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The World Health Organization has Global Guidelines on Handling Cells, Tissue, Blood and Semen-- So Why is Breast Milk Left in the Dark?

Jasmine Shafquat, JD

Sharing breast milk is an ancient and well-established practice. In fact, Greek and Roman mythology, the Bible, the Torah, and Islamic scripture all describe women who shared their breast milk with children that were not their own kin. Despite the fact that this primeval practice is continuously used in modern times to save preterm lives, there are no global guidelines or regulations on breast milk sharing. By comparison, there are international standards for how cells, tissue, blood, and semen should be screened, selected, and shared. This gap in regulation is especially alarming given that donated breast milk is received by the world’s most vulnerable population. Because there is a vast array of knowledge, experience, and research on safe and effective milk banking systems, it is time for the World Health Organization to implement a set of standards regarding the treatment and distribution of banked breast milk. Global direction on human milk banking would help frame some of the concerns, expedite their resolution, and remove the stigma associated with this practice. This Note will give a pragmatic set of recommendations for the World Health Organization to adopt. This Note will begin by discussing the worldwide proliferation of breast milk banks. It will then analyze differing breast milk networks in Brazil, Norway, and the United States to identify best practices for the World Health Organization to adopt. This Note will then address the current state of the regulatory gap and discuss the substantial and important role WHO plays in addressing this concern. Finally, the Note will analyze differing breast milk networks in Brazil, Norway, and the United States to identify best practices for human milk banking.

Introduction

Breast milk has always been highly regarded as a vital source of nutrition and has even earned the nickname “liquid gold.” (1) Over the last several decades, there has been an increased interest in selling and sharing breast milk across the globe. (2-5) This is, at least in part, due to substantial changes in the process of breast milk sharing. The practice of milk sharing originated with wet nursing, which was considered a “practical way to provide nutrition for infants and reinforce social class distinctions.” (6) The practice of breast milk sharing has since changed due to changes in clinic knowledge, technological advancements, and social norms and further discussion of these changes will be in part II. Particularly, the informal circulation of breast milk has now become more accessible with Facebook, Craigslist, and a plethora of other websites providing a platform for these exchanges to occur. (7, 8) Moreover, the formal distribution of breast milk, through institutionalized human milk banking systems, has multiplied considerably over the past few decades. There are now an estimated 500 human milk banks operating in more than thirty-seven countries. (3) This Note will primarily focus on the new formal method of breast milk distribution because the nutrition community has generally discouraged informal breast milk sharing (6, 9, 10) and encouraged institutionalized breast milk banking. (2)

“The question then arises, why has WHO failed to endorse standards regarding breast milk handling when it has historically endorsed other similar standards, (14) especially in light of the fact that it advocates for the use of donor human milk?”

This Note proposes that WHO can and should provide “best practices” regarding the selection and examination of breast milk. This Note will justify the recommended response by first examining the factors contributing to the booming market in banked donor milk. It will then address the current state of the regulatory gap and discuss the substantial and important role WHO plays in addressing this concern. Finally, the Note examines milk banking practices in Brazil, Norway, and the United States to identify best practices for WHO to endorse. Based on these countries’ experiences, as well as what is accepted by the scientific community, the Note then proposes that WHO should adopt specific guidelines for selecting breast milk donors and collecting, processing, handling, testing, and storing breast milk. By adopting the proposed standard, WHO can clarify confusion regarding its own recommendations, increase the chances of infant health and infant survival, and ultimately become one step closer to achieving its global health target in promoting the health and safety of infants and young children. (16)

Background: What is Driving the Booming Market in Breast Milk Banking?

Social attitudes regarding donor milk and milk sharing have fluctuated over time. In 1914, “donor banked milk” entered the medical literature when a physician noted that sick children “do very much better if they are fed wholly or in part on human milk.” (8) Thereafter, donor milk banks slowly started emerging in hospitals. By the
1980s, the number of milk banks began to increase dramatically. However, in the early 1990s, donor milk banks began to decline due to a growing fear of HIV transmission and the increased availability of “specialty infant formulas.” The current trend reveals that breast milk banking is becoming much more accepted and appreciated on an international scale. (17) A 2016 study on Kenyan public attitudes demonstrated that even when people were unfamiliar with the concept of human milk banks, most people supported human milk banks once they became educated on how breast milk banks operated. (18) Further, the growing demand for human milk and the subsequent increase in breast milk banking is unlikely to dwindle due to a combination of the following factors: the increased body of knowledge establishing breast milk as the optimum source of nutrition; some of the barriers to breastfeeding compelling mothers to select alternative infant feeding options; the investment in breast milk banks due to the global influx in preterm birth rates; and various socio-cultural changes. It should be noted that this Note only discusses some of the leading factors contributing to the demand in breast milk, it is in no way an exhaustive list of reasons for this increase.

World-Wide Recognition that “Breast is Best”

International acknowledgment and support that breast milk is the optimal feeding option is pushing the proliferation of institutionalized breast milk banks. (2) First, global advocacy for breast milk is exemplified by WHO’s own directive, which provides that in health situations where an infant cannot or should not use her mother’s milk, donated breast milk is the best alternative and infant formula is regarded as the less desirable alternative. (15) This is largely because breast milk is species specific. Even the most advanced, high-quality infant formulas cannot replicate the “bioactive matrix of benefits” that breast milk provides. (19) This is not to say that babies cannot grow up happy and healthy on infant formulas. (20) However, scientific and medical research has established that breast milk is essential for proper growth, nutrition, and the prevention of complications that could result in longer-term care, expenses, or premature death. Nonetheless, it is crucial that vulnerable infants—such as those who are born preterm or with low birth weight, are orphaned, or are severely malnourished—have access to human breast milk for proper growth, nutrition, and the prevention of infections or other complications that may lead to longer-term care, expenses, or premature death. (3, 21) Specifically, evidence-based research demonstrates that formula feeding is linked with an increased risk of necrotizing enterocolitis (NEC) (22), sudden infant death syndrome (SIDS) (23), ), and childhood obesity. (24) It is undeniable that breast milk is the most inexpensive, sustainable, and accessible method to provide all children, rich or poor, with the healthiest start to life. (11) There are some individuals that believe the benefits of breast milk are overemphasized, arguing that many studies on the benefits of breastfeeding are biased because women who breastfeed differ than those who do not—based on income, education, and race. They also argue that very few breastfeeding studies adjust for these differences across women and those studies that do adjust for the aforementioned factors, are not reliable because there are other unaccounted for characteristics that could be influencing the data, such as maternal IQ. (1) However, it is almost universally accepted that breast milk is the ideal source of nutrients for infants. (19)

Barriers to Breastfeeding

A woman’s decision to breastfeed is extremely complex. (25) Understanding some of the factors that influence a mother’s decision to breastfeed can help explain why breast milk has become progressively popular. For some women, breastfeeding is simply not a viable choice. Women with “insufficient glandular tissue (hypoplastic breasts), polycystic ovary syndrome (PCOS), hypothyroidism, a previous breast surgery, or prior radiation treatment for breast cancer” may not have the ability to produce a sufficient breast milk supply. (26) Additionally, some mothers may smoke cigarettes, drink alcohol, take medication, or have diseases that can be passed to their baby through breast milk. In those instances, the risk of transmitting certain substances or diseases greatly outweighs the benefits of breastfeeding. Still, it is important to note that alcohol and cigarettes can both be used while breastfeeding, in moderation. For instance, mothers may choose to express milk and bottle feed to prevent exposure to smoke or to time feeds depending on when substances will be present in the milk. (27) Research has also identified that “having an unsupportive partner, feeling embarrassed, [and] concerns about pain” are some other reasons why a woman may not initiate breastfeeding. (28) Even though breastfeeding is widely considered superior to other forms of infant feeding, many mothers are nonetheless pressed to choose a different feeding option because breastfeeding is unsafe, impossible, or undesirable. (19)

“Feeding babies exclusively with human milk in the first hours, days, and months of life has the greatest potential impact on child survival and development. It is therefore imperative that preterm infants and also those who have low birth weights, are orphaned, or are severely malnourished, have access to human breast milk in order to prevent unnecessary neonatal deaths.”

Global Influx in Preterm Birth Rates

Another factor contributing to the growth of human milk banks is the global influx in preterm birth rates. Each year there are approximately 15 million babies born prematurely (one in ten of all babies born around the world). Almost all countries, rich and poor, are experiencing an increase in premature births. The proliferation in premature birth rates is especially problematic because prematurity is the world’s leading cause of neonatal deaths. (29) Notably, a majority of these neonatal deaths are preventable and of all existing approaches, “feeding babies exclusively with human milk in the first hours, days, and months of life has the greatest potential impact on child survival and development. It is therefore imperative that preterm infants and also those who have low birth weights, are orphaned, or are severely malnourished, have access to human breast milk in order to prevent unnecessary neonatal deaths.” Consequently, investments in human milk banks are emerging all over the world as an effective mechanism to save preterm lives and advance the chances of survival of all vulnerable infants. (30)

Cultural-Shifts

The increased demand for sharing and selling breast milk can also be attributed to several socio-cultural changes across the globe. One of the most significant changes of the last century has been the substantial increase in women participating in the labor force. (31) Although working is not dispositive of a woman’s ability to breastfeed, “returning to work” is the most common reason that women stop breastfeeding and start supplementary feeding options. It should be noted that there are local and national laws, as well as corporate policies, put into place to support breastfeed-
ing breaks and facilities in the workplace. (32) However, women at higher paying jobs are the ones that disproportionately experience the benefits of these initiatives. For instance, new mothers who work at Starbucks’ corporate headquarters are able to pump breastmilk in lactation rooms with plush recliners whereas new mothers who staff the chains counters are restricted to pumping their milk in small restrooms intended for customers. (33) The harsh reality is that a vast number of companies still do not accommodate their employees with clean facilities for pumping and storing milk. Of the companies that do provide the necessary facilities, many employees are still subjected to timed breaks that make compliance very difficult or virtually impossible. (32) Subsequently, obtaining donor human milk is just one way for some working mothers to circumvent the obstacles of pumping at work. (34) Another socio-cultural change contributing to the demand in human milk likely stems from the increased number of couples adopting and using reproductive technology. Correspondingly, male same-sex parents, in particular, who want to raise their children on human milk have turned to breast milk banks to feed their infant children. This also extends to non-binary or non-gender identifying couples, or single fathers. (35) Lastly, there are several “wholesome” or “natural” food movements contributing to a preference for “natural” breast milk over “artificial” infant formulas. (17) For those parents with the resources to choose, many are opting for donated human milk rather than formulas derived from plants grown with pesticides and fertilizers. (36)

Dangers of the Regulatory Gap

Many parts of the world have no substantive regulation over breast milk sharing at all. (13) The absence of standards regarding breast milk sharing can result in health risks that endanger the lives of susceptible infants. (8) Some of these health risks include the transmission of certain infectious agents, like bacteria or viruses, from women who are not experiencing or showing symptoms themselves. (9) Particularly, CMV, HTLV-I, HIV 1 and 2, human T-cell leukemia virus 1 and 2, hepatitis B, hepatitis C, and syphilis are just some of the agents that can be transmitted through breast milk. (37) In addition, medicine and drugs can also be unintentionally transferred from contributor to recipient infant if proper screening and testing procedures are not in place. Furthermore, unhygienic storage and handling of breast milk can result in environmental contaminants that cause infection or disease. (9) The regulatory gap on breast milk sharing can also have an adverse impact on the emotional well-being of the parents who sought to give their infant optimal nutrition, but instead served their child contaminated breast milk. Some parents may be so embarrassed or ashamed that their child became sick from contaminated breastmilk that they are unwilling to disclose or report what happened, which further exacerbates the issue. (8)

“Many parts of the world have no substantive regulation over breast milk sharing at all. (13) The absence of standards regarding breast milk sharing can result in health risks that endanger the lives of susceptible infants.”

An additional risk of the regulatory gap is that it creates a “gray market” where sharing and selling breast milk is unregulated, but not illegal. (38, 39) This “gray market” in breast milk subsequently spreads misinformation and allows individuals to sell counterfeit or diluted breast milk without consequence. (38) Furthermore, when breast milk is obtained off the internet, it can be more difficult to prove that an infant’s sickness or condition was caused by the contaminated breastmilk. (1) This Note proposes that increased regulation would help prevent these situations by taking counterfeits off the market and providing legal protection to those families that want to acquire donated breast milk.

It is important to understand that many of the risks associated with unregulated breast milk are the same risks associated with unregulated formula or solid baby foods. (40) Therefore, it is not that breast milk itself is an inherently more dangerous product, but that sharing breast milk without substantive regulation is an inherently more dangerous practice. (1) Hence, many of the risks of sharing and selling breast milk can be prevented with guidelines, resources, and increased public awareness on the correct use and handling of breast milk. Brazil and Norway are examples of two countries that have demonstrated that the practice of sharing and selling breastmilk can be executed safely, as discussed in part IV.

“Brazil’s milk banking network “is credited with saving [the country] an estimated US $540 million annually in medical costs.” (42) .” It has also contributed to the country’s remarkable progress in reducing infant mortality. (43)”

Milk Banking Practices Across the Globe

In order to address the health concerns associated with the regulatory gap on breast milk, while also recognizing that access to breast milk reduces infant mortality and illness, as well as lowers health care costs (11), thirty-seven countries have implemented robust laws surrounding breast milk banking. Many of these countries have modeled their regulatory regimes based on Brazil’s milk banking system. (41) Nonetheless, the implementation and operation of breast milk banking systems can vary from country to country. This is because factors such as a nation’s culture, resources, and disease risk pool all play an integral role in determining how breast milk banks are structured. There are, nevertheless, fundamental similarities between effective milk banking systems. (5) As a result, this Section examines milk banking practices in Brazil, Norway, and the United States to understand the differing approaches and to identify a framework of best practices.

Brazil: The Global Leader in Breast Milk Banking

Brazil is considered the “global leader” in human milk banking. (5) Brazil’s title is well-deserved not only because it has the largest milk banking network, but also because the country’s efforts have proven to be incredibly effective. (42, 43) Brazil’s milk banking network “is credited with saving [the country] an estimated US $540 million annually in medical costs.” (42) .” It has also contributed to the country’s remarkable progress in reducing infant mortality, (43) . Notably, Brazil’s milk banking system and public health policies have been replicated by resource-poor and resource-rich countries alike “given the success and the nature of the Brazilian model.” (44) The Brazilian model, therefore, is a useful starting point for determining how breast milk should be regulated on a global scale.

Brazil’s Milk Banking Network
Breast milk banking in Brazil can be traced back to the 1930s. In the last thirty years, however, breast milk banks have become integrated into Brazil’s public health system. Today, Brazil has approximately 217 human milk banks and there is at least one bank in each of the country’s twenty-six states. Furthermore, Brazil’s milk banking system is not only vast, but centrally organized. The Oswaldo Cruz Foundation (hereinafter “FIOCRUZ” or “FIOCRUZ Institute”) serves as a national reference bank for the entire country. It is important to note that FIOCRUZ is a scientific institution for research and development, which operates under Brazil’s Ministry of Health. FIOCRUZ promotes and protects safe and effective milk banking practices in a number of different capacities. For instance, in addition to serving as a national reference bank, FIOCRUZ also does the following:

1) Oversees national networking among HMBs [human milk banks], communicating information in the field of milk banking, monitoring the compliance of donor milk banks with the national milk banking guidelines regarding quality control of donor milk supplies, organizing periodic conferences to improve milk banking services, and training professionals to work in HMBs;

2) acts as the liaison with the government to comply with the policies of the Ministry of Health;

3) conducts research in the areas of the basic and social sciences as well as the development of quality control methodology to lower processing costs and still maintain a quality product to meet national needs;

4) disseminates information among HMBs; and

5) publishes a biannual bulletin (Gota de Leite) which is distributed to all HMBs.

FIOCRUZ’s oversight of the country’s milk banking network, research on safe and effective milk banking methods, and continuous collaboration with government officials has played a substantial role in Brazil’s accomplishments with breast milk banking.

The Brazilian Regulatory System

Brazil has adopted clear and comprehensive guidelines that detail all of the steps necessary to establish and operate a human milk bank. These regulations were initiated in the mid-1980s and have been periodically updated as the scientific and medical community has become better informed about human milk and its properties. Many of these regulations stem from evidenced-based recommendations from the FIOCRUZ Institute. Remarkably, Brazil’s requirements for screening, storing, and handling breast milk are simple and can be implemented at a relatively low cost.

The standards set forth by the Agência Nacional de Vigilância Sanitária (The Brazilian Health Regulatory Agency, hereinafter “ANVISA”), require breast milk donors to be “healthy” already lactating individuals who produce more milk than their own children need. Specifically, the ANVISA stipulates that the donation of breast milk “must be voluntary, altruistic and unpaid, directly or indirectly.” Notably, this condition is not unique to breast milk. In Brazil, the donation of all biological material, such as organs, blood, cells, and genes must be “free and subject to voluntary consent.” In fact, Brazil’s Constitution “adopts the principle of ‘no commodification’ of the human body.” Moreover, this principle has been continuously upheld through various other legal instruments.

In regard to storage and handling, ANVISA requires specific temperature ranges for the transportation, storage, and distribution of breast milk. The regulation further stipulates that institutionalized milk banks must provide adequate, sterilized containers for each donor. It should be noted that storage and handling practices have changed considerably after several years of trial and error. Initially, breast milk banks used “imported beaker tubes that had accounted for a whopping eighty nine percent of operating costs at Brazilian milk banks.” Now, breast milk banks use sterilized “jars made for mayonnaise or instant coffee” to store milk for freezing. These vessels are significantly cheaper while still meeting the requisite requirements that the container must:

1) be of material that can be easily cleaned and disinfected;

2) present a closure in order to maintain the integrity of the product;

3) be constituted of inert and harmless material to the LHE with temperatures from -25°C (twenty-five degrees Celsius negative) to 128°C (one hundred and twenty-eight degrees Celsius) that preserves its biological value.

An additional handling requirement stipulates that all donated breast milk has to be pasteurized. This is arguably one of the country’s most salient regulations since there are several advantages and disadvantages to pasteurizing breast milk. Pasteurization is beneficial for breast milk because it inactivates viruses present and reduces microbial contamination. However, pasteurization also destroys breast milk fat concentration and energy content that help infant resistance against a number of diseases.

In fact, Brazil’s Constitution “adopts the principle of ‘no commodification’ of the human body.” Moreover, this principle has been continuously upheld through various other legal instruments. Because altruism has been a longstanding principle embedded in Brazil’s legal and social system, the requirement for free and voluntary donations has not noticeably hindered the country’s ability to recruit donors. In fact, in 2016, there were approximately 171,967 breast milk donors who collectively gave 183,035 liters of breast milk, and 166,000 infants benefited from these donations. While the requirement to keep donors uncompensated may be problematic for some, encouraging donors to charitably give their surplus breast milk evidently works in Brazil.

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requirements have been altered to become more feasible and cost-effective. Specifically, “high-end pasteurizing machines that cost $25,000 were swapped for $1,500 Brazilian-made machines used in food-testing laboratories.”(60) Scientists and public health officials in Brazil have been able to collaborate together to “adapt the system . . . without compromising the quality and safety of the milk.” (48) Brazil’s collaborative efforts demonstrate that a robust banking network can be implemented efficiently and can function off low-cost technology when clear and comprehensive regulations are in place. For this reason, the Brazilian model is considered “the ideal model” for low-income nations.” (44)

**Brazil’s Awareness and Advocacy Programs**

Brazil’s accomplishments can be traced to numerous public health initiatives concerning the promotion, protection, and support of both breastfeeding and breast milk banking. In regard to the former, the Brazilian government has taken significant steps towards integrating breastfeeding into the country’s universal primary health care system. (5) The country’s first stride toward integration began in 1981, when Brazilian health authorities launched the Programa Nacional de Incentivo ao Aleitamento Materno (Brazilian National Breastfeeding Program, hereinafter “PNIAM”) due to the alarming rate of early cessation of breastfeeding at the end of the 1970s. PNIAM started as a mass media campaign to inform the public of the “various aspects of breastfeeding and the importance of breast milk.” With assistance and cooperation from different community, administrative, education, and health authorities, the program was able to rapidly expand. PNIAM subsequently implemented the following measures to further its objective of increasing the use and duration of breastfeeding in Brazil: (61)

1) Train and update health professionals regarding breastfeeding;
2) Encourage research benefiting the [PNIAM];
3) Orient and sensitize non-professional health workers;
4) Convince administrators to redirect maternity structures to facilitate natural breastfeeding (in particular, by arranging for rooming-in facilities);
5) Include “breastfeeding” in health studies curricula; and in the study curricula of primary school teacher training and literacy teacher training;
6) Create a Brazilian Code, based on WHO/UNICEF International Code of Marketing of Breast milk Substitutes;
7) Implement labor laws for protecting the working mother;
8) Form mothers’ self-help groups;
9) Disseminate information on breastfeeding among authorities, making them aware of its long-term benefits; and
10) Inform mothers about breastfeeding both through personal contact and through the media. (61)

Two especially significant efforts include the passage of legislation that restricts the way in which formula companies can market their products, as well as legislation that guarantees four months of maternity leave for new mothers. (62) Importantly, these regulations and many of the other measures implemented by PNIAM can be attributed to directives from World Health Organization (WHO) and the United Nations Children’s Fund (UNICEF), such as Baby-friendly Hospital Initiative (1991), the International Code of Marketing of Breast-milk Substitutes (1981) and the Innocenti Declaration on the Protection, Promotion and Support of Breastfeeding (1990). (61)

The success of PNIAM is demonstrated by a number of studies conducted over the last decade. (63, 64) One cross-sectional study in 2011 demonstrated that the prevalence of exclusive breastfeeding for infants older than six months in Ribeirao Preto, Brazil, was significantly higher in places accredited by the Brazilian National Breastfeeding Program. (43) Additionally, according to the National Survey on Maternal and Child Health and Family Planning, the prevalence of exclusive breastfeeding among children under six months increased from 2.9 percent in 1986 to 36.6 percent in 2013. This is a total increase of 34.2 percentage points through 2006. Id. There were “statistically significant gains in each decade until 2006 and stabilization in 2013.” (62) It is evident that the Brazilian government’s efforts have contributed to a considerable improvement in the country’s breastfeeding rates. (62-64) Today, breastfeeding is even considered a cultural norm in Brazil. (46) Importantly, normalizing breastfeeding in Brazil has the added benefit of normalizing donor milk banking throughout the country as well. (45)

"It is evident that the Brazilian government’s efforts have contributed to a considerable improvement in the country’s breastfeeding rates. (62-64) Today, breastfeeding is even considered a cultural norm in Brazil. (46) Importantly, normalizing breastfeeding in Brazil has the added benefit of normalizing donor milk banking throughout the country as well."
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Norway's Milk Banking Network
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to fit the country's culture and population base, which is notably
ly, Norway has distinctively tailored its breast milk banking system
in the world of milk banking because it has implemented regula
Norway is another country that has developed a safe and suc
success yet, (5) it comes as no surprise that rich and poor coun
tries alike have started to replicate the Brazilian model. (71)

Norway: A Contrasting Approach to Breast Milk Banking
Norway is another country that has developed a safe and suc
cessful milk banking system. (5) Norway has an “almost universal”
initation of breastfeeding with only one percent of babies never
ceiving any breast milk. (72) Further, any infant that needs
ated breastmilk is provided it free of charge. Norway stands out in
the world of milk banking because it has implemented regula
tions that differ drastically from those of Brazil. (5) More specifi
cally, Norway has distinctively tailored its breast milk banking system
to fit the country’s culture and population base, which is notably
forty times smaller than Brazil’s population. (73, 74) There are,
nevertheless, some overlapping mechanisms shared between
Norway’s unique milk banking system and other successful milk
banking systems. Together, the Brazilian and Norwegian models
ultimately demonstrate that, with strong governmental support and
regulation over breast milk banking a country can increase its
breastfeeding rates and create an effective milk banking network
that saves lives. (5)

Norway's Milk Banking Network
Norway's first breast milk bank was established in 1941. There
after, the number of milk banks sharply increased and eventually
peaked in the late 1990s with seventeen milk banks throughout
the country in 1997. (75) Norway currently has twelve active milk
banks that generate a sufficient supply of breast milk for the coun
try’s needs. (76) Each milk bank is affiliated with a hospital and
connected to the hospital’s neonatal intensive care unit. The af
iliated hospital is then responsible for overseeing the operation of
the breast milk bank. Interestingly enough, Norway's breast
milk banks are united informally and there is not a single, specific
bank that serves as a reference for the entire country. Instead,
Norwegian milk banks use a Facebook page titled “Milk Banks in
Norway” as a platform to stay informed and connected with one
other. There is also a closed Facebook group titled “The milk
banks in Norway” that serves a platform for milk bank employees
to discuss and share internal experiences. Although the Norwe
gian milk banks generally collaborate in an unofficial manner, ev
er milk bank nonetheless reports to a designated person each year. The designated person then generates an annual report for
all of the milk banks, which depicts the number of donors and the
number of liters of milk generated at each facility. (77)

“Norway has an “almost universal”
initiation of breastfeeding with only one
percent of babies never receiving any
breast milk. (72) Further, any infant that
needs donated breastmilk is provided it
free of charge.”

