non-hospital maternal safety bundles within community-based organizations and outpatient clinical settings across the United States that serve communities experiencing high rates of maternal morbidity and mortality. NHTSA is currently partnering with pilot sites comprised of community-based organizations to work together collaboratively through Local Maternal Safety Workgroups, implement safety bundles, and measure improvement with the goal of improving maternal health outcomes. The ultimate goal of AIM CCI is to establish a standard approach in all communities across the United States. In addition, the maternal safety bundles are framed around equity. Now you may ask if the focus is on maternal health, how does that address health and racial equity in neonatal care?

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***“The ultimate goal of AIM CCI is to establish a standard approach in all communities across the United States. In addition, the maternal safety bundles are framed around equity.”***

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*Supporting Healthy Start Performance Project (SHSPP)*

NHTSA works in partnership with the National Institute for Child Health Quality on the SHSPP. The purpose of SHSPP is to promote consistency in service delivery across Healthy Start programs and support Healthy Start grant recipients in providing effective, evidence-based service delivery through training and technical assistance. SHSPP strengthens the implementation of Healthy Start activities by providing capacity-building assistance, including ongoing technical assistance training and education to HS grant recipients in the implementation of activities in accordance with the program's four approaches to reduce disparities in infant mortality and adverse perinatal outcomes. The four approaches are to 1) improve women's health, 2) improve family health and wellness, 3) promote systems change, and 4) assure impact and effectiveness through ongoing HS workforce development, data collection, quality improvement (QI), performance monitoring and program evaluation. NHTSA is subcontracted through NICHQ to provide training and technical assistance in the area of Fatherhood, Community Action Networks, Maternal Morbidity Mortality, and Women's Health, and Equity, Implicit Bias and Racism and Disparities lead the Healthy Start Mentoring Program and support the development of publication and presentations and communications strategies to inform community stakeholders about their sustainability strategy

*Where Dads Matter Initiative*

Healthy Start projects have consistently expressed a need to make Healthy Start sites more father-inclusive by involving dads in program activities and in the lives of their children and the promotion of responsible fatherhood with or without marriage. During pregnancy, the absence of fathers during increases the risk of fetal and infant morbidities such as low birth weight, preterm birth, and small-for-gestational-age. Women whose partners are more involved in the pregnancy experience better birth outcomes. Moreover, infant death in the first 28 days of life is four times higher when a father is not involved. Based on the literature, father's presence significantly impacts infant birth outcomes and overall emotional and social well-being. Here at NHTSA, we are taking a holistic approach by addressing the social determinants of health so that the total family can achieve health equity.

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***“Women whose partners are more involved in the pregnancy experience better birth outcomes. Moreover, infant death in the first 28 days of life is four times higher when a father is not involved. Based on the literature, father's presence significantly impacts infant birth outcomes and overall emotional and social well-being.”***

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

I started my career working in health communications, serving as a trusted community voice to build a collaborative of organizations and community members to convene and develop strategies to address racial and ethnic disparities and inequities in maternal and infant health outcomes. At the time, I was not fully aware of the risk factors that can adversely affect the birth outcome of an infant. My background was in marketing and community engagement, so my role was not public health content-based but focused on coalition-building and partnerships efforts. Because of this work, I became passionate about reducing infant mortality and improving maternal health because I was unaware of the disparities and inequities that existed in my own zip code.

After working in maternal and child health for over ten years, while working on my dissertation, focused on preconception health and preterm birth, I became pregnant with Monoamniotic Monochorionic twins. I was told that my babies only had a 50% chance of surviving pregnancy, and if they made it to 32 weeks, they would be delivered via cesarean. I was also told to expect a lengthy NICU stay. My sons were born at 30 weeks and had a NICU stay of 30 days. Prior to my pregnancy, I focused most of my work on prevention; therefore, I was not fully educated about the NICU and parents' experiences. After experiencing the NICU, I became more interested in other parents' experiences, primarily those of color and low-income families. Because of my public health background, I was able to ask the right questions, understand



the medical terminology, and advocate for my children to have the best care. My NICU experience strengthened my capacity to provide training, technical assistance, and support to community-based organizations serving infants and their families. This experience also opened my eyes to the potential inequities, bias, and other unfair treatment that can occur when a parent does not fully understand things such as the medical rounds, the right to breastfeeding and obtain lactation support, or being engaged in decisions that they have a right to make.

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

I would like to see hospital systems collaborating with local health departments, community-based organizations, and community members to develop a framework to address health and racial equity. Many organizations are now taking an approach to review program policies and practices from an equity lens to address any unintended or intended consequences that are inequitable. A great way that hospitals can do this through their community health needs assessment (CHNA). Every three years, to maintain their tax-exempt status, nonprofit hospitals are required to conduct a CHNA. Within that CHNA, they must represent the broad interests of the community served by the hospital facility.

I have always valued and encourages community voice and participatory methods to engage community-level organizations and members in the decision-making process of programs and policies that affect their community. The involvement of community voices in CHNAs can create a dialogue about the root cause of equity. In addition, including community members provides an opportunity to voice their lived experiences and provide insight into issues in the community such as lack of resources, housing, or bias that certain groups may have experienced.

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*“ In addition, including community members provides an opportunity to voice their lived experiences and provide insight into issues in the community such as lack of resources, housing, or bias that certain groups may have experienced.”*

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Also, the involvement of community voice can provide support to a hospital in building their internal capacity related to understanding institutional and structural racism. For example, historical trauma can exist in communities suffering from post-traumatic stress passed down from previously experienced trauma from colonialism and federal policies resulting in cultural genocide, enslavement, and medical experimentation. Hospital staff should also be aware of theories such as weathering, which states that there are psychosocial factors in racial/ethnic minority groups living in the

U.S. that contribute to their health diminishing over time. To demonstrate, college-educated U.S.-born Black women have worse birth outcomes than white women who are high school dropouts. Furthermore, foreign-born Black women who give birth in the U.S. have similar birth outcomes to U.S.-born white women. This is directly related to the Immigrant Paradox. Individuals who migrate to the U.S. have superior health outcomes than U.S.-born individuals of the same racial and ethnic background. Overall, the assertion is that is foreign-born Black women have not experienced the racism that Black women have experienced across their life course. Having conversations and becoming educated about racism, equity, and disparities are necessary for hospitals to develop any type of framework that addresses health equity.

Overall, I believe the keyword to this question is “action.” The industry must make addressing eliminate health and racial inequities in neonatal care a priority. Also, the strategies should be realistic and actionable and focus on improving the health outcomes of infants AND about actions before birth that may mitigate a pre-term birth or undue stress of a birthing person.

**Disclosure:** *The authors have no disclosures.*

**NT**



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**About the Author: Sheree H. Keitt, DrPH, MPH, CHES.:**



Title: Senior Program Manager

Organization: National Healthy Start Association

Bio: Sheree H. Keitt, DrPH, MPH, CHES, has over 15 years of working in the nonprofit and public health sectors on the local, state, and national levels. Sheree is currently a Senior Program Manager at the National Healthy Start Association and an Adjunct Professor at Trinity Washington University. Sheree earned a Bachelor of Arts in advertising from Michigan State University, a graduate certificate in public health at the State University of New York, Albany, and both Master of Public Health in Community Health and Doctor of Public Health degrees from Walden University. Sheree is also a certified health education specialist.

**About the Author: Jenné Johns, MPH:**



President, Once Upon A Premie [www.onceuponapremie.com](http://www.onceuponapremie.com)

Founder, Once Upon A Premie Academy [www.onceuponapremieacademy.com](http://www.onceuponapremieacademy.com)

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



# 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 5<sup>th</sup> RSV Vaccines for the World Conference in Accra, Ghana.

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



# The Survey says RSV



What you need to know about RSV

**RSV** stands for **Respiratory Syncytial Virus**

RSV is a **Really Serious Virus**

**WHEN IS RSV SEASON?**

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

Protect babies and families this RSV season  
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National Perinatal Association

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

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1

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2

### Post on Social Media

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3

### Recognize NICU Staff

Let them know the difference they are making in our babies' lives. Write a note, send an email, or deliver a gift to show them that you appreciate them.

4

### Share Your Story

Most people have never heard of a NICU before. Let others know about the extraordinary care that NICUs provide.

5

### Join Our Community

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[www.nicuawareness.org](http://www.nicuawareness.org)

[www.nationalperinatal.org/NICU\\_Awareness](http://www.nationalperinatal.org/NICU_Awareness)

# Goldilocks and the NICU: What is “Just Right”

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.*

*“While normal values in adults and older children are fairly static and widely accepted, values in the neonatal population are considerably more dynamic, particularly those relating to respiration and ventilation.”*

“Normal values”: what is normal in the neonatal population, particularly in micro-premature infants? While normal values in adults and older children are fairly static and widely accepted, values in the neonatal population are considerably more dynamic, particularly those relating to respiration and ventilation. Adding to this is the post-gestational age (PGA) of the patient; what is acceptable at two weeks PGA may not be advisable nor acceptable at 2 hours PGA. Metabolic compensation via the renal system also plays a role in which values are acceptable and which are not.

The role of PaCO<sub>2</sub> as it pertains to cerebral and pulmonary vascular tone and blood flow is well known. As PaCO<sub>2</sub> increases, cerebral vasculature relaxes, resulting in dilation and increased cerebral blood flow (CBF), whereas, in the lung, the opposite is true. Conversely, as PaCO<sub>2</sub> decreases, cerebral vasculature tone increases, which results in decreased blood flow. Again, the opposite is true in the lung.

In the very preterm infant, CO<sub>2</sub> cerebral vasculature reactivity is reduced during the first 24 hours PGA. CBF changes of 10-30% per 7.5 mmHg change in PaCO<sub>2</sub> have been reported. Decreased PaCO<sub>2</sub> results in decreased CBF progressively until a level of about 20 mmHg, after which point no further reduction occurs. In the brain, autoregulation of blood flow decreases as PaCO<sub>2</sub> rises

or falls. This further reduces the already limited ability of cerebral vasculature to compensate for changes in blood pressure, PaO<sub>2</sub>, and PaCO<sub>2</sub>. It is worth noting that CBF in chronic hypercapnia returns to normal baseline after a few hours. (1) More on that later.

At what point does hypocapnia become significant? PaCO<sub>2</sub> values of less than 40 mmHg are associated with an increased risk of chronic lung disease (CLD), and analysis of infants <29 weeks GA found that those whose PaCO<sub>2</sub> fell below 30 mmHg at any time during the first 48 hours PGA had a significantly increased risk of severe brain injury. (2)

Compensatory mechanisms to mitigate CBF are limited during the first five days PGA, markedly so during the first 24 hours, complicating matters further. By 72 hours PGA the risk of CBF-induced brain injury is significantly reduced, and thus clinicians must be particularly vigilant before this time.

*“By 72 hours PGA the risk of CBF-induced brain injury is significantly reduced, and thus clinicians must be particularly vigilant before this time.”*

What about oxygen? PaO<sub>2</sub> is different from that of PaCO<sub>2</sub> beyond the opposite vascular response. In the very preterm infant, CBF changes by 15-30% per 7.5 mmHg change in PaO<sub>2</sub>. It is very important to note that, unlike PaCO<sub>2</sub>, vasoreactivity does not normalize with sustained hyper/hypoxemia; a brief episode of hyperoxia results in vasodilation that persists up to 2 hours in preterm infants. Unlike hypercapnia, hyperoxia to the extent produced in the NICU does not occur naturally. As for hypoxia, the very preterm infant's cerebral oxygen extraction is likely already maximized and is thus unable to increase to compensate for low PaO<sub>2</sub> or decreased CBF. (1) This changes at approximately 26 weeks GA. (2) From a clinical perspective, it behooves us to prevent hyperoxia not just because of retinopathy of prematurity but also potential brain injury.

This brings us to the routine acceptance of permissive hypercapnia. Often considered PaCO<sub>2</sub> in the 45-55 mmHg range, the upper limit of this range is often much higher, and what upper limits are safe has not been established with high-level evidence. (4)

Originally conceived as a way to reduce lung injury, permissive hypercapnia has not necessarily achieved that end. Many factors

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are at play here. Mode of ventilation, volumes delivered, GA all serve to increase or decrease the efficacy of the practice. It is worth noting that the concept was born at a time when ventilation and ventilator options were limited to basic, non-synchronized modes with no volume measurement or targeting. Modern ventilators and modes such as high-frequency oscillation or jet ventilation (HFOV and HFJV) may themselves offer more lung protection than permissive hypercapnia alone.

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***“One analysis found that permissive hypercapnia virtually eliminated severe hypocapnia, but respiratory outcomes were not significantly better.”***

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One analysis found that permissive hypercapnia virtually eliminated severe hypocapnia, but respiratory outcomes were not significantly better. The composite outcomes of death or severe intraventricular hemorrhage were associated with higher **fluctuations** of PaCO<sub>2</sub> and the lowest arterial pH. (4) We know that the compensatory ability of the micropremature infant to mitigate changes in PaCO<sub>2</sub> is limited and takes time. Faced with a high PaCO<sub>2</sub>, a clinician often responds to increasing ventilation to rapidly decrease it to a more “comfortable” level. This may not be the best strategy as rapid changes in PaCO<sub>2</sub> may be equally or more harmful than hypercapnia itself.

Similarly, when choosing to take the permissive hypercapnia route, it is best to allow PaCO<sub>2</sub> to rise gradually and allow renal compensation and the cerebral vasculature to adapt. This should only be done after the first week PGA when the infant is better able to regulate CBF. Permissive hypercapnia is not likely to improve outcomes unless accompanied by judicious adherence to lung-protective ventilation strategies.

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***“Permissive hypercapnia is not likely to improve outcomes unless accompanied by judicious adherence to lung-protective ventilation strategies.”***

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What is safe? High PaCO<sub>2</sub> has been linked to white matter injury, but confounding factors make it difficult to determine how high and when. For example, a large PDA with a left to right shunting may flood the pulmonary vasculature and precipitate pulmonary hemorrhage while at the same time overwhelming the pre-ductal circulation. In this case, higher PaCO<sub>2</sub> may be lung protective through increased pulmonary vascular resistance but at the risk of exacerbating increased CBF and the risk of bleeds. Conversely, a lower PaCO<sub>2</sub> may be neuroprotective by decreasing CBF through cerebral vascular vasoconstriction but increases the risk of lung damage by decreasing PVR with resulting increase in pulmonary blood flow.

Increasing mean airway pressure (MAP), as will occur with es-

calating ventilation parameters, also decreases cerebral blood return and increases the risk of brain bleeds. At what point does increasing PaCO<sub>2</sub> no longer work to our advantage? It is not uncommon to see pH compensated PaCO<sub>2</sub> of 65 mmHg or higher in my clinical practice. This is higher than many units allow, but anecdotally the incidence of severe brain bleeds in the unit in which I practice is unremarkable compared with other units.

The use of HFJV poses another question: Does this mode’s gentle nature negate the need for permissive hypercapnia? The CLD patients I ventilate using HFJV are more challenging to oxygenate than to ventilate, and it is not unusual for them to have PaCO<sub>2</sub> in the range of 45-55 mmHg using low ventilating pressure i.e., with delta pressure of < 15 cmH<sub>2</sub>O. A similar argument could be used for HFOV with volume targeting using low amplitudes.

As GA decreases, the fragility of the cerebral vasculature increases. As the edge of viability has decreased to 22 weeks, GA and ventilators become increasingly sophisticated. Perhaps the risk:benefit ratio no longer favours permissive hypercapnia.

One area that begs investigation, in my opinion, is the use of non-invasive modes of ventilation (NIV). Despite caffeine, apnea, bradycardia, and desaturations are common, particularly in the <26 GA strata. These episodes are undoubtedly associated with spikes in PaCO<sub>2</sub> and low PaO<sub>2</sub>; however, how extreme these are is difficult to assess since nobody will do a blood gas on a baby during an apneic/bradycardic event. Increasing FiO<sub>2</sub> often leads to hyperoxia, and even though brief; the CBF effects linger after FiO<sub>2</sub> returns to baseline.

Are these infants at increased risk of neurological injury? Only the SUPPORT trial enrolled infants of 24 weeks GA. This study was well powered with 285 infants of 24-25 weeks GA enrolled in the CPAP arm. Failure criteria included PaCO<sub>2</sub> > 65 mmHg and pH < 7.20, values outside the acceptable range in many units. There was no significant difference in the rate of severe intraventricular hemorrhage suggesting that PaCO<sub>2</sub> of ≤ 65 mmHg may be safe neurologically; however, this is a single study. (5)

It is not clear to me that NIV affords the degree of lung protection hoped for in the <25-week GA infant, and the incidence of CLD is not significantly different in several studies. (5,6,7) Data from Iowa, where intubation and HFJV are standard practice, shows excellent survival rates in the 22–23-week GA strata. This challenges the perceived benefit of avoiding intubation in this group. It is a virtual certainty that 23 – 24-week GA infants will require intubation. In delaying, I fear we may be causing harm, albeit with the best of intentions.

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*Disclosures: The author receives compensation from Bunnell Inc for teaching and training users of the LifePulse HFJV in Canada. He is not involved in sales or marketing of the device nor does he receive more than per diem compensation. Also, while the author practices within Sunnybrook H.S.C. this paper should not be construed as*

Sunnybrook policy per se. This article contains elements considered "off label" as well as maneuvers, which may sometimes be very effective but come with inherent risks. As with any therapy, the risk-benefit ratio must be carefully considered before they are initiated.

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# Birth Trauma and Post Traumatic Stress Disorder (PTSD)

Morgan Staver BSN, RN, PMH-C

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*.



*“The recognition of birth trauma is a relatively new phenomenon, first referenced in the scientific literature in the 1990s. (1)”*

## What is birth trauma?

The recognition of birth trauma is a relatively new phenomenon, first referenced in the scientific literature in the 1990s. (1)



Birth trauma is a subjective experience: it is always in the eye of the beholder. (2) While we as clinicians cannot diagnose a birth as traumatic, we can recognize its place in obstetric, neonatal, and psychiatric care. Birth trauma is the perception of actual or threatened serious harm to the mother or the infant during any phase of childbirth. (2) The phenomenon of birth trauma is related to criterion A for posttraumatic stress disorder (PTSD): exposure to actual or threatened death, serious injury, or sexual violence through a direct experience, witnessing the event, learning that the event has happened to someone close, or experiencing repeated or extreme exposure to details of a traumatic event. (3) The existence of birth trauma and its potential consequences have been historically under-recognized by professionals and the public because of the societal belief that childbirth should always be a positive experience. (4) In reality, the birth process can be dangerous and requires a woman to put her trust in a medical team that likely includes individuals that the woman has never met. 45% of women who give birth perceive their birth as a traumatic event. (5)

Women who have experienced a traumatic birth describe an array of events that turned the birth from a positive experience into a traumatic one (see Table 1 for a non-exhaustive list of traumatic birth events). (2,6) The potentially traumatic events during childbirth outlined can result in infant complications and admission to a neonatal intensive care unit (NICU). The NICU environment carries with it additional potential traumatic events. A non-exhaustive list of potential NICU-specific traumatic events includes medical intervention at birth, unexpected or prolonged NICU hospitalization, immediate separation from newborn, seeing the infant in the NICU for the first time, code blue events, failed extubations, the NICU waiting room, or surgeries. (7)

No matter the reason that the birth is perceived as traumatic, traumatic birth is a complicated phenomenon. Women who have experienced a traumatic birth have described the following essential themes of birth trauma: perception of lack of caring from those who are supposed to care (feeling abandoned, stripped of dignity, lack of support or reassurance), poor communication from key players, feeling invisible, feeling powerless (betrayals of trust,

not feeling protected by staff), and wondering if the ends justify the means (i.e., pondering if having a healthy baby justifies the endured trauma and experiencing guilt associated with that thought). (2)

**Table 1.** Traumatic Birth Events

Stillbirth or infant death
Emergency cesarian delivery
Fetal distress
Cardiac arrest
Inadequate medical care
Fear of epidural
Congenital anomalies
Inadequate pain relief
Postpartum hemorrhage
Manual removal of placenta
Use of forceps
Vacuum extraction
Skull fracture
Severe toxemia
Premature birth
Prolonged or painful labor
Rapid delivery
Degrading experiences
Severe pre-eclampsia
3 <sup>rd</sup> or 4 <sup>th</sup> -degree laceration
Hyperemesis gravidarum
Shoulder dystocia

## Who experiences birth trauma?

A traumatic birth can happen to anyone: it is independent of race or socioeconomic status. (8) The most important factors regarding how a woman conceptualizes her delivery experience are a) the support she receives from caregivers, b) her involvement in decision-making processes, and c) her expectations of the birth experience and if they were met. (4) Some women are more likely than others to perceive their birth as traumatic due to their previous life experiences. Women with a history of psychological problems, trauma or sexual abuse, anxiety, or nulliparity are more likely than women with none of these experiences to perceive birth as a traumatic

event. (9)

Perceiving birth as traumatic does not always lead to the development of PTSD. Risk factors present before birth (i.e., before or during pregnancy) and during birth influence if a woman who experiences a traumatic birth will develop symptoms of PTSD and how quickly the PTSD symptoms may resolve (see Table 2 for a list of risk factors). (8,9)

PTSD does not occur in all populations equally. In a recent meta-analysis, researchers estimated that the community prevalence of postpartum PTSD is 3.1%. In contrast, the prevalence in the at-risk population (i.e., perinatal risk, trauma history, psychiatric history) is estimated to be 15.7%. (8) In women who develop PTSD after birth, postpartum depression, maternal complications, infant complications, trauma history, negative interactions with staff, (8) poor coping, and stress are all correlated with PTSD symptoms. (9)

---

***“ If all PTSD diagnostic criteria are met, but the symptoms do not last for more than one month, a diagnosis of acute stress disorder is more appropriate. (3).”***

---

#### **What is the relationship between birth trauma and PTSD?**

Not everyone who experiences a traumatic birth will go on to develop PTSD. While 45% of women state that their birth was traumatic, only around 3% of women develop clinically significant PTSD. (5) As described above, birth trauma fulfills criterion A, exposure to a traumatic event, to diagnose PTSD. Other diagnostic criteria for PTSD broadly include symptoms of re-experiencing, avoidance, negative changes in cognition or mood, and hyperarousal. These symptoms must last for at least one month, cause clinically significant impairment in functioning, and cannot be attributable to another medical condition or substance use. If all PTSD diagnostic criteria are met, but the symptoms do not last for more than one month, a diagnosis of acute stress disorder is more appropriate. (3) It is possible to experience PTSD or acute stress disorder symptoms after a traumatic birth and not meet full diagnostic criteria for either disorder.