The Norwegian Regulatory Network
Like Brazil, the Norwegian National Board of Health (hereinafter
“NNBH”) has implemented a robust set of guidelines that have
contributed to the country’s success with breast milk banking. The
guidelines define “the organizational structure of the milk banks,
what equipment is to be used and how it must be maintained,
donor qualifications and exclusion criteria, and procedures for
screening, handling, and dispensing the milk.” However, distinct
from Brazil, Norway's regulations are based on a long tradition of
using raw, unpasteurized breast milk. Only one of thirteen breast
milk banks in Norway pasteurizes all donor milk. The use of raw
milk is actually a plausible option in Norway because the country
has a very low incidence of HIV and hepatitis, as well as a high
standard of living and high breastfeeding rates. (75) Correspond-
ingly, systemic pasteurization is not required in Norway. Norwe-
gian milk banks have instead implemented an “extremely rigorous
and regularly repeated” testing process to bypass the pasteuriza-
tion process. (46) Under this system, breast milk donors are initial-
ly tested for various diseases and risk factors and subsequently
undergo a blood test every three months. (75) Each container of
donated breast milk is further screened for pathogens and bacte-
ria. Any breast milk that contains unwanted pathogens or a high
count of bacteria is discarded altogether. (77)
Norway's donor compensation process is another notable difference between Norwegian law and Brazilian law, which is considered the norm. In most countries that regulate breast milk banking, breast milk is gifted and donors cannot be paid directly or indirectly. (5, 49) In Norway, a direct payment for breast milk is generally prohibited. However, Norwegian national guidelines allow a donor to be reimbursed for certain expenses incurred such as electricity, parking, and toll roads. Compensation for donors varies, and some Norwegian milk banks do not reimburse donors at all. (75) Nonetheless, it is not unusual for milk banks to provide donors with a small reimbursement of about 150 NOK per liter (about $20 US per liter) of breast milk. (75, 77) Norway's regulatory system thus attempts to minimize the financial burden imposed on mothers for donating their milk. (5)

Norway's Awareness and Advocacy Programs

Analogous to Brazil, Norway's success with milk banking can also be attributed to several initiatives protecting, promoting, and supporting both breastfeeding and breast milk banking. First, like many other industrialized nations, Norway experienced a significant reduction in breastfeeding rates at the end of the twentieth century. To address this concern, Norwegian health authorities entered into a voluntary agreement with officials in the food industry to regulate the way in which infant formula was advertised. Importantly, this agreement was entered into in 1983, which was shortly after the WHO Code of Marketing of Breast Milk Substitutes (1981) was enacted. The Norwegian health authorities suitably adopted many but not all of the WHO's recommendations. On the other hand in 2001, to further improve the country's breastfeeding rates, the Norwegian Government amended the country's infant feeding recommendations to mirror WHO's guidelines. The Norwegian Health Department has since issued several publications on infant feeding in accordance with both the government and WHO's endorsements for exclusive breastfeeding. (78)

The enactment of legislation that generously extended parental leave is another way in which the Norwegian Government promoted breastfeeding and breast milk banking. Under Norwegian law, parents are entitled to forty-six weeks at full salary, or fifty-six weeks at eighty percent pay. (78) The law further stipulates that mothers who do not qualify for parental leave are still entitled to a lump-sum payment. (77) Altogether, these regulations have the mutual benefit of safeguarding both breastfeeding and breast milk banking by reducing some of the economic burdens imposed on mothers. (77, 79)

The Norwegian Government has implemented a number of measures to promote, protect, and support breast milk banking on an international level as well. (79) As a member of the European Milk Banking Association (hereinafter “EMBA”), Norway advocates for breast milk banking across Europe and encourages international cooperation between milk banks. Moreover, every two years participating countries in the EMBA join forces at an international conference to improve breast milk banking. (77) In addition to participating in the EMBA, the Norwegian Government has also assisted in the development of breast milk banks and lactation counselling centers in India. The Norwegian Government has demonstrated a commitment to promoting safe and effective milk banking systems not just within Norway, but across the globe. (80)

It is evident that the Norwegian Government’s initiatives have improved the country's breastfeeding rates and infant health outcomes. The prevalence of breastfeeding mothers substantially increased from less than 5 percent in 1968, to more than 90 percent today. (81) Further, the country's infant mortality rate has decreased from 13.526 percent in 1968, to 1.921 percent today. (82) Given Norway’s remarkable accomplishments, it comes as no surprise that the country is praised for promoting, protecting, and supporting both breastfeeding and breast milk banking. (81)

“Distinct from Brazil and Norway, in the United States there are not any federal regulations or federal public health policies concerning breast milk banking. (83) It is not clear why the U.S. Food and Drug Administration has deliberately declined to regulate breast milk banks, especially when the administration oversees blood, cord, oocytes, semen, and stool banks.”
following recommended best practices. (1, 53) This system additionally raises concerns regarding the accessibility, cost, and acceptance of breast milk banking. (53) The U.S. model ultimately exemplifies the imperative need for global direction on human milk banking. (1)

The Haphazard Milk Banking Network and System in the U.S.

There are twenty-six nonprofit milk banks, and five nonprofit milk banks that are in the development process in the United States. All of these nonprofit breast milk banks have been accredited by the Human Milk Banking Association of North America (hereinafter “HMBANA”). (85) HMBANA is a professional organization that oversees nonprofit milk banking in the U.S. and Canada. (86) Specifically, the organization aims to advance the field of nonprofit milk banking by accrediting certain banks, developing evidence-based best practices, and advocating for breastfeeding and breast milk banking. (83) In an effort to achieve this goal, HMBANA establishes voluntary guidelines for member banks for screening potential donors, and for collecting, processing, handling, testing and storing milk. Hence, all of the non-profit milk banks that have been accredited by HMBANA have met the minimum standards set forth in HMBANA’s Guidelines for the Establishment and Operation of Donor Human Milk Banks (2011).

On the other hand, there are three for-profit milk banks in the United States that provide safe breast milk even though these companies are not accredited by HMBANA. (87) Some of these for-profit milk banks even claim that they provide a better form of quality assurance than HMBANA banks. Nevertheless, the primary difference between for-profit and nonprofit milk banks is not necessarily a distinction between the quality of breast milk at each facility. (53) Rather, the difference between these two organizations boils down to conflicting policy preferences. For-profit companies generally assert that breast milk donors deserve to be compensated due to the “tolling” milk donation process. (87) Correspondingly, for-profit milk banks tend to regulate milk banks similar to egg and sperm banks. (1) Nonprofit companies take the opposing view and stress that breast milk donations should be completely altruistic. (87) Accordingly, nonprofit milk banks tend to regulate breast milk similar to blood banks. It is not evident that one approach is necessarily superior to the other. Both for-profit and nonprofit milk banks in the U.S. have provided families with safe breast milk without exploiting donors, but this is predominantly because these entities have voluntarily self-regulated themselves. The primary issue with the country’s approach, therefore, lies with those individuals who exchange breastmilk without conforming their behavior to nationally-recognized standards. (53)

“Stories about parents purchasing contaminated breast milk online have unfortunately become an increasingly popular headline in U.S. news. (88, 89) These articles can indirectly mislead the public about other, safer forms of breast milk sharing.”

The Need for Government Regulation and Support of Donor Milk Banking

While HMBANA oversees some forms of milk banking in the United States, the organization is not an adequate substitute for federal regulation. First, silence from the federal government only exacerbates the informal circulation of breast milk and the ease with which misinformation is spread. (1) For example, stories about parents purchasing contaminated breast milk online have unfortunately become an increasingly popular headline in U.S. news. (88, 89) These articles can indirectly mislead the public about other, safer forms of breast milk sharing. Next, access to scrupulously tested breast milk is far more difficult in the U.S. than in countries with strong government-support for milk banks and robust regulatory systems. Specifically, even though breast milk is theoretically abundant, many infants cannot obtain this ideal source of nutrition. (53) Increased regulation and oversight over breast milk banking would undoubtedly address many of these concerns. (1) Specially, federal support of breast milk banking would increase the number of institutionalized breast milk banks in each state, and would also remove some of the economic burdens to accessing breastmilk. (53) Most notably, federal regulation would additionally discourage the informal market in breast milk sharing. (1)

“Specially, federal support of breast milk banking would increase the number of institutionalized breast milk banks in each state, and would also remove some of the economic burdens to accessing breastmilk. (53) Most notably, federal regulation would additionally discourage the informal market in breast milk sharing.”

Unfortunately, the prevalence of issues that could be resolved with more regulation on breast milk banking is not a situation that is unique to the United States. There are many nations that do not have any substantive regulation on donating and sharing breast milk. In sum, these countries exemplify the urgent need for the WHO to move forward with evidence-based standards and procedures on breast milk sharing, so that more countries are inclined to regulate this practice. (13)

WHO’s Integral Role on Global Health Promotion

WHO is the principal leader in global health. The Organization is comprised of 194 Member States (90) and therefore, has access to the “best international experts” on matters of science, medicine, ethics, and human rights. (91) Each year, all WHO Member States gather together in Geneva, Switzerland, to facilitate global governance regarding matters of health and disease. (92) The purpose of WHO is to “promote health, keep the world safe, and serve the vulnerable.” (93) Appropriately, WHO has played a vital role in the eradication of smallpox, improving the treatment of tuberculosis, and executing vaccinations against common infections in many countries. (91) WHO has and will continue to have a significant impact on world health because of its rare and extensive “legal” and “normative” authority. (94)

WHO’s Legal Authority

First, WHO has the legal authority to make binding law. More
specifically, Articles 2, 19, and 21 of WHO Constitution grant the Organization the power to make binding international law through conventions, agreements, and regulations. (95) WHO’s law-making powers are exceptionally important because it is unusual in international law for a governing body to impose affirmative requirements on sovereign states. (94) For instance, by exercising the Organization’s Article 21 powers, the World Health Assembly adopted the International Health Regulations (hereinafter “IHR”), which imposed requirements on all Member States. (96) The IHR (2005) mandated that all countries have the ability to do the following:

1) Detect: Make sure surveillance systems and laboratories can detect potential threat
2) Assess: Work together with other countries to make decisions in public health emergencies
3) Report: Report specific diseases, plus any potential international public health emergencies, through participation in a network of National Focal Points
4) Respond: Respond to public health events (97)

The IHR (2005) was created to keep the world informed about certain infectious disease outbreaks by ensuring that each country “develop, strengthen, and maintain core public health capacities.” (98) Notably, both government leaders and non-governmental health agencies admit that their own accomplishments in disease prevention and control are “largely rooted [in] WHO’s constitutionally mandated policies and programs.” (96) While WHO is avidly employing reforms to better respond to global health threats, (94) the IHR represents a step in the right direction for coordinating global health activities. (96) Ultimately, WHO’s ability to create and implement instruments of international law can be an effective tool for generating consensus and change. (94)

WHO’s Normative Authority

In addition, WHO has the normative authority to make highly influential proposals that can coordinate several State actors toward a common goal. (94) Specifically, Article 23 grants the Assembly the authority to make recommendations to Member States. Furthermore, Article 62 requires States to report the actions they have taken to comply with WHO’s recommendations. (95) Even without a compulsory obligation, many countries comply with the norms and standards set forth by WHO because of its “high social capital and credibility.” (91) Furthermore, the Organizations recommendations often become the building blocks of national legislation. By way of example, one of WHO’s “most prominent” recommendations have been the International Code of Marketing of Breast Milk Substitutes (1981). (94) Several countries incorporated the International Code into their legislation. What is more, countries that adopted legislation reflecting the provisions of the International Code demonstrated an increase in breastfeeding rates. (99) WHO’s recommendation, in effect, furthered its objective to increase the proportion of infants who are ever breastfed. (100) It is evident that WHO’s normative authority can have an immense impact on global health. (94)

Analysis and Recommendation

It is unclear why WHO has failed to exercise its normative and legal authority to address the large regulatory gap that exists in breast milk. Perhaps WHO has not endorsed any standards on breast milk sharing because this practice has always existed, so a guiding framework may not seem necessary. Yet, if WHO were to provide global guidelines on safe and effective milk banking, more countries would be inclined to regulate this practice. This, in effect, would help safeguard the health and well-being of the world’s most defenseless population. It is therefore imperative that WHO endorses a set best practices regarding the selection and examination of breast milk. (94)

WHO’s best practices for breast milk donation and sharing should first begin by recommending that institutionalized milk banks are complying with scientific standards and discouraging the informal circulation of breast milk. (1) Thereafter, WHO’s best practices should include guidelines for screening potential donors. (3) More specifically, WHO should require donors to be individuals who produce milk in excess of what their own children need. Notably, these recommendations largely resemble what Brazilian law requires. (49) It should further dictate that donors must be healthy individuals who are not taking any drugs, alcohol, or unsafe medications at the time of donation. The best practices should then recommend continuous and rigorous testing of donors, as well as a system for tracing and tracking the breast milk. Additionally, WHO should include guidelines for collecting, processing, handling, testing, and storing breast milk based on standards that have been endorsed by the scientific and medical community. These guidelines should contain the steps for handling both raw breast milk and pasteurized breast milk. WHO can subsequently discuss the pros and cons for pasteurizing breast milk against the pros and cons of using raw breast milk, and encourage individual lawmakers to decide which method would be a best fit for their community based on a nation’s culture, resources, and disease risk pool. (3) Lastly, to help policymakers, researchers, and practitioners be as safe and successful as possible, this Note suggests that WHO should include a step-by-step map of the milk banking process that identifies points of potential hazards.

Conclusion

The practice of donating and sharing breast milk has and will continue to escalate on a global scale. (13) Accordingly, WHO needs to address the regulatory gap in breast milk sharing by endorsing and promoting safe milk banking practices. A guiding framework on breast milk banking would also go hand in hand with many of WHO’s own initiatives to improve infant health, such as the International Code of Marketing of Breast-milk Substitutes and the Global Strategy on Infant and Young Child Feeding. (99) Furthermore, since WHO explicitly recommends donated breast milk, it is only fitting that the organization provides some parameters for handling and sharing breast milk. Finally, if WHO can provide global guidelines on how cells, tissue, blood, and semen are handled and shared, then it is both possible and necessary for WHO to provide a similar framework for breast milk. (13)

References


Disclosure: The author has no relevant disclosures

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MRIs offer many benefits for newborns in the Neonatal Intensive Care Unit (NICU), but performing off-unit MRIs is incredibly complex and creates many risks for this vulnerable population. On-unit MRI options for NICU patients greatly reduce these risks and can lead to significant benefits that make them cost-effective and clinically superior to off-unit MRIs.

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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?

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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Gravens by Design: Should Nurturing Stimuli be Limited to Times When a Preterm Baby is Awake?

Robert D. White, MD

“For many years, the NICU was an undesirable place for a baby’s brain to develop. Lights were bright, the noise was pervasive, painful procedures plentiful, sleep disturbed frequently, and parental access severely restricted.”

For many years, the NICU was an undesirable place for a baby’s brain to develop. Lights were bright, the noise was pervasive, painful procedures plentiful, sleep disturbed frequently, and parental access severely restricted. There has been a gradual awakening to the adverse effects this can have on a premature infant who is in the “synaptic explosion” stage of brain growth and development, which, coupled with technological changes that allow us to monitor babies better and less invasively, has enabled us to minimize these noxious stimuli. The importance of infant sleep to brain development has also gained greater recognition so that timing necessary interventions to protect sleep is happening more often.

Concurrently, there has also been a move to introduce nurturing stimuli into the baby’s experience. Skin-to-skin care (1), music (2), reading (3,4), and circadian lighting (5) are examples of such stimuli that are much more commonly offered today than they were in the earlier days of NICU care.

“Unfortunately, in many NICUs, the effort to reduce overstimulation and protect infant sleep has come into conflict with the desire to provide nurturing stimuli.”

Unfortunately, in many NICUs, the effort to reduce overstimulation and protect infant sleep has come into conflict with the desire to provide nurturing stimuli. It is hypothesized by some practitioners that there is danger in providing these stimuli when an infant is asleep on the grounds that it may cause overstimulation or interfere with the important sleep cycle itself. Thus, nurses and parents are often admonished to stop reading and providing music once their baby falls asleep and to keep the lights dim. Some also prescribe a maximum amount of time these stimuli should be provided in the course of a day, suggesting again that there is a risk of overstimulation. In fact, there is no data to support these beliefs; it is more likely an overly enthusiastic acceptance of the desire to protect babies that has led to this practice – good intentions can have unintended consequences. William Fifer demonstrated that newborns, unlike any other age group, learn while they are asleep (6,7). In utero, we know that infants learn to recognize their mother’s voice (8) and smell; we also know that the fetus sleeps most of the time, so these stimuli are likely presented and learned for many hours every day, much of that time while the fetus is asleep.

Unless new data demonstrate that presenting these nurturing stimuli to babies is harmful or that limits are necessary, then we should no longer proscribe their use once an infant falls asleep. Babies are likely to benefit and, in all likelihood, will not be harmed by continuing to provide them with auditory, vestibular, and circadian stimuli throughout the sleep cycle. Of course, these stimuli should be removed if the baby appears to react adversely, but it is much more common to see that babies continue to sleep peacefully even when the nurturing stimuli are continued. Incubators and private rooms are important tools for protecting babies from overstimulation, but they can also become isolation chambers if parents are absent and we do not enrich their sensory environment or do so only in small doses. The best environment for neurosensory development in the NICU is in the arms of a caregiver or when that is not feasible in the presence of nurturing stimuli. Certainly, we need more data to determine what that should look like exactly, but our default should not limit sensory input altogether in a well-meaning effort to protect infant sleep.

“The best environment for neurosensory development in the NICU is in the arms of a caregiver or when that is not feasible in the presence of nurturing stimuli. Certainly, we need more data to determine what that should look like exactly, but our default should not limit sensory input altogether in a well-meaning effort to protect infant sleep.”

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References:

Dr. White is a Fellow of the American Academy of Pediatrics, co-chair of the Gravens Conference, chair of the Committee to Establish Recommended Standards for Newborn ICU Design, co-chair of the Newborn Brain Conference, and an adjunct professor at the University of Notre Dame and the Indiana University School of Medicine.

Disclosures: The author has no relevant disclosures
**COVID-19**

**STOP THE SPREAD AT HOME**

**HYGIENE TIPS**

- **MOUTH**
  - Use a face mask or face shield.
  - If in car, use mask & put windows down.
  - Avoid cloth face masks for children younger than 2 yrs.
  - 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**

- **If infected, notify emergency in contact from the past 10 days.**
- **Call 211 for FREE delivery services.**

**CONSEJOS DE HIGIENE**

- **BOCA**
  - Use a mask or face shield.
  - Avoid kissing.
- **OJOS**
  - Use eye protection.
- **ROPA**
  - Wear a jacket.
  - Do not share clothing, sheets, or pillows.
- **MANOS**
  - Always wash your hands.