PTSD in the postpartum period can occur due to birth trauma. However, it can also present as a result of other traumatic events in the mother's lifetime that put her at risk for PTSD after childbirth (e.g., history of domestic violence or sexual assault). (8) Birth experiences and trauma history interact and put a woman at higher risk for developing PTSD after birth. (9)

#### **How is postpartum PTSD different from 'general' PTSD?**

While postpartum PTSD meets all the DSM 5 criteria for PTSD, unique factors make it distinct from PTSD resulting from another traumatic event. For instance, childbirth may be the only criterion A event for a PTSD diagnosis that is generally assumed to be a joyous event. Experiencing a seemingly positive life event such as childbirth as traumatic may affect how a woman conceptualizes the legitimacy of the traumatic experience and may influence reporting of symptoms. The symptom presentation of postpartum PTSD shows a unique clustered pattern:

- Re-experiencing and avoidance related to childbirth, with the physical sequelae of birth and the baby acting as a constant reminder of the traumatic birth, and
- Symptoms of arousal and negative alterations in cognition or mood that align with the general PTSD criteria

The social implications resulting from a traumatic birth also affect symptom presentation of postpartum PTSD uniquely from 'general' PTSD. The effects of the traumatic birth are experienced by and affect the whole family. A traumatic birth and postpartum PTSD are unique because biologic women exclusively experience them; the woman-only survivor profile's clinical, social, and political implications may play a role in the survivor's experiences after a traumatic birth. (10)

#### **Why does birth trauma matter?**

Although most women who experience a traumatic birth do not develop PTSD, the core life experience of childbirth has been corrupted. If a woman develops PTSD after a traumatic birth, she will face potential consequences related to her healthcare and her family and baby's functioning. Documented behavioral consequences of PTSD due to birth trauma include avoidance of postpartum care, impaired parental-infant bonding, PTSD in a partner who witnessed the birth, sexual dysfunction, avoidance of future pregnancies, elective cesarean births in future pregnancies, difficulties with breastfeeding, yearly anniversary of traumatic birth, low self-esteem, lower birth weight infants, and lower breastfeed-

**Table 2.** Risk Factors Associated with PTSD After Childbirth

<b>Pre-Birth Factors</b>	<b>Birth Factors</b>
Pregnancy psychopathology or depression during pregnancy	Subjective distress during labor
Fear of giving birth	Negative feelings during birth
Health complications during pregnancy	Lack of control or agency during birth
Previous counseling for pregnancy or birth problems	Obstetric emergencies
History of PTSD	Operative births
	Lack of support from staff
	Dissociation during birth

ing rates. (4,6) Potential links also exist between maternal PTSD and infant cortisol, sleeping, and eating problems. There is mixed evidence for the associations between postpartum PTSD and preterm birth, fetal growth, head circumference, mother-infant bonding, and infant development. (11)

Obstetric and neonatal clinicians also should recognize that a traumatic birth experience has a complicated relationship with breastfeeding. A traumatic birth can impede breastfeeding by producing feelings of violation, physical pain, and detachment from the infant. Women who experienced a traumatic birth may perceive a relationship between the trauma and decreased milk supply. Breastfeeding may also produce intrusive flashbacks in some women. However, a traumatic birth can promote breastfeeding in some women because it may be a way for the mother to 'redeem' herself after a traumatic birth or provide an opportunity for grounding, a type of coping mechanism. The reasons why traumatic birth can be a motivating factor for some women but impede breastfeeding in other women are currently unknown. (12)

#### **What should neonatal care providers know about birth trauma?**

Obstetric and neonatal clinicians may encounter women who have experienced a traumatic birth more often than they realize. Because seemingly 'normal' births may be perceived as traumatic, it is vital for professionals working in this area to ask the mother about her thoughts and feelings about her birth experience. Pay special attention to women whose birth experiences included observable risk factors for a traumatic birth associated with developing PTSD (e.g., operative births or obstetric emergencies). (9) Clinicians should consider assessing women during pregnancy for the factors associated with an increased risk of developing PTSD after birth (e.g., depression during pregnancy, fear of childbirth, poor health or pregnancy complications, and a history of PTSD). (9)

If a patient has experienced traumatic birth or is at risk for developing PTSD, refer her for mental health treatment by a clinician that specializes in perinatal mental health, if possible. There are many effective treatments for PTSD, and the mental health professional will work with the patient to identify a treatment that best fits her needs. Potential treatments include psychotherapy and pharmacotherapy. Psychotherapy may be more likely to lead to a more significant reduction in PTSD symptoms that last longer than using first-line medications such as selective serotonin reuptake inhibitors alone. Trauma-focused psychotherapies effective for PTSD treatment are prolonged exposure therapy, cognitive processing therapy, and eye movement desensitization and reprocessing. (13) Currently, there is no evidence addressing primary prevention of birth trauma. However, expressive writing soon after delivery of a healthy infant may be an effective intervention to prevent the development of PTSD symptoms after childbirth. (4)

Obstetric clinicians should promote factors that have shown to be protective against traumatic birth. The factor with the most empirical support that may reduce a woman's chance of experiencing a traumatic birth or reduce her likelihood of developing postpartum PTSD is social support during birth. (9) Allowing the presence of a support person during birth is critical to reducing the risk for birth trauma and PTSD. Perceived lack of staff support and negative interactions with staff during delivery are modifiable risk factors for birth trauma and subsequent PTSD that obstetric and neonatal clinicians can target to reduce adverse outcomes.

#### **Conclusion**

Just under half of the women who give birth perceive their birth experience as traumatic, and a small but significant percentage of this population develops PTSD. The symptoms and experiences

of women who experience traumatic birth are important to evaluate because birth trauma can go unrecognized if not assessed. Clinicians who work with this population should be aware of the risk factors for experiencing birth as traumatic, the risks for developing PTSD after birth, and the potential consequences of postpartum PTSD. Bringing a conversation about birth trauma to our patients can decrease any stigma attached to the experience and potentially identify more women who would benefit from psychiatric care.

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***“Clinicians who work with this population should be aware of the risk factors for experiencing birth as traumatic, the risks for developing PTSD after birth, and the potential consequences of postpartum PTSD. Bringing a conversation about birth trauma to our patients can decrease any stigma attached to the experience and potentially identify more women who would benefit from psychiatric care.”***

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Disclosures: The author does not have any conflicts to disclose.

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

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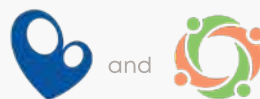
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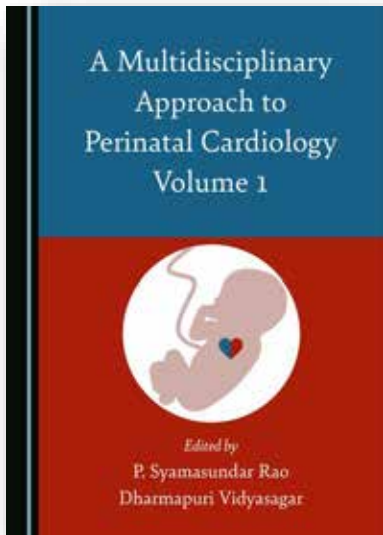


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# A Multidisciplinary Approach to Perinatal Cardiology Volume 1

*Edited by P. Syamasundar Rao and Dharmapuri Vidyasagar*



## Hardback

### ISBN-13:

978-1-5275-6722-1

### ISBN-10:

1-5275-6722-2

### Date of Publication:

24/04/2021

### Pages / Size:

794 / A5

### Price:

£99.99

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## About the Editors

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

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

## Program Objectives

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

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# PROGRAM CONTENT



## COMMUNICATION SKILLS CEUs offered: 1

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

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



## PERINATAL MOOD AND ANXIETY DISORDERS CEUs offered: 1

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

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



## PROVIDING ANTEPARTUM SUPPORT CEUs offered: 1

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

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



## PROVIDING INTRAPARTUM SUPPORT CEUs offered: 1

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

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



## PROVIDING POSTPARTUM SUPPORT CEUs offered: 1

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

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



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

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

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

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**Tracy Pella, MA**

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**Erin Thatcher, BA**

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## CANCELLATIONS AND REFUNDS

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- Communicate with parents using **plain language**.
- Partner with **Black parents** to deliver bias free care.
- Hire, retain, or partner with **Black Premie family support groups + professionals** to fill diversity gaps.
- Make **digital + virtual resources** available.
- Encourage **reading to Premie babies** while bedside.



[ONCEUPONAPREEMIEACADEMY.COM](http://ONCEUPONAPREEMIEACADEMY.COM)

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

Take precautions & LIMIT INTERACTIONS.

6 FT

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

Keep prenatal **APPOINTMENTS.**

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

LEARN MORE >

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

NATIONAL PERINATAL ASSOCIATION

Update: **CORONAVIRUS COVID-19**



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

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

THERE ARE RARE EXCEPTIONS. ASK YOUR HEALTHCARE TEAM.



[www.nationalperinatal.org](http://www.nationalperinatal.org)

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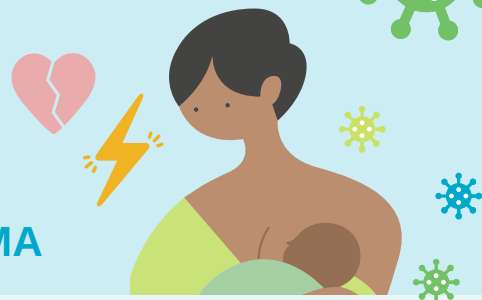
# SHARED DECISION-MAKING PROTECTS MOTHERS + INFANTS

DURING COVID-19

## KEEPING MOTHERS + INFANTS TOGETHER

Means balancing  
the risks of...

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



## EVIDENCE

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



## PARTNERSHIP

What is the best  
for this unique dyad?

### SHARED DECISION-MAKING

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



## TRAUMA-INFORMED

Both parents and providers  
are confronting significant...

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

## LONGITUDINAL DATA

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

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



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

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when it matters most.

[nann.org](http://nann.org) [nationalperinatal.org](http://nationalperinatal.org)



National  
Association of  
Neonatal  
Nurses



# Coping with COVID-19



A viral pandemic

A racial pandemic within a viral pandemic



Will mental illness be the next inevitable pandemic?

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- Bonding with Your Baby
- Caregivers Need Care Too



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newly  
validated

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## National Perinatal Association PERINATAL SUBSTANCE USE

[nationalperinatal.org/position](http://nationalperinatal.org/position)  
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# Keeping Your Baby Safe

during the COVID-19 pandemic

## How to protect your little one from germs and viruses

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

### Here's what you can do...

#### Wash Your Hands

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



#### Limit Contact with Others

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



#### Provide Protective Immunity

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



#### Take Care of Yourself

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



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



**WARNING**

#### Never Put a Mask on Your Baby

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



#### If you are positive for COVID-19

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



We can help protect each other.

[Learn more](#)

[www.nationalperinatal.org/COVID-19](http://www.nationalperinatal.org/COVID-19)



## The Gap Baby: An RSV Story



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



### The National Coalition for Infant Health advocates for:

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

[www.infanthealth.org](http://www.infanthealth.org)



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Providing Psychosocial Support During  
Pregnancy, Labor and Delivery

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 affects  
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 of fathers

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# What's in Biden's Budget Proposal for Moms and Babies?

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

The Alliance for Patient Access ([allianceforpatientaccess.org](http://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.



**“President Joe Biden’s \$6 trillion budget is the highest level of proposed spending since the Second World War. (1) So what does it offer for moms and infants?”**

President Joe Biden’s \$6 trillion budget is the highest level of proposed spending since the Second World War. (1) So what does it offer for moms and infants?

Framed as an investment for future generations, the budget calls for funds to:

- **Reduce maternal mortality and morbidity rates nationwide.** The president identified more than \$200 million for programs to improve care for pregnant moms, including the creation of more state pregnancy medical homes. The medical home model aims to coordinate services and supports in a patient-centered way, with the ultimate goal of reducing preterm births.

President Biden also wants to bolster maternal mortality review committees, which perform comprehensive reviews of women’s deaths within a year of the end of a pregnancy. The multidisciplinary committees are tasked with identifying prevention opportunities and helping to understand better the drivers of maternal mortality and the associated disparities. The Centers for Disease Control and Prevention currently supports just 25 states’ review efforts. (2) New funds could allow the federal government to support committees in more states.

- **Lower health insurance premiums.** President Biden’s proposed budget includes funding to make permanent the health insurance tax credits instituted by the COVID-19 rescue package. As it was officially named, the American Rescue Plan reduced the premiums of 9 million people by an average of \$50 per month.
- **Address disparities in health care.** Social determinants of health, the social and economic factors that affect how people live, work, and play, have an outsized role in maternal health outcomes. If Congress approves the president’s proposal, the Centers for Disease Control and Prevention will get another \$153 million to support states and territories in their efforts to collect more data and address health inequities caused by social determinants.

Related, the administration is interested in doubling the federal investment in community health centers, which play a critical role in providing access to care, including prenatal care, in underserved communities. Expanding this funding, the administration says, would help reduce health disparities.

- **Invest in innovation.** The president also would like to address some of the most resource-intensive diseases, reducing their burden for the next generation. He proposed \$6.5 billion for the creation of the Defense Advanced Research Projects Agency for Health, which would focus on breakthrough treatments and cures for diseases like cancer, diabetes, and Alzheimer’s.

**“While the proposed budget provides important investments and generous support to those who need it, paying for those programs will depend on increasing revenues or adding to the federal debt.”**

## Funding the Budget

While the proposed budget provides important investments and generous support to those who need it, paying for those programs will depend on increasing revenues or adding to the federal debt.

The president has suggested higher taxes on the wealthy and

corporations to offset much of his new spending. He has also proposed allowing the Trump-era tax cuts on the low and middle class to expire, as scheduled, in 2025.

The president's proposed budget – and funding suggestions – begin the negotiation process with Congress. The fate and details of his proposal will be hammered out over the coming months.

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1. [https://www.whitehouse.gov/wp-content/uploads/2021/05/budget\\_fy22.pdf](https://www.whitehouse.gov/wp-content/uploads/2021/05/budget_fy22.pdf)
2. <https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/index.html>

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**Disclosures:** The author has no disclosures

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# Still a Premie?




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

**But that's not every preemie's story.**


### Born between 34 and 36 weeks' gestation?

**STILL A PREMIE**

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

-  Jaundice
-  Feeding issues
-  Respiratory problems

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




### Born preterm at a "normal" weight?

**STILL A PREMIE**

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

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




### Born preterm but not admitted to the NICU?




**STILL A PREMIE**

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




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




#### Some Premies

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

#### All Premies

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



**NCJIH** National Coalition for Infant Health  
Protecting Access for Premature Infants through Age Two  
[www.infanthealth.org](http://www.infanthealth.org)

# I CAN Digitally Involved (I CANDI): 2021 Virtual Summit

Amy Ohmer



*“Now in the 7th year, iCAN was launched June 22, 2015, by founder Dr. Charlie Thompson to support children around the world living with rare, chronic, and complicated diagnoses. Today, iCAN has 30 chapters around the world which provide opportunities to youth members to share their expert stories and experiences.”*

The International Children's Advisory Network, Inc. (iCAN) is about to celebrate a major milestone in a few weeks. Now in the 7th year, iCAN was launched June 22, 2015, by founder Dr. Charlie Thompson to support children around the world living with rare, chronic, and complicated diagnoses. Today, iCAN has 30 chapters around the world which provide opportunities to youth members to share their expert stories and experiences. With wonderful excitement, we are proud to announce our latest iCAN Chapter - KIDS CHOC-Rady, created by Dr. Carstairs, Chief Population Health Officer, Rady Children's Hospital and Tiffani Ghere, CHOC Children's Hospital, Medical Intelligence and Innovation Institute (MI3), International Society of Pediatric Innovation (iSPI). We cannot wait to share the patient voice throughout southern California.

To celebrate another milestone, iCAN invites everyone to attend the upcoming *Jumo Health presents the iCAN 2021 Virtual Summit* to be held on June 12 - June 16, from 10:00 a.m. - 12:00 p.m. daily. (1) This interactive week-long event brings together children from ages 8-18 that will share their stories while spending time learning from pediatric healthcare community leaders. This year, the iCAN keynote speaker is Ms. Tracy Gray, FDA, who will be sharing an inside look at pediatric healthcare innovation within the FDA. To register for the event, visit [www.icanresearch.org](http://www.icanresearch.org). (1) Summit participants are invited to send in a Chapter Poster - a culmination of work done throughout the year to support their local chapters or abstract from within the professional medical community that might interest youth members. We are excited to share the terrific work and accomplishments from around the world to showcase the expertise of pediatric voices.

*“With wonderful excitement, we are proud to announce our latest iCAN Chapter - KIDS CHOC-Rady, created by Dr. Carstairs, Chief Population Health Officer, Rady Children's Hospital and Tiffani Ghere, CHOC Children's Hospital, Medical Intelligence and Innovation Institute (MI3), International Society of Pediatric Innovation (iSPI).”*

Continuing the theme of innovation, iCAN hosted the most recent episode of “Ask the Experts” (ATE) with Dr. Anthony Chang (CHOC, AIMed, iSPI) and special guest speakers - Dr. Shareif Taraman, specializing in Neurology and Artificial Intelligence (AI) at Children's Hospital of Orange County (CHOC), an amazing 15-year-old youth presenter, Sebastian Flores, the creator of

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## The 34<sup>th</sup> 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](http://www.thegravensconference.com)  
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Provided by:



For more information, contact the meeting planner at [nrose@usf.edu](mailto:nrose@usf.edu)

[OctoGifts](#), (2) a unique paper card company located in Alpharetta, Georgia and Dr. Kris Laudanski, M.D., Ph.D., FCCM, MHCI, President of the Society for Healthcare Innovation ([SHCI](#)). (3) The episode focused on helping kids better understand innovation in many forms through science, medicine, technology, and even commerce. To view this episode and others, visit <https://www.icanresearch.org/videos>. (4) Additionally, all are invited to attend the next session of ATE focusing on the MI3 Internship Program hosted by CHOC on June 5, 2021, at 10:00 a.m. eastern, by registering in advance [www.icanresearch.org](http://www.icanresearch.org). (1)

Later this month, iCAN and KIDS Barcelona are collaborating with Boston Children's Hospital to help share feedback from youth members during the 2021 Hackathon. This exciting event is designed to draw out creativity from the community to help support new pediatric medical devices and process innovation. iCAN youth members have been invited to serve as judges to help narrow down the finalists in an online voting process. We are confident this will be a terrific event—details on our news page at [www.icanresearch.org](http://www.icanresearch.org). (1)

iCAN youth members participated globally through several surveys designed to capture feedback on clinical research trial design and helped create new iCAN Youth Member recruitment flyers. For our organization, it is essential to ensure that the kid's voice is infused everywhere, so kids review almost everything. In completion, all of the finalized work with feedback incorporated was given the "iCAN Seal of Approval". Going forward, if you see the seal, you can rest assured that it was "kid reviewed - kid approved"

As a reminder, if any interested kids are not involved in an iCAN chapter but would like to participate, iCAN offers a Virtual Chapter to accommodate any child, anywhere in the world. There is no cost to create a chapter or for a child to participate as iCAN is supported through sponsoring partnerships. If you would like to sponsor a child, a chapter, or our summit, please contact us by email at [info@icanresearch.org](mailto:info@icanresearch.org) or visit [www.icanresearch.org](http://www.icanresearch.org). (1)

#iCANMakeADifference #iCAN #iCANBeDigitallyInvolved #GlobalGenes #CareAboutRARE

**References:**

1. <http://www.icanresearch.org/>
2. <http://www.octogifts.com/>
3. <http://shci.org/>
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**Disclosure:** The author has no conflicts of interests to disclose.

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## OPIOIDS and NAS

When reporting on mothers, babies, and substance use

# LANGUAGE MATTERS



### I am not an addict.

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



### I was exposed to opioids.

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



### NAS is a temporary and treatable condition.

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



### My mother may have a SUD.

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

### My potential is limitless.

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



Learn more about Neonatal Abstinence Syndrome at [www.nationalperinatal.org](http://www.nationalperinatal.org)



# Clinical Pediatric Surgery: A Case-Based Interactive Approach

With generous grants from the Mirella and Lino Saputo Foundation in Canada and the Colorectal Teams Overseas Foundation in the United States, Dr. Sherif Emil and Dr. Marc Levitt have secured a limited number of copies of their books for distribution to surgeons in low and middle income countries who can benefit from the books but do not have the means to buy them. The following books are included:

- **Clinical Pediatric Surgery: A Case-Based Interactive Approach** By *Sherif Emil* ISBN 9780367635602
- **Pediatric Colorectal and Pelvic Surgery: Case Studies** By *Victoria A. Lane, Richard J. Wood, Carlos Reck, Marc A. Levitt* ISBN 9781138031777
- **Fecal Incontinence and Constipation in Children: Case Studies** By *Onnalisa Nash, Julie Choueiki, Marc Levitt* ISBN 9780367151614
- **Pediatric Colorectal and Pelvic Reconstructive Surgery** By *Alejandra Vilanova-Sanchez, Marc A. Levitt* ISBN 9780367136475

These copies will be distributed completely free of charge, including free shipping, according to the criteria below upon receiving an eligible application. These copies are **not** intended to be for the sole use of the recipient only. Surgeons and trainees who receive these copies have to pledge to make them available to all their trainee and consultant colleagues at their institution, in order to maximize distribution of the book. There is a limit of one copy per institution. Recipients also have to pledge to send an email confirmation of receipt. **We ask those who do not believe that the books will be of much use in their practice or those who can afford to buy the books to refrain from applying for a gratis copy, in order to allow us to distribute the books in the most efficient and effective manner.**

## Criteria for Receipt of Free Copy:

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2. Specialty: First Priority: Pediatric Surgery
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4. Practice type: Public or university hospital
5. Practice mix: At least 75% non-private practice
6. Institution limits: One copy per institution.