**KITCHEN**

- **Use SEPARATE utensils.**
- **If sick, stay away from the kitchen.**

**ASILAMIENTO**

- **Mantenga agua y sanidad de buurt cerca.**
- **Mantenga una bolsa de basura en la habitación.**
- **Evite acostarse con los animales.**
- **Use SEPARATE utensils.**
- **Limpie los utensilios por separado.**
- **Si está enfermo, evite la cocina.**

**COCINA**

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

**MANERA DE MANEJAR COVID-19 EN CASA**

1. **Hogar**
   - Mantenga 6 pies de distancia de las demás en la habitación.
   - Use una cubierta protectora sobre la boca y la nariz.
2. **Enfermo**
   - Aíslense permanentemente en una habitación separada con habitación. No se lo comparte con el área. Visite Miora.org
   - Lleve una mascarilla siempre que esté en contacto con personas que no estén infectadas.
   - No comparte ropa, ropa, almohadas o almohadones.
   - Mantenga una bolsa de basura en la habitación.
   - Proteja las mascarillas, medias, etc.
   - Notifique a todos los contactos de los últimos 10 días.
   - Lleve al 211 para obtener servicios de entrega GRATUITOS.

**HYGIENE TIPS**

1. **MOUTH**
   - Use a face mask or face shield.
2. **EYES**
   - Wear protective eye gear (glasses).
3. **HANDS**
   - Always wash your hands.
4. **CLOTHING**
   - Wear a jacket.
5. **BATHROOM**
   - Call 211 for FREE delivery services.
6. **KITCHEN**
   - Use SEPARATE utensils.
7. **ASILAMIENTO**
   - Keep water and sanitation liquids near.
8. **COCINA**
   - Use SEPARATE utensils.

**STOP THE SPREAD AT HOME**

**Hogar**

1. **Mamá**
   - Llame a 211 para obtener servicios de entrega GRATUITOS.
2. **Enfermo**
   - Llame al 211 para obtener servicios de entrega GRATUITOS.

**Maneras de manejar COVID-19 en casa**

1. **Hogar**
   - Lleve una cobertura protectora sobre la boca y la nariz.
2. **Enfermo**
   - Aíslense permanentemente en una habitación separada con habitación.
   - Lleve una mascarilla siempre que esté en contacto con personas que no estén infectadas.
   - No comparte ropa, ropa, almohadas o almohadones.
   - Mantenga una bolsa de basura en la habitación.
   - Proteja las mascarillas, medias, etc.
   - Notifique a todos los contactos de los últimos 10 días.
   - Lleve al 211 para obtener servicios de entrega GRATUITOS.

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4:00 p.m. Eastern time

Wednesday, October 6, 2021
4:00 p.m. Eastern time

Wednesday, November 3, 2021
4:00 p.m. Eastern time

Wednesday, December 1, 2021
4:00 p.m. Eastern time

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**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.

---

**SHARE DECISION-MAKING PROTECTS MOTHERS + INFANTS DURING COVID-19**

**KEEPING MOTHERS + INFANTS TOGETHER**
Means balancing...

**Risks of separation and trauma**

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

**Partnership**

**Seek participation**
HELP EXPLORE OPTIONS
ASSESS PREFERENCES
REACH A DECISION
EVALUATE THE DECISION

**Trauma-Informed**
Both parents and providers are confronting significant...

**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.
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**SUPPORTING KANGAROO CARE**

**SKIN-TO-SKIN CARE DURING COVID-19**

**GET INFORMED ABOUT THE RISKS + BENEFITS**

work with your medical team to create a plan

**GET CLEAN**

WASH YOUR HANDS, ARMS, and CHEST

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

**PUT ON FRESH CLOTHES**

change into a clean gown or shirt.

**IF COVID-19 + WEAR A MASK**

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

---

**National Perinatal Association**

nicuparentnetwork.org

nationalperinatal.org/skin-to-skin
The umbilical cord blood gas results obviously do not reflect the severe respiratory and metabolic acidosis present in a clinically dead infant. The blood sample drawn through the UVC during resuscitation reflects this very clearly.

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

Jeffrey Pomerance, MD, MPH

Case 15: Cord Prolapse

The mother was a 20-year-old, gravida 3, para 1, aborta 1, with an intrauterine pregnancy at 38 0/7 weeks gestation. (1) She presented at the hospital in active labor. The cervix was completely dilated and effaced, and the breech was at plus three station with a non-pulsatile cord protruding from the vagina. The mother was taken emergently for a vaginal delivery with the assistance of Pipper forceps. A male infant was delivered with Apgar scores of 0, 0, and 0 at one, five, and 10 minutes, respectively. On further questioning, the mother stated she felt a gush of water and something “funny” near her leg while in transit to the hospital. The exact time from the cord prolapse to arrival at the hospital was unknown but probably exceeded 20 minutes.

Cord blood gas results were as follows:

<table>
<thead>
<tr>
<th>Umbilical Vein</th>
<th>Umbilical Artery</th>
</tr>
</thead>
<tbody>
<tr>
<td>pH</td>
<td>7.24</td>
</tr>
<tr>
<td>Pco₂ (mmHg)</td>
<td>7.33</td>
</tr>
<tr>
<td></td>
<td>7.33</td>
</tr>
<tr>
<td>Pco₂ (kPa)</td>
<td>55</td>
</tr>
<tr>
<td>Pco₂ (kPa)</td>
<td>7.33</td>
</tr>
<tr>
<td>P₂ (mmHg)</td>
<td>20</td>
</tr>
<tr>
<td>P₂ (kPa)</td>
<td>2.67</td>
</tr>
<tr>
<td>BD (mmol/L)</td>
<td>4</td>
</tr>
</tbody>
</table>

Attempts to resuscitate the infant were not successful. During resuscitation, an umbilical venous catheter was placed, and blood was drawn.

Results of the umbilical venous catheter blood gas were:

<table>
<thead>
<tr>
<th>UVC</th>
</tr>
</thead>
<tbody>
<tr>
<td>pH</td>
</tr>
<tr>
<td>Pco₂ (mmHg)</td>
</tr>
<tr>
<td>Pco₂ (kPa)</td>
</tr>
<tr>
<td>P₂ (mmHg)</td>
</tr>
<tr>
<td>P₂ (kPa)</td>
</tr>
<tr>
<td>BD (mmol/L)</td>
</tr>
</tbody>
</table>

Interpretation

The umbilical venous blood gas sample has a borderline low pH, a mild elevation of the Pco₂, and a normal PO₂ and base deficit. The umbilical arterial blood gas sample has a modestly low pH, a mildly elevated Pco₂ and a mildly elevated base deficit. The difference between the umbilical venous and arterial pH is widened (>0.10), as is the difference between base deficits (≥4). This suggests that following cord prolapse, the umbilical cord was occluded; however, umbilical arterial blood flow was briefly restored while the umbilical vein remained occluded.

Cord prolapse has been reported to occur in 0.24% of vertex presentations, 3.5% of breech presentations (frank breech 0.5%, complete breech 5%, footling breech 15% (2)), and 9.6% of transverse presentations. (3,4) Other factors besides abnormal fetal presentation (51%) associated with cord prolapse include prematurity (38%), obstetric manipulation (19%), multiparity (13%), multiple gestations (10%), and placental problems (8%). (3) Umbilical cord accidents are most frequent in the presence of a long cord. (5)

The umbilical cord blood gas results obviously do not reflect the severe respiratory and metabolic acidosis present in a clinically dead infant. The blood sample drawn through the UVC during resuscitation reflects this very clearly. Total cord occlusion from cord prolapse has completely interrupted the flow of blood to and from the placenta. The umbilical cord blood gas values do not reflect the infant’s current status, only the status just before the occlusion. There is insufficient metabolically active tissue in the umbilical cord (largely water) to either utilize sufficient oxygen or produce sufficient carbon dioxide or lactic acid over a limited period of time, to significantly alter blood gas results in the stagnant umbilical cord blood. Blood left in a doubly clamped umbilical cord (6,7) at room temperature (8,9) does not change in a clinically significant manner for at least 60 minutes after delivery. From the information on the patient presented above, it seems apparent that umbilical cord blood gas results probably do not change in a clinically significant manner when blood is stored “in situ” at body temperature over 20 minutes or more.

“These reports suggest that the umbilical arteries have remained patent for a much longer period of time than in the case above.”

Others have reported even greater differences between umbilical venous and arterial pH and Pco₂ associated with a prolapsed cord than presented here. (10,11) These reports suggest that the umbilical arteries have remained patent for a much longer period of time than in the case above. Depending upon the forces involved and the interventions applied (manually elevating the head off the cord, for example), the umbilical arteries or even the umbilical vein may remain patent or have circulation restored during cord prolapse.
A central hematocrit was 51%. When the hematocrit was repeated was:

At 43 minutes of age, an arterial blood gas in 70% oxygen was:

Cord blood gas results were as follows:

<table>
<thead>
<tr>
<th></th>
<th>Umbilical Vein</th>
<th>Umbilical Artery</th>
</tr>
</thead>
<tbody>
<tr>
<td>pH</td>
<td>7.23</td>
<td>6.85</td>
</tr>
<tr>
<td>Pco₂ (mmHg)</td>
<td>51</td>
<td>126</td>
</tr>
<tr>
<td>(kPa)</td>
<td>6.80</td>
<td>16.80</td>
</tr>
<tr>
<td>P₂ (mmHg)</td>
<td>42</td>
<td>13</td>
</tr>
<tr>
<td>(kPa)</td>
<td>5.60</td>
<td>1.73</td>
</tr>
<tr>
<td>BD (mmol/L)</td>
<td>6</td>
<td>12</td>
</tr>
</tbody>
</table>

At 43 minutes of age, an arterial blood gas in 70% oxygen was:

<table>
<thead>
<tr>
<th></th>
<th>UAC</th>
</tr>
</thead>
<tbody>
<tr>
<td>pH</td>
<td>7.09</td>
</tr>
<tr>
<td>Pco₂ (mmHg)</td>
<td>16</td>
</tr>
<tr>
<td>(kPa)</td>
<td>2.13</td>
</tr>
<tr>
<td>P₂ (mmHg)</td>
<td>280</td>
</tr>
<tr>
<td>(kPa)</td>
<td>37.33</td>
</tr>
<tr>
<td>BD (mmol/L)</td>
<td>25</td>
</tr>
</tbody>
</table>

A central hematocrit was 51%. When the hematocrit was repeated 18 hours later, it was 40%.

On follow-up pediatric examination at age three years and nine months, the infant had moderate choreoathetoid extrapyramidal cerebral palsy.
Please note that the reported base deficit of 12 mmol/L is approximately 19 when the pH and Pco₂ values are plotted on a Siggaard-Andersen Alignment Nomogram. (16) This nomogram estimates blood base deficit. If one plots the same pH and Pco₂ values on the Siggaard-Andersen Acid-Base Chart,(17) a chart that estimates extracellular fluid base deficit, then the estimate agrees with the reported value of 12. Again, it is important to know the standard reporting practice of the blood gas laboratory at your hospital. Choosing one estimate of the base deficit over the other is no longer simply an academic matter. Criteria for deciding whether to treat a newborn with hypoxic-ischemic encephalopathy by cooling is decided in part by data that use extracellular base deficits. (18)

Key Points:

- Occult cord prolapse may be suspected not only on clinical grounds but also by analysis of the umbilical cord blood gas values.
- In the face of a history of severe variable decelerations, especially if followed by severe terminal bradycardia, and in the absence of any obvious cause of cord occlusion, occult prolapse becomes the most likely diagnosis.
- While preparation for emergency cesarean delivery continues, and with the mother in Trendelenburg position, the elevation of the fetal head out of the pelvis may result in a dramatic amelioration of either severe variable decelerations or a sudden, severe, and sustained FHR deceleration.

References:

14. Cohen WE, Schiffrin BS, Doctor G. Elevation of the fetal pre-
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In Loving Memory
August 9, 1996 - April 3, 2010

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

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

<table>
<thead>
<tr>
<th>Duration</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 session</td>
<td>$15</td>
</tr>
<tr>
<td>1 week</td>
<td>$30</td>
</tr>
<tr>
<td>1 month</td>
<td>$120</td>
</tr>
<tr>
<td>1 semester</td>
<td>$540</td>
</tr>
<tr>
<td>1 year</td>
<td>$1,080</td>
</tr>
<tr>
<td>Middle School</td>
<td>$3,240</td>
</tr>
</tbody>
</table>

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

- bonding
- healing
- growing

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Artificial Intelligence and Machine Learning Based Decision-Making Tools: A Seminal Advancement for Neonatology?

Fu-Sheng Chou, MD, PhD, Monalisa Patel, MD

Last month, I had the pleasure of reading Dr. Gilbert Martin’s article on the role of artificial intelligence (AI) in the NICU. (1) Numerous questions were raised in that article. I believe these are the exact questions that are on everyone’s mind, including us.

Earlier this month, many of us attended the annual Pediatric Academic Society (PAS) conference. We were surprised yet delighted to see that there were more than a handful of presentations that used machine learning (ML) algorithms for analysis. A study compared linear and non-linear ML models for growth failure prediction and another one that used the Hidden Markov Model on serial microbiome data to predict growth failure. A multinational group is using unsupervised ML algorithms to redefine bronchopulmonary dysplasia (BPD). ML was also used to learn from MRI and clinical features to predict outcomes in newborns with hypoxic-ischemic encephalopathy. A study showed that ML-based models have greater sensitivity and specifically than the modified Bell criteria for predicting necrotizing enterocolitis. There was another study that compared various ML algorithms in critical congenital heart disease screening.

“A study showed that ML-based models have greater sensitivity and specificity than the modified Bell criteria for predicting necrotizing enterocolitis.”

Moreover, there was also a meta-analysis of studies that used various ML-based models for neonatal mortality prediction. The authors concluded that ML-based modeling is a feasible approach. Additionally, in a live Q&A session, one of the presenters for a California Perinatal Quality Care Collaborative study on active resuscitation of perivable infants hinted that the analysis is underway to use ML algorithms to predict outcomes of perivable infants based on maternal and perinatal clinical factors. Our apologies to the authors whose ML projects were not mentioned here.

The field of newborn medicine has seen the least progress in ML and Artificial Intelligence (AI) thus far. However, based on recent PAS presentations, it is likely that studies using ML or deep learning (DL) algorithms in our field will explode in the next few years. As we anticipate reading these articles very soon, it is probably a good time to learn some basic language about AI.

AI and its Clinical Utility:

AI is math, computer science, and statistics in a nutshell. ML and DL are both components of AI. While human neonatologists learn how to manage transient tachypnea of newborns after seeing three cases, or five at most, machines need hundreds if not thousands of observations to delineate a pattern to correlate with the outcome. On the other hand, machines can gather all kinds of relevant or irrelevant information, sort through AI algorithms to identify hidden patterns that are not visible to human eyes, especially non-linear. Machines can pay attention to the speed of the car in front of you without getting tired, but humans can only do that for hours at most. Machines may not perform well in what humans can do well, such as abstract reasoning or creative problem solving or end-of-life discussions (based on current AI progress in medicine). Machines can perform exceedingly well on specific tasks where human brains simply cannot, whether because of overwhelming amounts of information, mental exhaustion, or dogma passed down from generations ago that may not be applicable anymore.

Machines were initially created to assist humans in performing tasks. It is thought that there are three different strategies for how humans can utilize machines – the 3 A’s: assisted, augmented, and autonomous. Assisted learning is when machines can perform basic repetitive tasks with no human involvement. An example of that is an alert system of the electronic record system (for example, prompting clinicians to consult an infectious disease specialist if a specific antibiotic is being ordered). On the other end of the spectrum, there is autonomous, where machines can complete the task at hand with little or no human involvement, including writing their own codes to instruct themselves. An example of that could be the FDA-approved device to screen for diabetic retinopathy without physician input. This autonomy is what human clinicians are scared of: I do not want a computer to tell me what to do; I do not trust the computer’s decision; physicians will be out of the job market because of AI.

“This autonomy is what human clinicians are scared of: I do not want a computer to tell me what to do; I do not trust the computer’s decision; physicians will be out of the job market because of AI.”

When we know more about AI and where we are with its development that is applicable to healthcare, immediately, we know that we are far from having fully autonomous AI to complete the “SOAP” process (well, there is no S in the eyes of AI). We likely are not going to have such a humanized machine for clinical decision-making in the next three decades or a century. One of the reasons is that five neonatologists sitting at the round table may have seven different ideas when discussing a complex case. If human neonatologists cannot agree with each other, how do we begin to instruct the machines to learn? AI will be implemented when humans do not perform well, but it does not take over human decision-making processes. The optimal way of using AI in medicine is to use it synergistically to take away a lot of repetitive and trainable work like documentation and billing to focus more time on direct patient care and communication.

Where we are with AI is well put by Dr. Anthony Chang of the Children’s Hospital Orange County. Dr. Chang is a pediatric cardiologist specializing in cardiac intensive care. He is the founder of the medical intelligence society (2) and the editor-in-chief of Intelligence-Based Medicine (3), an Elsevier journal. Dr. Chang said he chose the title “Intelligence-Based” as opposed to “Artificial Intelligence-Based” because human intelligence is an integral part of the new era of medicine. What Dr. Chang meant precisely is how we should perceive AI in medicine, that machine intelligence should “augment” human intelligence to inform the best decision-making process. It should be symbiotic between human and machine, not additive, not in tandem.
Dr. Chang suggested that intelligence-based medicine will replace evidence-based medicine, which appears to be a positive healthcare change. Evidence is at best based on findings humans can interpret, not necessarily the facts. For example, linear regression models and odds ratios are easy to interpret and understand, but not all variables are additive and linear, so when we say a particular risk factor is an independent one after adjusting for x, y, and z, is it an independent risk factor? All models are prone to bias; some are more useful than others, but are we learning the useful ones? Is that part of the reason we also say medicine is not pure science?

**Statistical Modeling vs. AI:**

AI is a branch of statistical modeling with an emphasis on generalizability. AI aims to learn from the present and the past to predict the outcome of future events. Both statistical and AI models begin with data. Statistical modeling is to use mathematical approaches to characterize and summarize existing data. On the other hand, AI models characterize existing data and use additional mathematical techniques to fine-tune how the model characterizes the data. Hence, it is "less" perfect but "better" generalizable. The fine-tuning part of model development is the spirit of the "learning" process by the machine, turning data into information and knowledge. A commonly used technique for model tuning is called k-fold cross-validation, where data is split into k parts, followed by training the model using the random (k-1) parts of the data and assessing model performance using a holdout fold of the data. This process can be repeated numerous times with a different holdout fold, and can also be nested, where n-fold cross-validation for hyperparameter tuning is performed within the (k-1) parts of data to find the optimal hyperparameters.

**Machine learning vs. deep learning:**

ML, or classic ML, takes a data set and runs through an algorithm to obtain predicted outcomes. The ML algorithms are categorized into linear and non-linear and based on the availability of outcome data, ML algorithms are also categorized into unsupervised (no outcome correlation) and supervised (with outcome correlation). A supervised linear model is like a linear regression model, where there are independent variables (called *features*) and dependent variables (called *outcome*). Additional techniques are built into the algorithm for post-processing to compress or eliminate features that are less likely to influence the generalized outcome. There are multiple approaches to non-linear modeling, which we will dis-
cuss in greater detail in the coming months. Unsupervised learning is complicated, and many algorithms are still under development. An easy way to visualize it mentally is to think about taking a bunch of cardiopulmonary data and allow the machine to cluster the data based on learned patterns. These clusters do not have any labels attached to them but may allow clinicians to redefine disease severity, BPD as an example. The powerfulness of unsupervised learning is it could revolutionize disease classification based on hidden pathophysiology or discover new phenotypes.

DL is a subset of ML. The structure of DL is to mimic how the human brain functions: environmental input (data input) travels through multiple interconnected neurons (nodes) arranged hierarchically (artificial neural network) to produce a nerve impulse to instruct behavior (outcome prediction). Nodes within a layer are interconnected, and each node contains a linear regression algorithm that receives input from upstream nodes and provides output to downstream nodes. Multiple layers were developed by human design to decode and process the information for pattern development. Deep learning is used for image recognition (convoluted neural networks, or CNN) or temporal data recognition such as murmur detection or continuous vital sign monitoring (recursive neural networks, or RNN). Developing a model to recognize pneumatosis on abdominal x-ray would require CNN; developing a model to recognize flow directions of a patent ductus arteriosus would probably require both CNN and RNN and a lot of computing power.

“The powerfulness of unsupervised learning is it could revolutionize disease classification based on hidden pathophysiology or discover new phenotypes.”

In general, data for supervised ML are less complex and smaller in scale when compared to DL. DL is powerful but also consumes significant computing power. Choosing between ML and DL and which specific algorithms for training largely depend on the clinical question asked.

Cognitive Computing:
Cognitive computing deploys AI methodologies (like reinforcement learning, deep learning, natural language processing, machine learning, neural networks, sentiment analysis, and contextual awareness) to simulate a human-like cognition characterized by self-learning behavior with intelligence. This strategy is going to be the future wave of AI.

Limitations:
Algorithms are very prone to bias. After all, most of the learning so far is still supervised, which requires human labeling of data during the training process. An infamous example of this is the major flaw in the Google algorithm that could not differentiate an African American from a gorilla. Another big issue with AI is the black box. In particular, with DL systems, the lack of explainability of how the AI program can reach a particular conclusion or make a particular recommendation can be daunting for clinicians and perhaps patients as well. Many AI systems lack interpretability, and again, this will be a hindrance to the clinician buy-in.

Moreover, it takes enormous amounts of data, training, programming, and funding to create a well-trained, reliable algorithm that can produce results that will augment human performance. And as medicine advances, newer testing and treatment options are discovered, the algorithms will need to be constantly updated, which can be a gargantuan task. Lastly, abstract reasoning, creative problem solving, and complex decision-making remain limitations of AI as we know it.

Summary:
Similar to statistical inference and the famous line in statistics, “all models are wrong, some are useful,” AI models are being developed to augment human decision; some of them will become useful in clinical settings, others will be abandoned quickly as prospective validation fails to prove its value. We will discuss bias vs. variance, model performance, and what to pay attention to when reviewing manuscripts that report AI-based models in the coming months.

References:

Disclosure: The author identifies no conflict of interest

NT

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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.

2. Reviewers will be able to review the manuscript online. This portal will shorten the time from receipt of review to getting feedback to the submitting authors.