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Please provide a short statement (4-5 sentences) indicating how the books may contribute to your training or practice:

## Attestation

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\_\_\_\_\_  
Name

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Respiratory Syncytial Virus is a

# Really Serious Virus

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

Coughing that gets worse and worse



Breathing that causes their ribcage to "cave-in"

Rapid breathing and wheezing



Bluish skin, lips, or fingertips

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

Call your doctor and meet them at the hospital.

If your baby isn't breathing call 911.



Thick yellow, green, or grey mucus



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

Fever that is higher than 101° Fahrenheit



which is especially dangerous for babies younger than 3 months

 National Perinatal Association

[www.nationalperinatal.org/rsv](http://www.nationalperinatal.org/rsv)

PROTECT YOUR FAMILY FROM RESPIRATORY VIRUSES

flu

coronavirus

pertussis

RSV



SOAP

**WASH YOUR HANDS**

often with soap and warm water.

**GET VACCINATED**

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



**COVER COUGHS AND SNEEZES.**

Sneeze and cough into your elbow.

**USE AN ALCOHOL-BASED HAND SANITIZER.**



**STAY AWAY FROM SICK PEOPLE**

Avoid crowds. Protect vulnerable babies and children.

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# High-Reliability Organizing (HRO) and Abrupt Change from COVID 19: Failure of Scientific Rationality and Classical Logic

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

## Abstract

Neonatologists built the science of neonatology with logic and rationality. The cognitive processes of scientific rationality and classical logic, developed for a structured environment, are poorly defined for operational use. The first impairments from even mild uncontrollable stress are in the cognitive and memory areas of the brain. A 'cosmology' event collapses our sensemaking even as we believe in our own rationality. The novice does not have personal anecdotes that are protective in such a collapse. When applying the abstractions of logic to a particular concrete situation, we can fulfill our own sensemaking, or we can make sense for the good of the community. It is the premise and logic that differ. The dominant narrative from scientific rationality and classical logic has become privileged with the loss of knowledge gained during risky operations. Such lost knowledge creates inaccurate models with long-lasting effects on education and policy. In the operational environment, lost knowledge can kill.

*“Neonatologists built the science of neonatology from scientific rationality and classical logic. It was gaining life through the extension of neonatology to smaller and sicker babies developed with different forms of rationality and other logic systems.”*

## Introduction

Neonatologists built the science of neonatology from scientific rationality and classical logic. It was gaining life through the extension of neonatology to smaller and sicker babies developed with different forms of rationality and other logic systems. This is more than a gap between theory and practice (1); it is a gap between the normative stance of a spectator at a fixed point outside the flux of events and the pragmatic stance of a participant engaging the turbulence from within the trajectory of events (2). The liminal threshold beyond which the pragmatic stance operates conceals the rationality and system of logic used by operators. The operator neuromodulates to reduce stress and fear and draws on methods for reasoning with imperfect information in flux. Otherwise, events cascade toward failure.

The obstetrician hands a premature newborn baby to the neonatal team. With the heart rate dropping, the nurse vigorously dries

and stimulates the baby, the heart rate increases. The respiratory care practitioner (RCP) gives supplemental oxygen, thrusts the jaw forward, and starts bag-mask ventilation; the heart rate again decreases. Tension is more than emotional; it is physical as the baby is pulled by each caregiver. The physician intubates the infant. The heart rate becomes normal and steady. The baby is now active.

*“Tension is more than emotional; it is physical as the baby is pulled by each caregiver. The physician intubates the infant. The heart rate becomes normal and steady. The baby is now active.”*

The NICU charge nurse enters the delivery room, and the RCP immediately explains how the nurse missed the need for intubation. The nurse follows with an explanation that the baby needed drying and stimulation—the RCP counters with the need for intubation, evidenced by the pediatrician intubating the baby.

The pediatrician (the author, DvS) stated, “I intubated because the heart rate dropped too low, but the baby had responded to drying and stimulation.” The charge nurse countered, “The nurse is new. We have to get to know you before we can trust you.”

“I came from the fire department. We had a saying; If you don't trust me, then you can't be trusted. We trusted new people because we knew we could carry them when they needed it. We had the strength and trust in ourselves that we could carry our partner if needed. That's how you go into danger.” The pediatrician was startled to note everyone in the room staring at him. The labor nurses approached and said thank you.

Note in this vignette the sources and reliability of the information, the use of reasoning and cognition, and the influence of stress and fear. Each participant believed in themselves, was only a few feet apart, yet inferred different conclusions, made different decisions, then acted in opposition. Each believed in their own rationality and logical conclusions. Yet each was different.

A high-risk situation, or any exigency, necessitates interaction to generate information while also creating structure. With information, we transform abstract concepts into concrete actions. We infer useful conclusions from vague signals or developing circumstances. Reasoned evaluation supports how we think to decide, decide to act, and modify those actions. Then stress and threat mix this up.

Education, planning, rules, and protocols for exigencies such as this all go into the cognitive and memory parts of the brain. The first impairments from even mild uncontrollable stress are in the

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brain's same cognitive and memory areas. While the participants in the vignette identified the problem of bradycardia, interpretations differed between hypothermia from evaporative water loss versus bradycardia from hypoxemia. Linking these abstract concepts to the concrete situation failed. An element of fear abruptly drives efforts to keep distance from the threat observed in the form of blaming and accusation or by deflection and justification (3). To keep distance from the threat (rapid bradycardia) for self-preservation, the participants explained their own actions and the actions of the others. Information was lost.

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***“Rationality and reason, along with rules and protocols, derive support from classical logic. We are accustomed to linearity, deduction and analysis, the law of the excluded middle, and the law of non-contradiction.”***

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Rationality and reason, along with rules and protocols, derive support from classical logic. We are accustomed to linearity, deduction and analysis, the law of the excluded middle, and the law of non-contradiction. In the vignette above, time branched with a course of different possible events between drying with stimulation and hand ventilation with intubation. Beliefs were revised as new information was incorporated or the circumstances changed. A binary truth value did not exist as each circumstance and action could be interpreted right or wrong depending on where they occurred. We began evaluation, but the series of contingencies from each treatment on the other treatment confounded interpretation. Rationality and reason from classical logic were lost.

What appears strongly “right” during the time before an abrupt disruption, based on cognitive science and classical logic, becomes irrelevant amid the exigency. This article describes how the environment of *as experienced* creates practical rationality and the logic of practice. The mental reaction to the environment creates a gap between scientific rationality and classical logic. This gap does not become visible through investigation or interrogation.

#### **Logic as the use of information**

We need relevant information to ensure that our actions match our observed reality and known concepts, reduce error, and confirm the *consistency of these concepts*. We need relevant information when we purposely risk error to investigate inconsistencies and contradictions between observed reality and known concepts. We strengthen our knowledge with *deduction* and the analysis of new information. We create knowledge through *induction* for synthesis when we encounter new information. Information reassures us that we are on a safe path or prepares us at the edge of a crisis. Information reveals contradictions for further investigation. Neonatologists have used the information to extend their experience to help smaller and sicker neonates (4). How we use information has a great influence on how we achieve HRO.

As a medical discipline, neonatology makes use of information through *scientific rationality*, a system of analytic methodology, classical logical inference, and detached observation ((5), 93-95); (6). Amartya Sen, economics Nobel laureate, described *rationality* as subjecting one's decisions to *reasoned* scrutiny rather than following formula (7), 3-5. Using *classical logic*, which relies on true premises, we preserve truth, not falling into the acceptance of falsity. Scientific rationality creates a representational world that

we can transport to any circumstance. However, the abstraction of a representational world is neither the actual world nor necessarily a possible world. It is only a *representation* of the actual world.

In the field of uncertainty and threat, we must reliably use information. We must avoid the trap of a false belief that our subconscious wants to be true. We must avoid the seduction of logical inference that appears to prove our belief. The abstraction of a representational world can be applied anywhere. We must not, however, sacrifice our real-world for the tractability of discrete concepts and classical logic.

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***“In the field of uncertainty and threat, we must reliably use information. We must avoid the trap of a false belief that our subconscious wants to be true. We must avoid the seduction of logical inference that appears to prove our belief.”***

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#### **Uncertainty and logic**

This becomes a fundamental problem for implementing and using HRO – in high risk, how do we rationally use the information and generate reasoned inferences from that information when our information is imperfect, unstable, unavailable, and the time to act is limited. Academicians offer theory within the normative stance, yet the NICU is a place of practice from the pragmatic stance. Through engagement, we can bridge the gap between theory and practice (1), discrete concepts and continuous perceptions (8), and the normative stance and pragmatic stance (2). The academic lexicon, though, may not provide effective contributions for that engagement.

Note the concepts and wording in the academic and professional literature for decision making: cognition, intuition, rational, irrationality, logic, analysis, heuristics, biases, error, complexity, chaos, and information processing. Then recall the NICU environment: uncertainty, time compression, stress, emotions, and doubt. Ambiguity may lead us to construct a world that is not true while supported by evidence (9). In the realm of uncertainty and ambiguity, an error has critical functions for decision-making and safety. Error corrects heuristic bias (10). Error, unfortunately, has become an indicator of careless or poor performance to engender fear of the system and supervisors. The inability to neuromodulate the resulting endemic stress-fear-threat (3) corrupts safe and effective operations, creating the ecology of fear (11).

The structured, academic presentation of theory and logic does not match the experience of Neonatologists, particularly in relation to their years of experience. Perhaps we do not sense the futility or the effects of stress on our cognition, rationality, and logic because of the shifting baseline of experience and what we perceive as normal (12). We draw upon anecdotes from early in our careers to evaluate changes and provide context. Mark those infants who will now live and think of all the lives gained. Anecdotes from our experience provide the mental and emotional stability for reflective reasoning and give meaning to the work of the Neonatologist (4, 13). We accept as a baseline the survival and death for infants of certain gestational ages and weights at the beginning of our careers. With experience, we see these babies who previously would have died now thrive. These babies give value to what neonatology has accomplished. The extension of neonatology to gain life is remembered through personal anecdotes triggered by

a vibrant infant who once would have died.

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***“The novice does not have those anecdotes. Should a baby die, the novice experiences a life cut short while the experienced Neonatologist counteracts the pain with knowledge of lives gained that were once lost.”***

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The novice does not have those anecdotes. Should a baby die, the novice experiences a life cut short while the experienced Neonatologist counteracts the pain with knowledge of lives gained that were once lost. This unrecognized stress impairs the rationality of the novice, engenders a beginning sense of futility, and impairs their ability to infer optimism amid critical illness.

Rather than ‘gained life,’ the novice comes to expect babies to live who would have died at the beginning of the veteran Neonatologist’s career.

During the first years of a new PICU, staffing came from ward nurses and NICU respiratory care practitioners (RCP). Several days before Christmas, in the third year of the PICU, 24 infants received mechanical ventilation due to RSV bronchiolitis. At the end of patient care rounds, the level of agitation of the staff became palpable. Finally, the question was asked, “Why can’t we wean these babies and extubate them so they can be home by Christmas?” The question was not about a response to treatment. It emerged from days spent with frightened, anxious parents, limited information and prediction, and the lack of a logical system for understanding. Staff did not have personal anecdotes that would give meaning to their work. The author (DvS) had personal experience with the abrupt death of infants from RSV and had worked to keep these infants alive, un-intubated, pending transfer to a PICU. Thus, the question from the author, “Where did these infants go three years ago? I was at the regional receiving PICU. We did not see infants from this area.” Sometimes we must use our own anecdote to shift the baseline. “These 24 infants would have died three years ago, just days before Christmas. They are alive today and will go home to their parents *because of you.*”

We had a similar problem with Adult Respiratory Distress Syndrome (ARDS), a disease new to the PICU. After a few weeks of treating ARDS, staff began to urge PICU attendings to encourage parents to withdraw ventilator support as the ethical response. Again, we sometimes must artificially shift the baseline with an anecdote. The apparent deterioration from tension pneumothorax indicated a healing lung. We counted the children with ARDS, those who lived, and those who died. Our survival rate of 50% was the national average, but those who lived transferred to the ward after about a month while those who died lingered on the ventilator for 5-7 months. The ones who died were easier to remember because of their longer admission. We were saving the lives of children who otherwise would have died.

The intellectual strength and power of cognitive science, scientific rationality, and classical logic readily give way to the mental effects of novelty, uncertainty, and uncontrollability. Psychological stress is the neuroanatomic reaction, with even minor uncontrollable stress impairing abstract thought, memory retrieval, work-

ing memory, cognitive flexibility, and executive functions (14-17). Organizations invest heavily in the objective, structured systems, rely on cognitive flexibility, and presume classical logic will suffice. Yet, even minor stress corrupts their plans while the logic we can use in turmoil is not well identified.

Within the trajectory of turmoil, we must use information. To not use or distrust information is a decision about its use. The search for and evaluation of information delays action even as confirmed information changes or becomes unreliable. Methods of rationality and logic in a stable environment with well-structured problems offer little guidance. People revert to their “common sense.” Karl Weick (18) describes how such a ‘cosmology’ event collapses our sensemaking even as we believe in our own rationality.

Regardless of physical threats and social interactions, we respond to our mental environment in a way that makes sense to us at the moment but becomes refined with reflection as we gain experience. We likely call this “common sense” or “reasoned expertise.” Common sense, rationality, reasoning, and logic become subsumed into an individual’s logic of practice (6). Scientific rationality guides interpretation and understanding, but we must not forget this is objective and reasoned (7). Formal logical systems for truth become difficult when truth shifts or is contingent. Linear classical logic, separated from experience, influences thinking *during* the experience.

### **The Mental Environment of HRO**

Logic and rationality, developed for a structured environment, are poorly defined for operational use. A threshold divides the stable, structured environment from more tumultuous circumstances.

However, what is stable and structured for one person may be tumultuous for the individual a foot away. The threshold dividing these worlds is both physical and mental.

Compared to concrete action, superficial comparison of abstract thought readily puts abstract thought at a higher level of function. This makes sense for abstraction as the depth of reflection versus the immediacy of concreteness. Combining concreteness with action, as Aristotle did, creates a much higher level of thought, the first of Aristotle’s Cardinal Virtues (19). When applying abstractions to a particular concrete situation, we can fulfill our own sensemaking, or we can make sense for the good of the community. The former is a vice, the latter a virtue(19). It is the premise and logic that differ.

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***“Rationality and logic are sufficiently developed for stable states that we become accustomed to relying on them for emergencies, despite the differences in premises, truth values, and the rules of inference. Unfortunately, operators may not necessarily agree on which premises to use, their truth value, and whether an inference is possible.”***

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Rationality and logic are sufficiently developed for stable states that we become accustomed to relying on them for emergencies, despite the differences in premises, truth values, and the rules of inference. Unfortunately, operators may not necessarily agree on

which premises to use, their truth value, and whether an inference is possible. At its most basic, we disagree and may disagree quite emotionally. At a deeper and more fundamental level, those with more extensive experience will stop talking.

I had the rear-door position. My weapon was drawn and ready. When the main force went in the front door, I heard yelling and a warning that “they” were running out the back towards another agent and me. When the back door flew open, I was in the ready position (weapon up) and prepped to announce ourselves, etc. That lasted for about ½ a second as the first thing out the door was a snarling and angry German Shepherd - which launched right at me and, when I ducked, went right over me and kept on trucking. The suspect was next out, and he was moving almost as fast and was past me before I could react. I yelled for him to stop, but he was a fast-mover. Could I / Should I have shot him in the back - for a drug offense of unknown size/quantity - no way - and I didn't see a weapon.

Richard Holbrook, Special Agent, Air Force Office of Special Investigations (AFOSI), joint narcotics raid with local law enforcement assistance, 1984.

An officer-involved shooting, 11:30 pm, limited moonlight. The victim, a 17-year-old male, lay on the driveway in front of a “garage in the rear.” The suspect in a rape assault, he had wielded a knife in a knife-fighter stance running toward a police officer. Examining the victim, I noticed numerous entry wounds in the shins, with a few in the thigh from a shotgun. “I thought you said you shot him,” I said to the officer. “I did. But when I saw he was a kid, I aimed for the legs. I didn't want to shoot a kid.”

Daved van Stralen, 1973

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***“The rationality and logic used by both operators a decade apart are not described in the academic literature and not amenable to laboratory study.”***

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The rationality and logic used by both operators a decade apart are not described in the academic literature and not amenable to laboratory study. More seriously, it is not shared across the liminal threshold with those who have underfed experience in the environment of threat, time compression, existential threat, and the obligation to do the right thing.

We must not rely on a predictable, linear flow or trajectory of events, even during a rapid deterioration. In our experience, “punctuated events” abruptly occur to create seemingly unconnected situations. Karl Wieck (personal communication) observed these “punctuated events” need “punctuated sensemaking,” the ability to rapidly create a sense of new events almost independent of the most recent experience.

“During a crisis, there is not 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)

#### *The environment of VUCA-2T*

Elsewhere we have described the environment of practice (20), that is, the experienced environment we have in common with military operations, public safety, neonatology, critical care, medical care, nursing care, respiratory care, dietetics, K-12 education, social work, and pediatric subacute care. We have worked closely with all these programs with a robust human behavior component in both internal and external environments, a distinguishing feature from socio-technical systems. We call this environment VUCA-2T.

The military concept of “VUCA” describes the new global environment at the end of the Cold War (21, 22) – *volatile, uncertain, complex, and ambiguous*.

- *Volatility* comes from rapid and abrupt changes in events.
- *Uncertainty* describes the lack of precise knowledge about the situation.
- *Complexity* refers to a large number of interconnected and changing parts coming together.
- *Ambiguity* describes the multiple interpretations, causes, or outcomes for one situation.

VUCA, however, is a *military* concept. Military professionals carry the implicit assumption that they work in a dangerous and lethal environment. Consequently, the concept of threat is not translated into civilian applications (23).

- *Threat* impairs cognition and decision-making.

Discussions between a special group in SOCOM (Special Operations Command) and the author (DvS) led to the separation of time compression from volatility. Time compression has meaning and carries special information about the environment, distinguishing these events from urgency or time dependence (23, 24). The group now uses VUCA-2T or VUCA-T<sup>2</sup> (Sean McKay, personal communication) (25).

- *Time compression* describes the limitations on acquiring information, deciding, or acting before consequential changes in circumstances. Time compression is not a quality of time dependence or time-limitation.

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***“ The liminal zone is the space between the world we know and the world we do not. Old rules do not apply, we have not learned new rules, and we do not know what rules will work.”***

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#### *The liminal environment*

VUCA-2T fits the anthropological experience of liminality as a transition (26) and the operational environment of the HRO. The liminal zone is the space between the world we know and the world we do not. Old rules do not apply, we have not learned new rules, and we do not know what rules will work. This magnifies the gap between theory and practice (1), discrete concepts and continuous perceptions (27), abstractions and concreteness (Karl Weick, personal communication), and the static normative stance and the pragmatic stance from within the trajectory of events (2).

We can infer information in these situations. For that, we must reduce affective responses to threat in known ways, such as acceptance and control of the feeling of fear (20), neuromodulation of stress-fear-threat (3), and social organizing to prevent the ecology of fear (11). Behaviors come in suites coordinated for various purposes (28, 29). These suites of behaviors create sustained, coordinated defensive responses for survival. The primary defensive and survival functions are 1) reflexive, subcortical actions, 2) hindering memory systems from limiting cognition, and 3) volitional behaviors directed toward self-preservation.

Unlike a suite of behaviors, an *ensemble of behaviors* is learned and is selectively activated by specific threat cues—the ensemble functions *for the individual*. The behaviors in an ensemble are considered only in relation to the whole, unlike a suite of behaviors where behaviors are considered as a single property with an ecological function. An ensemble of behaviors serves a social and cultural function (30) by maintaining continuity and ongoing social interaction by evoking social support and validating responses from others in ongoing social interaction (31).

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***“The organized grouping of stress and fear behaviors gives them a semblance of rationality, making them difficult to identify or isolate. Consequently, individuals with maladaptive stress ensembles resist change. Without change, the affective responses as suites of stress behaviors change to behavioral ensembles through operant conditioning”***

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The organized grouping of stress and fear behaviors gives them a semblance of rationality, making them difficult to identify or isolate. Consequently, individuals with maladaptive stress ensembles resist change. Without change, the affective responses as suites of stress behaviors change to behavioral ensembles through operant conditioning. Maladaptive behavioral ensembles disrupt rationality to become normalized. Agitation, operant anger, and self-protection become leadership styles and management tools that create the ecology of fear (3, 11).

It becomes difficult to distinguish rational and logical reasoning from stress and fear once they become normative. The inability to translate cognitive and affective processes for VUCA-2T, liminality, and HRO theory into the practice of reliability and safety comes with the loss of nuance and missed, subtle cues within the environment (2). Unrecognized is the loss of neuromodulation as a skill and how to acquire the skill.

#### *Mental responses*

We can adopt rationality as defined by Sen (above) with the caveat that we can have *‘reasoned scrutiny,’* but the reason that is bounded by time and constrained cognition. What is needed for explication and translation of HRO are methods to infer meaningful and relevant information from uncertainty and ambiguity.

We paraphrase Vanessa Heggie’s (32) comments about the science for climbing Mount Everest: predicting what will happen to a premature infant is a matter of life or death – inaccurate models can kill. Consequently, Neonatologists prioritize neonatal respiratory physiology, not in the laboratory but in the NICU.

The mental responses in this environment, the rationality, and the methods for logical inference are not accessible across the threshold. They remain unstudied and under-described except for the disconnected first-person literature of reflective experience. Often this rationality and logic is reflexively rejected by outsiders and spectators. For operators, the acceptance of uncertainty and fear is unique (20), capability calibrates the threat response (3), and operators focus on possibility over probability. The more significant delineator between spectator and operator is the willingness to say, “I don’t know.”

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***“Often this rationality and logic is reflexively rejected by outsiders and spectators. For operators, the acceptance of uncertainty and fear is unique (20), capability calibrates the threat response (3), and operators focus on possibility over probability.”***

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The mental environment as experienced has profound effects on rationality and logic, whether effective or putative. As John Hickey, LAFD engineer, advised the author (DvS), “Davey, it’s OK to say, ‘I don’t know.’” A powerful and practical basis for inductivism in an environment at the time of major fires and recent deaths of firefighters. In the fire service during that era, “I don’t know” yielded trust. Yet, in healthcare, such a statement lowers respect and invites a barrage of disconnected, almost random, advice.

Information in all vignettes presented in this article is incomplete and in flux. The meaning of information is contingent on other information and changes in rapid succession. The capabilities of those accompanying the protagonist have a direct effect on rational reasoning and inference.

Probabilities influence deductive rational inference and decision-making. However, during a VUCA-2T event, the individual becomes part of the problem (2, 13) with direct influence on probabilities. When treating patients with poor responses to treatment, staff often echoed the question of parents – “What are the chances of survival?” One author (DvS) would stress that the job of the PICU team was to change those probabilities. If the child had a 20% survival, we work to make it 40%. If 40% survival, we work to make it 60%. Regardless of the percent survival, we work to put our patients into the survival side, approaching 100%. This avoids the unspoken situation of some caregivers quietly reducing their effort as the chance of success becomes the chance of failure followed by resignation and the emotion of failure. Shifting toward the creation of a new probability also shifts thinking from passive cognition to more effective motor cognition (4), Weick’s (33) “We think by acting.”

#### *Thoroughbred racehorses*

The author (DvS) worked with a partner on the fire rescue ambulance who bet at the races. He made as much money at the racetrack as he did from the fire department. He studied each jockey and horse and how they ran against each other in all combinations. The author asked, “But wouldn’t the jockey hold back once to change the odds and then make more money?” “No,” he answered, “If you hold back once, then the horse does not know when to do it next time. The horse will hold back at the wrong time. A thoroughbred racehorse knows only one way to run – full strength.”

The author shared this story with the staff. The mustang looks wild and free but cannot win the race. The thoroughbred racehorse is disciplined and runs with full strength. In the PICU, we are the thoroughbred.

The author used this metaphor when staff became weary, emotionally depleted, or showed hidden biases or prejudices. Staff did not realize how prejudice and emotional depletion act in negative feedback to create more depletion. Having witnessed complete exhaustion in moments of dire survival, the authors became familiar with the power of that final positive push.

*We have only one way to run – full strength.*

*The dominant account: Planning and rules*

Planning to reduce the mental workload during a VUCA-2T event seems prudent.

A police officer led a team of police officers into a building during an active shooter incident. As he moves closer to the shooter, the shots became louder with the stronger smell of gunpowder. Reaching a set of double doors in the hallway, he could not tell if the shots he heard several seconds before came from the cafeteria behind the double doors or around the hallway corner ahead. As he reaches the double doors, another shot rang out, and it was now clear the shot was around the corner ahead and to the left. Moving forward towards the corner with several officers, he noticed several other officers from his team behind him, attempting to open the double doors to confirm what threat was behind them. The leader led rather than directed movement from a fixed point in the hallway. They were not executing the exact communication, movement, cornering, or clearing techniques from training. Coming to a T-intersection in the hallway, he noticed a second team from a different entry arriving around the corner. Natural verbal and visual signaling rather than formal, structured statements avoided the friendly fire. The team around the corner crossed the hallway in front of his team, moving towards the suspect. The suspect had died by suicide.

The recognition of not following “trained techniques” only came to him during my debrief with him. During the event, they simply handled problems.

*Steve Papenfuhs, Sergeant, San Jose Police Department (retired)*

The authors, including the above author, have interviewed civilians, EMS, firefighters, and law enforcement personnel after a shooting incident. As with this officer, none of the individuals followed the prescribed response (34). They “simply handled problems.” However, the responders to a terrorist shooting effectively evacuated 14 shooting victims in 18 minutes without loss of life (24, 35), and school staff, following a school shooting, quietly evacuated about 400 elementary school children before the arrival of the first law enforcement officer (36).

We must not confuse being around danger with being in it. Sci-

entific rationality and classical logic decontextualize observation and engagement, forming conclusions not tested in the environment. Such conclusions become a substantial portion of the organization’s knowledge, constraining actions in confusing situations (37). Nevertheless, the experienced veteran responds to concrete circumstances, but abstract, ‘rational’ constraints conflict the novice from effective action. However, the narrative of both follows the dominant, ‘rational’ account (38, 39). Positive feedback from these narratives strengthens the dominant account, influencing actions followed by further conforming, though inaccurate, narratives and increasing ignorance of the environment (37).

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***“ Nevertheless, the experienced veteran responds to concrete circumstances, but abstract, ‘rational’ constraints conflict the novice from effective action. However, the narrative of both follows the dominant, ‘rational’ account (38, 39). Positive feedback from these narratives strengthens the dominant account, influencing actions followed by further conforming, though inaccurate, narratives and increasing ignorance of the environment (37). ”***

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The dominant narrative from scientific rationality and classical logic becomes privileged. To spectators, the actions of the experienced veteran then appear irrational, lacking discipline (2, 18, 37-39). Novices follow the dominant ‘rational’ methods, shifting the baseline from the environment to the office (“laboratory”). The lost knowledge creates inaccurate models with long-lasting effects on education and policy. In the VUCA-2T environment, lost knowledge can kill.

The linearity and sequencing of rules and plans produce reason and logic, distracting from the abstract character of rules and plans created apart from concrete reality. The expert following the rules performs poorly (40-43). We must guard against false protective mechanisms such as abstractions, rules, false confidence, or self-admiration.

### **Formal Logic Systems**

Proper reasoning permits the identification of valid patterns of inference while at the same time abstracting their content. The field of symbolic logic derives from Aristotle’s theory of reasoning. We want to connect ideas and observations through reason in a manner that preserves truth. Formal logic systems confirm ideas and infer new ideas while preserving truth. *Validity* preserves truth by logical necessity; that is, applying the rules of inference to true premises means the conclusion must follow *and* be true. Validity reflects the accuracy of form that we cannot have a false statement for our conclusion if the premises are true. If the premises are false, the conclusion is still valid; it is simply not a true conclusion. Validity does not ensure true premises; validity only ensures that the premises will lead to a valid conclusion.

An argument is shown to be valid through *derivation*. A *proof* is a formal derivation with stated premises, and each non-premise statement in the proof must be true by a specific rule of inference. Therefore, the conclusion in a proof must be true. In a proof, ev-



ery line must be true, making the proof valid. On the other hand, if the premises are false, the argument can be valid since validity depends solely on its form; it is just no proof.

The roots of proof are from Late Latin *proba*, meaning «a test.» *proof of the pudding shall be in the eating* (1708). Today's version is "The proof is in the pudding" (44).

Formal logic systems should only allow us to derive valid conclusions and verify all valid assertions. They have a similar structure: a set of propositions, apply rules of inference, then derive a conclusion to find a truth statement. An argument is *derivable* if a conclusion can be reached from its premises. An argument is *valid* if that conclusion cannot be false, given that the premises are true. Derivability and validity form the basis of soundness, completeness and consistency, critical principles in a formal logic system, and Kurt Gödel's incompleteness theorems.

**“Derivability and validity form the basis of soundness, completeness and consistency, critical principles in a formal logic system, and Kurt Gödel’s incompleteness theorems.”**

**Soundness.** The system must prove only true sentences. An argument is derivable *only if* it is valid; only valid formulas can be derived. No deduction can take the argument from true premises to a false conclusion. Thus, deductions *preserve truth* with the claim that everything derivable in the system is true.

**Completeness.** The system can prove all valid formulas, the converse of soundness. An argument is valid *only if* it is derivable. A formal system is *complete* if, for every statement, either the statement or its negation can be derived (proved) in the system. The deductive system can provide a deduction for every valid argument. The form of completeness differs between logic and math where, in math, it becomes the basis for Gödel's Completeness and Incompleteness Theorems.

**Consistency.** The system contains no contradictions and contains at least one situation when all formulas are true.

**Inconsistency.** There is no statement with its own negation that both can be derived within the system. Inconsistency permits a formal system to derive every statement, which means the logic

system is meaningless. Triviality in logic describes meaninglessness.

A formal system of logic has completeness, consistency, and effective axiomatization (necessary for decidability).

**Kurt Gödel, completeness, and incompleteness (45)**

To have a set of consistent axioms (never a contradiction) and complete (all formulas can be proved) would give mathematics a solid foundation. Gödel used the above concepts to demonstrate that such a foundation is impossible; any foundation for mathematics would be incomplete, there will always be truths that cannot be proved or disproved. He also proved that any set of axioms necessary for decidability could prove its own consistency. Gödel proved there can be no unification of mathematical theory. What can be proved depends on one's starting assumptions.

**The Completeness Theorem.** Every valid logical expression is provable. That is, every logical expression is either satisfiable or refutable. First-order logic is *semantically* complete but not *syntactically* complete.

**First incompleteness theorem.** Any consistent formal system within which a certain amount of elementary arithmetic can be carried out is incomplete. This only concerns derivability, not provability.

**The Second Incompleteness.** The consistency of arithmetic cannot be proved by arithmetic.

Truth and falsity are incompatible. Every proposition is either true or false (*law of excluded middle*); there is no gradation. The same proposition cannot be both true *and* false at the same time (*law of non-contradiction*). We can produce a truth table with a two-value logic, but the proposition has neither a value between truth and falsity nor both simultaneously.

The two principles *excluded middle* and *contradiction*, along with *identity*, form the traditional three "laws of thought." Once thought to be independent of each other, Alfred North Whitehead and Bertrand Russell (46) use the principles of logic to deduce the 'law' of (non)contradiction ((46), 77, 111 equation 3.24) from the 'law' of the excluded middle ((46), 101 equation 2.11, (47)). Thus, the two laws are equivalent rather than independent.

To better appreciate how classical logic supports the science and practice of neonatology and resuscitation, we will present a few principles of metalogic, that is, the metatheory of logic. Along with the above elements, a formal logic system demonstrates completeness, consistency, and decidability (axiomatization); the first

Table: A formal system of logic possesses decidability, completeness, and consistency (45)		
Decidability	Completeness	Consistency
Formalized system	The law of the excluded middle	The law of non-contradiction
Axioms and the proof relation to derive conclusions	Every property or statement of the system can be derived from within the system	No statement <u>and</u> its negation can be derived within the system
All formal and symbolic logic systems	<i>Incompleteness</i> (50) - an element cannot be completely classified - incomplete or partial information - the excluded middle is not enforced	<i>Inconsistency</i> (51) - inconsistent premises will yield <u>any</u> well-formed statement - inferential explosion of triviality - <i>explosion</i> , anything follows from a contradiction - <i>triviality</i> , little importance because <u>any</u> proposition can be inferred

two are germane to logic that tolerates contradictions and does not enforce the excluded middle (48, 49).

### *Induction and deduction*

Logic supports empirical science. Empirical science develops by evidence from the senses or builds from experience. Logical inference extends evidence in the creation of knowledge while distinguishing truth from falsity. The ability to prove or disprove the properties of knowledge is fundamental in our use of knowledge. This ability lies at the heart of inductive reasoning and deductive reasoning and influences the selection of formalized logic systems.

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***“Inductivism and inductive reasoning build knowledge from observation, but in inductivism, knowledge is not truth. Conclusions from inductive reasoning are plausible rather than having the certainty of truth we see with deductive reasoning.”***

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Inductivism and inductive reasoning build knowledge from observation, but in inductivism, knowledge is not truth. Conclusions from inductive reasoning are plausible rather than having the certainty of truth we see with deductive reasoning. The strength of inductive reasoning comes from the relentless pressure to confirm the plausible conclusion, described by Leonhard Euler (52) in George Pólya (53):

“[Observations] will lead us continually to new properties which we shall endeavor to prove afterwards. The kind of knowledge which is supported only by observations and is not yet proved must be carefully distinguished from the truth; it is gained by induction as we usually say... Indeed, we should use such a discovery as an opportunity to investigate more than exactly the properties discovered and to prove or disprove them; in both cases, we may learn something useful.”

Euler believed knowledge could be inductively “assured of its truth” by the number of examples: “anybody can satisfy himself of its truth by as many examples as he may wish to develop. And since I must admit that I am not in a position to give it a rigorous demonstration, I will justify it by a sufficiently large number of examples” (52, 53).

The pursuit of inductive confirmation in this fashion can lead to error which then could lead to harm. During the more deliberate extension of a discipline, we can identify and correct inductive errors to reduce the effects of harm (4). Note that in uncertainty, acting or not acting and engaging or not engaging can be equally harmful. In uncertain situations where a consequence includes death, inductive reasoning to identify ‘probably correct’ conclusions engenders vulnerability, which paradoxically increases safety (20). On the other hand, deductive reasoning seems a better approach as the conclusion is guaranteed to be true. However, this is only if the premises are true. We miss the falsity as the safety margin is only putative. The premises for deductive reasoning *must* be correct.

It is impossible to deductively treat a premature infant, even with knowledge of anatomy and physiology. The pulmonary system is straightforward because it is included in all science classes and physicians are well-versed in physiology. This can lead to overconfidence by a non-Neonatologist.

- Insufficient oxygen in the airways constricts pulmonary arterioles, leading to pulmonary hypertension, right heart strain, and death. We administer supplemental oxygen. The lung can continue to develop and heal from injury through early childhood.
- Excessive oxygen in the airways leads to Retinopathy of Prematurity and blindness. A relatively straightforward balance can be achieved. The influence of the lung on the retina does not become noticeable until after the damage has started. Damage of a few retina cells impairs growth into more retina cells; a small insult inflicts exponential harm.
- Mechanical ventilation increases exposure to bacteria and subsequent pneumonia, increasing the likelihood of death. Prudence guides us to wean the ventilator.
- Excessive work by the diaphragm steals energy necessary for muscle growth and brain development. There is now a mismatch in timelines as pneumonia will likely occur before muscle wasting is noted and long before brain development becomes measurable.
- The infant’s diaphragm contains fast-twitch fibers with fewer fatigue-resistant fibers. A higher breathing rate is adaptive for the infant’s chest with its relatively fixed tidal volume. The need for increased blood supply steals blood from other organs, including the brain.
- Decreased chest expansion is an interoceptive signal carried by the dorsal vagus nerve to the insular cortex. Decreased tidal volume can cause hypoactive delirium, identified by decreased interactions.

The Neonatologist is aware of this, but the balance is an inductive process of contingent interactions with physiological processes, including different time horizons. Outside physicians are unlikely to grasp these diverse balances.

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***“The Neonatologist is aware of this, but the balance is an inductive process of contingent interactions with physiological processes, including different time horizons.”***

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### *The limits of logic*

Abstractions, rules, and protocols do not reliably have the truth, which interferes with their use as truth premises for logical inference. It seems counterintuitive that abstractions limit reason, but even minimal stress impairs cognition (3, 16), and abstractions can unintentionally be substituted as concrete information.

Alfred North Whitehead’s “Fallacy of Misplaced Concreteness” (54) 52, 57.

In recognition of the dangers of plausible or inductive reasoning, George Pólya (53) characterized the moral qualities of a scientist:

1. The intellectual courage to be ready to revise beliefs
2. The intellectual honesty to change belief for a compelling reason
3. The wise restraint to not change belief wantonly

Doxastic logic and deontic logic are modal logics for belief revision and duty, respectively.



For Karl Popper, one of the most influential science philosophers of the last century, it was not logical that any positive outcomes from experimental testing could confirm a scientific theory. More problematic was *demarcating* scientific theory from non-science when some meaningful scientific statements could *not* be conclusively verified (55). Rather than verifiability, falsifiability became the criterion of whether a theory was testable (p 95-96) and could then demarcate science from non-science (p 17-19). The forms must be logically possible to verify and falsify. Popper (p 66) differentiated falsifiability, a criterion for the empirical character, from falsification, which requires special rules to regard a system as falsified.

---

***“Popper used ‘inconsistency’ from classical logic for falsifiability to demarcate empirical science from non-science. To accept inconsistency, equivalent to self-contradiction, is to collapse science.”***

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Popper (55) (p 65-66, 71-73) used the two classes of inconsistency and non-contradiction to determine if a theory is ‘empirical’ or ‘falsifiable.’ Inconsistency and non-contradiction derive from the classical logic law of non-contradiction, as described above in “Classical Logic.” “The importance of the requirement of consistency will be appreciated if one realizes that a self-contradictory system [inconsistent] is uninformative...Any conclusion we please can be derived from it” (p 73). Popper used ‘inconsistency’ from classical logic for falsifiability to demarcate empirical science from non-science. To accept inconsistency, equivalent to self-contradiction, is to collapse science.

We continue to experience the influence of Popper when someone offers a single counterexample as proof you are wrong.

“For it can easily be shown that if one were to accept contradictions, then one would have to give up any kind of scientific activity: it would mean a complete break-down of science. This can be shown by proving that if two contradictory sentences are admitted, any sentence whatsoever must be admitted” (56). [The] “law of contradiction; that is to say, upon the demand that contradictions, whenever we discover them, must be eliminated. Critical error-elimination on the scientific level proceeds by way of a conscious search for contradictions” (57).

*Karl R. Popper*

Though first-order logic seems like a pillar of science, a presentation of its emergence (58) reveals the limitations of first-order logic and describes the benefits of other logic. John Dewey (59), American philosopher, educator, and psychologist, opposed reliance on first-order logic in the natural sciences, disagreeing with the “assumption that logical and formal principles have a direct material and ontological application, rather than conclusions from empirical evidence.”

We can, however, use logical inconsistencies to drive investigation without rejecting available information (60).

### **Classical First-Order Logic**

Logic is found in philosophy, mathematics, and computer science, which use logic for different purposes, although similar in structure (61). Classical, or classical first-order logic, has entered medical care through the sciences and humanities. Classical first-order logic tells us what follows from a proposition but does not tell us

what to believe when to act, how to manage ambiguity or describe our duty to subordinates, family, or the infant. Classical logic can interfere when the Neonatologist uses inductive processes to guide the neonate’s care (59).

The scientific method uses classical logic closely related to the study of *correct reasoning*, making this the presumptive correct logic for science (61). Nevertheless, our experience belies classical logic as correct reasoning, as noted in the vignettes above. Classical logic can impair the extension of a discipline.

At the beginning of the author’s (DvS) experience with long-term ventilation, he followed the goal of weaning the child from the ventilator following blood gas evaluation for O<sub>2</sub> and CO<sub>2</sub>. One day a child’s grandmother beseeched an LVN to ask if the doctor could leave her grandson on the ventilator. She liked that he smiled, and he had never smiled before. The difference in ventilator management by blood gas versus smile created logical inconsistency in management with staff from various PICUs. Use of the child’s affective response appeared to contradict scientific rationality and logic, along with standard respiratory care references that mechanical ventilation was difficult for a patient to tolerate.

Logical pluralism reflects the possibility that other logic can offer solutions (62). Nonclassical logical operators, given the same premises but with different interpretations of ‘valid,’ can lead to different logical consequences. What one system captures as valid differs from what the other system captures.

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***“ Nonclassical logical operators, given the same premises but with different interpretations of ‘valid,’ can lead to different logical consequences. What one system captures as valid differs from what the other system captures.”***

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*The classical predicate or first-order logic* is a formal language expressing propositions in terms of predicates, variables, and quantifiers. Predicates express propositions as statements involving the arguments with the simplest predicates expressing properties of things. A statement makes an assertion that may be true or false contingent on the values of the variables.

An agitated patient with mechanical ventilation can disconnect from the ventilator. Cardiac arrest can come quickly. Rapid administration of sedative medication brings quick resolution. Sedation is not available in the subacute nursing facility. The author taught the subacute RCPs to hand ventilate for patient calm (63). Over time the property of mechanical ventilation shifted from *enabling life* to *enhancing life* as children began smiling, talking, and interacting with parents.

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Further extension occurred for infants with weak abdominal musculature who developed acute respiratory distress during a bowel movement. The RCPs learned that mild back-pressure, a PEEP of 8 cm H<sub>2</sub>O, would prevent ventilator-related agitation. More significant was the experience of hand ventilation for agitation in children with neurological deficits. After a few breaths, they awaken, older children may begin talking. Discussion with a neuropsychiatrist revealed these children were likely in hypoactive delirium secondary to hypoventilation.

Like the vignette in labor and delivery, the rigidity of classical logic can artificially create tension, corrupt communication, and impair the extension of medical care for the benefit of patients.

#### *Data, statistics, and probability*

A premature infant is a state of nonlinear interactions within each developing organ, between developing organs, and within the environment. Collected and analyzed data creates a body of knowledge for medical evaluation and management. However, numerous nonlinear interactions generate a flux of contradictory information and conflicting data making necessary information inconsistent. Reliance on statistics and probability (for example, evidence-based medicine) is not wrong. We must, though, acknowledge the insight shared by Bob Bea (64) (personal communication):

“The key problem in statistics is the validity of the data that has been gathered.”