3. An archive search will be available for journals older than 2012.

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

5. Sponsors will be able to sign up directly on the website and submit content for both the digital and PDF issues of Neonatology Today.

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

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

fu-sheng.chou@neonatologytoday.net

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**Put On Fresh Clothes**

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**If COVID-19 + Wear a Mask**

And ask others to hold your baby when you can’t be there.

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

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

**INFECTION RISK**
- The moat design can increase risk for infection if residual breast milk or formula remains in the moat and transfers to the feeding tube.

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

Improved standards are important to protect patients from the dangers of tubing misconnections. But we must avoid mitigating existing risks by creating new ones.

Individual hospitals should consider all factors impacting their NICU patients before adopting a new tubing design.

*ENFit® is a registered trademark of GEDSA*
In a nationwide atmosphere of federally illegal but varying state legalization of marijuana compounded by the effort to reduce opioid prescriptions, interest has risen in finding safer and often more ‘natural’ alternatives. CBD oil, one component of marijuana, has been proposed as potentially beneficial with a low level of the psychoactive component, tetrahydrocannabinol or THC. Currently, pharmaceutical-grade CBD oil is being used effectively for severe forms of epilepsy but is also being trialed for use with pain, addictions, nausea, spasticity, increasing weight gain, sleep disorders, Tourette Syndrome, and mental health disorders. However, while research is continuing and answers are developing, a markedly high population of use resides among pregnant women begging the question: what is currently known about the effects of marijuana on a fetus and their long-term outcomes?

Due to a long history of recreational non-pharmaceutical marijuana use, the effect of the psychoactive THC is better understood than the proposed medicinal CBD. THC binds cannabinoid receptors such as CB1&2, which are located in the amygdala, hippocampus, and ventral striatum, and reduces dopamine receptor expression in both the ventral striatum and the nucleus accumbens. Furthermore, THC binds the endogenous fetal CB1 receptors and acts to reduce endocannabinoid synthesis (such as 2-arachidonoylglycerol) and thereby the expression of CB1. The long-term implications must include the knowledge that fetal CB1 receptors are distributed among the mesocorticolimbic system compared to the adult, areas of emotional control, cognition, and memory.(1) Alternatively, the non-euphoric CBD has not been found to bind the CB1 receptor, and the full mechanism of action remains unknown.

Currently, marijuana in any form is the most widely used substance during pregnancy, with a wide range of use among an estimated 4.9-28% of ‘urban, young, and socioeconomically disadvantaged pregnant women and is associated with higher rates of concomitant substance use.(1,2) It has also been reported that 3.7% of women with significant nausea report marijuana use, as compared to 2.3% without severe nausea. Finally, marijuana use decreased from 9% to 4.5% between the first and second trimesters, correlating with reduction. Importantly, marijuana use during pregnancy compared to tobacco or no substance use was found to increase placental artery resistance, affect pulsatility resulting in lower uterine blood flow and alter axonal cell elongation and neuronal growth.(1)

While many reports contradict one another and most are unable to isolate marijuana use without confounders, most studies agree that intratertiary marijuana exposure results in lower birth weight, smaller head circumferences, earlier deliveries, and increased NICU admissions – some children also exhibit signs of withdraws like tremors, increased movement, and high pitched cries. However, studies neither report an increased risk of neonatal death with exposure nor the increased incidence of grade 3-4 interventricular hemorrhages, necrotizing enterocolitis, bronchopulmonary dysplasia, or cerebral palsy.(1) As the child’s age increases, research has found conflicting results pertaining to school performance, behaviors, and visual-spatial ability. One study completed between 1983 and 1990 in Jamaica controlled for isolated marijuana use and matched to non-uses of similar variables whose children ages birth to 5 years old were assessed behavioral-developmental outcomes. This study found that there was no association between marijuana exposure and IQ, memory, verbal ability, or perception. (2,3)

“At a time when the totality of exposure and outcomes is forthcoming, we as physicians should continue to screen for marijuana use among teenagers, pregnant women, and others at risk for abuse.”

At a time when the totality of exposure and outcomes is forthcoming, we as physicians should continue to screen for marijuana use among teenagers, pregnant women, and others at risk for abuse. Two screening tools have been successful in alcohol and substance screening, where two or more positive answers are highly sensitive and quite specific. Then can also be applied to marijuana abuse:

CAGE: Have you ever felt you could cut down use? Have others been annoyed at your use? Have you felt guilty about using? Have you ever needed to use marijuana as an eye-opener to wake up or steady your nerves?(4)

CRAFT: Have you ridden in a vehicle with someone who was “high” or under an influence? Do you ever use to relax or fit in? Do you ever use marijuana when you are alone? Have you ever forgotten things you did while using? Do your family or friends tell you to cut down your use? Have you ever gotten in trouble while using?(5)

To date, we know that non-pharmaceutical marijuana exposure with THC adversely affects uterine blood flow and placental artery resistance. It has also been noted that fetal exposure likely has different effects than adults given different locations of THC receptors, and further concern arises given the locations predominantly in areas of impulse modulation and emotion. Ultimately, the concern remains that the neurologic effects of exposure to marijuana are not fully known, and thereby the effect of exposure on brain development requires continued and ongoing research. As physicians, we must be keenly aware that there have been no rigorous studies performed to assess the safety profile of cannabinoid oils other than Epidiolex, which has been specifically FDA approved for three neurologic disorders: Lennox-Gastaut Syndrome, Dravet Syndrome, and Tuberous Sclerosis Complex; but otherwise, it is not FDA approved for prescription and continues to require screening for intratertiary exposure.

References:
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Twenty-three years ago, my firstborn child, Connor, died from Sudden Infant Death Syndrome (SIDS). He was born in April, and I’ll always remember how incredibly significant that first Mother’s Day was for me. Little did I know at the time that the next Mother’s Day, I would be hiding in my house, with a torrent of emotions overwhelming me. Connor died in August of that same year at three months and 24 days old.

Needless to say, the most powerful emotion was raw, agonizing grief. It’s impossible to describe the physical pain you feel when your baby has died. And on Mother’s Day, when other moms are celebrating, you realize how incredibly alone you really are. You cannot talk to your other mom friends because both you and they feel so awkward, unsure of what to say.

As a friend, how do you celebrate the day while someone else has lost her reason for being? And as the person who is grieving, how do you rise above your sadness to smile and wish your friend a happy Mother’s Day?

No, for everyone involved, it is much easier to hide in your home and wait for the day to be over.

And then, to be honest, there’s the anger and resentment. Why would God allow this to happen to you?! I’ll admit to many times thinking of abusive and negligent parents whose babies were still alive. Yet for me, who did everything right, my baby is dead. It takes many years for this anger to abate. One day I finally realized that no one is immune to tragedy and everyone has their own story. The answer to the question “Why me?” is “Why not me?” Who am I to never experience sorrow or tragedy?

I went on to have three more amazing children who now are 22, 18, and 15 years old. Each of them, in their own way, has helped me heal. The pain has softened, but there will always be a sense
of sadness and longing for what might have been.

I channeled my grief into activism and am now the CEO of First Candle, the non-profit that works to eliminate sleep-related infant death and provides bereavement support to families who have lost a baby to Sudden Unexpected Infant Death (SUID) and Stillbirth. When I speak with a young mom who has recently lost her baby, I’m transported right back to that moment when my own precious baby died. It is hard to believe it was 23 years ago. In some ways, it feels like a lifetime ago.

In truth, I am a different person, wiser, and at peace. What I can offer young moms is hope. When they see me, they see that indeed you can survive the heartbreaking grief.

“**When my second son Spencer was born, I started celebrating Mother’s Day again. I love looking at the picture every year as my family grows up and my children have become young adults. And somewhere in those pictures, I always see their little guardian angel, their brother Connor.”**

When my second son Spencer was born, I started celebrating Mother’s Day again. I love looking at the picture every year as my family grows up and my children have become young adults. And somewhere in those pictures, I always see their little guardian angel, their brother Connor. It could be a butterfly, a sunbeam, or an orb over one of their shoulders, but I always know he is there, my firstborn who made me a mom that first Mother’s Day.

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

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**About First Candle**

First Candle, based in New Canaan, CT, is a 501c (3) committed to eliminating Sudden Infant Death Syndrome and other sleep-related infant deaths while providing bereavement support for families who have suffered a loss. Sudden unexpected infant death (SUID), which includes SIDS and accidental suffocation and strangulation in bed (ASSB), remains the leading cause of death for babies one month to one year of age, resulting in 3,600 infant deaths nationwide per year.
among VLBW decreased from 16.7% in pre-EHR era to 14% in post-EHR era. Among babies born less than 1,500 grams, rates of necrotizing enterocolitis and cystic periventricular leukomalacia, were not significantly affected (Table 2). Retinopathy of Prematurity rate was significantly reduced from 28% to 26%, with a P-value of 0.0045. In the Extreme Low Birth Weight group, there was a decrease in mortality rate from 23% to 18.6% with a P-value of 0.0268, and an increase in CLD rate (Table 3). However, infection control data showed improvement where CLABSI was 3.8% vs 3%, with a P-value of 0.7, VAP 2.1% vs 1.6%, with a P-value of 0.08, and CONS infection 2.1 vs 0.93%, with a P-value of 0.03 (Table 4).

Discussion
Several studies have been conducted in ambulatory services and less intensive areas, assessing the information flow and logistics of electronic health care records on the quality of work performance.12,13 These studies claimed that the patient-related outcomes were better in adult patients, with enhanced overall patient care, less ordered medications and lab requests. Cordero et al demonstrated the advantage of remote...
The Psychology of Vaccine Hesitancy: How Health Providers May Help

Carlos Fayard, PhD, Lisa M. Fayard, MD

“Health care providers have correctly been called “heroes” during this pandemic. As vaccines have become available, they are now able to continue to save lives by encouraging their patients to get vaccinated. Are there ways to help overcome vaccine hesitancy?”

Health care providers have correctly been called “heroes” during this pandemic. As vaccines have become available, they are now able to continue to save lives by encouraging their patients to get vaccinated. Are there ways to help overcome vaccine hesitancy?

Among the most harmful and deadly features of the pandemic are the psychological factors (i.e., beliefs and behaviors) from the impact of the initial lockdown (1) to the embracing of mitigation measures (2), coping with pandemic fatigue (3), and now vaccine hesitancy (4). Attention to actionable, evidence-based psychological issues has been scarce.

A few months ago, my wife and I joined a WhatsApp group created by our former High School classmates as we are approaching the 50th graduation anniversary. We enjoyed seeing pictures of their children and grandchildren, their gardens and homes, and stories of old. We were not prepared to see the intense reaction of many to the pandemic and now the vaccines. “Covid is a hoax,” “this is a maneuver from those in power to control the people,” “the vaccines are dangerous,” “if you get vaccinated, you are a guinea pig,” “trust the natural remedies instead,” “where do you place your trust? Weren’t you supposed to trust God?” There are a couple of physicians, a handful of nurses, including one who had oversight on vaccination programs at a large city among the skeptics. A brief and excellent video explanation of the Covid vaccines by a professor and expert from a well-known University was summarily dismissed as “misinformed.” Even when our sister-in-law died from Covid, the naysayers did not express words of condolence, even though we all have a common religious background.

I do not know how prevalent this sentiment is among your patients and the community where you live, but most agree that getting vaccinated is critical to turning the tide of the pandemic and protecting lives (5). “Vaccine hesitancy” is how researchers are describing this phenomenon. The situation and arguments surrounding Covid are fairly unique to this virus. However, the behavior and beliefs about vaccination are not radically different from those seen in the past regarding other medical conditions (6).

How are we to understand vaccine hesitancy? Might we play a constructive role with our patients, their families, and members of our surrounding communities in decreasing the suspicion and even countering the misinformation?

Beliefs, Behaviors and Vaccine Hesitancy

There is nothing new about people being hesitant about medical treatments and vaccines. The pandemic, however, has made it imperative that most of us get vaccinated to achieve herd immunity. Vaccine hesitancy refers to delay in acceptance or refusal of vaccination despite the availability of vaccination services. Research suggests five main individual-level determinants of vaccine hesitancy: confidence, complacency, convenience (or constraints), risk calculation, and collective responsibility (7). Confidence denotes trust in the effectiveness and safety of vaccines. Complacency is said to occur when perceived risks of vaccine-preventable diseases are low, and vaccination is not considered necessary (“Covid only affects a very small percentage of the population” or “it is curable in the majority of the cases”). Constraints denote barriers to access vaccination. “Risk calculation indicates a deliberate comparison of the risks of infection versus those of vaccination, from which to derive a decision (“nobody knows if the vaccine provides true protection over time”). Collective responsibility refers to the willingness to protect others by one’s own vaccination (“I’ll let others get vaccinated to achieve herd immunity,” putting one’s interest ahead of those of the community).

“Collective responsibility refers to the willingness to protect others by one’s own vaccination (“I’ll let others get vaccinated to achieve herd immunity,” putting one’s interest ahead of those of the community).”

You can see the salience of beliefs and behaviors for each one of these drivers of vaccine hesitancy. Let me highlight the role of confidence or trust. A recent study in the United Kingdom highlights the role of confidence in the information for those accepting the vaccine and those who are hesitant about it, “those resistant to a COVID-19 vaccine were less likely to obtain information about the pandemic from traditional and authoritative sources and had higher levels of mistrust in these sources compared to vaccine accepting respondents.” (8) Paying attention to the role of emotions is essential. Psychologist and Public Health scientist Perry Halkitis puts it this way, “emotions and psychosocial conditions too often usurp logic and reason, which in turn fuel disease… experts tend to overlook medical mistrust, fear/avoidance, and stigma.” (9) In fact, we are talking about very distinct areas of the brain that process rational information and emotion-based reactions. Emo-
tions then, more than logic, drive misinformation, disinformation, and conspiracy theories about the vaccine.

**Misinformation, Disinformation and Conspiracy Theories**

Disinformation (strategically and deliberately spread false information), misinformation (false information, not necessarily with intent to mislead), and mistrust (more than the lack of trust; suspicion of ill intent – what is commonly referred to as “conspiracy theories”) fuel fear, promote avoidance and become the “rationale” to be hesitant about the vaccination process. Conspiracy beliefs are “attempts to explain the ultimate cause of an event...as a secret plot by a covert alliance of powerful individuals or organizations, rather than as an overt activity or natural occurrence. It can be difficult to persuasively present evidence to refute these types of ideas, especially because experts are often seen as part of the conspiracy. New pieces of contrary evidence can be rationalized into an existing narrative” (10). Our former classmates engaged in misinformation (e.g., “nobody knows how the vaccine affects your genes”) and echoed conspiracy theories (e.g., “pharmaceutical companies are out to make money instead of promoting natural remedies”). Schwarz (11) researched the conditions under which individuals decide whether the information is acceptable: is it compatible with information previously known? Is the source credible? Do others perceived as belonging to one’s group believe it as well? Is the information consistent? Is there some evidence to support it?

While fear and mistrust may guide some beliefs, reactance psychology informs the motivational state of those who feel their freedoms being curtailed (12). You can see why our classmates summarily dismissed our expert’s explanation. He aimed at the part of the brain dealing with reason while our classmates processed primarily dismissed our expert’s explanation. He aimed at the part of the brain dealing with emotion – what is commonly referred to as “conspiracy theories” (which will not be persuaded by information alone). Our former classmates engaged in misinformation (e.g., “nobody knows how the vaccine affects your genes”) and echoed conspiracy theories (e.g., “pharmaceutical companies are out to make money instead of promoting natural remedies”). Schwarz (11) researched the conditions under which individuals decide whether the information is acceptable: is it compatible with information previously known? Is the source credible? Do others perceived as belonging to one’s group believe it as well? Is the information consistent? Is there some evidence to support it?

**How Health Providers May Help?**

Could we help address vaccination hesitancy, misinformation, and even conspiracy beliefs as a health community? Could we help by more directly addressing the fears/avoidance vaccine hesitancy? I believe we could. Let me share a few ways to do this based on some of my work consulting with a faith community serving a population riddled with vaccine hesitancy.

1. **Maintain yourself well informed regarding the development, efficacy, and safety of the vaccine.** Find ways to transmit this message at the patient level, be it a farmer or a pharmacist.
2. **Tailor the message to the understanding (or misunderstanding) and biases of those you meet.** You will fairly quickly learn whether you are dealing with misinformation (which can be corrected with more accurate information), mistrust (which can be addressed by recognizing the fear) or conspiracy theories (which will not be persuaded by information but rather by affirming the importance of protecting their individual rights).
3. **Follow general bedside principles, such as empathy with those who are fearful, when appropriate; disclose something personal that can help make a more personal connection; do not shame the person, but rather provide the information in a non-confrontational manner; avoid arguing about the veracity of the conspiratorial ideas (13). Health care providers who have a strong working alliance with their patients are most likely to influence their beliefs (14).**
4. **Evoke a sense of hope and altruism (15).** One of the best examples of this approach is the commercial featuring singer John Legend where he starts by saying, “this shot is our shot, our opportunity to return to the places, the faces that we love and miss,” “we are ready when you are ready.” As he speaks, you can see in the background people coming together, sharing happy moments after the initial image of health professionals masked and gloomy music. Being a commercial, he points to the organization sponsoring the ad, but he says, “These are the pharmacies you know, with the people you know.” Legend’s ad highlights hope, connection, altruism, and trust.
5. **Lead by example.** Share in your social media not only that you received your shot but also that you had some discomfort but recovered quickly. Hesitant people may be fearful of side effects. This is a sort of “psychological vaccine,” where sharing some personal information that connects to portions already believed by the hesitant and skeptical may “inoculate” against misinformation (16).
6. **Build partnerships with trusted individuals and organizations in your community.** For instance, spiritual leaders play a powerful role, particularly in communities of color. You can partner with a leader to help address the fears and beliefs present in the community. Here are some of the fears/beliefs in the faith community I consulted with: “Getting the vaccine shows a lack of faith in God’s protection and power,” “I trust in natural and spiritual remedies,” “I am young and healthy,” “I don’t trust science, I only trust the Word of God,” “I don’t trust the government.” You can make yourself available to be interviewed by the spiritual leader to address these concerns. Be non-defensive and acknowledge that some of the messaging has been confusing (remember when we were told that masking did not help?) You can serve as a bridge to bring your health organization to the community and increase access and harness their credibility by sharing information in non-jargon language, having their location become a vaccination site (17), be it in their church, school, gym.
7. **Be courageous and realistic.** Talking about these issues can result in intense reactions. Remember that emotions usurp logic and reason. Be courageous and keep in mind that you will not be able to “win them all.” Just aim at moving the needle in the right direction.

John Legend goes on to emphasize the theme “this is our shot.” “Our shot to get back our communities together, providing healing not for some but for all,” “reconnecting with the ones we love, with the world we lost. This is our shot”. As a health professional, you too have a shot. Indeed, through you, this becomes “our shot.”

**References:**


Health Equity Column: Cultural Humility and Equity

Ariane Marie-Mitchell, MD

I remember learning in medical school about differences in disease rates by race, gender, and age. These were presented as facts, such as the fact that African-Americans have higher rates of diabetes than Whites or that women have higher rates of depression than men. I remember assuming, or maybe even being told, that differences by race and gender were part of biological differences in genetics, hormones, and biochemistry. These differences were unfortunate, but like other facts, just part of the way things are.

Several years have passed since I graduated, and in that time, there has been a rising consciousness that much of what we learned as inevitable is, in fact, preventable. This shift in awareness starts with realizing the widespread impact of stress and trauma on our biological and institutional systems. This leads to recognizing the effects of stress and trauma, including societal oppressions, on our systems, and therefore propels a desire for transformation. Cultural humility is a cornerstone of this transformation. Cultural humility is an individual-level shift in perspective, a willingness to recognize that my experience of the world is influenced by my race, gender, sexuality, age and so on and that my experience may be very different from that of my colleague or my patient. Differences in experience may lead us to have different beliefs, expectations, or behaviors. I can respond to these differences by being judgmental and wondering why that person doesn't think and act as I do, or I can respond from a place of humility, one in which I am willing to reflect on variations in lived experience, listen to stories about different realities, and find ways to promote understanding.

“There are a variety of types of societal oppressions, such as racism, sexism, homophobia, xenophobia, ableism, and ageism. These can be thought of like coin tosses because they all represent aspects of who we are that are out of our control.”

There are a variety of types of societal oppressions, such as racism, sexism, homophobia, xenophobia, ableism, and ageism. These can be thought of like coin tosses because they all represent aspects of who we are that are out of our control. Depending on how your coin toss landed for your birth, family circumstances, or current age, you may enjoy a greater sense of belonging and freedom in society, or you may feel excluded and discriminated against. The result for those on the oppressed side is a chronic sense of threat and vulnerability. While all of these oppressions can show up in the workplace as different degrees of stress and bias, I am going to focus on racism because race is one of the most difficult oppressions to talk about and yet strongly associated with many differences in health care outcomes.

You might wonder about the need to talk about race and racism in 2021. After all, the Civil Rights Act was passed over fifty years ago and included provisions to end discrimination based upon race, color, and national origin. And we elected Barack Obama, which suggests that we have made great progress toward being a “color blind” society. Some, mostly White, people might even add that anyone in this country can go to school, work hard, get jobs and be successful, and mostly White people sincerely believe this because that is their lived experience.

I understand the White experience because I grew up White, but my understanding of race began to shift when I went on a cross-country trip with a friend who later became my husband. We had just graduated college and thought it would be fun to spend a few weeks driving from the west coast to the east coast. As we plotted our route, I was surprised to find out that there were places we had to avoid because my friend didn’t feel safe. When we chose restaurants, my friend preferred restaurant chains near the highway rather than quaint “mom and pop” diners. When I talked him into eating at a small diner in Kentucky, we left without eating. This is because the waitress brought him lemonade that tasted like soap, and when she brought out his pancakes, there was a dead fly on top. The only thing that my friend had done differently than me was to walk into that diner while being Black. We were living in the same country, and we had graduated from the same college, but we were living in different realities. I would like to say that so much has changed since then, but in fact we recently decided against taking our own bi-racial children on a cross-country trip because, after four years of hate-filled political rhetoric, it doesn’t feel safe.

The problem with not talking about racism and pretending that we are a “color blind” society where everyone has equal opportunity is that it allows us to ignore and fail to address the persistence of disparities by race. One reason why disparities still exist in 2021 is that historical racism continues to affect communities today. For example, after the Great Depression, the government wanted to help homeowners refinance their mortgages. They sent surveyors out to assess neighborhoods to decide how “risky” it would be to give mortgage loans to the residents. But they made these decisions very explicitly based on race - neighborhoods with black and brown people were considered risky and marked with red lines on their maps. This was just the beginning of similar practices that continued for decades, resulting in long-term financial disinvestment and increasing racial segregation in these neighborhoods. Redlining was done all over the country, and we continue to see the effects today. Communities with lower homeownership also have lower property taxes. Lower property taxes means lower community investments.
funding for schools. Poorer schools mean higher crime rates and the perpetuation of disinvestment in the community, including reduced access to banking, insurance, supermarkets, and health care. This leads to differences in health and psychosocial outcomes, which we tend to blame on communities of color, thereby perpetuating an ongoing cycle of bias and racism.

The majority of Americans want to realize the dream of living in a nation where all people- regardless of race, gender, class, sexual orientation, ability, or any other difference- can realize their full potential. So how do we get from where we are today, where differences like our zip code or what we look like still matter, to the dream of freedom and liberty for everyone?

On an individual level, it starts with a willingness to reflect on our own experience and engage in conversations with other people about their experiences. From a perspective of cultural humility, it becomes possible to recognize how implicit biases influence all of us. Implicit biases are negative associations that people unknowingly or unconsciously hold. These negative associations become hard-wired in our brains based on numerous messages in our social environment about race, gender, and other characteristics. We receive these messages in various ways, such as through conversations, what we read and see in the media, or who plays a leadership role in our personal or political lives. These messages become part of our brain wiring and can bias us for or against a group of people. The biology of implicit bias is the result of years of evolution designed to help us quickly process information about people and situations. While this ability was needed for quick decisions related to survival, the same cognitive processing can unknowingly influence our perception of other people and our decisions.

Studies of physicians show that their biases are no different from the general population and may influence patient-provider interactions, treatment choices, patient compliance, and health outcomes. For example, Black and Hispanic patients are less likely to receive pain medications, even for acute injuries like bone fractures. (3) Black patients are less likely to receive thrombolysis, despite having conditions comparable to White patients. Pro-White bias among primary care physicians influences the patient perception of warmth and friendliness, as well as patient adherence to treatment prescriptions. In addition, studies have reported lower quality of care metrics in hospitals serving a higher percentage of Black infants, fewer early intervention referrals for Black infants, and differential treatment for necrotizing enterocolitis in infants of color. (4) Particularly when we are stressed and time-pressured, unconscious biases are likely to influence our communication and decisions. The good news is that we can become aware of our biases by taking a test for implicit bias (implicit.harvard.edu). We can then use that information to try to stay conscious of our biases so that they do not negatively impact our interactions or decisions.

“\textit{The biology of implicit bias is the result of years of evolution designed to help us quickly process information about people and situations. While this ability was needed for quick decisions related to survival, the same cognitive processing can unknowingly influence our perception of other people and our decisions.}”

On an organizational level, we can use the principle of equity to guide the transformation of our health care system. Key to the principle of equity is the recognition that different groups of people are born into vastly different resources. This is uncomfortable to admit. After all, it is a basic American belief that we are the land of equal opportunity. But in reality, some children are born into very rich families who have accumulated wealth and societal connections over generations, while other children are born into families who don’t even have a savings account. Some children are born with a skin color that allows them to feel welcomed in leadership positions throughout society, while other children are born with a skin color that may make them feel unwelcome and unsafe. The examples could go on, but the underlying point is that- depending on how the coin toss worked out-- the current reality is that some groups have advantages and some groups have disadvantages, and these disadvantages show up as differences in health care outcomes.

But the influence of societal oppressions on health care outcomes is not inevitable because society can change, and we as health care professionals can be part of that change. We can transform...
our health care system to make sure that we are reducing stress and trauma and promoting safety, compassion, trust, collaboration and resilience. The first step in that transformation is the realization that we are not achieving the best possible outcomes for everyone. For example, African-Americans, Native Americans, and Alaskan Natives have higher infant mortality rates than White infants.(4,5) Mortality from intraventricular hemorrhage is two times higher in Black compared to White infants. Hispanic infants with necrotizing enterocolitis are less likely to survive than non-Hispanic infants. In 2015 the rate of low-birthweight infants for African-American and Hispanic infants increased. These are just a few from the long list of disparities in our medical system, and although many of these problems start outside the health care walls, we can make sure that the inequities are not perpetuated inside the health care walls.

On an individual level, we start with being self-reflective. Similarly, on an organizational level, we start by examining our own system. What outcomes are we producing? Do we need to change our thinking to produce different outcomes? For example, what are the demographics of the employees we are recruiting? Does this fit the needs of the services we are providing? Or how do our employees feel about working here? Do they feel respected? Included? Do they have opportunities to provide input? Do they have choices for religious and cultural holidays? And do we have representation where we need it? To answer this question, we need to know who is affected by the decisions being made by a particular committee or team. Are the voices of the people affected by the decisions represented on the team or committee? These are just a few examples of the kinds of questions that could be asked as part of a reflective organization.

Next, we need to assess the outcomes that we deliver by demographic groups. If we don’t measure disparities, then we won’t know about disparities.(6) Are the outcomes for our patients comparable across different demographic groups? If not, are there differences in the timing of medical care? Are there differences in treatments offered or utilized? Are there differences in patient satisfaction with care? If yes, can we re-design our system to impact these differences and improve outcomes? Measurement is the first step toward eliminating disparities. Equally important is stakeholder engagement because the identification of successful interventions will require input from the members of the community being served.

It is uncomfortable talking about racial disparities and other societal inequities. It takes courage to share the truth of your own experience and listen to someone else who has had different experiences.

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Dell’s unexpected telephone call interrupted a rather busy, unproductive paper-shuffling day. “Ralph,” she began, “I’ve got great news. The promotion came through—it’s just what I want.”

“Great, great, honey,” I replied. Dell had been trying to land this job as Chief X-ray Technician for two years, and it seemed that all of her hard work had now paid off.”

“Let’s celebrate,” Dell continued. “Make reservations at Villa Vincenzo’s at 8 o’clock. I’ll meet you there.”

“Okay, honey, I’ll see you then.” I hung up, feeling a special glow. Dell was seven months pregnant, feeling well, able to continue working, and had received great progress reports from her obstetrician, Dr. Copeland. I decided to call the restaurant and ask them to place a bottle of Brut champagne on the middle of the table surrounded by a dozen yellow roses.

I arrived at Villa Vincenzo’s at the same time as Dell, kissed her quickly, and ushered her inside. She looked lovely in her materni-
ty dress—just the right amount of makeup with a touch of Giorgio perfume. I looked at her, smiled, and thought to myself how lucky I was to have married this wonderful woman. We sat down, and I immediately asked the waiter to pour the champagne. We toasted to Dell’s new job and decided to order.

“What would you like this evening, Madame?” the waiter asked.

“I think I will have breaded veal cutlet, pasta Alfredo, and a baked potato. Please bring black coffee with dinner.”

“Would you care for any other vegetables?” the waiter continued.

“I think not,” replied Dell.

“And for you, sir,” he said, turning toward me.

“I believe I will have the antipasto, veal scaloppini with a side order of eggplant, and bring me a Lite beer as well.”

“Very good, sir,” he said as he turned and walked away. I poured another glass of champagne, and we talked for a few moments. Suddenly the maître d’ of the restaurant appeared in front of us.

“Buona Sera,” he began.

“Good evening,” I replied.

“I am sorry to interrupt your dinner, but Mr. Skurow, the manager of the restaurant, would like to see you in his office. It’s important. Please follow me.”

“What about our dinner?” I exclaimed.

“Dinner will wait for your return,” he replied. “Please follow me.”

Rather bewildered, quite annoyed, and still hungry, we followed him into the manager’s office. Mr. Skurow was fiftyish, rather suave, with graying hair and jet black eyes, which quickly darted as he spoke.

“Please sit down,” as he motioned us to a small couch at one end of the room. He sat down at a desk at least ten feet from us across a plush, British racing green carpet.

Hoping to take the offensive quickly, I said, “I hope you have an adequate explanation for interrupting our dinner.”

“Yes, yes, yes,” he continued. “As you know, Mr., eh….?”

“Rubin,” I replied.

“Ah, yes, Mr. Rubin, the “Protect the Newborn Act,” which Congress recently passed, is quite specific about do’s and don’ts for pregnant women in an attempt to protect the unborn child from illness and stress. All restaurants, employers, physicians, and industries have had to read and understand the law and abide by it. You know about the law, don’t you? Your obstetrician should have been quite explicit about it.”

“Dr. Copeland did mention the law, but he is old-fashioned about his practice and actually did not spend too much time telling us...”
"Ah, yes, Mr. Rubin, the “Protect the Newborn Act,” which Congress recently passed, is quite specific about do’s and don’ts for pregnant women in an attempt to protect the unborn child from illness and stress. All restaurants, employers, physicians, and industries have had to read and understand the law and abide by it. You know about the law, don’t you? Your obstetrician should have been quite explicit about it."

Please get to the point, and be brief. We are both hungry, and my wife, who is seven months pregnant in case you haven’t noticed, needs her nourishment.

“Yes, yes, yes.” He continued. “The law specifically states that pregnant women shall not be allowed to consume alcoholic beverages of any type during pregnancy and they are also not allowed to use caffeine products of any sort. There have apparently been some problem cases through the courts stating that a baby was injured by the mother having even an occasional drink and a few cups of coffee during pregnancy. The ‘Newborns-Have-Rights-Also’ groups have won several cases concerning the rights of the newborn child and the apparent fault of the mother. Second, the diet must be carefully controlled and nutrition balanced. As you can see the meal which Mrs. Rubin, it is Rubin, isn’t it? Your first name is ……"

“Dell,” I interrupted, “Go on, man, go on.”

“Yes, yes, yes.”

I was getting more annoyed by the minute, and the “yes, yes, yes” was not helping any.

“As you can see,” he continued, “a dinner consisting of breaded veal cutlet, pasta, and potatoes is loaded with starch and does not contain enough vegetables or a balance between protein, fat, and carbohydrates. This is something which we “restaurateurs” must be careful of today because if an inspector is present, our license can be revoked. Also, if a federal or state official noticed Mrs. Rubin drinking champagne or coffee in Villa Vincenzo’s, we would be fined, and you would be asked to appear in court to defend your actions in jeopardizing your newborn infant."

“This is preposterous,” I said, rising and pulling Dell with me.

“Preposterous, maybe,” he continued, “but I would advise making an appointment with your obstetrician tomorrow for he can fill you in on other parts of the law. These, I believe, deal with allowable types of employment, smoking, and other potential hazards to the baby. As you can see, there is no smoking allowed in most public places today, for apparently, the baby remains at risk."

“It seems to me,” said Dell, obviously bewildered and upset, “that the unborn baby has begun to have more rights than the parents.”

“Yes, yes, yes,” was the reply. "Now, before it gets too late. Could I interest Madame in the zucchini squash?"

Disclosure: There are no reported conflicts.
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

Disclaimer:
This column does not give specific legal advice, but rather is intended to provide general information on medicolegal issues. As always, it is important to recognize that laws vary state-to-state and legal decisions are dependent on the particular facts at hand. It is important to consult a qualified attorney for legal issues affecting your practice.
**The PREGNANT MOM’S Guide To Staying SAFE DURING COVID-19**

**Take precautions & LIMIT INTERACTIONS.**

- Keep prenatal APPOINTMENTS.
- Maintain at least A 30-DAY SUPPLY OF YOUR MEDICATIONS.
- Talk to your health care provider about STAYING SAFE DURING COVID-19.

**Keep your environment clean and safe.**

- **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.

**Supporting KANGAROO 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.

**IF COVID-19 + WEAR A MASK**

- Wear a mask and ask others to hold your baby when you can’t be there.

**Learn More**

- Visit the National Perinatal Association (nicuparentnetwork.org) or the National Perinatal Association (nationalperinatal.org/skin-to-skin) for more information on skin-to-skin care during COVID-19.
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The Neonatology Solutions Job Directory is now beginning to feature positions for both NNPs and NICU Hospitalists. We are working actively to source job requisitions and get them posted on the site, and we anticipate that these numbers will grow quickly. To view currently listed positions, click here: [https://neonatologysolutions.com/search-open-positions/](https://neonatologysolutions.com/search-open-positions/)

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on the website or click here:  https://neonatologysolutions.com/add-your-neonatology-job-requisition/

As always, feel free to reach out to us to let us know what we can do to make this the most useful site for free neonatology resources on the interweb!

Disclosure: The author is a principal of Neonatology Solutions, LLC.

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“After this lockdown after March, I have segregated myself and opened up my own health care facility, which is by the name of Nimbus Hospital. This hospital has ten beds dedicated to pediatrics and neonatology. Plus, we are doing pediatric surgery also because my partner is a pediatric surgeon, so we have a facility of doing pediatrics and neonatal medicine and surgical practice under one roof.”

What is your practice, how long have you been practicing?

I’m Dr. Virdi. I’ve done my education in pediatrics and fellowship in neonatology. I have been practicing since 1998, almost 20 to 25 years of practice. Most of my practice has been in the private sector, and I practice neonatology as well as general pediatrics.

Tell me about your hospital. How many beds? Whom do you treat? How many patients do you see?

Prior to the lock down last March, I was engaged with a bigger hospital, which was a 50 bedded hospital multi-specialty where I was looking after the pediatrics and neonatology department itself. It was a level 2 NICU plus a level 1 to level 2 pediatric. We used to ventilate neonates plus taking care of preterm and term babies. In pediatrics, we were not ventilating but taking care of general pediatrics.

After this lock down after March, I have segregated myself and opened up my own health care facility, which is by the name of Nimbus Hospital. This hospital has ten beds dedicated to pediatrics and neonatology. Plus, we are doing pediatric surgery because my partner is a pediatric surgeon, so we have a facility of pediatrics and neonatal medicine and surgical practice under one roof. That is the setup I’m now working.

What encouraged you to branch out and start your own hospital? Was it due to COVID?

Yes, multiple issues, one that we were not able to practice social distancing and segregate our patients because there was a lot of adult patient population, also in that multi-specialty hospital. So we had to come over to a separate place where we could, practice social distancing as well as practice exclusively pediatrics, for that

What is your patient population like? Where is the hospital located? (rural, urban, North, South etc.)

It is located in Mohali, which is a satellite town of Chandigarh in Punjab. It’s an urban area, in a sector that is still not completely built, it’s an upcoming sector. It is not as good as the previous hospital which was located in the other sector. But definitely, it is in an urban area, and we are catering to some local population, but most of the population we are catering to is from around the area, like 40 kilometers. They do come from the rural background, also because most of my patients are those who have been attached with me for the last 20 to 25 years.

The first year of COVID did not hit India as hard

Why do you think India initially did not have many problems/ was able to manage COVID better?

I think it was managed at an acceptably good level initially because the government was very prompt in taking up the lock downs as well as arranging the facilities. Big infrastructure was built up within days or months for the first wave of COVID, but then the things were dismantled very quickly thereafter once they found that the things are going away, it is fading away, and they did not prepare themselves for the second wave, so this second wave has hit very hard for the Indian population.

In the initial wave, probably the population, was also geared up and convinced to practice social distancing and other majors like putting up a mask and other things. But as time went by, they became complacent, and people started lowering their guard, so that is why the things have been very hard for the last one and a half months now.

How was the initial year for you?
Was your experience typical of other areas in India, or did you have any specific problems pertaining to your demographics?

One thing is that actually the pediatric population or the neonatal population was not that severely affected in the first wave. We did not see very many; I would definitely agree that I didn’t even see a single COVID pediatric patient in the first phase.

But now we have seen neonates as well as the general pediatric population suffering or having COVID positive reports, but we are not taking care of those who are going to level three facility to require that medical health.

I have seen it in neonates last week. I had a neonate around 28 days old whose mother tested positive, and then the child also tested positive, but then that did not have any complications and has recovered. They have a better response to the given infection. They are not getting to so many complications as the adults.

In this second wave, young adults or maybe middle-aged adults like 30-35 years are getting a lot more complications when compared to the first wave, where the elderly were more affected.

“So this second wave is affecting young adults a lot more?”

Yes, and this is probably because of the mutant B117

Was COVID a problem in certain parts of India, and it was just under reported in the news?

Why do you think there is a surge in COVID now?

Multiple reasons. One that the people have lowered their guard. Two, the administrative workup has also lowered their guard. Three, it could be the mutant which has caused this much havoc and, fourthly, you know people have become fed up now, with the repeated lock downs and not earning as much because India has such a vast population. And now, a very large percentage of population have to go out, they have to earn for their family, for themselves, and that is what is taking them away or lowering their guard.

Is there a lot of government support?

No, there is not a lot of governments support either economic or for that matter, you know I might not be the right person to be saying this, but they have not actually come up to the mark, to provide even the healthcare facilities. Now this COVID spread is going towards the villages, it is going towards the countryside.

So in the previous wave, there were very few reports of people being affected in the countryside or in the villages. And at that point of time in the previous wave, people in the villages themselves took up their cause and did not allow the city people or outsiders to enter their villages. But now that guard has also gone, so now COVID has entered into the interiors, especially in Punjab, Uttar Pradesh—I think in every place in India it has gone into the interiors now, and that is why it affects a very large base of population.

Are a lot of these villages far from hospitals?

Yes, definitely. People will have to travel at least 40 kilometers to reach a level three hospital in case they require that stay.

What are you seeing now?

If your hospital/ area is doing ok, can you describe how other areas are doing?

Do you have oxygen, ventilators, and medications?

Are you running out of hospital beds?

How are you treating?

The government guidelines or the WHO guidelines combined are being followed for all COVID patients. Initially, they were quarantining every person who tested positive; then, they started coming up with the idea of home quarantining. And now, most of the asymptomatic or mildly symptomatic patient, they are managed at the home level with teleconsultation by the government sector doctors, doctors engaged by NGOs or the private doctors who give teleconsultation on a fee basis. But those requiring oxygen support or ventilator support, they have to be taken to the government or private sector where the facilities for level 2 or level 3 are available. And then, they are managed according to the protocols that the institutes follow.

Is it common to run out of supplies or have to share hospital beds?

Yes. Many have been seen even sitting outside the emergencies with their own oxygen cylinders and taking oxygen on their own. People even started providing free oxygen cylinders outside the religious places like Gurdwaras, especially in Delhi and Uttar Pradesh. And people have been hoarding also, I would say oxygen cylinders and oxygen at their homes, also for home oxygen therapy. Maybe after they get disturbed or maybe in the initial phase of the illness, where they feel that they will not be able to get a bed in the hospital and they have to fight for this.

With all of that shortage, how is your pediatric hospital doing?

We ran out of oxygen. We even had to deny admission to non-COVID patients. Just last week, we had a child with Meckel’s Diverticulum who had an acute intestinal obstruction and required surgery immediately. But we had to shift that patient to a tertiary level hospital where our pediatric surgeon went and operated on the child.

So definitely, things have not been good for the small care centers. The government is not allowing the COVID centers to be in less than 50 bedded hospitals. The supply chain to these hospitals, like my hospital, is very less. It has to be arranged on your own, and then, if you are not able to arrange one day, it falls on the hospital owner or the doctor who is treating and that is what causes the medical, legal complications, and that is why we are at this point of time, not able to help very many patients, even the non-COVID patients who require pediatric admissions or neonatal admissions.

And oxygen has all been rationed. The oxygen is now under the control of the administration. They are keeping a daily check on every cylinder which is being taken out from the facility, where the oxygen is being bottled or manufactured, so that is how they’re doing it, and they’re taking it away on their own. Some of the time, even the bigger containers of oxygen are being buried under police protection.

Is your hospital seeing COVID patients?

We are not allowed to admit COVID patients. We cannot do that. We are just providing them the home teleconsultation for asymptomatic of mildly symptomatic patients. If we feel on the telecon-
sultation that they require hospitalization or oxygen, we refer them to a COVID center, be it private or public sector. Less than 50-bed hospitals are not allowed to admit COVID patients.

Is the hospital you worked at before allowed to admit COVID patients?

It was a 50-bed hospital, but I have feedback, and they are still not admitting COVID patients. You have to get all these statutory permissions to run a COVID hospital.

Because of these shortages and limitations, are you finding it is harder to care for non-COVID patients?

Yes, definitely, there is a lot of pressure. We are not able to help them out. We are not able to do as much work as we could with the given resources. This is only because there are two issues. One, the issues of logistics or the oxygen which is being rationed which is not being allowed to the smaller hospitals or Non COVID hospitals or non-priority areas. And secondly, people also are now very afraid to get admitted to a hospital because of the dangers of cross-infection or other things, so to a limit, they try to avoid getting admitted for even the acute emergencies. Those are issues affecting us, but definitely, we are helping our patients on the telephone consultations, video consultations, as well as in-person consultations for situations where we feel that we have to call the patient and examine physically.

Are there any PPE shortages?

We are having enough supplies. There was a shortage of N95 masks for medical personnel who are working in the ICU but then it is a place-to-place problem. Like every place has its own problems, and definitely, masks tend to go into short supply for many of the places. But AAA masks for the general population or for us who are not seeing COVID patients that is in abundance.

India currently has three vaccines available (Sputnik V, Covishield, Covaxin) but why is there a problem with logistics?

Why are there vaccine shortages?

Why is it so hard to vaccinate people?

Three vaccines are available. I got my own vaccine on a priority basis because of being a health care professional. My second dose was two months back.

Are most healthcare workers vaccinated?

No, for the initial dose, there was a lot of hesitation even amongst the healthcare personnel to receive the vaccination. It was Covishield only, which was available at that time. What I have read is that almost 40% of healthcare personnel they had refused a dose at that point of time. Some departments in big hospitals have succumbed to COVID-related illness because they did not get their vaccinations in time. There was initial resistance, but now that things have picked up, the general population is also not very reluctant. They are very keen to get the vaccination, but now the vaccine is in very short supply these days. Especially after May 1, it has been in very short supply.