“The key problem in probability is the potential for changes in conditions in the future that invalidate the data that has been gathered during the past.”

“The ‘tails of distributions’ generally are controlled by ‘rare events’ = ‘outliers.’ If the concerns for ‘reliability’ are primarily concerned with the *rare events* (for example, commercial aviation and nuclear power generation), then the focus will be on the distribution tails. If the concerns are primarily concerned with *frequently occurring events*, then the central portions of the distributions are of most interest.”

Thus, the problem for the Neonatologist: application of statistics and probability to contradictory and inconsistent information as a *particular* infant moves from one state of nonlinear interactions to another. Using classical logic to deduce conclusions by inference, reasoning rather than observation lessens our ability to make desirable worlds actual. We lose grasp of the situation.

---

***“Using classical logic to deduce conclusions by inference, reasoning rather than observation lessens our ability to make desirable worlds actual. We lose grasp of the situation.”***

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#### **Conclusion**

How do we use the information? Information preserves truth and extends the experience. The reasoning for both has not been identified. Those who have accomplished this find it difficult to describe to the scientific rationalist and classical logician. Such experts may suffer heavy criticism.

Fire changed human diet, extended human geography, and changed culture. If HRO describes the ability to control and use

dangerous energy for the common good, then early humans developed the first HROs around the use of fire. For bringing fire to humans, Prometheus was punished by the gods.

How do we use the information? The author (DvS) gave a lecture on traffic safety for a state office. The audience came from public safety and healthcare. The author elected to teach ‘how to think’ using his public safety experience, combat decision methods, and the Affective Domain of Learning, an approach that had engendered criticism from healthcare and EMS administrators. Two senior police detectives approached after the lecture to say it was the first lecture describing and explaining how they think. The title of the lecture? “Where is Prometheus?”

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Disclosures: The authors have no relevant disclosures

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Thomas A. Mercer  
Rear Admiral  
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### Acknowledgments

Karl Weick, *Rensis Likert Distinguished University Professor of Organizational Behavior and Psychology, Emeritus, University of Michigan*

Sean McKay, *Element Rescue, LLC*

Errol van Stralen, *Ancora Education*

Steve Papenfuhs, *Insight Training Strategies*

Tim Watson, *Mission Pediatrics*



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## OPIOIDS and NAS

When reporting on mothers, babies, and substance use

## LANGUAGE MATTERS



### I am not an addict.

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



### I was exposed to opioids.

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



### NAS is a temporary and treatable condition.

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



### My mother may have a SUD.

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

### My potential is limitless.

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



Learn more about Neonatal Abstinence Syndrome at [www.nationalperinatal.org](http://www.nationalperinatal.org)



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

## KEEPING MOTHERS + INFANTS TOGETHER

Means balancing the risks of...

- HORIZONTAL INFECTION
- SEPARATION AND TRAUMA



## EVIDENCE

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

## PARTNERSHIP

What is the best for this unique dyad?

### SHARED DECISION-MAKING

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



## TRAUMA-INFORMED

Both parents and providers are confronting significant...

- FEAR
- GRIEF
- UNCERTAINTY



## LONGITUDINAL DATA

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

- MENTAL HEALTH
- POSTPARTUM CARE DELIVERY



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

Partnering for patient-centered care when it matters most.  
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# Coping During COVID-19



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



## BONDING WITH YOUR BABY



## HELPING CHILDREN AND FAMILIES COPE

## CAREGIVERS NEED CARE TOO



nationalperinatal.org/psychologists



# Respiratory Syncytial Virus:

## How you can advocate for babies this RSV season

Track national data and trends at the CDC's website [www.cdc.gov/rsv](http://www.cdc.gov/rsv)



Identify babies at greatest risk



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

Teach families how to protect



their babies from respiratory infections

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



Use your best clinical judgement



when prescribing RSV prophylaxis

Tell insurers what families need



and provide the supporting evidence



\*See the NPA's evidence-based guidelines at [www.nationalperinatal.org/rsv](http://www.nationalperinatal.org/rsv)

## Survey Says: RSV

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

- Hospitalization
- Lifelong health complications
- Death

for infants and young children



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

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



But Parents are Unprepared.

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



RSV EDUCATION & AWARENESS CAN HELP

After parents learned more about RSV, they were:

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



NCJIH National Coalition for Infant Health  
Preventing RSV in Preterm Infant through Age Two

Learn More about RSV at [www.infanthealth.org/rsv](http://www.infanthealth.org/rsv)

PREEMIE BOOK ON SALE

# ONCE UPON A PREEMIE

BY JENNÉ JOHNS

AUTHOR | SPEAKER | ADVOCATE



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

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## Survey Says: RSV

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

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

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

- 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 RSV treatment

### But Parents are Unprepared.

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

### RSV EDUCATION & AWARENESS CAN HELP

After parents learned more about RSV, they were:

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



**NCJIH** National Coalition for Infant Health

Learn More about RSV at [www.infanthealth.org/RSV](http://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.

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### 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  
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# Medical News, Products & Information

Compiled and Reviewed by David Vasconcellos, MSIII

## AAP updates guidance on returning to sports/activity after COVID-19

June 10, 2021

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

How should pediatricians evaluate patients who want to return to sports or physical activities after COVID-19 infection? Should kids wear a mask during athletic practices and games?

The updated AAP [COVID-19 Interim Guidance: Return to Sports and Physical Activity](#) addresses these questions based on the growing understanding of SARS-CoV-2 infection, increased number of fully vaccinated individuals as young as 12 years and a drop in COVID-19 cases and deaths in the U.S.

The AAP guidance on face masks is consistent with Centers for Disease Control and Prevention (CDC) guidance. A face mask may not be necessary for all sport-related activities. But for those keeping score:

- Everyone should consider wearing a mask in crowded indoor spaces such as locker rooms and shared transportation, regardless of their vaccination status.
- Athletes who are not fully vaccinated should wear face masks when on the sidelines at outdoor sports and during all group training and competition when there is sustained contact of 3 feet or less. They also should wear a mask when arriving at or departing from the playing facility and off the playing field.
- Proper use of a face mask for all indoors sports training, competition and on the sidelines is strongly recommended for those who are not fully vaccinated, except when the mask is a safety risk.
- Unless fully vaccinated, coaches, officials, spectators and volunteers should wear a mask.

“Sports performed outside are lower risk for transmission of SARS-CoV-2, and a face mask may not be necessary for all sport-related activities,” according to the guidance.

Mitigation strategies such as wearing a face mask (when appropriate) can reduce transmission rates for indoor sports to as low as outdoor sports. Exceptions to mask-wearing might be appropriate when the risk of heat-related illness is increased.

### Return to activity after infection

The guidance includes new information on evaluating patients for resumption of physical activity or sports after testing positive for SARS-CoV-2. Pediatricians should have patients notify them if they test positive for SARS-CoV-2 and document the infection in the medical record.

- For patients with asymptomatic or mildly symptomatic COVID-19 illness: A phone or telemedicine visit is recommended, at a minimum. Recent studies report a lower incidence of myocarditis (0.5% to 3%) from SARS-CoV-2 infection, than reported earlier in the pandemic. However, myocarditis has been reported in patients with asymptomatic or mildly symptomatic illness. Therefore, pediatricians should ask about chest pain, shortness of breath out of proportion for upper respiratory tract infection, new-onset palpitations or syncope. Any reports of these symptoms warrant an in-office visit, physical examination and consideration of EKG before clearing the patient to return to physical activity.
- For patients with moderate symptoms and no evidence of multisystem inflammatory syndrome in children (MIS-C): An in-person evaluation by the primary care pediatrician is recommended. Patients should not exercise until cleared, and the evaluation should occur after symptoms have resolved and quarantine is completed. The guidance recommends reviewing the American Heart Association 14-element screening evaluation with emphasis on cardiac symptoms, complete physical examination and EKG. Next steps depend on cardiac screening or EKG findings.
- For children with severe COVID-19 symptoms or MIS-C: AAP guidance remains unchanged. These children should forgo exercise for at least three to six months and receive cardiology clearance before resuming training or

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competition.

Further workup is not required for children who had SARS-CoV-2 infection and have returned to physical activity or sports on their own and do not have any abnormal signs or symptoms.

### Health supervision visits

At the annual health supervision visit and preparticipation physical evaluation, pediatricians can provide guidance on gradual return to physical activity if the patient has recovered from COVID-19 and has not participated in consistent physical activity for more than a month. This includes:

- Starting at 25% of usual volume and intensity of activity and consider exercising every other day.
- Increasing volume by 10% each week until desired volume is reached.
- Increasing intensity by 10% each week until desired intensity is reached.

Finally, the AAP encourages COVID-19 vaccination for all eligible people. An athlete who is fully vaccinated can follow CDC

transmission mitigation recommendations for vaccinated people.

### Resource

Sports checklist for parents from HealthyChildren.org, <https://bit.ly/3xaCiFm>

Contact information for AAP headquarters

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345 Park Blvd, Itasca, IL 60143

New AAP main number: 630-626-6000

Trisha Koriath, Staff Writer

**NT**

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

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

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

- Connect with other AAP members who share your interests in improving effective drug therapies and devices in children.
- Receive the SOATT newsletter containing AAP and Section news.
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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 <http://membership.aap.org/Application/AddSectionChapterCouncil>.

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

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

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Mitchell Goldstein, MD, FAAP, Immediate Past Chair, [MGoldstein@llu.edu](mailto:MGoldstein@llu.edu) and

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*being of infants, children, adolescents and young adults. For more information, visit [www.aap.org](http://www.aap.org). Reporters can access the meeting program and other relevant meeting information through the AAP meeting website at <http://www.aapexperience.org/>*

NT

## CDC advises broader testing for RSV due to regional spikes

June 10, 2021

Clinicians are being advised to broaden their testing for respiratory syncytial virus (RSV) in patients with acute respiratory illness who test negative for SARS-CoV-2, following a recent spike in areas of the South.

In a [health alert advisory](#) issued today, the Centers for Disease Control and Prevention (CDC) also is reminding health care personnel, child care providers and staff of long-term care facilities to avoid reporting to work while acutely ill — even if they test negative for SARS-CoV-2.

While RSV activity remained low from May 2020 to early March 2021, the CDC has noticed an increase in RSV cases reported since late March to the [National Respiratory and Enteric Virus Surveillance System](#) (NREVSS), a laboratory-based surveillance network.

Increases have been observed in laboratory detections and in the percentages of positive detections for both antigen and polymerase chain reaction testing in parts of region 4 of the U.S. Department of Health and Human Services (Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina and Tennessee) and region 6 (Arkansas, Louisiana, New Mexico, Oklahoma and Texas). Due to limited testing outside of the typical

RSV season, data are limited in some jurisdictions and may be incomplete for the most recent weeks.

Since this elevated interseasonal activity is a deviation from the typical circulation patterns for RSV, it is not possible to anticipate the likely spread, peak or duration of activity, according to the CDC advisory.

Due to reduced circulation of RSV during the winter months of 2020–'21, older infants and toddlers might now be at increased risk of severe RSV-associated illness since they likely have not had typical levels of exposure to RSV during the past 15 months. In infants younger than 6 months, RSV infection may result in symptoms of irritability, poor feeding, lethargy and/or apnea with or without fever. In older infants and young children, rhinorrhea and decreased appetite may appear one to three days before cough, often followed by sneezing, fever and sometimes wheezing.

There is no specific treatment for RSV infection other than [symptom management](#).

CDC guidance includes the following recommendations:

- Clinicians and caregivers should be aware of the typical clinical presentation of RSV for different age groups.
- Clinicians should consider testing patients with a negative SARS-CoV-2 test and acute respiratory illness or the age-specific symptoms listed above for non-SARS-CoV-2 respiratory pathogens, such as RSV. Real-time reverse transcription-polymerase chain reaction is the preferred method to test for respiratory viruses.
- Clinicians should report laboratory-confirmed RSV cases and suspected clusters of severe respiratory illness to local and state health departments according to their routine reporting requirements.
- Clinicians can review weekly

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updates to the [NREVSS website](#) and refer to surveillance data collected by local hospitals and health departments for information on RSV circulation trends in their area.

RSV is the most common cause of bronchiolitis and pneumonia in children under a year old. The virus leads to about 58,000 hospitalizations annually, with 100 to 500 deaths among children younger than 5 years.

#### Resources

1. [Information from the CDC on RSV](#)
2. [Information from the AAP Red Book on RSV](#)
3. [AAP News article on surge in RSV cases in New York hospital](#)
4. [Information for parents from HealthyChildren.org on RSV](#)

Contact information for AAP headquarters

American Academy of Pediatrics

345 Park Blvd, Itasca, IL 60143

New AAP main number: 630-626-6000

Alyson Sulaski Wyckoff, Associate Editor

NT

## Optic nerve firing may spark growth of vision-threatening childhood tumor

Tuesday, June 1, 2021

*NIH-funded pre-clinical study supports key role of neural activity in brain cancers.*

In a study of mice, researchers showed how the act of seeing light may trigger the formation of vision-harming tumors in



## 8th World Congress of Pediatric Cardiology and Cardiac Surgery

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young children who are born with neurofibromatosis type 1 (NF1) cancer predisposition syndrome. The research team, funded by the National Institutes of Health, focused on tumors that grow within the optic nerve, which relays visual signals from the eyes to brain. They discovered that the neural activity which underlies these signals can both ignite and feed the tumors. Tumor growth was prevented or slowed by raising young mice in the dark or treating them with an experimental cancer drug during a critical period of cancer development.

“Brain cancers recruit the resources they need from the environment they are in,” said Michelle Monje, M.D., Ph.D., associate professor of neurology at Stanford University, Palo Alto, California, and co-senior author of the study published in *Nature*. “To fight brain cancers, you have to know your enemies. We hope that understanding how brain tumors weaponize neural activity will ultimately help us save lives and reduce suffering for many patients and their loved ones.”

The study was a joint project between Dr. Monje’s team and scientists in the laboratory of David H. Gutmann, M.D., Ph.D., the Donald O. Schnuck Family Professor and the director of the Neurofibromatosis Center at the Washington University School of Medicine in St. Louis.

In 2015, Dr. Monje’s team [showed for the first time](#) that stimulation of neural activity in mice can speed the growth of existing malignant brain tumors and that this enhancement may be controlled by the secretion of a protein called neuroligin-3. In this new study, the researchers hoped to test out these ideas during earlier stages of tumor development.

“Over the years, cancer researchers have become more and more focused on the role of the tumor microenvironment in cancer development and growth. Until recently, neuronal activity has not been considered, as most studies have focused on immune and vascular cell interactions,” said Jane Fountain, Ph.D., program director at the NIH’s [National Institute of Neurological Disorders and Stroke](#) (NINDS), which par-





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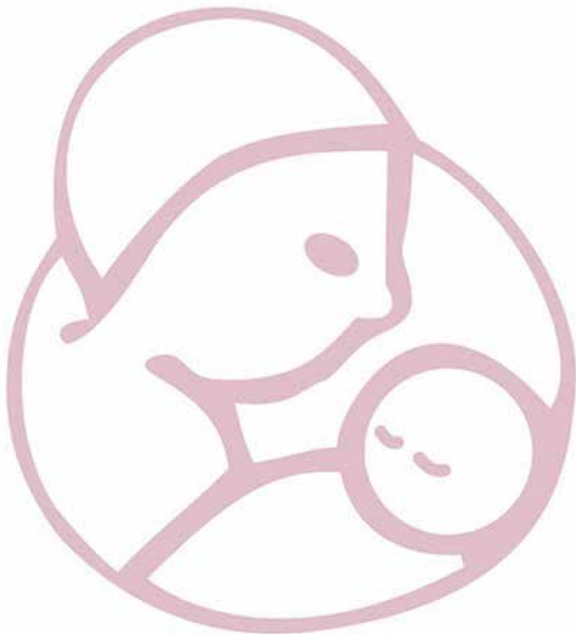
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tially funded the study. "This study is one of the first to show a definitive role for neurons in influencing tumor initiation. It's both scary and exciting to see that controlling neuronal activity can have such a profound influence on tumor growth."

Specifically, the researchers chose to study optic nerve gliomas in mice. Gliomas are formed from newborn cells that usually become a type of brain cell called glia. The tumors examined in this study are reminiscent of those found in about 15-20% of children who are born with a genetic mutation that causes NF1. About half of these children develop vision problems.

Dr. Gutmann helped discover the disease-causing mutation linked to NF1 and its encoded protein, neurofibromin, while working in a lab at the University of Michigan, Ann Arbor, which was then led by the current NIH director, Francis S. Collins, M.D., Ph.D. Since then, the Gutman team's pioneering work on NF1, and particularly NF1-brain tumors, has greatly shaped the medical research community's understanding of low-grade glioma formation and progression.

"Based on multiple lines of converging evidence, we knew that these optic nerve gliomas arose from neural precursor cells. However, the tumor cells required help from surrounding non-cancerous cells in the optic nerve to form gliomas," said Dr. Gutmann, who was also a senior author of this study. "While we had previously shown that immune cells, like T-cells and microglia, provide growth factors essential for tumor growth, the big question was: 'What role did neurons and neural activity play in optic glioma initiation and progression?'"

To address this, the researchers performed experiments on mice engineered by the Gutmann laboratory to generate tumors that genetically resembled human NF1-associated optic gliomas. Typically, optic nerve gliomas appear in these mice between six to sixteen weeks of age.

Initial experiments suggested that optic nerve activity drives the formation of the tumors. Artificially stimulating neural ac-

tivity during the critical ages of tumor development enhanced cancer cell growth, resulting in bigger optic nerve tumors. In contrast, raising the mice in the dark during that same time completely prevented new tumors from forming.

Interestingly, the exact timing of the dark period also appeared to be important. For instance, two out of nine mice developed tumors when they were raised in the dark beginning at twelve weeks of age.

"These results suggest there is a temporal window during childhood development when genetic susceptibility and visual system activity critically intersect. If a susceptible neural precursor cell receives the key signals at a vulnerable time, then it will become cancerous. Otherwise no tumors form," said Yuan Pan, Ph.D., a post-doctoral fellow at Stanford and the lead author. "We needed to understand how this happens at a molecular level."

Further experiments supported the idea that neuroligin-3 may be a key player in this process. For instance, the scientists found high levels of neuroligin-3 gene activity in both mouse and human gliomas. Conversely, silencing the neuroligin-3 gene prevented tumors from developing in the neurofibromatosis mice.

Traditionally, neuroligin-3 proteins are thought to act like tie rods that physically brace neurons together at communication points called synapses. In this study, the researchers found that the protein may work differently. The optic nerves of neurofibromatosis mice raised under normal light conditions had higher levels of a short, free-floating version of neuroligin-3 than the nerves of mice raised in the dark.

"Previously our lab showed that neural activity causes shedding of neuroligin-3 and that this shedding hastens malignant brain tumor growth. Here our results suggest that neuroligin-3 shedding is the link between neural activity and optic nerve glioma formation. Visual activity causes shedding and shedding, in turn, transforms susceptible cells into gliomas," said Dr. Monje.

Finally, the researchers showed that an experimental drug may be effective at combating gliomas. The drug is designed to block the activity of ADAM10, a protein that is important for neuroligin-3 shedding. Treating the neurofibromatosis mutant mice with the drug during the critical period of six to sixteen weeks after birth prevented the development of tumors. Treatment delayed to twelve weeks did not prevent tumor formation but reduced the growth of the optic gliomas.

"These results show that understanding the relationship between neural activity and tumor growth provides promising avenues for novel treatments of NF-1 optic gliomas," said Jill Morris, Ph.D., program director, NINDS.

Dr. Monje's team is currently testing neuroligin-3-targeting drugs and light exposure modifications that may in the future help treat patients with this form of cancer.

This work was supported by grants from the NIH (NS092597, NS111132, NS097211, CA165962, EY026877, EY029137, CA233164); the Department of Defense (W81XWH-15-1-0131, W81XWH-19-1-0260); Brantley's Project supported by Ian's Friends Foundation; Gilbert Family Foundation; Robert J. Kleberg, Jr. and Helen C. Kleberg Foundation; Cancer Research UK; Unravel Pediatric Cancer; McKenna Claire Foundation; Kyle O'Connell Foundation; Virginia and D. K. Ludwig Fund for Cancer Research; Waxman Family Research Fund; Stanford Maternal and Child Health Research Institute; Stanford Bio-X Institute; Will Irwin Research Fund; Research to Prevent Blindness, Inc.; Schnuck Markets Inc., and Alex's Lemonade Stand Foundation.

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Pan, Y. et al., NF1 mutation drives neuronal-activity dependent initiation of optic glioma. *Nature*, May 26, 2021 DOI: 10.1038/s41586-021-03580-6

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Contact

[Christopher G. Thomas\(link sends e-mail\)](#)

301-496-5751

NT

## Scientists discover a new genetic form of ALS in children

Tuesday, June 1, 2021

*NIH- and USU- led study links ALS to a fat manufacturing gene and maps out a genetic therapy*

In a study of 11 medical-mystery patients, an international team of researchers led by scientists at the National Institutes of Health and the Uniformed Services University (USU) discovered a new and unique form of amyotrophic lateral sclerosis (ALS). Unlike most cases of ALS, the disease began attacking these patients during childhood, worsened more slowly than usual, and was linked to a gene, called SPTLC1, that is part of the body's fat production system. Preliminary results suggested that genetically silencing SPTLC1 activity would be an effective strategy for combating this type of ALS.

"ALS is a paralyzing and often fatal disease that usually affects middle-aged people. We found that a genetic form of the disease can also threaten children. Our results show for the first time that ALS can be caused by changes in the way the body metabolizes lipids," said Carsten Bönnemann, M.D., senior investigator at the NIH's [National Institute of Neurological Disorders and Stroke \(NINDS\)](#) and a senior author of the study published in *Nature Medicine*. "We hope these results will help doctors recognize this new form

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of ALS and lead to the development of treatments that will improve the lives of these children and young adults. We also hope that our results may provide new clues to understanding and treating other forms of the disease.”

Dr. Bönemann leads a team of researchers that uses advanced genetic techniques to solve some of the most mysterious childhood neurological disorders around the world. In this study, the team discovered that 11 of these cases had ALS that was linked to variations in the DNA sequence of SPLTC1, a gene responsible for manufacturing a diverse class of fats called sphingolipids.

In addition, the team worked with scientists in labs led by Teresa M. Dunn, Ph.D., professor and chair at USU, and Thorsten Hornemann, Ph.D., at the University of Zurich in Switzerland. Together they not only found clues as to how variations in the SPLTC1 gene lead to ALS but also developed a strategy for counteracting these problems.

The study began with Claudia Digregorio, a young woman from the Apulia region of Italy. [Her case had been so vexing](#) that Pope Francis imparted an in-person blessing on her at the Vatican before she left for the United States to be examined by Dr. Bönemann’s team at the NIH’s [Clinical Center](#).

Like many of the other patients, Claudia needed a wheelchair to move around and a surgically implanted tracheostomy tube to help with breathing. Neurological examinations by the team revealed that she and the others had many of the hallmarks of ALS, including severely weakened or paralyzed muscles. In addition, some patients’ muscles showed signs of atrophy when examined under a microscope or with non-invasive scanners.

Nevertheless, this form of ALS appeared to be different. Most patients are diagnosed with ALS around 50 to 60 years of age. The disease then worsens so rapidly that patients typically die within three to five years of diagnosis. In contrast, initial

symptoms, like toe walking and spasticity, appeared in these patients around four years of age. Moreover, by the end of the study, the patients had lived anywhere from five to 20 years longer.

“These young patients had many of the upper and lower motor neuron problems that are indicative of ALS,” said Payam Mohassel, M.D., an NIH clinical research fellow and the lead author of the study. “What made these cases unique was the early age of onset and the slower progression of symptoms. This made us wonder what was underlying this distinct form of ALS.”

The first clues came from analyzing the DNA of the patients. The researchers used next-generation genetic tools to read the patients’ exomes, the sequences of DNA that hold the instructions for making proteins. They found that the patients had conspicuous changes in the same narrow portion of the SPLTC1 gene. Four of the patients inherited these changes from a parent. Meanwhile, the other six cases appeared to be the result of what scientist call “*de novo*” mutations in the gene. These types of mutations can spontaneously occur as cells rapidly multiply before or shortly after conception.

Mutations in SPLTC1 are also known to cause a different neurological disorder called hereditary sensory and autonomic neuropathy type 1 (HSAN1). The SPLTC1 protein is a subunit of an enzyme, called SPT, which catalyzes the first of several reactions needed to make sphingolipids. HSAN1 mutations cause the enzyme to produce atypical and harmful versions of sphingolipids.

At first, the team thought the ALS-causing mutations they discovered may produce similar problems. However, blood tests from the patients showed no signs of the harmful sphingolipids.

“At that point, we felt like we had hit a roadblock. We could not fully understand how the mutations seen in the ALS patients did not show the abnormalities expected from what was known about SPTLC1 mutations,” said Dr. Bönemann. “Fortunately,

Dr. Dunn’s team had some ideas.”

For decades Dr. Dunn’s team had studied the role of sphingolipids in health and disease. With the help of the Dunn team, the researchers reexamined blood samples from the ALS patients and discovered that the levels of typical sphingolipids were abnormally high. This suggested that the ALS mutations enhanced SPT activity.

Similar results were seen when the researchers programmed neurons grown in petri dishes to carry the ALS-causing mutations in SPLTC1. The mutant carrying neurons produced higher levels of typical sphingolipids than control cells. This difference was enhanced when the neurons were fed the amino acid serine, a key ingredient in the SPT reaction.

Previous studies have suggested that serine supplementation may be an effective treatment for HSAN1. Based on their results, the authors of this study recommended avoiding serine supplementation when treating the ALS patients.

Next, Dr. Dunn’s team performed a series of experiments which showed that the ALS-causing mutations prevent another protein called ORMDL from inhibiting SPT activity.

“Our results suggest that these ALS patients are essentially living without a brake on SPT activity. SPT is controlled by a feedback loop. When sphingolipid levels are high then ORMDL proteins bind to and slow down SPT. The mutations these patients carry essentially short circuit this feedback loop,” said Dr. Dunn. “We thought that restoring this brake may be a good strategy for treating this type of ALS.”

To test this idea, the Bönemann team created small interfering strands of RNA designed to turn off the mutant SPLTC1 genes found in the patients. Experiments on the patients’ skin cells showed that these RNA strands both reduced the levels of SPLTC1 gene activity and restored sphingosine levels to normal.

“These preliminary results suggest that we may be able to use a precision gene silenc-

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ing strategy to treat patients with this type of ALS. In addition, we are also exploring other ways to step on the brake that slows SPT activity,” said Dr. Bonnemann. “Our ultimate goal is to translate these ideas into effective treatments for our patients who currently have no therapeutic options.”

This study was supported by the NIH Intramural Research Program at the NINDS; NIH grants (NS10762, NS072446); the U.S. Department of Defense’s Congressionally Directed Medical Research Programs (W81XWH-20-1-0219); the Swiss National Foundation (31003A\_179371); the Deater foundation, Inc. The views expressed here do not represent those of the Department of Defense.

**NINDS** is the nation’s leading funder of research on the brain and nervous system. The mission of NINDS is to seek fundamental knowledge about the brain and nervous system and to use that knowledge to reduce the burden of neurological disease

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#### Article

Mohassel, P. et al., Childhood Amyotrophic Lateral Sclerosis Caused by Excess Sphingolipid Synthesis. *Nature Medicine*, May 31, 2021 DOI: 10.1038/s41591-021-01346-1

###

Institute/Center

[National Institute of Neurological Disorders and Stroke \(NINDS\)](#)

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NT

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## Study suggests no association between antiseizure drugs used during pregnancy and neurodevelopmental problems in children at age 2

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Monday, June 7, 2021

#### What

New findings published in *JAMA Neurology* suggest there is no difference in cognitive outcomes at age 2 among children of healthy women and children of women with epilepsy who took antiseizure medication during pregnancy. The findings are part of the large research project Maternal Outcomes and Neurodevelopmental Effects of Antiepileptic Drugs (MONEAD), which is a prospective, long-term study looking at outcomes in pregnant women with epilepsy and their children. The study was funded by the National Institute of Neurological Disorders and Stroke (NINDS), part of the National Institutes of Health.

This study reports findings from 382 children (292 children born to women with epilepsy and 90 born to healthy women) who were assessed for language development at age 2. The researchers also compared developmental scores with third trimester blood levels of antiseizure medication in these children.

Results suggest that children born to healthy women and those born to women with epilepsy do not show significant differences in language development scores at age 2. Neither was language development linked to third trimester blood levels of epilepsy medications. Most women with epilepsy in the study were taking lamotrigine and/or levetiracetam.

However, the study did find that those children born to mothers with the very highest levels of antiseizure medication in the blood during the third trimester did have somewhat lower scores on tests in the motor and general adaptive domains, which refer to skills related to self-care, such as feeding.

The children in this study will continue to be followed and will participate in additional cognitive tests through age 6. Results so far indicate that controlling epilepsy with these medications during pregnancy may be safe for babies.

#### Who

Adam Hartman, M.D., program director, NIH’s National Institute of Neurological Disorders and Stroke (NINDS). To arrange an interview, please contact [ninds-spressteam@ninds.nih.gov](mailto:ninds-spressteam@ninds.nih.gov)([link sends e-mail](#))

#### Article

Meador KJ et al., Two-year old cognitive outcomes in children of pregnant women with epilepsy in the Maternal Outcomes and Neurodevelopmental Effects of Antiepileptic Drugs Study, *JAMA Neurology*, June 7, 2021. DOI:[10.1001/jama-neurology.2021.1583](https://doi.org/10.1001/jama-neurology.2021.1583) ([link is external](#))

This study was supported by the NINDS (NS038455 and NS050659).

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## Surgeon general addresses myocarditis, pediatricians' role in COVID-19 vaccination efforts

June 11, 2021

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

U.S. Surgeon General Vivek H. Murthy, M.D., M.B.A., responded to pediatricians' questions about myocarditis and mRNA vaccines and discussed pediatricians' role in supporting vaccine confidence at an interactive [virtual COVID-19 town hall](#) hosted by the AAP and Children's Hospital Association Thursday.

Top of mind was [news](#) about cases of myocarditis in young people after COVID-19 mRNA (Pfizer-BioNTech and Moderna) vaccination. Members of the Food and Drug Administration's (FDA's) Vaccines and Related Biological Products Advisory Committee met virtually Thursday to discuss 226 cases of myocarditis or pericarditis reported in people ages 30 and younger since April 2021 and 250 more still under investigation.

Dr. Murthy said most of the cases reported to the [Vaccine Adverse Event Reporting System](#) have been mild.

"They have occurred predominantly in male adolescents and young adults up to their early 20s. ... Most often, it has happened after the second dose of the vaccine and typically within several days after that second dose," he said. Most patients have recovered with supportive care.

The overall number of cases is small compared to the millions of doses administered to adolescents, he said. "(But) anything regarding the health of children — or anyone for that matter — we want to take absolutely seriously."

The Centers for Disease Control and Prevention (CDC) and FDA are continuing to evaluate reports to determine whether they are related to the vaccine or other causes. The CDC's Advisory Committee on Immunization Practices will hold an [emergency meeting](#) on June 18 to discuss myocarditis cases.

"The bottom line is this: When you compare the risk of cardiac complications among adolescents who have had COVID vs. the numbers that we're seeing here, it is very clear to us at this point in time that the benefits still outweigh the risk when it comes to vaccination," he said.

### Small practices, large quantities of vaccine

With many physicians' offices awaiting COVID-19 vaccines, pediatricians in small practices may have concerns about managing a large quantity of vaccine doses.

Dr. Murthy said funding through the [American Rescue Plan](#) is intended to support states in managing and breaking up large quantities of doses so that physicians' offices and other smaller locations can participate in COVID-19 vaccine rollout efforts.

He also suggested that pediatricians connect with nearby practices to break up and share the vaccine supply. But even with the

## Family Centered Care is trendy, but are providers really meeting parents needs in the NICU?

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Surveys show hospital support groups are being widely underutilized by parents.



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You may be surprised to see what NICUs are doing right and where their efforts are clearly falling short.

Graham's Foundation empowers parents of premature babies through support, advocacy and research to improve outcomes for their preemies and themselves.



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best efforts, pediatricians should expect some doses will go to waste.

"I just want to say that out loud, because even if you waste some vaccine but if you're able to vaccinate other children, we want that to happen," he said. "Of course, our mind always goes to those who may be looking for a vaccine and can't get it, whether



# Keeping Your Baby Safe

during the COVID-19 pandemic

## How to protect your little one from germs and viruses

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

Here's what you can do...

### Wash Your Hands

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



### Limit Contact with Others

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



### Provide Protective Immunity

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



### Take Care of Yourself

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



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

**WARNING**

### Never Put a Mask on Your Baby

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



### If you are positive for COVID-19

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



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flu

coronavirus

pertussis

RSV



### WASH YOUR HANDS

often with soap and warm water.

### GET VACCINATED

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



### COVER COUGHS AND SNEEZES.

Sneeze and cough into your elbow.

### USE AN ALCOHOL-BASED HAND SANITIZER.



### STAY AWAY FROM SICK PEOPLE

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it's in the United States or other parts of the world ... We'd rather have some wastage but get people vaccinated than not have vials opened, and ultimately, we will be worse off in that case."

**Questions asked, answered**

Pediatricians had an opportunity to chat with Dr. Murthy, ask questions and share personal stories. Among topics discussed:

- What pediatricians can do to make equity central and in turn, vaccinate more youths.
- How to work with [schools](#) to extend vaccination to more families.
- How to address COVID-19 myths that the vaccine is linked to infertility or changes a person's DNA.
- How to prioritize mental health for patients and pediatricians.

Finally, Dr. Murthy urged pediatricians to continue addressing vaccine hesitancy in their communities. With new information about COVID-19 vaccines spreading as rapidly as misinformation, he said, one-on-one conversations can make a difference even when the person does not follow the pediatrician's advice after the first conversation.

"The most powerful and important messengers in this effort to protect our country, our patients and our communities are you. ... When people have a chance to talk to you, their doctors, whether they're your patients themselves or their parents, it can make a huge difference," he said. "You have the information. You have the relationships, which give you the trust. That's why you have the power to help more people get vaccinated."

**Resource**

CDC guidance for clinicians on myocarditis/pericarditis after COVID-19 vaccination, <https://bit.ly/3zi8ngb>

Contact information for AAP headquarters

American Academy of Pediatrics

345 Park Blvd, Itasca, IL 60143

New AAP main number: 630-626-6000

Trisha Koriath, Staff Writer

**NT**

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**COVID-19**

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# Genetics Corner: Multisuture Craniosynostosis Secondary to Intrauterine Constraint During Gestation in a Bicornuate Uterus

Robin Dawn Clark, MD, Subhadra Ramanathan MSc, MS, CGC

A 10 year 8-month-old. Female status post sagittal and metopic craniosynostosis was seen for an initial genetic evaluation in the Craniofacial Team Clinic. Her Spanish-speaking mother provided the history through an interpreter.

She was the product of her 27-year old mother's first pregnancy. The gestation was complicated by a maternal bicornuate uterus and vaginal spotting at ~2 months' gestation when the pregnancy was detected. An ultrasound exam was suspicious for a subchorionic hemorrhage. Fetal movements were reduced, and the fetal position was always "transverse." The mother denied teratogenic exposures, illnesses, and diabetes. She gained about 15 lbs in the pregnancy.

***"At six months of age, cranial remodeling surgery was aborted for excessive bleeding and blood loss. Brain MRI at ten months showed mild scaphocephaly and turricephaly and was otherwise normal, without evidence of a vascular anomaly. Surgery was successfully performed at 14 months of age."***

The infant was delivered at 38 weeks by scheduled C-section for breech presentation. Birth weight was 6 lb 3 oz. She was admitted to the NICU for two weeks primarily for hypoglycemia and respiratory distress. CT scan confirmed metopic and sagittal craniosynostosis at ten days of age. She was referred to the craniofacial clinic when she was 2 ½ months of age. At six months of age, cranial remodeling surgery was aborted for excessive bleeding and blood loss. Brain MRI at ten months showed mild scaphocephaly and turricephaly and was otherwise normal, without evidence of a vascular anomaly. Surgery was successfully performed at 14 months of age. Early milestones were delayed. She walked at two years of age and said her first words at 2 1/2 to 3 years of age. However, at age 10, she is doing well in the 5th grade, attending GATE (gifted and talented) classes.

The family history was non-contributory. Parental consanguinity was denied. She has one healthy 4-year old brother. Parents, who are both 37 years old, are of Hispanic ancestry from Mexico. There is no other reported family history of birth defects, developmental delay, intellectual disability, early infant deaths, or multiple miscarriages.

She was an alert, cooperative, well-spoken and nondysmorphic

school-aged child with normal growth parameters on the exam. There was mild bitemporal narrowing. Her fingers were tapered, but the remainder of the exam was normal.

## Assessment and counseling:

This child has multisuture craniosynostoses involving the metopic and sagittal sutures without other congenital anomalies or dysmorphic features. It is most likely that her craniosynostosis is secondary to fetal head constraint and abnormal mechanical forces related to gestation in a bicornuate uterus (Figure 1). Uterine malformations are relatively common, affecting up to 7% of the female population and 18% of women with recurrent pregnancy loss. Approximately 1-2% of women have a significant uterine abnormality (Moh *et al.* 2010) that poses a 30% general risk for fetal deformation. In their case-control study from 75 participating hospitals in Spain, Martinez-Frías *et al.* analyzed the outcome of 38 pregnancies (32 liveborn) in women with a bicornuate uterus noting a four-fold increase in congenital anomalies compared to women without a uterine anomaly. However, their data did not reach statistical significance for any particular anomaly (except nasal hypoplasia), possibly because of the limited sample size. The mothers with a bicornuate uterus also had significantly more uterine bleeding during pregnancy (54.1% vs. 14.1%), increasing the risk for some types of vascularly-mediated anomalies (disruptions), such as limb defects.

***"Intrauterine constraint causes fetal deformation by applying abnormal mechanical forces to the developing fetus, altering the shape of the trapped body parts. A fetal constraint has been implicated in the etiology of plagiocephaly, torticollis, micrognathia, limb contractures, pulmonary hypoplasia, congenital hip dislocation, talipes equinovarus, and craniosynostosis."***

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Intrauterine constraint causes fetal deformation by applying abnormal mechanical forces to the developing fetus, altering the shape of the trapped body parts. A fetal constraint has been implicated in the etiology of plagiocephaly, torticollis, micrognathia, limb contractures, pulmonary hypoplasia, congenital hip dislocation, talipes equinovarus, and craniosynostosis.

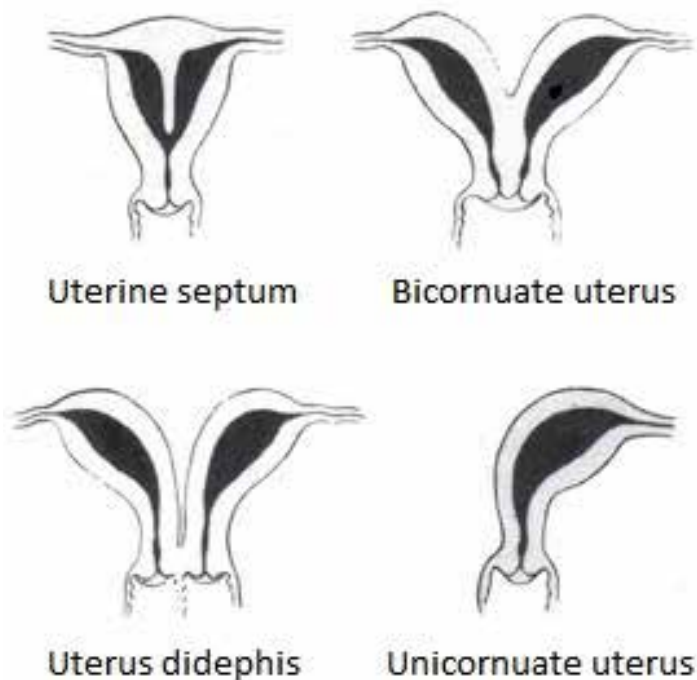
Over 40 years ago, Graham and Smith (the same Smith who authored "Smith's Recognizable Patterns of Human Malformation") and various colleagues published a series of reports illustrating the relationship between fetal head constraint and metopic, coronal, and sagittal craniosynostosis. They published what may have been the first report of metopic craniosynostosis in the child of a woman with a bicornuate uterus. In the same report, they described metopic craniosynostosis in one of monozygotic triplets reared in a small mother in which the affected fetal head had been wedged between the hips of the two unaffected siblings. In 1980, Higginbottom *et al.* reported five infants with craniosynostosis who had evidence of intrauterine constraint, including breech presentation, primigravidity, uterine malformations, amniotic bands, and defects in fetal neuromuscular development.

In 2010, Sanchez-Lara *et al.* reported fetal constraint as a risk factor for some types of craniosynostosis. Specifically: plurality and nulliparity were associated with a twofold increased risk for metopic craniosynostosis. Macrosomia had almost twice the risk of developing coronal craniosynostosis.

In our patient, genetic testing was not recommended. Based on her mother's history of bicornuate uterus, the lack of a family history of craniosynostosis, the absence of other congenital anomalies or dysmorphic features, and her normal or even superior developmental outcome, the chance of a genetic etiology for her craniosynostosis would be too low to justify the cost of the testing. Note that the patient's brother was unaffected, perhaps because he had the advantage of gestating in the somewhat larger parous bicornuate uterus.

#### Practical applications:

1. Infants born to women with uterine anomalies, such as a bicornuate uterus, may have a higher rate of congenital anomalies. Examine these infants carefully for deformations and vascularly-mediated disruptions.
2. Suspect intrauterine constraint in the etiology of craniosynostosis in the context of a breech or transverse lie, bicornuate uterus or other scenarios that restrict fetal movement, especially in a primigravida mother.
3. Fetal head constraint can cause craniosynostosis of any suture and even multiple sutures as in this child.



**Figure 1.** Types of bicornuate uterus malformation. Attribution: Wikimedia User: EternamenteAprendiz (CC BY-SA 4.0 <https://creativecommons.org/licenses/by-sa/4.0/deed.en>)

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**Figure 1**



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Disclosures: The authors have no relevant disclosures.