Other than India having a very large population, why do you think the vaccine is in short supply?

One reason was the population. Second reason was that India exported the vaccine to other countries while it was still required in our own country. Third reason is that it is a centralized process by the central government to procure the vaccine and then distribute it to the states. The federal structure was not followed in spirit. And then after May 1, they have allowed the states to procure their own vaccines directly from the company. There are different rates for the central government, which is the minimum. A different rate for the state government which is in the middle and a very different rate for the private practitioners or the private players which is on the very high side.

Most of the Indian health care relies on private health care system. Almost 70% rely on the small healthcare facilities or the private healthcare facilities. The corporate teams are able to procure the vaccines directly from the company. But these small players will not be able to get the vaccine at their own level and offer it to the general population in their local area, so that is another constraint.

Why does most of India’s population rely on these private hospitals? Is it hard to go to a government or corporate one?

Before this COVID struck, the government infrastructure, especially for Level two, Level three care was not up to date. You have a shortage of everything in the government hospitals. It is not at all the kind of social security that we get in the developed countries. You have to be on your own whichever way you go, either in the private or public sector. After the COVID struck, the government took up very many reforms, very many challenges were taken up. Then it was made mandatory that people will be put into quarantine only in government facilities. So people had to definitely go towards the public sector setup. It was revamped also, but then things slackened after the first wave, and that is why it has shown up like this in the second wave.

How do you give and store vaccines when it comes to those who don’t live in cities?

How does it get to those in villages or even slums?

See, India has done a remarkable job in containing vaccine-preventable diseases. For example, we are Polio-free. We were able to take these vaccines to the doorstep level of even the rural population or the remote population. That is not a problem. The vaccines, which are to be stored at two to eight degrees, can always be taken up and shifted to the doorstep, at the very remotest places, but the thing is, the vaccine itself is still not available for that but. Otherwise, everybody would have done their bit to vaccinate the whole population in there, given it.

So you are capable of vaccinating the population. It’s just a matter of vaccine number?

Yes, definitely we had every system in place to do that, but the thing is, the government first opened the vaccination for those who were above 60. Then selectively about 45 with co-morbidities and now after first May they have opened for 18 to 45 years and for those less than 18 years, they’re still not allowing vaccination.

So if someone over 18 years was to get the vaccine in India today, is there a long waitlist?

Yes, yes, it is a very long way. They have to get registered on a particular app. They have to wait for their appointment, and even on the given appointment date, they may not get their vaccine because the vaccine might not be available on that particular day. It was very easy to get vaccines when it was for the selective group, like the health care workers or the frontline warriors but, as the things opened up, the system started crumbling down, and now it is just you know, a rat race to get the vaccine, but not everybody is able to get the vaccine.

Since this, have you noticed a lot of the general populating taking COVID even more seriously, such as more people are wearing masks and social distancing?

See, there is still a lot of complacency in the general population. They are still not up to the required level of guard which is required regarding masking or social distancing. I suppose they are more worried or more concerned about earning their livelihood, and that is why they do not want to get locked down or do something. But I personally believe, even if there is no lock down, even if they
are going to their workplace, they should be taking up the general precautions like masking and social distancing in a good way. It is not being practiced religiously. That is one thing I would say. There have been social gatherings. There have been religious gatherings. And all these things in the last one and a half months have led to a very widespread disease in the urban as well as rural population.

“A lot of things need to be done. I believe one that the vaccine supplies should come up very quickly. The other players in the field should also be given express entry for the vaccine production as well as delivery for the Indian population because we have a huge population. To cover that population, to go anywhere near the herd immunity, we need to vaccinate a very large number of people.”

How does the government play in this? Are they mandating a lock down or encouraging these gatherings?

See, they’ve given these powers to the district magistrates or the distant electors. So they are the ones who are taking up this on a day to day basis, depending on the infectivity rate, the number of active cases in the area and the number of deaths which are occurring, and then they are advocating or putting up the lock downs for a brief period. Our neighboring state Haryana has been under lock down for the last 15 days now. Similarly, Delhi has been under lock down after third May till now. It is in a segregated basis. The places where there is a very high case load, they are certainly opting for lock downs. There are containment zones also where there is a very high proliferation of the disease. They are doing micro containment for those areas. These things have to be managed on a district level by the district electoral or the district minister.

Comment on your feelings

What do you think needs to be done to find a solution?

Do you think you will need additional vaccines from elsewhere?

A lot of things need to be done. I believe one that the vaccine supplies should come up very quickly. The other players in the field should also be given express entry for the vaccine production as well as delivery for the Indian population because we have a huge population. To cover that population, to go anywhere near the herd immunity, we need to vaccinate a very large number of people. So we need to have more players because one or two companies will not be able to ramp up their production overnight and provide vaccination to all those who require. That is one thing. Secondly, more awareness is required amongst the general populations for them to opt for vaccination as a way to prevent a severe disease. Because there are a lot of rumors in the air, on the social media that even after getting two doses of vaccine, people are getting positive or people are dying, but this at present time is misinformation for these general population.

The vaccine is for their own good, and they should opt for getting vaccinated. Also the infrastructure for vaccinating a large group of populations should also be ramped up. It should be done on a shift basis rather than doing it for a few hours in a day so that you are able to cover up a large number of population, but this is only possible if you have an adequate supply of the vaccine.

Like you mentioned with the media, have you found that Indian media is down playing this COVID situation or are they giving accurate information to the public?

No, I don’t believe the media is doing justice to themselves as well as the general population. Lately, the things have started changing, but if you go by the general media, things were not very good at some point of time, like 1-1 ½ month back. But lately, things have started opening up. They have started reporting the realities which are there, but they need to do a lot of groundwork, a lot of research in their local area, local population, and local facilities. Then they will be able to project a picture of what is there and what is required that comes into the notice of the local government.

How can we help?

What is it that you need, and if you feel that you don’t need anything, what do people in India need to turn things around? If anyone has personal shortages, how can we help? What can countries such as the US who has resources, do?

Definitely, these days I think oxygen containers are in session or in demand, whatever the way you put it. But definitely oxygen equipment, for that matter: like the oxygen regulators, the oxygen cylinders, and the oxygen concentrators. These are all things in short supply. The black markets are having a heyday in this. They are actually selling these at exorbitant prices, and for that matter, even the drugs, whether they have been useful for the disease or not, like remdesivir or tocilizumab, which is still not being produced in India. But we are definitely short on these drugs. So this is not my personal experience, this is what I gather from the media or the groups that we are involved in, but definitely, there is a shortage of drugs and shortage of oxygen equipment. For that matter, ramping up the infrastructure also is important, such as bed facility, building new infrastructure for at least level 2 facilities where people can get oxygen on a bed under medical supervision. Not on a home care basis or their own setup. They should not be doing that. They should also not be seen sitting outside the emergencies of hospitals and taking up oxygen from their own cylinders. That infrastructure has to be ramped up. The government is now again ramping up the infrastructure, but they’re very quick to dismantle everything. They had built up 500 bed, 1000 bed facilities in the initial wave, but they dismantled it very quickly. And now they are doing it again. There are many NGOs and religious groups which are coming forwards. I know in Punjab, they are coming up with 500 bed or 200 bed facilities at very many places, now with facilities for oxygen, with the help of either cylinders or oxygen concentrators. So those are the things which would be required in the coming days.

Where are the NGOs or religious groups getting supplied?

These religious groups, like the Delhi Gurdwara Management Committee, they have their own resources because they have been doing very well over these theirs. And the NGOs, like the Khalsa Aid, they have resources from or funding from other countries like UK, your country, Canada, or other places. These are the players that are doing this.

So if someone were to donate, it would be good to donate to these players?

Definitely, I think that will be the best way. Your donation will not reach the masses directly from your end so it has to be through somewhere. Media and these big players have to be worked in to
provide these facilities for the common population.

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

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

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

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

5 THINGS YOU CAN DO TO CELEBRATE NICU AWARENESS

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

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
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5. Join Our Community
   Get involved. Become a member of our organizations and share your talents.

This project is a collaboration between

Project Sweet Peas + National Perinatal Association

www.nicuawareness.org
www.nationalperinatal.org/NICU_Awareness
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.

“High-frequency jet ventilation (HFJV) has been used in the NICU for decades. It has proven beneficial in treating varying pathologies, such as pneumothoraces, broncho-pleural fistulae, and pulmonary interstitial emphysema (PIE).”

With COVID-19 ICU admissions at record levels in several Canadian jurisdictions, this month, I will stray from the NICU to the ICU. (With full admission that adult ventilation is not my field of specialty).

High-frequency jet ventilation (HFJV) has been used in the NICU for decades. It has proven beneficial in treating varying pathologies, such as pneumothoraces, broncho-pleural fistulae, and pulmonary interstitial emphysema (PIE).

In the adult ICU, HFJV is far less commonly used. There is one commercially available jet ventilator, the Monsoon® from Acutronic®. This machine did not exist during my clinical training at Toronto General Hospital (TGH); however, several jet ventilators were in the city. These machines were rudimentary and were built by the University of Toronto. Like the LifePulse® jet ventilator from Bunnell Inc, they were used in tandem with a conventional ventilator.

I had the occasion to use HFJV once during my time at TGH. As was (and still too often is) the case with HFJV in the NICU, these devices were used as rescue therapy. There were no adult oscillators available at the time. I know of one case wherein a patient with severe ARDS was jet ventilated for a month and recovered. As we fast-forward to the present COVID-19 pandemic, there are compelling reasons to consider HFJV in treating COVID-19 patients who require mechanical ventilation. The gentleness of HFJV and its ability to facilitate the clearance of airway secretions, as well as the ability (at least in neonates) to oxygenate at lower mean airway pressure, should be to its advantage.

There is a problem, that being the availability of jet ventilators. The Monsoon® is not in widespread use, at least in North America, and many clinicians are unfamiliar with the concept of HFJV. Reading through the operating manual of the Monsoon® gives me the impression that, while having useful adjuncts like end-tidal CO₂ monitoring, the machine is complicated when compared to the LifePulse®. What appears to be lacking is servo-control of the jet pulses.

“There is a problem, that being the availability of jet ventilators. The Monsoon® is not in widespread use, at least in North America, and many clinicians are unfamiliar with the concept of HFJV.”

The driving (or servo) pressure of the LifePulse® is limited to 21 p.s.i., inspiratory time to 0.02 to 0.034 seconds, and peak inspiratory pressure (PIP) of 50 cmH₂O. With the Monsoon®, jet valve time is adjusted as a fraction of cycle time. Humidification differs between the two machines, with the Bunnell product providing temperature settings while the Monsoon® humidification system is adjusted by “power.” The operating manual suggests verifying adequate humidification by bronchoscopy, suggesting to me that its system is less than ideal.

The LifePulse® is capable of ventilating paediatric patients and has been used at weights up to 26kg. (I have heard of it being used to ventilate a small adult). The Lifeport® adaptor, which replaces the 15mm endotracheal tube (ETT) connector, is limited in size to 5.5mm, too small to use with a 7mm or larger ETT. Nonetheless, there are ways to adjust the machine to provide maximum servo pressure and PIP higher than 50 cmH₂O. Doing so could conceivably provide enough power to ventilate a small adult.

The infant/paediatric version of the LifePulse® is elegant in its simplicity and ease of use. Building on its design to make an adult capable machine seems logical. It turns out doing so is not so
simple, but, in fact, it has been done. This begs the question: why doesn’t an adult version of the Life-Pulse® exist? I believe there are two main reasons: The Food and Drug Administration (FDA) and a company that, given its history with the FDA, is risk-averse. Prototype machines were built, and one was used on an adult patient under compassionate grounds, but that is where this story has thus far ended. Venturing into a market in competition with another machine certainly involves risk, especially given the sparsity of studies on the use of HFJV in the ICU.

“While HFJV has been well studied and is widely used in the neonatal population, its use has been less common in the adult world. I found one study on H1N1 patients with ARDS in which the Monsoon® jet ventilator was used.”

While HFJV has been well studied and is widely used in the neonatal population, its use has been less common in the adult world. I found one study on H1N1 patients with ARDS in which the Monsoon® jet ventilator was used. Pressures used in this study were a maximum of just over 30 cmH₂O (1) which could be well within the range of a LifePulse® altered to ventilate patients larger than 26kg.

Because it is a set percentage of respiratory cycle time, Ti on the Monsoon® is longer than that of the LifePulse® and shortens with higher rates. A shorter Ti requires a higher PIP to deliver the same volume as a longer one. The higher rates of the Bunnell machine work to its advantage here as the short Ti reduces the risk of gas trapping even at rates approaching HFO. Set as real-time, Ti does not decrease as the rate increases. Comparable minute ventilation may be possible with proper adjustments.

“If I were placed in that difficult situation, my inclination would be to set Ti at 0.034 seconds and PIP at 50 cmH₂O, initially at a rate of 240 on the LifePulse® with PEEP at conventional mode MAP. If there were no improvement or deterioration occurs, I would increase the rate in 1 Hz increments to 360-420. Beyond a certain point, increasing jet rate becomes less effective, and modification is required. Bench testing may be able to approximate comparable settings between the two machines.

Given the prevalence of ARDS and its approximate mortality rate of 35-46% (2), an effective ventilation strategy is wanting. Extra-corpooreal membranous oxygenation (ECMO) is the current endpoint for those failing mechanical ventilation.

The Oscillate Trial did not favour high-frequency oscillation (HFO) for the treatment of ARDS. (#) Whether it was HFO to blame for the poor outcomes of the HFO group or the design of the study itself (for instance, a 1:1 I:E ratio, “highest possible frequency,” and an initial recruitment maneuver of 40cmH₂O for 40 seconds) cannot, in my opinion, be determined. The greater use of vasoactive drugs, paralysis, and “new-onset barotrauma” (3) within the HFO group begs the question of whether MAP used in the HFO group was patient-appropriate. To me, the key take-home message from the Oscillate Trial was the use of smaller tidal volumes in conventional modes in concert with higher PEEP.

“The greater use of vasoactive drugs, paralysis, and “new-onset barotrauma” (3) within the HFO group begs the question of whether MAP used in the HFO group was patient-appropriate. To me, the key take-home message from the Oscillate Trial was the use of smaller tidal volumes in conventional modes in concert with higher PEEP.”

While I recognize the difficulty of conducting a clinical trial in mechanical ventilation, protocolized ventilation is, shall we say, not my cup of tea. I prefer to tailor ventilation to individual patient needs/responses within flexible guidelines. Those guidelines allow a clinician to operate beyond them when required.

Nevertheless, HFJV is fundamentally different from HFO in terms of I:E ratio, passive vs. active expiration, and the lower MAP required to achieve adequate oxygenation. (Lower MAP requirements have been demonstrated in the neonatal population but not in adults).

I believe the relative simplicity of the LifePulse®, the ability to set actual inspiratory time, and servo-controlled PIP make it a superior machine and one more likely to gain acceptance in an ICU setting. Given the enormous, tragic loss of life to COVID-19 (not to mention ARDS), it is a shame that clinicians fighting this pandemic do not have it at their disposal.

In the current tense, COVID-19 is striking ever younger (and potentially smaller) patients. At the time of writing, variants of the virus threaten the efficacy of current inoculations and the rate at which we can administer them. The virus is always one step ahead.

For decades, using HFJV to manage the most fragile and challenging NICU patients has a track record of success. Should the agonizing decision come to ventilate, a COVID-19 patient HFJV
may prove to be the best option. When a Monsoon® is not available, using the LifePulse® may be justifiable, even for some with bodyweight outside its rated operating range. When ECMO is the only other option, the nature of HFJV should make it a consideration before abandoning mechanical ventilation entirely, machine choice notwithstanding.

It is not whether we are up to the challenge; the challenge is here. Now.

Perhaps next time.

Footnote: this column strictly represents the author’s opinions and in no way represents the endorsement of Bunnell Inc., Acutronic®, or anyone associated with either company.

References:

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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Infant massage has been performed for centuries across many societies worldwide, where the practice is fully integrated into postpartum care and passed down intergenerationally from mother to mother.

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

The Power of Touch: Benefits of Infant Massage for Infants and Their Parents

Mona Elgohail, Ph.D., Pamela A. Geller

Infant massage is an emerging practice in the United States, albeit slowly. A growing body of research has documented many benefits of infant massage for both infants and parents. As a result, infant massage is an emerging practice in the United States that has become a specialty within the field of massage therapy and is conducted by other professionals from varied disciplines who care for children and families (e.g., clinical psychologists, physical therapists, occupational therapists, nurses, child life specialists). These professionals have obtained certified training in infant massage and teach the massage skills to the infant’s parents and conduct the massage themselves.

Infant massage is the process of using specialized techniques to rub the soft tissues of the infant’s body in a smooth, rhythmic manner with moderate, intermittent pressure and varying speeds. (2,3) The typical strokes taught by certified infant massage instructors are a combination of techniques from the East Indian and Swedish traditions, as well as reflexology and conditioned relaxation. (2) Reinforcement of the parent-infant attachment is strongly emphasized when teaching infant massage. (2) Positive behavioral reinforcements, such as vocalizations (e.g., singing, humming, talking), smiling, and eye-to-eye contact, are considered critical components that help strengthen parent-infant attachment. (2) Additionally, the use of unscented organic oils (e.g., apricot, grape seed) is encouraged to maximize the massage impact and enable infants to recognize their parents’ scent (as opposed to masking caregiver scent with added fragrances), further strengthening parent-infant attachment. (2,4)

The optimal time for parents to conduct infant massage is when the infant is in a quiet, alert state, meaning the infant is attentive but not physically active. (5) Infant massage is not something done to an infant; instead, it is an activity done with an infant. As such, the crucial first step of the massage is to cradle the infant’s head in one’s hands and ask for permission while making eye contact. (2) If the infant’s behavioral cues suggest that it is okay to continue (e.g., eye-to-eye contact, smiling, cooing, babbling, reaching toward caregiver), strokes are typically conducted in the following sequence: legs and feet, stomach, chest, arms, and hands, back, and face. (2) Although this is the sequence taught by professionals, parents can and should, of course, modify as needed to create a personalized experience for their infants based on their likes, dislikes, and needs. Massages typically last 10-20 minutes, with less time spent on preterm infants and newborns. (2) The art of massage requires that the provider be flexible and attentive, modifying and shortening the massage as needed based on signs from the infant of overstimulation or disengagement (e.g., gaze aversion, crying, turning away, arching body, pushing away). In other words, the massage should only last as long as the infant is enjoying the process. The massage can also last longer than 20 minutes if the infant shows signs of enjoyment and engagement.

Benefits of Massage for Infants:

The research literature suggests a wide range of physiological, psychological, and social benefits of massage for healthy full-term and high-risk infants that generally fall into one of four categories: providing stimulation, promoting relaxation, improving circulation, and enhancing bonding/attachment. The key benefits of massage for healthy full-term infants are highlighted below.

Stimulation:

- Promotes growth, including increased weight gain, body length, head circumference, chest circumference, arm circumference, and leg circumference (3,6-10)
- Enhances cognitive performance (e.g., improves orientation, increases alertness, improves attention) (3,10,11)
- Improves mental-motor development (e.g., lingual-cognitive, fine motor, gross motor, and social
Mental Health:

• Engages pre-language skills (e.g., eye contact, listening, cooing, gestures, facial expressions, imitation)

Relaxation:

• Reduces stress neurotransmitters/hormones (norepinephrine, epinephrine, and cortisol) (4,10)
• Enhances coordination of the circadian system (13)
• Improves sleep, including reducing sleep onset latency, reducing the frequency of nighttime awakenings, reducing agitated behavior during sleep, and increasing total sleep time (3,14-18)
• Increases use of self-comfort regulatory behaviors (19)
• Improves mood (e.g., reduces colic symptoms and time spent crying and fussing) (9,18)

Circulation:

• Lowers transcutaneous bilirubin levels (9,20)
• Promotes digestion and elimination (e.g., can relieve trapped gas, constipation, and diarrhea) (2)

Bonding and Attachment:

• Provides quality, intimate one-on-one time with the parent
• Increases salivary oxytocin level in mothers and infants with normal bonding (21)
• Promotes healthy attachment/bonding with parent (e.g., increases infant’s attentiveness, liveliness, and happiness; interactions are smoother, more fun, mutually satisfying, more exciting, and more engaging) (17,21-23)

Benefits of Infant Massage for Parents:

Studies suggest that parents also significantly benefit physiologically, psychologically, and socially from massaging their infants. Below is a brief list of these research findings.

Sleep:

• Improves maternal sleep quality, including reducing sleep onset latency and increasing total sleep time (15,16)
• Improves maternal perceptions of infant’s morning mood and sleep (i.e., reduced sleep onset latency, fewer nighttime awakenings, increased total sleep time, less difficulty falling asleep and staying asleep, improved sleep quality) (15,16)

Parenting Skills and Confidence:

• Increases mothers’ confidence in managing their infants’ sleep when massage is incorporated into the bedtime routine (15,16)
• Promotes positive perceptions of infant’s temperament (24)
• Promotes positive adaptation to motherhood (25)
• Increases confidence in parenting abilities (25)
• Promotes positive attitudes towards motherhood (25)

Mental Health:

• Improves maternal daytime mood (15)
• Reduces depressive symptoms (24, 26)
• Increases self-esteem and sense of empowerment (27)
• Reduces parenting stress (26)

Bonding and Attachment:

• Provides quality, intimate one-on-one time with the infant
• Promotes stronger, closer, and more positive relationships with the infant (25)
• Promotes healthy interactions with the infant (e.g., mothers increase warmth and decrease intrusiveness towards the infant; interactions are smoother, more fun, mutually satisfying, more exciting, and more engaging) (22,24,28)
• Increases support from the mother’s mother and husband (25)

Possible Mechanisms of Change:

Some of the mechanisms by which infant massage might promote benefits for infants and their parents have been explored. It has been speculated that massage stimulates pressure receptors leading to increased vagal activity, (3,29) The vagal activation then stimulates gastric motility and the secretion of food-absorption hormones (i.e., insulin and gastrin), and thereby promote infant digestion and growth (i.e., weight gain, body length, head circumference, chest circumference, arm circumference, and leg circumference). (3,29) massage may also reduce infant stress by increasing parasympathetic activity, which is a relaxed state characterized by slower heart rate and lower cortisol levels, which may improve sleep. (4) One study reported that the tactile stimulation of massage releases melatonin which adjusts the circadian system and improves sleep. (13) Studies using animal models suggest that massage may stimulate synaptogenesis and neuronal survival in the hippocampus, improving cognitive development (e.g., greater spatial learning and memory performance). (30,31) Hypothesized mechanisms for improvements in attachment/bonding and interaction include relaxation of parent and infant, increased confidence in parenting abilities, improvement in parent’s understanding of infant’s cues, and the release of oxytocin in both parent and infant. (32)

Limitations of the Current Research Literature:

Research findings in the current literature on the benefits of infant massage for healthy full-term infants and their parents are promising. However, it is important to note that these findings are based on few studies, as most research on infant massage has focused on premature infants. Additionally, most studies on full-term infants are of poor quality due to methodological inadequacies and failure to address the underlying mechanisms by which observed outcomes might be achieved. (9) It is also important to note that most studies include mothers but do not include fathers or other primary or secondary caregivers (e.g., grandparents).