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

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

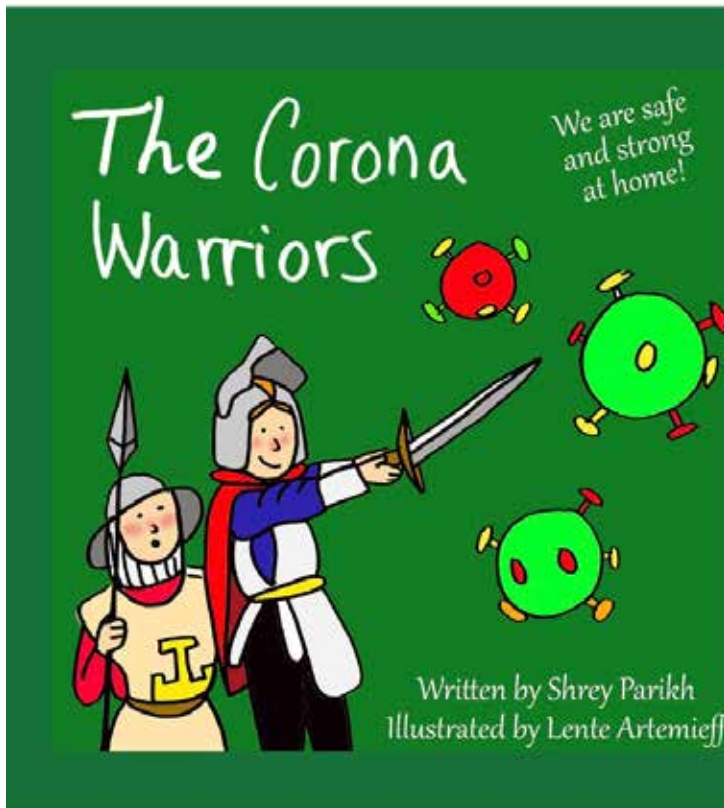
But risk factors associated with RSV don't touch all infants equally.\*

\*Source: Respirator Syncytial Virus and African Americans

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



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





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

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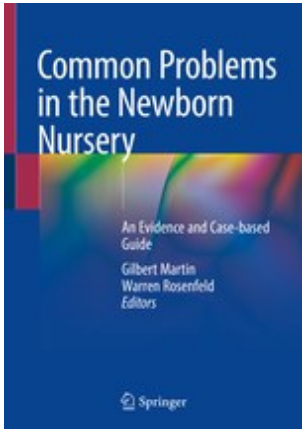
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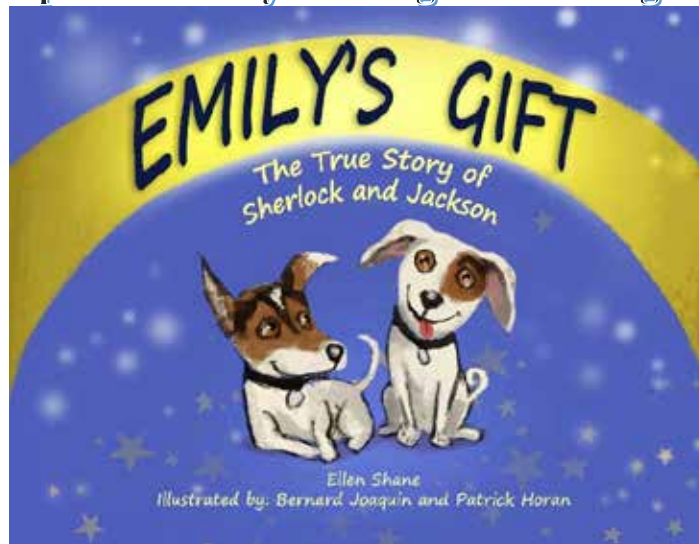
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## Black Maternal Health Crisis Captures White House Attention

Susan Hepworth



*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.*

America's maternal mortality rates are among the highest in the developed world. It is a crisis of epic proportions. Moreover, like many other crises, not all Americans are equitably affected.

Black mothers are **three to four** (1) times more likely to experience a pregnancy-related death than white women — regardless of their income or education level. The grievous statistic has caught the attention of the White House, which recently announced **initial actions** (2) to address the Black maternal health crisis.

***“Black mothers are three to four (1) times more likely to experience a pregnancy-related death than white women — regardless of their income or education level. The grievous statistic has caught the attention of the White House, which recently announced initial actions (2) to address the Black maternal health crisis.”***



The plan focuses on strengthening health equity by creating pregnancy medical home programs and expanding rural maternity care. These actions, among others, may help address gaps in care that stem from long-standing societal and health system factors. Black women are more likely to experience barriers to quality care, **studies** (1) show, and can face racial discrimination. In one **national study**, (3) 21% of Black mothers reported that hospital staff treated them poorly due to their race, ethnicity, or cultural background.

The White House's plan also includes an investment in implicit bias training for health care providers. The approach guides providers to adjust their thinking patterns in a way that can reduce discriminatory behaviors.

Such a shift in thought and behavior can improve outcomes and save lives. The Centers for Disease Control and Prevention suggested that at least **60%** (4) of Black maternal deaths could have been prevented by better knowledge of warning signs among patients and providers, among other factors.

Addressing racial disparities can also lower costs to the health care system. Researchers posited that eliminating racial disparities could generate **\$114 to \$214** (5) million per year in Medicaid cost savings from just 14 southern states.

Black women have suffered higher rates of maternal mortality for long enough. President Biden's actions and **proclamation** (6) are a critical acknowledgment of the Black maternal health crisis and a commitment to better protecting what is most at stake: the lives and long-term health of Black Americans.

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4. <https://www.cdc.gov/media/releases/2019/p0905-racial-ethnic-disparities-pregnancy-deaths.html>
5. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4039287/>
6. <https://www.whitehouse.gov/briefing-room/presidential-actions/2021/04/13/a-proclamation-on-black-maternal-health-week-2021/>

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.



Jennifer Heidi Goldstein Zadok  
April 14, 1966 - June 4, 2021  
May her memory be a blessing to those  
who knew her.

READ

NPA's  
statement:

**BLACK LIVES MATTER**



# The Premie Parent's SURVIVAL GUIDE to the NICU

By

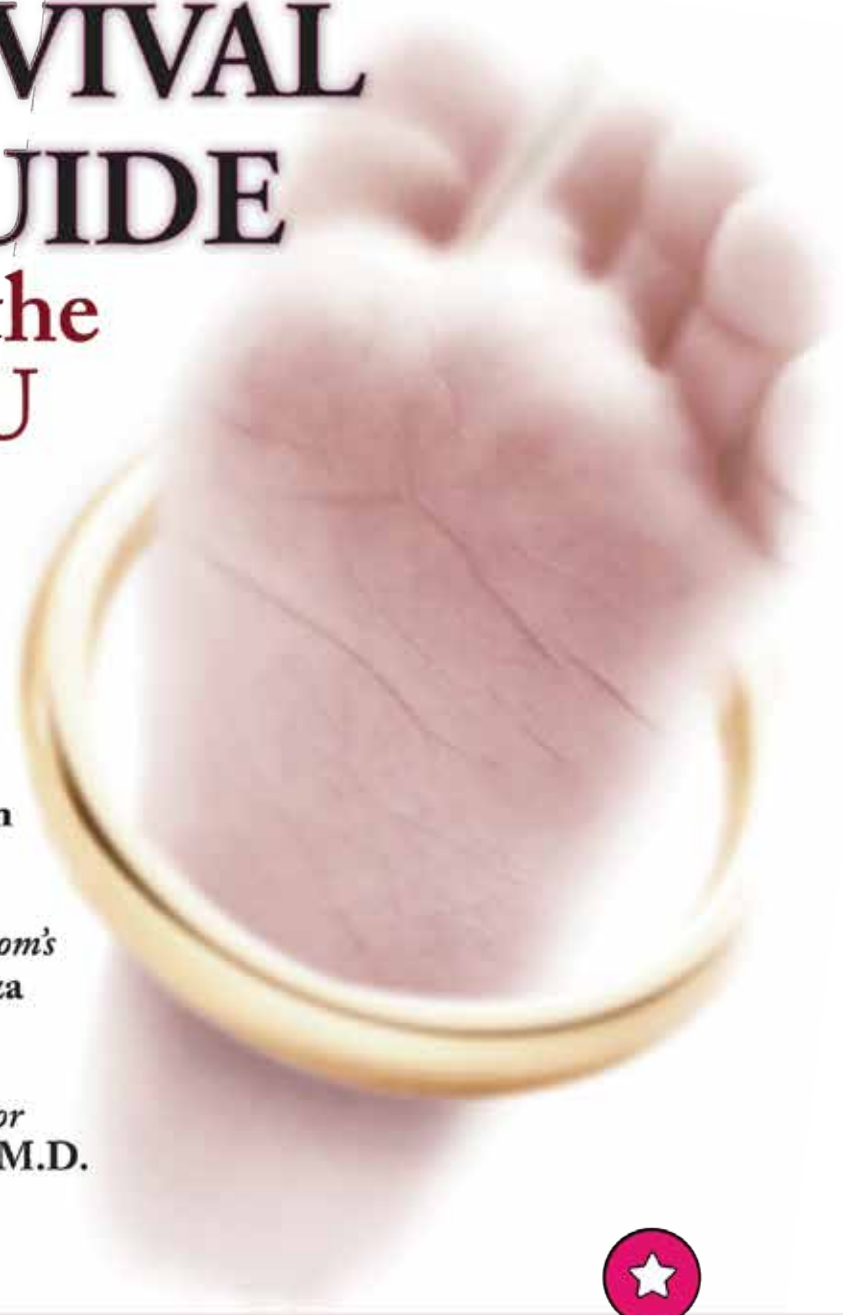
*little man's*  
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HOW TO  
MAINTAIN YOUR SANITY  
& CREATE A NEW NORMAL

second edition



# National Statistics

## Respiratory Syncytial Virus



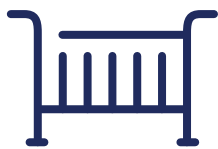
### About Respiratory Syncytial Virus

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

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

### National Health Plan Coverage & Access

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



#### "Gap" Babies

Commercial Plans Denied

**40%**

Medicaid: **25%**

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



#### "In-Guidance" Babies

Commercial Plans Denied

**25%**

Medicaid: **14%**

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

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

# National Perinatal Association PERINATAL SUBSTANCE USE

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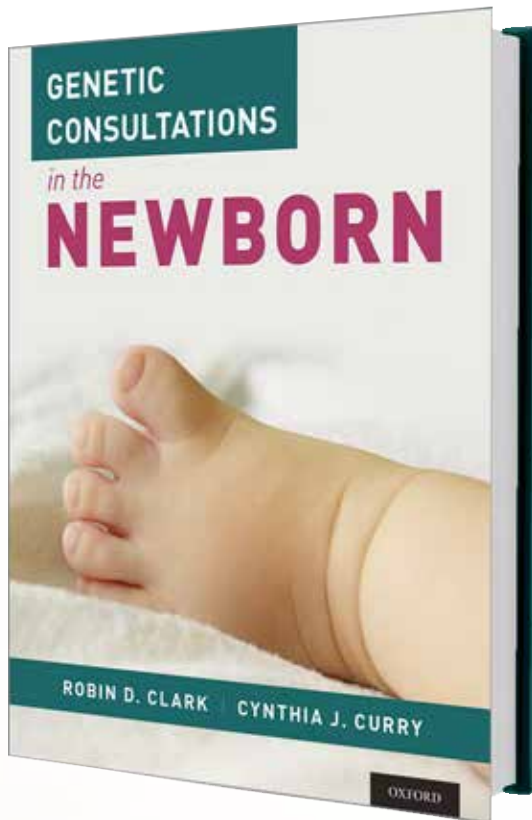
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# RSV AWARENESS:

## *A National Poll of Parents & Health Care Providers*

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

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

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

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

## KEY FINDINGS

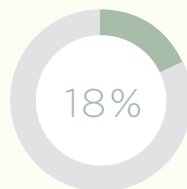
### *Preparedness*

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

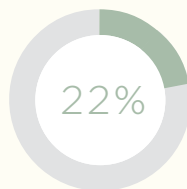
Specialty health care providers reiterated these concerns; 70% agreed that parents of their patients have a low awareness of RSV. Meanwhile, specialty health care providers themselves actively monitor for RSV. They reported that:

#### PARENTS

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

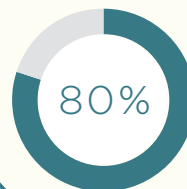


**Only 22% of parents consider themselves “very well prepared” to prevent RSV.**

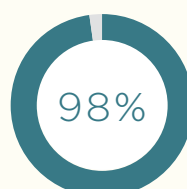


#### SPECIALTY HEALTH CARE PROVIDERS

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



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



# Clinical Pearl: The COVID-19 Pandemic and Breast Milk in the NICU and Obstetrics and Newborn Unit at the University of Chicago

Amy Meyer, RN, BSN, CLC, Christina Billy, MSN, Melissa Benesh, MSN., Poj Lysouvakon, MD, Joseph R Hageman, MD

***“The COVID-19 pandemic has had multiple effects on the care of pregnant patients and their infants prenatally, in labor and delivery, postpartum, well newborn and neonatal intensive care units (NICU) (1). One of these effects that we have noted in the Comer NICU is breastfeeding rates which are the lowest they have ever been.”***

The COVID-19 pandemic has had multiple effects on the care of pregnant patients and their infants prenatally, in labor and delivery, postpartum, well newborn and neonatal intensive care units (NICU) (1). One of these effects that we have noted in the Comer NICU is breastfeeding rates which are the lowest they have ever been. Furthermore, while nationally, breastfeeding rates have taken a 17% dip because of COVID, ours have dipped 20% (A Meyer, personal communication, June 9, 2021). The University of Chicago Medicine is a Baby-Friendly designated facility. As a Baby-Friendly hospital, we have instituted standardized workflows and practice guidelines and fostered a culture of breastfeeding positivity that is well documented and recognized by Baby-Friendly USA. Of note, our consistent, team-based implementation of these standards at all levels of care has led to our continued maintenance of Baby-Friendly standards in the well newborn unit. Our breastfeeding initiation rates still consistently meet the 80% goal set by Baby-Friendly USA despite the pandemic (personal communication, M Benesh, June 9, 2021).

New workflows created in the early part of the pandemic did not adequately address the needs of breastfeeding parents. Resource reallocation due to COVID, rescheduled appointments, and virtual clinic appointments may have led to decreased breastfeeding education. In addition, the pandemic had significantly decreased the amount of time from admission to delivery to discharge home. This shortened length of stay in the hospital; adaptation of, adjustments to, and time to familiarize ourselves with these new COVID-related workflows; and frequent staff shortages due to COVID infection or exposure have impacted our breastfeeding initiatives. As a result, our ability to assess the birthing parent's breastfeeding needs, supply breast pumps in the immediate postpartum period, and provide adequate support, education, and lactation services were negatively impacted. In the postpartum and well newborn units, we have addressed these challenges and mitigated the negative impacts on breastfeeding initiation. For those patients

who were unable or unwilling to initiate breastfeeding or breast pumping, the downstream result is decreased breastfeeding rates in those newborns who had to be transferred to the NICU. In addition, there have been challenges in providing follow-up lactation consultations post-hospital discharge, especially home lactation visits.

***“For those patients who were unable or unwilling to initiate breastfeeding or breast pumping, the downstream result is decreased breastfeeding rates in those newborns who had to be transferred to the NICU. In addition, there have been challenges in providing follow-up lactation consultations post-hospital discharge, especially home lactation visits.”***

Some of the barriers and fears which have been discussed in the Medela White Paper leading to COVID-related stress include the following: (1) giving birth without the support of a partner, (2) fear of infection, (3) reduced access to support for maternal health and breastfeeding, (4) confusing changes in breastfeeding and birthing recommendations, (5) physical distancing and containment measures, (6) financial concerns due to loss of income during lockdowns (3). These stressors then make early breastfeeding and pumping more challenging for new mothers.

This passage is the conclusion paragraph from the Medela 'Preserving Breastfeeding in the Age of COVID' White paper (3):

- “It is clear that the COVID-19 pandemic has had a marked impact on maternity and breastfeeding practices.
- As the pandemic progressed, our understanding of the decreased risk of transmitting infection from mothers to their infants via breast milk has been confirmed (4).
- Evidence also showed the protective value of human milk against the virus, with neutralizing antibodies being detected in milk from previously infected women (5-8).
- It is therefore largely recognized that breastfeeding should be encouraged and supported even in women infected with COVID-19. Healthcare professionals can provide invaluable guidance and support to help mothers breastfeed successfully, despite the challenges posed by the pandemic and infection control measures.
- During the mother's hospital stay, mothers and babies should be kept together and supported to initiate lactation appropriately.



- Given the shortened length of maternal stay in COVID-19 times, it is imperative that community-based support and hospital-grade pump technology are prescribed as appropriate and become indications in clinical guidelines (3)".

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**Disclosures:** The authors have no conflicts to disclose

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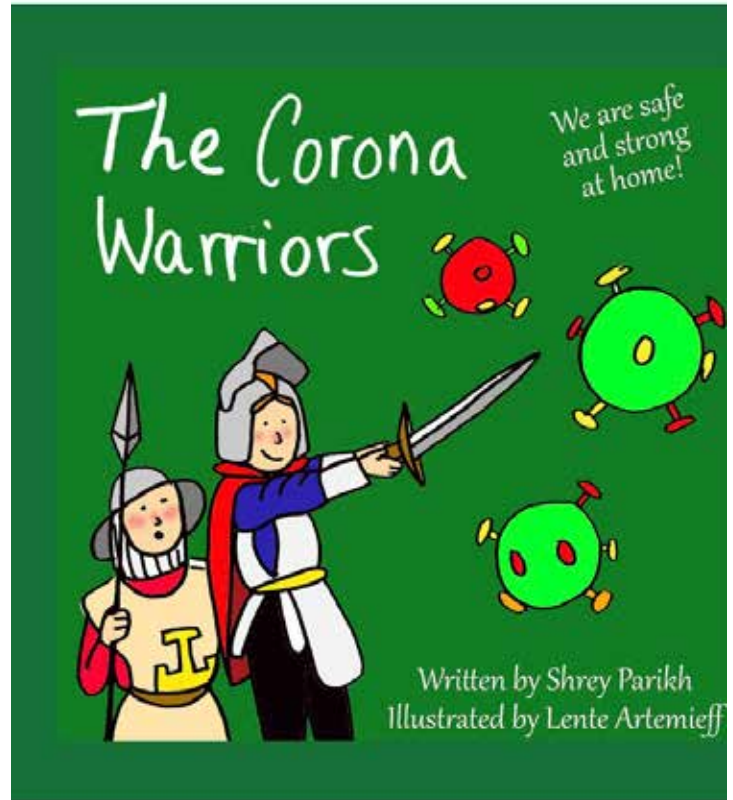
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## OPIOIDS and NAS

When reporting on mothers, babies, and substance use

# LANGUAGE MATTERS



### I am not an addict.

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



### I was exposed to opioids.

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



### NAS is a temporary and treatable condition.

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



### My mother may have a SUD.

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

### My potential is limitless.

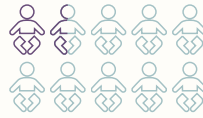
I am so much more than my NAS diagnosis. My drug exposure will not determine my long-term outcomes. But how you treat me will. When you invest in my family's health and wellbeing by supporting Medicaid and Early Childhood Education you can expect that I will do as well as any of my peers!



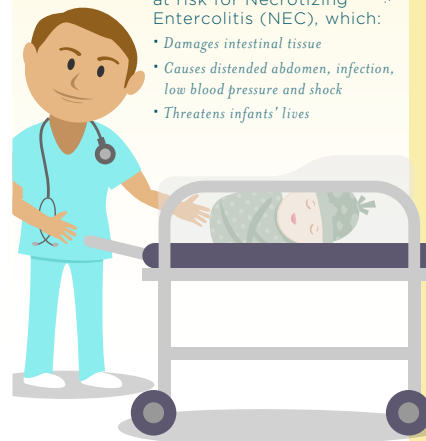
Learn more about Neonatal Abstinence Syndrome at [www.nationalperinatal.org](http://www.nationalperinatal.org)



## Why PREMATURE INFANTS Need Access to an EXCLUSIVE HUMAN MILK DIET



In the United States, more than **1 IN 10 BABIES ARE BORN PREMATURE**. Micro preemies are born severely premature, weighing less than 1,250 grams.

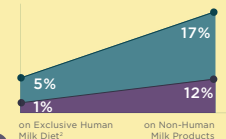


### MICRO PREMIES are at risk for Necrotizing Enterocolitis (NEC), which:

- Damages intestinal tissue
- Causes distended abdomen, infection, low blood pressure and shock
- Threatens infants' lives

NEC occurrence increases when a preemie consumes non-human milk products.

When that happens:



Micro preemies who get NEC

Micro preemies requiring surgery to treat NEC

30% of micro preemies needing surgery will die from NEC†

## HOW TO HELP PREVENT NEC: EXCLUSIVE HUMAN MILK DIET

What is an Exclusive Human Milk Diet?



NO cow's milk

NO sheep's milk

NO goat's milk

NO formula

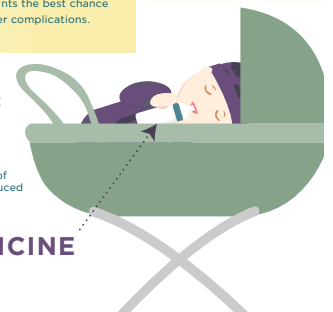
- ✓ mother's milk
- ✓ human donor milk
- ✓ human milk-based fortifier

### Why Is An Exclusive Human Milk Diet Important?

An Exclusive Human Milk Diet gives vulnerable infants the best chance to be healthy and reduces the risk of NEC and other complications.

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

- Mortality is reduced by **75%**\*
- Feeding intolerance decreases\*
- Chances of NEC are reduced by **77%**†



## HUMAN MILK = MEDICINE

LEARN MORE ▶



\* Hair AB, et al. "Beyond Necrotizing Enterocolitis Prevention: Improving Outcomes with an Exclusive Human Milk-Based Diet." *Breastfeeding Medicine* 2015; 10:106-116. DOI: 10.1089/bfm.2015.0124

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work with your medical  
team to create a plan

## GET CLEAN WASH YOUR HANDS, ARMS, and CHEST

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



## PUT ON FRESH CLOTHES

change into a clean  
gown or shirt.