Conclusion:

The power of touch is profound. Infant massage can lead to a wide range of physiological, psychological, and social benefits for infants and their parents. It is an effective, inexpensive, easy-to-learn, natural, health-promoting intervention that should be utilized as a part of the developmental care of all healthy full-term infants. Yet, in the United States, infant massage remains largely undiscovered, undervalued and/or underutilized by families and pediatric and maternal health professionals. It is time to change our ways, to pick up the threads of the ancient wisdom of non-western cultures, and weave them into the fabric of our standard of care practices for infants and their parents. Adaptation to parenthood and infants’ early and long-term development deserve as much forethought as pregnancy and birth. Infant massage is a powerful tool that can help form a harmonious relationship be-
tween infants and their parents while providing parents with an easy, effective way to enhance physiological, psychological, and social well-being. To ensure optimal recommendations and practices, more methodologically rigorous research, preferably in the form of randomized controlled trials, is needed to understand better the benefits of infant massage for healthy full-term infants and their parents.

References:


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A Multidisciplinary Approach to Perinatal Cardiology

*Volume 1*

*Edited by P. Syamasundar Rao and Dharmapuri Vidyasagar*

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**Book Description**

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

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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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*A Multidisciplinary Approach to Perinatal Cardiology Volume 1* is available now in Hardback from the Cambridge Scholars website, where you can also access a free 30-page sample.
Caring for Pregnant Patients & Their Families: Providing Psychosocial Support During Pregnancy, Labor and Delivery

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About the Program

• **WHO SHOULD TAKE THE PROGRAM?** This program is designed for both office and hospital staff in all disciplines that interact with pregnant patients and their families. A key focus is recognizing risk factors for perinatal mood and anxiety disorders, and mitigating their impact through provision of trauma-informed care.

• **WHY TAKE THE PROGRAM?** Families will benefit when staff have improved skills, through enhanced parental resilience and better mental health, and improved parent-baby bonding leading to better developmental outcomes for babies. Benefits to staff include improved skills in communicating with patients; improved teamwork, engagement and staff morale; reduced burnout, and reduced staff turnover.

• **HOW DOES THE PROGRAM ACHIEVE ITS GOALS?** Program content is representative of best practices, engaging and story-driven, resource-rich, and developed by a unique interprofessional collaboration of obstetric and neonatal professionals and patients. The program presents practical tips and an abundance of clinical information that together provide solutions to the emotional needs of expectant and new parents.

• **HOW WAS THE PROGRAM DEVELOPED?** This program was developed through collaboration among three organizations: a multidisciplinary group of professionals from the National Perinatal Association and Patient + Family Care, and parents from the NICU Parent Network. The six courses represent the different stages of pregnancy (antepartum, intrapartum, postpartum), as well as perinatal mood and anxiety disorders, communication techniques, and staff support.

Program Objectives

• Describe principles of trauma-informed care as standards underlying all communication during provision of maternity care in both inpatient and outpatient settings.

• Identify risk factors, signs, and symptoms of perinatal mood and anxiety disorders; describe treatment options.

• Define ways to support pregnant patients with high-risk conditions during the antepartum period.

• Describe obstetric violence, including ways that providers may contribute to a patient’s experience of maternity care as being traumatic; equally describe ways providers can mitigate obstetric trauma.

• Describe the importance of providing psychosocial support to women and their families in times of pregnancy loss and fetal and infant death.

• Define the Fourth Trimester, and identify the key areas for providing psychosocial support to women during the postpartum period.

• Identify signs and symptoms of burnout as well as their ill effects, and describe both individual and systemic methods for reducing burnout in maternity care staff.

Continuing education credits will be provided for physicians, clinic and bedside nurses, social workers, psychologists, and licensed marriage and family therapists. CEUs will be provided by Perinatal Advisory Council: Leadership, Advocacy, and Consultation.
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 Davis, 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 Davis, Founder of Keep ‘Em Cookin’, Baltimore, MD; Erin Thatcher, BA, Founder and Executive Director of The PPROM Foundation, Denver, CO.

PROVIDING INTRAPARTUM SUPPORT  CEUs offered: 1
Describe how to manage patient expectations for labor and delivery including pain management; identify examples of obstetric violence, including identification of provider factors that may increase patients’ experience of trauma; learn how to mitigate patients’ trauma, and how to provide support during the process of labor and delivery.

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

PROVIDING POSTPARTUM SUPPORT  CEUs offered: 1
Define the 4th Trimester and the importance of follow-up especially for high risk and minority patients, learn to recognize risk factors for traumatic birth experience and how to discuss patients’ experiences postpartum; describe the application of trauma-informed care during this period, including support for patients who are breastfeeding and those whose babies don’t get to go home with them.

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

SUPPORTING STAFF AS THEY SUPPORT FAMILIES  CEUs offered: 1
Define burnout and compassion fatigue; identify the risks of secondary traumatic stress syndrome to obstetric staff; describe adverse impacts of bullying among staff; identify the importance of both work-life balance and staff support.

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

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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

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.
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Understands the American Families Plan

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

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

“By now, most everyone has heard of President Biden’s American Families Plan, the $1.8 trillion proposal presented to Congress on April 28. (1) While the details are not all final, the proposal is poised to impact families with babies and young children. Here is a look at a few key components.”

By now, most everyone has heard of President Biden’s American Families Plan, the $1.8 trillion proposal presented to Congress on April 28. (1) While the details are not all final, the proposal is poised to impact families with babies and young children. Here is a look at a few key components.

National Comprehensive Paid Family and Medical Leave

President Biden described the country as “on the move again,” which includes being back at work. That requires supporting those who may need to step back from work to care for themselves or a family member.

“President Biden proposed an investment of $225 billion for a partial wage replacement of up to $4,000 a month for workers who take leave to bond with a new child, care for a seriously ill loved one or heal from their own illness, among other reasons.”

President Biden proposed an investment of $225 billion for a partial wage replacement of up to $4,000 a month for workers who take leave to bond with a new child, care for a seriously ill loved one or heal from their own illness, among other reasons. As outlined, his plan would take a decade to implement fully, building to 12 weeks of paid parental, family, and personal illness leave in the final year.

The proposed changes would “bring the American system in line with competitor nations that offer paid leave programs.”

Expanded Nutrition Programs

The American Families Plan includes a $45 billion investment in reducing childhood hunger and food insecurity, disproportionately affecting low-income families and communities of color. One component of President Biden’s plan would make permanent the summer EBT program. The existing pilot provides money for food to the families of the 29 million children who receive free and reduced-price meals at school during the academic year.

The funds for this and other newly proposed nutrition plans appear to be separate from those the White House announced in mid-April as part of its efforts to curb Black maternal mortality. That proposal included $6 billion to expand the Special Supplemental Nutrition Program for Women, Infants, and Children. (2) When taken together, the actions demonstrate that the Biden-Harris administration aims to tackle nutrition access on multiple fronts.

Extend Tax Credit Programs

The American Families Plan also builds upon the groundwork laid by the Trump administration and the stimulus package that was passed in March by expanding the child care tax credit. Families with children younger than 13 could receive up to $4,000 for child care for one child or $8,000 for multiple children.

It also extends the existing child tax credit through 2025 and makes it “fully refundable.” This extension means low-income households that do not earn enough to claim it would still receive the benefit – $3,600 for children under age six and $3,000 a year for children ages 6 to 17, for most families.
Paying for It

The power to fund the president’s American Families Plan lies with Congress. The White House has suggested several ways to generate the needed revenue, including increasing capital gains taxes and raising the income tax rate for high-income individuals and businesses.

Now members of Congress will determine the next steps. While Republicans are balking at new taxes, some Democrats say the plan does not go far enough. These concerns paint an uncertain future for the plan. For now, the Biden-Harris administration, like all Americans, will have to wait and see what happens.

References:

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I CAN Digitally Involved (I CANDI): A Major Milestone

Amy Ohmer

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. 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. 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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I was exposed to opioids.

I am not an addict.

Addiction is a set of behaviors associated with having a Substance Use Disorder (SUD).

My mother may have a SUD.

My potential is limitless.

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.

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.

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.

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 or visit www.icanresearch.org.

#iCANMakeADifference #iCAN #iCANBeDigitallyInvolved #GlobalGenes #CareAboutRARE

References:

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

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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.

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Attestation

I confirm that I am a trainee in pediatric surgery or a consultant in pediatric surgery in a low or low middle-income country who commits at least 75% of my practice to providing surgical services to public patients who do not reimburse me for my services. I confirm that these textbooks will contribute significantly to my training or practice, and that I do not have the financial means to purchase the books. I pledge to share the books with all pediatric surgical trainees and consultants in my institution who stand to benefit from the knowledge provided in the book. I pledge to provide email confirmation to Dr. Sherif Emil (Sherif.Emil@McGill.ca) upon receipt of my copies.

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- Fever that is higher than 101°F Fahrenheit, which is especially dangerous for babies younger than 3 months

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.

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- flu
- coronavirus
- pertussis
- RSV

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

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

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High Reliability Organizing (HRO) is the Extension of Neonatology during Pandemic COVID-19

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

Abstract
Neonatology began with the extension of care to smaller babies born earlier in gestation and now extending into the threat of COVID-19. Extending operations into a new environment places everyone in novel situations. Emerging from actual operations within dangerous contexts, HRO extends operations and the organization into uncertain, adverse, and hostile environments. The physical actions of care come from motor cognition, the influence of the cerebellum and motor cortex on cognition, and how we learn through physical action to understand events. Rather than study the myriad ways a system can fail or how it can reach the final common pathway of failing, we can study and respond to it as a liminal zone. It is common to all failures — an exigency of ambiguous information, impending proximal threat, uncertainty, and demand for action. Engagement in the liminal zone is the same as engagement for extension, drawing from four domains: categorization, methods of decision making, the significance of the affective processes, and modulation of stress and fear responses. Perhaps the purpose of safety, reliability, and resilience is not to safely work in a dangerous context but to support the extension of the organization into uncertainty, a new environment, unpredictable circumstances, or to penetrate threats. When a person believes in themselves, they will leave their place of safety and engage the unknown when they know they are supported. This is the extension of neonatology.

“The continuing extension of neonatology now includes surgical care, complex mechanical ventilation, and pulmonary care, support for families, and more.”

Introduction
What falls under neonatology? The discipline of neonatology started as the extension of care to smaller babies born earlier in gestation. That, alone, is commendable. But the characteristics of the Neonatologist and neonatal nurses extended neonatology to babies with respiratory disease, and respiratory care practitioners brought their expertise. The continuing extension of neonatology now includes surgical care, complex mechanical ventilation, and pulmonary care, support for families, and more.

The extension of neonatology asserted effective care over more difficult physiology, dealing with low oxygen values and low temperatures, somewhat aligned with the problems of early high altitude climbers in the Himalaya (1). Climbers gained altitude, but it was the synthesis of science and climbing, created by an individual with experience in both domains, that brought them to the top of Mount Everest. Similarly, Neonatologists with experience in both domains of science and bedside medical care have gained life for those newborns who would have died and for those who would have suffered a severe disability.

The extension of neonatology into the threat of COVID-19 is the most recent expansion of neonatology. Neonatology demonstrates many of the characteristics of High-Reliability Organizing (HRO). The problem common to organizations seeking greater effectiveness is the translation of HRO characteristics to neonatology. Mistranslations and misunderstandings undermine the benefits of HRO as a method of extension into new realms (2). Therefore, it’s critical to scrutinize the exact translation of HRO into the neonatology domain.

““The problem common to organizations seeking greater effectiveness is the translation of HRO characteristics to neonatology. Mistranslations and misunderstandings undermine the benefits of HRO as a method of extension into new realms (2).””

Dangerous contexts remain dangerous. We commend the outside observer who suggests bringing order and creating structure through design and command. The outside vantage point gives a better view of identifying discrete principles, reducing mistakes, and stopping errors. Organizing the confused, dangerous work environment from the outside seems prudent. Outside observers, however, miss the meaning of weak yet salient signals and the power of subtle or nuanced actions taken at the right time.

An observer, removed from the problem, evaluates the situation with theory and scientific rationality. The operator, engaged in the turbulence of events, becomes part of the problem (2). The operator learns what works through action; experienced operators think best while acting (3, 4). Karl Weick captured this in his “recipe” for sensemaking, “How can I know what I think until I see what I say?” (5). Other distinctions in thinking between observers and operators include the use of abstractions over concreteness and nouns versus verbs, respectively (2, 6-12). We see this in Weick’s distinction between High-Reliability Organization versus High-Reliability Organizing (10).

Advances in neuroscience provide support for several characteristics found in dangerous contexts -- for example, language processing and the link between cognition and action. This is not a trite digression. There is order within a difficult period, but it is likely more pragmatic than normative, and the nature of that order

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is rendered less accurately by the concepts of a spectator than by the detailed acquaintance of the insider (2). Unrecognized by operators and invisible to spectators is the influence of action on cognition. The extension of neonatology to gain life emerged from Neonatologists physically engaged in care at the bedside. The Captain of a US Navy nuclear aircraft carrier is on the bridge for all dynamic operations (TAM). It is the intimate experience of problem-solving on the fly where we experience what Weick (personal communication) describes as “the clash between a mistaken old belief and an updated belief.” That is the extension of an organization into uncertainty rather than laboratory studies and evidence-based knowledge.

Extending operations into a new environment places everyone in novel situations. Motor cognition describes how we adjust our actions to changing situations and learn through physical actions. New encounters increase the possibility of failing but, past a threshold, the environment of failing is shared amongst all cautions and situations. Developing the skill of responding to the final common pathway of failing supports extension and learning. Nothing is entirely new; knowledge and experience from an environment with some shared similarities initiates extension from our capabilities. Extension through the final common pathway draws upon four domains of engagement that differ from how these domains are used in stable environments (categorization, methods of decision making, the significance of the affective processes, and modulation of the stress and fear responses). We end with some observations on hidden impairments to extension. They seem to help but will block the extension of individuals, teams, groups, and organizations.

“Extension through the final common pathway draws upon four domains of engagement that differ from how these domains are used in stable environments (categorization, methods of decision making, the significance of the affective processes, and modulation of the stress and fear responses).”

The Motor Cognition of Extension

“Whenever movement follows unhesitatingly and immediately the notion of it in mind, we have ideo-motor action. We are then aware of nothing between the conception and the execution,” William James (13).

The historical roots of motor cognition are the pragmatist school of philosophy and William James (14). Motor cognition is action representation for voluntary action. Their perceivable effects represent actions under our control. In fact, the intent or thinking of the effects in mind is sufficient to act immediately (15). Cognitive processes for action include the urge and intention to act and adjust those actions while acting immediately. A mirror system allows us to understand the intent and actions of others, creating a gateway to social cognition. Mirror systems have motor output, differentiating them from visual perception processing (14). HRO operations have common elements with motor cognition. During an emergency, we focus on the consequences of our actions and bottom-up feedback (2). This is similar to pragmatist philosophy and represented in motor cognition by perceivable effects as bottom-up feedback. (14, 15). Mirror systems support the heedful interrelating and trust found on an aircraft carrier flight deck (16), physical rescue in the field (8), or neonatal resuscitation.

The Mirror system is how we learn by watching others (17) and figure out their intent without speaking (18). Because the mirror system neurons are in the pre-motor cortex, they do not respond unless action is executable. Through the mirror system, we can communicate to others by our actions, a process called communicative intention (19).

The academic background of the Neonatologist supports the routine use of abstract thought while operations with uncertainty or adversity in a liminal environment demand accurate, concrete descriptions (1, 3). This has neuroanatomic consequences. The sensorimotor neural network processes sentences with concrete nouns and words and abstract words but with a preference for concrete terms. The linguistic system preferentially processes abstract nouns and verbs (20). For motor versus visual abstract words, abstract motor words will specifically activate motor areas while visual abstract words specifically elicit higher visual area activity (21). The use of concrete, active words facilitates action, while abstract words tend to generate thinking. This seems prudent until you realize the brain’s response to stress constrains executive functions and impairs abstract thought (22). During an emergency, abstract words send messages to areas of the brain impaired by stress.

Operators in dangerous contexts use concrete nouns for description and emphasize action verbs for communication. Recent neurosience findings support this behavior. Action words and motor action noted above share common cortical representations. Action verbs, more so than concrete nouns, affect overt motor performance dependent on timing. That is, an action verb will interfere with a reaching movement in progress within 200 msec. The same words processed before movement will assist the movement (23). This action, fortunately, is category-specific. A quick shout to move a hand causes hands to move and not random body parts. The category-specific, functional linking of language and motor action in the left hemispheric cortical systems link arm and leg actions with the processing of specific kinds of words. The two systems interact to produce meaningful information about language and action (24-26). “We assume the process to be a continuing one – more organizing than an organization,” Karl Weick (10). The distinction of organizing (verb) vs. organization (noun) is one of the twelve most frequently cited concepts on organizing from Weick (27). The brain processes verbs faster than nouns.

The cerebellum and motor cortex also influence cognition. Executive functions and higher-level cognitive cortical functions draw upon interactions with cerebellar motor functions (28-30). High-level knowledge is grounded in sensory and motor experience (28). This shapes the motor system on anticipation and provides information for the meaning of potential action (26, 31). We rely on reciprocal feedback from the environment (8). We think by acting (4).

Because uncertainty, adverse situations, and hostile environments have different environmental geometry, they require a different engagement geometry. Circumstances may change during sensemaking or acting, and your mind must keep up. The time course described is not necessarily minutes but could be days. Time compression matches the time horizon, minutes for an active resuscitation, weeks for a growing, healing lung. The problem is how we mentally map events and our responses. We are taught by organizing knowledge and concepts in hierarchies that show relationships and connect terms with measurable distances between points. This is a Euclidean space. There is growth but no movement.
The circumstances during COVID-19 and neonatology as a discipline are in a continuously changing actual world. Our team's actions are continuous, independent, and interdependent. This geometry describes a scale-free topology (32). The central concept of topology is continuity, a notion of nearness that is preserved by a continuous function. Topology does not localize an object in Euclidean space, allowing a discipline to extend beyond Euclidean restrictions (33). The geometry is preserved under continuous motions because distance and dimension are not relevant. In neonatology, operations occur in different kinds of space, the distance between objects is a matter of function of the relations, and differences between objects are a matter of variety in the relations (33). Topology provides a language of continuity that is general enough to be developed in new ways. Topology extends neonatology beyond the restrictions of Euclidean space. The major extensions of neonatology have occurred through topological space rather than Euclidean space.

“The topology extends neonatology beyond the restrictions of Euclidean space. The major extensions of neonatology have occurred through topological space rather than Euclidean space.”

Karl Weick’s ‘sensemaking recipe’ now applies to these topological events: “How can I know what I think until I see what I say?” (5). We can distinguish the neuroscience of his recipe.

I can’t know what I think until I act. Intention cannot cause our actions because conscious intention occurs after preparatory brain activity in the frontal and parietal brain areas (34). It would make sense that purposive action derives from intention, which would mediate between cognitive desires and purposive motor behavior. Rather than mediating, the two distinct brain operations, cognitive intention and motor behavior, must coordinate. This is the “Interface Problem,” made difficult because of the importance of motor representations in creating purposive behavior (35).

The subjective experience of conscious intention often contains two components: a sense of urgency, or being about to move, and a reference forward to the goal object or event (22). Our perceptions help us recognize whether a response was due to our own actions, giving us a sense of agency (34). Without action, we do not gain a sense of agency.

Actions create what we think, which continuously changes until we finish acting. During our behavioral interactions with the environment, our brain specifies desirable actions as the environment changes (36). Continuous, bottom-up feedback for sensorimotor control, through the motor system, detects prediction error, updating ongoing action. This feedback enhances or cancels some sensorimotor signals. Self-generated cancellation as a motor function also explains why we cannot tickle ourselves. It is due to the sensory feedback through the motor system (37). Alternative actions continue to be mentally processed (36). This may extend to language comprehension, social cognition (38), and interpreting sensory signals (39). This makes visible to ourselves our intention.

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

Karl Weick (personal communication)

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

The Final Common Pathway of Failing

Ensuring effective operations in difficult situations continues to be devilish healthcare and organization science. A system appears to be running well, and leaders believe in the capability of their organization. Yet systems continue to fail, and organizations still experience failure. After the accident at the Three Mile Island nuclear power plant, characterized by Charles Perrow (40) as a “normal accident,” academicians and organization leaders searched for remedies. One of the early findings was identifying the High-Reliability Organization (HRO) (41–44), with more approaches coming into existence since. However, we have not seemed to have reached a reliable solution for achieving reliability.

To achieve a safe workplace, do not do anything dangerous. An aircraft carrier has the fewest accidents when in port with its planes secured on deck. The focus on danger may be a product of the outsider’s frame of reference (45). Operators within the dangerous context recognize the danger, fear the danger, do not show that fear, and continue working (8). Error, as the “experience of failing,” is instrumental in achieving safety. Short, negative feedback, sometimes called an error, denotes the boundary of performance, knowledge, and operations. Error corrects heuristic bias (45).