## IF COVID-19 + WEAR A MASK

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



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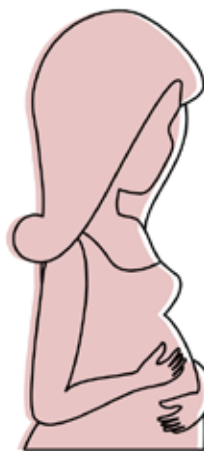
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## Update: CORONAVIRUS COVID-19



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

2 to 3 servings per week of properly cooked fish can provide health benefits for pregnant women and babies alike:



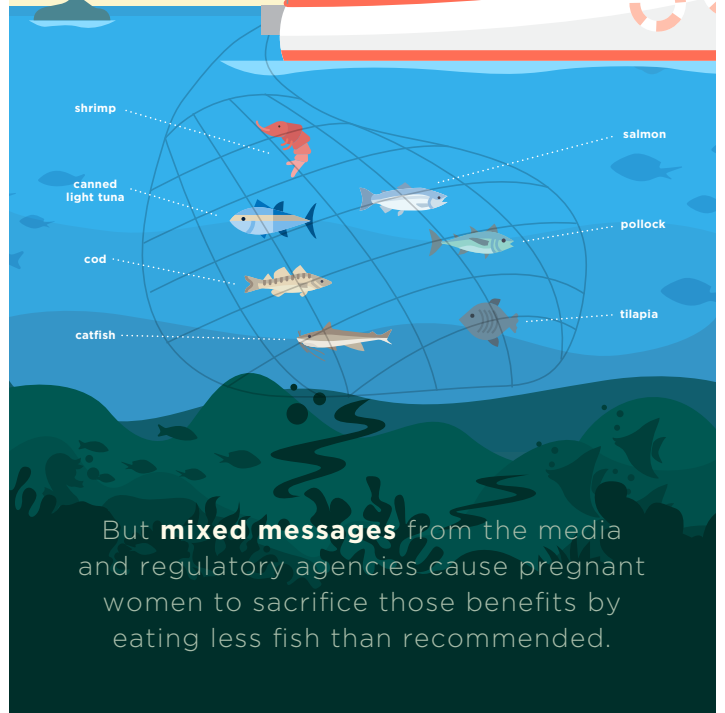
Iron



Omega 3 fatty acids



Earlier Milestones for Babies



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



Did you know that PMAD related suicides account for **20%** of Postpartum Maternal Deaths?

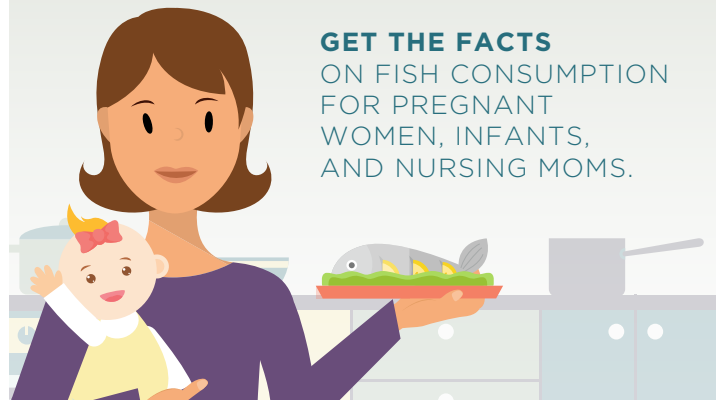
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Breastfeeding Innovations Team



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

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Protecting Access for Premature Infants through Age Two

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## Letters to the Editor

### Follow up to The Importance of Specialized Nursing Care for NICU Patients and Families

*“As you will recall, the impetus for this article was the response, from a group of California Neonatal Clinical Nurse Specialists, about a new draft that was put out by the California Children’s Services (CCS) outlining a significant change in the specifications related to the role of the CNS in the Neonatal Intensive Care Unit (NICU).”*

Dear Dr. Goldstein:

This is in response to the article published back in March titled “Neonatal Clinical Nurse Specialist: The Importance of Specialized Nursing Care for NICU Patients and Families.”

As you will recall, the impetus for this article was the response, from a group of California Neonatal Clinical Nurse Specialists, about a new draft that was put out by the California Children’s Services (CCS) outlining a significant change in the specifications related to the role of the CNS in the Neonatal Intensive Care Unit (NICU).

The exposure we received in the March publication of Neonatology Today was an enormous help in bringing to light the significant problems with the misunderstanding of the CNS role in the Neonatal Intensive Care Unit. This publication also provided some much-needed clarification on the differences in Advanced Practice Registered Nursing roles, Clinical Nurse Specialist, Neonatal Nurse Practitioner, and Nurse Educator role as it pertains to fulfilling their individual scope of practice in the NICU. I recently had the opportunity to share our plight with a group of CNSs from across the nation, and when I shared with them the publication in Neonatology Today, it gave them a sense of pride and renewed strength, reminding them that there are still ways to have our voices heard. Many CNS’s struggle with administrative and other healthcare professionals not understanding the CNS’s full scope of practice as an Advanced Practice Registered Nurse (APRN), and the lack of understanding doesn’t stop at that level; it trails all the way up to the state levels and varies greatly across the nation.

I wanted to take this time to write you and thank you for the support in publicizing this article on behalf of all Clinical Nurse Specialists. In doing so, this has helped not only our cause in the NICU but has ignited a fire and renewed passion in helping the campaign to resolve the inconsistency in the scope of practice for the Clinical Nurse Specialist in the Advance Practice Arena in all areas across the nation. Lastly, I want to share with the readers that since the submission of this letter directly to CCS, they have taken into consideration our concerns and listened to our argument regarding the changes they wanted to make. CCS instead has decided to keep the role of the CNS intact as it was originally stated in the CCS regulations, which defines the

Neonatal CNS as being the best suited to manage the complex health care needs for the Neonatal Intensive Care Unit. We are grateful for their consideration and discernment in seeing the value that the CNS brings to this very special and fragile patient population and to the entire NICU healthcare team.

*“We are grateful for their consideration and discernment in seeing the value that the CNS brings to this very special and fragile patient population and to the entire NICU healthcare team.”*

Thank you for your support,

Nancy Simmons, MSN, CNS-NICU, RNC

Dear Ms. Simmons,

Thank you very much for your kind words. It is reassuring to know that the Clinical Nurse Specialist role will be kept intact in the NICU here in California according to the original CCS regulations. As you are well aware, this challenge to the traditional nursing infrastructure would have made it very difficult, if not improbable, to assure uniform quality of care across the NICUs in California. The complex health care needs supported by the role provide the backbone for advanced practice nursing in this venue.

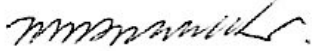
Indeed, this issue is present nationwide and is not confined to the NICU. However, support for the CNS role and advanced practice is requisite for compliance with increasing complex protocols and best practice guidelines. More importantly, this role has supported various quality improvement initiatives statewide and is a significant impetus to CPQCC and the success of this collaborative. Any dilution of this role would be counterintuitive and potentially disrupt care pathways by removing the architect of best practice and continuous quality improvement in the NICU.

Neonatology Today is pleased that this “inconsistency in the scope of practice” has been taken seriously by CCS and that the CNS role will continue to provide the necessary support for our most at-risk neonates.

*“Neonatology Today is pleased that this “inconsistency in the scope of practice” has been taken seriously by CCS and that the CNS role will continue to provide the necessary support for our most at-risk neonates.”*

We believe that we must provide a platform, not only for research, opinion editorials, and original research but in publicizing concerns that affect our practice and our patients directly. Although the scope of this decision only pertains to California NICUs, we hope that through our subscriber base, knowledge of the need for this role may inspire other regions both in the United States and abroad and other care areas to investigate the need for a CNS's full scope of practice as an APRN in provisioning quality of care and quality improvement metrics.

Sincerely,



Mitchell Goldstein, MD

Editor in Chief



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c/o Mitchell Goldstein, MD

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

Please address your response in the form of a letter. For further formatting questions and submissions, please contact Mitchell Goldstein, MD at [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com).

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### Erratum (Neonatology Today May 2021)

Neonatology Today is not aware of any erratum affecting the May, 2021 edition.

Corrections can be sent directly to [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com). The most recent edition of Neonatology Today including any previously identified erratum may be downloaded from [www.neonatologytoday.net](http://www.neonatologytoday.net).

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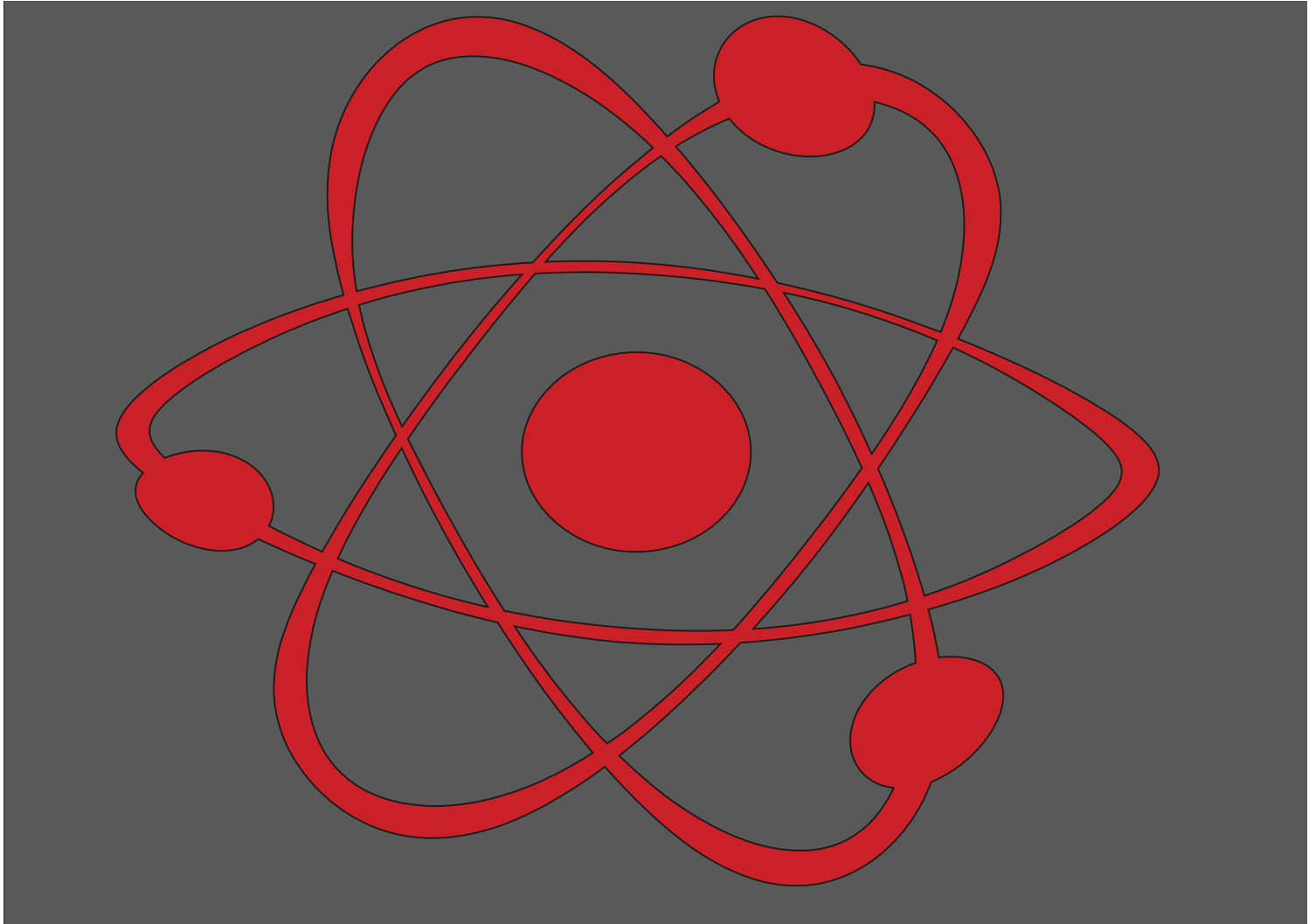
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ISSN: 1932-7137 (Online), 1932-7129 (Print)

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Will your **PRETERM INFANT** need **EARLY INTERVENTION** services?

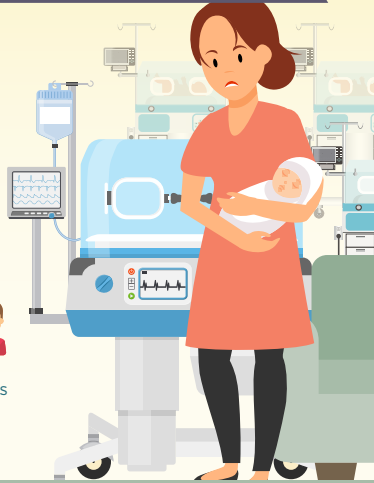
Preterm infants are:

**2x** more likely to have developmental delays

**5x** more likely to have learning challenges



**1 in 3** preterm infants will require support services at school



Early intervention can help preterm infants:



Enhance language and communication skills



Build more effective learning techniques



Process social and emotional situations



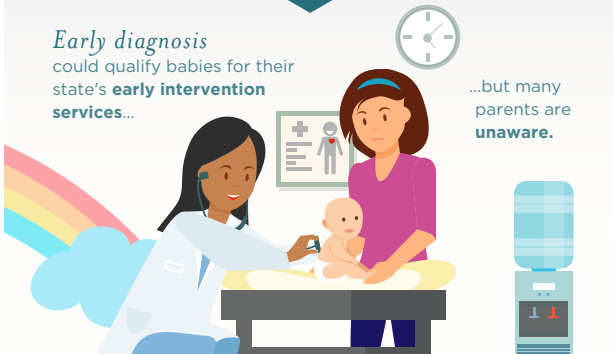
Address physical challenges



Prevent mild difficulties from developing into major problems

Early diagnosis could qualify babies for their state's **early intervention services**...

...but many parents are **unaware**.



**NICU staff, nurses, pediatricians and social workers should talk** with NICU families about the challenges their baby may face.

Awareness, referral & timely enrollment in early intervention programs can help **infants thrive** and grow.



**NCFIH** National Coalition for Infant Health  
Protecting Access for Premature Infants through Age Two  
[www.infanthealth.org](http://www.infanthealth.org)

Visit [CDC.gov](http://CDC.gov) to find contact information for your state's early intervention program.

Las nuevas mamás necesitan acceso a la detección y tratamiento para **LA DEPRESIÓN POSTPARTO**



**1 DE CADA 7** MADRES AFRONTA LA DEPRESIÓN POSTPARTO, experimentando



Sin embargo, sólo el **15%** recibe tratamiento!

LA DEPRESIÓN POSTPARTO **NO TRATADA PUEDE AFECTAR:**

El sueño, la alimentación y el comportamiento del bebé a medida que crece?



La salud de la madre

La capacidad para cuidar de un bebé y sus hermanos

PARA AYUDAR A LAS MADRES A ENFRENTAR LA DEPRESIÓN POSTPARTO



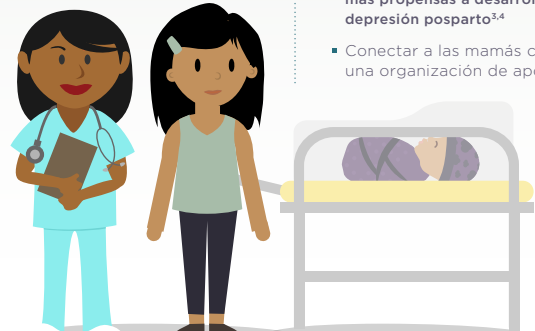
**LOS ENCARGADOS DE FORMULAR POLÍTICAS PUEDEN:**

- Financiar los esfuerzos de despistaje y diagnóstico
- Proteger el acceso al tratamiento



**LOS HOSPITALES PUEDEN:**

- Capacitar a los profesionales de la salud para proporcionar apoyo psicosocial a las familias... **Especialmente aquellas con bebés prematuros, que son 40% más propensas a desarrollar depresión postparto**<sup>3,4</sup>
- Conectar a las mamás con una organización de apoyo



**NCFIH** National Coalition for Infant Health  
Protecting Access for Premature Infants through Age Two  
[www.infanthealth.org](http://www.infanthealth.org)

<sup>1</sup> American Psychological Association. Accessed on: <http://www.apa.org/women/resources/reports/postpartum-depression.aspx>

<sup>2</sup> National Institute of Mental Health. Accessed on: <http://www.nimh.nih.gov/health/publications/postpartum-depression-facts/index.shtml>

<sup>3</sup> Journal of Perinatology (2015) 35, 529–536. doi:10.1097/JP.0000000000000147

<sup>4</sup> Prevalence and risk factors for postpartum depression among women with problem and low-birth-weight infants: a systematic review. Vigod SN, Villages L, Dennis CL. *PLoS One* 2010 Apr; 11(7):1540-50.

## Upcoming Medical Meetings

44<sup>th</sup> Annual Conference on Neonatal  
Perinatal Medicine  
June 17 - 21, 2021  
AAP District VIII Section on  
Neonatal-Perinatal Medicine  
<https://nm2020.district8sonpm.org/>

American Academy of Pediatrics  
National Conference and Exhibition  
October 8-12, 2021  
Philadelphia, PA  
<https://aapexperience.org/>

Hot Topics in Neonatology®  
Gaylord National  
National Harbor, MD  
December 6-8, 2021  
<http://www.hottopicsinneonatology.org/>

42<sup>nd</sup> Conference on Pediatric Health  
Care.  
Phase 1:  
March 10-13 (Orlando, FL)  
Phase 2:  
March 24-27 (Virtual)  
NAPNAP  
<https://www.napnap.org/national-conference/>

NEO: The Conference for  
Neonatology  
Feb 23-25, 2022  
San Diego, CA  
[www.neoconference.com](http://www.neoconference.com)

Specialty Review in Neonatology  
Feb 21-26, 2022  
San Diego, CA  
[www.specialtyreview.com](http://www.specialtyreview.com)

*For up to date Meeting  
Information, visit  
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- 24/7 coverage provided by NNP team and Fellows



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RSV



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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 provided by Paula Whiteman, MD. Is Art Imitating Life or Life Imitating Art? Our Bird for this month is provided by Yasmine Razi, OSMIII who provides us with "A Peacock."

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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](mailto: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 7<sup>th</sup> may also be used). Bibliography Software should be used to facilitate formatting and to ensure that the correct formatting and abbreviations are used for references.

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

10. Only manuscripts that have not been published previously will be considered for publication except under special circumstances. Prior publication must be disclosed on submission. Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.

11. NT recommends reading Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals from ICMJE prior to submission if there is any question regarding the appropriateness of a manuscript. NT follows Principles of Transparency and Best Practice in Scholarly Publishing (a joint statement by COPE, DOAJ, WAME, and OASPA). Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.

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**NEONATOLOGY TODAY is interested in publishing manuscripts from Neonatologists, Fellows, NNPs and those involved in caring for neonates on case studies, research results, hospital news, meeting announcements, and other pertinent topics.**

**Please submit your manuscript to: [LomaLindaPublishingCompany@gmail.com](mailto:LomaLindaPublishingCompany@gmail.com)**



# NICU BABY'S Bill of Rights

## 1- THE RIGHT TO ADVOCACY

My parents know me well. They are my voice and my best advocates. They need to be knowledgeable about my progress, medical records, and prognosis, so they celebrate my achievements and support me when things get challenging.

## 2- THE RIGHT TO MY PARENTS' CARE

In order to meet my unique needs, my parents need to learn about my developmental needs. Be patient with them and teach them well. Make sure hospital policies and protocols, including visiting hours and rounding, are as inclusive as possible.

## 3- THE RIGHT TO BOND WITH MY FAMILY

Bonding is crucial for my sleep and neuroprotection. Encourage my parents to practice skin-to-skin contact as soon as and as often as possible and to read, sing, and talk to me each time they visit.

## 4- THE RIGHT TO NEUROPROTECTIVE CARE

Protect me from things that startle, stress, or overwhelm me and my brain. Support things that calm me. Ensure I get as much sleep as possible. My brain is developing for the first time and faster than it ever will again. The way I am cared for today will help my brain when I grow up. Connect me with my parents for the best opportunities to help my brain develop.

## 5- THE RIGHT TO BE NOURISHED

Encourage my parents to feed me at the breast or by bottle, whichever way works for us both. Also, let my parents know that donor milk may be an option for me.

## 6- THE RIGHT TO PERSONHOOD

Address me by my name when possible, communicate with me before touching me, and if I or one of my siblings pass away while in the NICU, continue referring to us as multiples (twin/triplets/quads, and more). It is important to acknowledge our lives.

## 7- THE RIGHT TO CONFIDENT AND COMPETENT CARE GIVING

The NICU may be a traumatic place for my parents. Ensure that they receive tender loving care, information, education, and as many resources as possible to help educate them about my unique needs, development, diagnoses, and more.

## 8- THE RIGHT TO FAMILY-CENTERED CARE

Help me feel that I am a part of my own family. Teach my parents, grandparents, and siblings how to read my cues, how to care for me, and how to meet my needs. Encourage them to participate in or perform my daily care activities, such as bathing and diaper changes.

## 9- THE RIGHT TO HEALTHY AND SUPPORTED PARENTS

My parents may be experiencing a range of new and challenging emotions. Be patient, listen to them, and lend your support. Share information with my parents about resources such as peer-to-peer support programs, support groups, and counseling, which can help reduce PMAD, PPD, PTSD, anxiety and depression, and more.

## 10- THE RIGHT TO INCLUSION AND BELONGING

Celebrate my family's diversity and mine; including our religion, race, and culture. Ensure that my parents, grandparents, and siblings feel accepted and welcomed in the NICU, and respected and valued in all forms of engagement and communication.

Presented by:



## NICU Parent Network

NICU PARENT NETWORK

Visit [nicuparentnetwork.org](http://nicuparentnetwork.org) to identify national, state, and local NICU family support programs.

\* The information provided on the NICU Baby's Bill of Rights does not, and is not intended to, constitute legal or medical advice. Always consult with your NICU care team for all matters concerning the care of your baby.

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