Perhaps the purpose of safety, reliability, and resilience is not to safely work in a dangerous context but to support the extension of the organization into uncertainty, a new environment, unpredictable circumstances, or to penetrate threats.

The safety, reliability, and resilience literature seem to have two components: causality and remedy, with some overlap. Focus on causality resulting from an error, failure, resilience, followership, complexity/chaos, and human factors move the discussion away from a person’s experience in the moment of overwhelming events. Focus on remedies such as leadership, team, decision theory, engineered or designed programs moves the remedies away from those intimately involved. It appears we create categories that make sense to those away from events, make decisions that address the situation using logical sequences, study cognitive processes to ensure clear thought and action, treat stress as something lesser people must deal with while fear reactions become invisible. We gloss over the gaps between theory and practice, fear and thought, and abstractions and concreteness.

What makes sense for this approach is using the lexical elements, lexicon, and phrases that develop deep within the experience of those who have worked in a live-or-die context. Failure, then, would not be due to mistranslations but to misapplications by subordinates (2). Reviews then focus on what reviewers, themselves, would have never considered doing rather than how they would act in similar circumstances. This subtle form of blame (“That is something I would never do. Why did they?”) is the source of humor for lectures while protecting those outside the event – they now feel safe because they would not have done that.

What is missed with deadly consequences is the action that happens within the funnel of activity that forms from the diverse circumstances that initiate failing, drawing to the singular point of failure. What is missed is the function and utility of error and how failure may be a product of expectations or stopping too soon. Operations within this final common pathway are the same in all situations. What differs between effective operations and ineffective responses is not due to the industry, organization, or type of activity. The differences arise within several domains, which are
made invisible because of the time compression of local responses and events.

We can describe this final common pathway through engagement (2, 3, 8), describing four distinct domains (described below), and HRO operating in a topological space. The act of engagement bridges conceptual gaps and extends responsiveness which, in turn, forms prevention and generates resilience. The four domains are sets of properties with functions and characteristics that differ between stable environments (or environments where we can expect stability) and abrupt change or liminal situations. The concepts of HRO effectively operate when used in a manner dependent on how the organization puts them together, rather than operating as discrete, measurable properties. HRO concepts are close to each other in terms of practical relationships rather than distinct and discrete categories or classifications. Such a set of concepts function in a topological, rather than a Euclidean, space. That is, to follow one concept is to travel along a Moebius strip. You end up on the other side.

**Extension from Within**

We do not want this topic to become lost in theory or esoterica. We must remain rooted in the concept that we “learn” HRO when we are young and inexperienced. We use the dynamics of HRO throughout our daily routines. Our discussions come from these early experiences that we later apply to extreme circumstances. Experience grows from experience (3). As well, how do we learn from those whose failure turned into wisdom?

Hitting a patch of ice under the snow while descending a mountain one winter, I (DvS) fell quite a distance. Losing my ice axe when the pick caught another patch of ice, I began to spin face down. Not sure how to stop, I began to weigh the advantage of landing at the bottom head first or feet first. A quick death from head trauma or break my thighs and perhaps survive through the night for possible rescue. Then I was not moving. Now I had a different problem. What was holding me in place on the thin snow over scree (small gravel)? It could be one of my knees, my toes, my elbows. With my face pressed into the snow, I thought it could be my chin and nose. This was important to me since I did not want to move my anchor without first creating a better anchor. BTW, I was 18 years old at the time of the fall. The year before, a climber in my climbing group fell to his death in this same way.

Picture cords tied to each wrist. They both pull on you, but you cannot tell which cord is pulling you down the mountain and which is pulling you up. Which cord do you release? That is what happens when the naive enters a dynamic, unstructured state. We observe them holding dearly to beliefs and behaviors learned in a safe, controlled, structured environment, and not only can they not sort out what works from what hurts, they are afraid to let go even if they know.

People commonly create binary decision frames – let go with the right wrist or the left, go or stay, cut the red wire or the black wire. This may frame the situation for managing risk, but the HRO exists to engage risk. An operator with a Special Operations Group (SOCOMM, Special Operations Command) asked the author (DvS) to explain risk and risk management. “Risk is a determination whether to accept a project. You cannot do that, like I cannot decide to accept a resuscitation. Risk for you is to evaluate your capabilities, augment where you are short, then take the mission.” On the mountain, rather than choose a limb to move, the author identified the limb with the most freedom of movement. That is the limb he used to dig in for a stable platform.

In a wildland fire, running from a firestorm, we do not drop our tools. It is not because we are responsible for them or we are captured by fear, but because we were told our tools will save our lives – until they do not. Smokejumpers encumbered by their tools in the Mann Gulch Fire could not reach safety. Their fire foreman, Wagner Dodge, called out, “Drop your tools!” His crew held onto their tools. Thirteen men died (46). Experiencing a fire burning up a steep slope on a hot day and you are near the ridgeline, does your tool protect you, or does it kill you? Is there a sharp line? Tools for the Neonatologist are protocols and evidence-based medicine.

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Teachers, academicians, and consultants from the structured environment are no help. Experienced veterans from the unstructured environment lack the words and defined principles to make sense for the “danger-naive.” Early Mount Everest climbers encountered this tension between climber and scientist, experience and model, contextual practice, and decontextualized theory (1, 47-49). Supplemental oxygen may make climbing less difficult but would not help gain altitude. The gap became visible in practice.

Scientists used research from high altitude flights to warn high altitude climbers who use oxygen of sudden unconsciousness from disruption of the oxygen flow (1). Since climbers at the same altitude were conscious, one could surmise two climbers standing together, one with an oxygen supply and one without. Disrupted oxygen flow would cause one climber to lose consciousness while the climber not using oxygen apparatus remained conscious...at the same altitude. Scientists also suffered credibility from their lack of familiarity with the environment. The oxygen apparatus gave the climber a higher center of gravity. Maintaining verticality on a steep slope, the climber had less margin for error before losing balance. A slightly excess lean to either side, and the climber falls to his death. In the liminal environment, inaccurate models can kill (47).

It is counter-intuitive, but what works across the threshold inside the unstructured environment, the liminal space, also works in the structured environment. This is because everyone, from the most naive among us to the most experienced, encounters a situation where they, alone and without support or review, must decide on an action. They feel the knot in the stomach. That is at the thresh-

**“That is what happens when the naive enters a dynamic, unstructured state. We observe them holding dearly to beliefs and behaviors learned in a safe, controlled, structured environment, and not only can they not sort out what works from what hurts, they are afraid to let go even if they know.”**
These dynamics form the basis of all actions in all industries, organizations, and activities. It occurs from the youngest, least experienced, to the most senior in the organization.

When I first went to work offshore - it was as a roughneck handling pipe on an offshore drilling unit. I was given no instructions about what to do or how to do it. But I was told to keep my head out of my XXX, or I would probably lose it (one of my fellow workers later did lose part of his face/head when a drill pipe hit him in the face). Terror is a fine instructor. Later, one of the workers lost three fingers in a cable shiv up on the monkey board in the derrick - 100 feet in the air. He went to the hospital via boat. Guess whom they sent to take his place? Up I went – no instructions - again, terror is a fine instructor.

Our [dangerous] work has termed this interactive - real-time assessment and management of risks. This approach was completely overlooked until the early 1990s. We were taught that there was only proactive (before operations) and reactive (after) - and that was it. And we thought we could capture all of the risks with the proactive approaches - and then provide adequate defenses if "justified" - but we were missing some really major risks that were fundamentally unpredictable and unknowable.

Bob Bea, 8/30/2005, personal communication

While operators work to extend operations from within, observers from a fixed point outside of the trajectory of events will share their expertise from that point of view. The British Everest Committee made decisions for climbing Mount Everest, yet none of the members had experience with high altitude climbing. Similarly, within the NICU, infants who would have died will survive with severe disabilities, drawing the attention of outside observers. In their respective liminal environments, high-altitude climbers work to gain life for these infants (53-56). To make these possible worlds become an actual world for these infants and their families, Neonatologists traversed a liminal environment. Any action could help or hurt, and at any moment, what once hurt will help and what helped could now hurt.

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We do not think of HRO as a "safety program." Though HRO emerged from dangerous contexts (8, 45), "we achieve safety through operations and operations through safety," the mantra of the US Navy and firefighting. Weick captured this in the HRO characteristic "Sensitivity to Operations" (52) when he observed how a disruption distracted an organization leading it to misjudge what was happening (personal communication).

As a result of my very painful recent experience studying Hurricane Katrina New Orleans, BP Deepwater Horizon, and PG&E San Bruno disasters, I have come to be very uncomfortable when the word 'safe' is used. In all of these experiences, the people who were 'operating' the systems (at the pointed end of the activity spears) thought they were 'safe enough.' They were not required to 'prove it.' They based their assessments on beliefs and feelings...that proved to be tragically wrong.

Bob Bea, personal communication

Human performance and organizational operations have extended people and organizations into adverse situations or environments. Likewise, they have extended people and organizations into new areas for productivity, in business terms, simultaneous "explore and exploit." HRO describes these organizations. Unfortunately, these descriptions are prescriptive – we know what and why, but not how.

An ecological approach, extending operators into an adverse environment, makes this extension visible into a possible world. High altitude climbers dealt with the primary problems of oxygenation and hypothermia, reliant solely on their attitudes, strength, and material readily available. Their methods to solve these problems can inform Neonatologists who also work with problems of oxygenation and hypothermia. While the NICU has great resources readily available, the fragile physiology of the neonate compresses time, effectively creating an austere environment.

The world is a product of study, either as the actual world in which we live or a possible world we strive to inhabit. Neonatology operates in the actual world of infants entering the world before complete physiological development. In the past, these infants would die. Their actual world was a world of the dying. Physicians could only support compassionate death, for example, an infant with hypoplastic left heart syndrome or extremely low birth weight. Conjuring new possible worlds inspired Neonatologists to gain life for these infants (53-56). To make these possible worlds become an actual world for these infants and their families, Neonatologists traversed a liminal environment. Any action could help or hurt, and at any moment, what once hurt will help and what helped could now hurt.

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Emerging from actual operations within dangerous contexts, HRO extends operations and the organization into uncertain, adverse, and hostile environments. The actual world is an open system where energy, resources, and people are mobile and free to enter and leave. Energy can unexpectedly transform or dissipate through entropy. Novel or uncontrollable situations, uncertainty, and unpredictability constrain human cognitive abilities and thinking. Threats drive behaviors in unexpected ways that seem prudent and logical at the time. HRO describes effective personal and
organizational characteristics for operations in these liminal environments. Neonatology has much in common with known HROs and can benefit from HRO as an operational model.

The Four Domains of Engagement

Introducing residents and staff to critical care while developing a PICU, the author (DvS) (6) presented high-risk operations from four domains. These domains supported the extension of pediatric critical care into critical care transport, EMS, home mechanical ventilation, long-term subacute care, and work with public safety and groups in SOCOM (Special Operations Command). For over 30 years, these have become the most requested domains for lectures and articles, regardless of the discipline or organization.

- categorization
- methods of decision making
- the significance of affective processes
- modulation of the stress and fear responses

The difficulty in translating this method to other industries lies in the interests of corporate administrations for a risk assessment and management model that reduces risk and avoids failure. Business management seeks mastery, accountability, and operational command, particularly for surprise and novel situations. Organizational science builds on models, using quantifiable outcome measures from assessment and transformation tools.

The interests of these HRO “customers” have shifted emphasis away from the characteristics of the liminal environment and the operator’s goal of redirecting the trajectory of events from within the event. Safety, reliability, and resilience are becoming consequences of causation, classical predicate (scientific) logic, categorization, and the cognitive sciences. Human intentions and organizing structures and systems from outside, a safer place to be, now inform design and engineering. These new dominant accounts have washed out the strength and meaning of HRO.

“HROs focus on function and consequences. As Weick observed (personal communication), a disruption can distract an organization leading it to misjudge what is happening.”

HROs focus on function and consequences. As Weick observed (personal communication), a disruption can distract an organization leading it to misjudge what is happening. While collecting sufficient information to act, circumstances have changed -- when you do not have the necessary information, acting immediately. This is the uncertainty principle bedeviling all who arrive at an exigent situation. HROs focus on function. With insufficient information as a given, the HRO generates information through action.

The organization must extend its operations into new environments, sustain activity, and transform this actual world into a new, better world. The HRO stands up and changes the world while the world changes the HRO -- both for the better. Strength through change -- *allostasis*. That is the goal of extension.

For this to happen, members of the HRO must think clearly while in adverse situations. They suppress their fear reactions (57) and modulate their stress and threat responses (22) with flexibility from the affective processes (6). Decision-making is a continuous, adaptive process focused on negative feedback to ensure safety (58). HROs categorize their actions, flexible thinking, and options for function, salience, and relevance.

“High-Reliability Organizing, the verb form (10), maintains active forward motion from its topological geometry of adaptive relationships compared to Euclidean programs of points and connections.”

Categories

The author (DvS) was involved with several types of medical situations in the same category:

- Physicians on a state EMS committee argue about the minimum blood pressure for the administration of nitroglycerin by paramedics. The author realized the physicians from cooler, northern regions wanted the lower blood pressure used while those from hotter arid regions wanted the higher blood pressure.

- A pediatric emergency medicine fellow has administered 40 mL/kg saline to an infant with diarrhea. Her attending tells her that, after administering half a blood volume of fluid, she should start dopamine for heart failure and transfer the infant to the PICU. She gives another 30 mL/kg and transfers the infant to the ward.

- The PICU transport team treats a two-week-old infant in the ED with intubation and 100% oxygen. The heart rate remains 100% and oxygen saturation about 70%. They call the attending for recommendations to increase oxygen saturation.

- A paramedic in a southern state responds to an overturned vehicle hidden down an embankment. It has been hot and humid for several days and nights. An elderly lady in the car, missing overnight, has heart medication in her possession. He follows state protocol and treats her for heart failure by administering dopamine. She does not respond. Following protocol, he increases the rate of infusion. She dies on the way to the hospital.

- A physician in an arid region had been administering fluids to the elderly who are in heart failure. He had just lost his staff privileges for providing significantly lower than the standard of care to treat heart failure.

These patients fit the category of heart failure. Though in the correct category, they were also in the category “hypovolemia” and “dehydration.” Clinically distinguishing between heart failure with normal blood volume and heart failure with low blood volume is
In Kantian philosophy, all elements can be contained within known concepts, with a fundamental principle being causation. Refined since Kant’s original work, concepts have become a foundation of modern science (3).

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In Kantian philosophy, all elements can be contained within known concepts, with a fundamental principle being causation. Refined since Kant’s original work, concepts have become a foundation of modern science (3). The Linnean system categorizes typologies into taxonomic hierarchies to show relationships. ICD-10 codes create discrete categories out of continuous processes for public health data analysis. The categories of evidence-based medicine are intended to reduce waste and medical complications.

For classification systems, a derivative of categorization, ambiguity in classifying can balance service to multiple constituencies. Others may be excluded; the ‘other’ category, called “residual categories” by Leigh Star (60), can render elements and people invisible. Such people in the organization’s operations may have acquired valuable experience and can offer useful insights during severe liminal episodes (61).

“Boundary objects” are ambiguous yet constant objects shared by adjacent categories. This allows their use by several communities of practice, such as meeting their educational requirements (62). Boundary objects allow for cooperation and communication across borders, often without the need for different groups to communicate, and can help manage the tension between divergent viewpoints (61).

HROs work in liminal environments with ill-structured problems embedded in unstable environments. Standards, residual categories, and boundary objects for an HRO are fluid. Over time, leaders, administrators, and regulators will mistranslate the nature of an HRO and try to control or reduce this fluidity (60). This is usually accomplished with increased standardization and reduced diversity and variability.

**Decision making**

In the liminal zone, decisions become a process over time with several evaluations and corrections. In motor cognition, the intention is not complete until the motor function ends (34). Because we do not know the situation, our objective guides decision-making. We have several *simultaneous* objectives since we may not reach our desired objective—we direct efforts to increase the chance of success while decreasing failure. If we cannot reach an objective, we decompose it until we begin moving toward our objective (6).

“*How do you manage error?” A federal health agency posed the question at a national conference for HRO in healthcare. There was silence at the author’s (DvS) table. The author then stated that an error is golden. “It tells me where we are weak, what to teach, what people don’t know, where the problems are… error is valuable” The CEO of a major healthcare system, proud of their HRO program, sat in silence. For the remaining 10 minutes, no one spoke.

For the ill-defined, embedded problem, we rely on heuristics for shortcuts, constantly re-evaluate, vigilant for errors. Error corrects heuristic bias. Error marks the limits of our individual and team performance and the organization’s capabilities. That is how error makes us safe (58).

For the novice, we gave two guidelines in these situations (6).

- Is it reversible? If so, it becomes a titration. If not, consult with others.
- What would happen if you treated too soon or too late? What would happen if you gave too much or too little? This creates a decision frame the neophyte can operate within.

Fundamental differences for decision-making in liminal environments and stable environments lie in the purpose and function. Decisions and actions have the purpose of generating information. Even unwanted results are information with meaning and relevance. Error for outsiders is unwanted, sometimes worthy of opprobrium. Error then creates the ecology of fear (58, 63). For the HRO, “error” has functions to identify boundaries of performance and operations, the “envelope” that HROs seek to expand. “Error” identifies a mismatch between what is known and what is uncertain or ambiguous. “Error” identifies unexpected or unrecognized changes in conditions or the environment.

The authors, coming from operational environments, had not encountered the everyday use of error for operations. This makes sense because, in the operational environment, we do not know what works until we act. One cannot find solutions by reasoning. One cannot organize or build a structure from the outside. We must enter the problem, thus becoming part of the problem (2).

**Affective processes**

Neonatologists are often more comfortable with cognitive processes—objective, reasoned, and classical predicate (scientific) logic. Most of all, cognitive processes readily incorporate evidence-based medicine. However, in the flux of changing events and unrecognized fear, the Neonatologist must give value, meaning, and relevance to changing information in unstable contexts.

To support the function of HRO in unstable circumstances, we have characterized the affective processes or domain (6):

- attitudes and values
- situational value of information
- neuromodulated emotion
- the Affective Domain of Learning (Bloom’s Taxonomy) (64)

**Attitudes and values**
Attitudes influence and follow behavior. “Attitudes are preferen-
tes, ‘the predisposition to treat entities with favor or disfavor’” (65). Attitudes drive action and influence the meaning we give to uncer-
tain or ambiguous information.

The five HRO principles (52) describe natural, effective, adaptive responses to adversity and hostile environments. Positioned as attitudes, we see how they develop from experience and frame the processes necessary to reach High-Reliability Organizing:

- one’s attitude toward failure
- acceptance of the complexity of even simple events
- awareness of how one fits into the scheme of life (situa-
tion-centric versus person-centric)
- perseverance
- respect for the knowledge and experience of others

“Values are more strongly held and more permanent beliefs compared to attitudes. We use our values to judge information and actions. Though values are personal, some specific values are binding us to our cultures.”

Values are more strongly held and more permanent beliefs compared to attitudes. We use our values to judge information and actions. Though values are personal, some specific values are binding us to our cultures. In the HRO, some values shift as need ed, such as obedience and conformity in low tempo times shift to initiative and creativity in high tempo events. We have identified five values of HROs (6):

- **Duty.** We will not let others down; we have a duty to our larger community
  - “Responsibility” or “accountability” can be limiting
- **Empathy.** We are all capable of making mistakes at virtually any time; HROs work in tough situations where people are going to fail
  - “Compassion” will focus on the other person or response toward that person
- **Dignity.** Acknowledge the value of everybody’s contribu-
tion, every job, every task, is important
  - Discipline people without taking away their dignity
  - “Respect” is generally considered earned and can easily be lost
- **Honesty.** What you say represents the circumstances
  - “Trust,” like respect, is transactional between two people
- **Humility.** The foundation of learning, required to improve people

Situational value of information.
The salience of signs and information prevents distraction when approaching an emergency.
The meaning of information changes during events and also among participants. There is no useless information in an emergen-
cy.
The relevance of information, how you use it, is also situational.
The value of information, the sum of the above, shifts and chang-es throughout the event.

Neuromodulated emotion. See below.

Affective Domain of Learning (Bloom’s Taxonomy).

All the time, effort, and cost of teaching can be lost in seconds. “I know that’s what they taught you. Let me tell you how it’s re-
ally done.” Teaching from Bloom’s Affective Domain of Learning brings focus to “How this will help.” That can become a mantra of bedside teaching – how this will help you treat the baby and sup-port the parents.

People respond to the environment in ways that make sense to them. Teaching from the Affective Domain helps students make sense of the environment and the situation. This is also contextual teaching.

“The affective domain of learning includes awareness, responsiveness, attitudes, placing value on information, and internalizing values.”

The affective domain of learning includes awareness, responsive-
ness, attitudes, placing value on information, and internalizing values. We provide the context necessary to give meaning to in-
formation. This increases motivation to learn and to understand better the knowledge we have gained. Motivation, as affective learning, describes responsiveness to phenomena, the valuing of knowledge, and the worth applied to an object or idea.

Effect on decision-making. See above.

Stress and fear responses

The negative results from unmodulated stress, fear, and threat distract us from their adaptive and survival functions. The overlap of their effects confounds our ability to reach practical manage-
ment approaches. They each respond to different signals, develop in different brain regions, and have different purposes. Organisms do not have a panoply of responses nor the ability to select the response measured to the attack. This all-or-none system makes sense because, in the beginning, the most severe attack looks no different than a mild attack. Only the time course differs (22, 66).

Stress responses are from the amygdala, and the neurochemi-
cal (cortisol) response to novelty, uncertainty, and uncontrollabil-
ity. Impairment of the prefrontal cortex constrains executive func-
tions and abstract thought. Impairment of the hippocampus blocks memory retrieval except for procedural (habit or motor) memory, which is enhanced. The effect of intentional motor activity on thought as motor cognition, described above, may explain why intentional movement can break the grip of cortisol on thinking (22, 66).

Fear maintains a safe distance from the “enemy” by the “escape reaction” to maintain a “flight distance” (67). Enemy proximity (it need not be a predator or other threat) is initially processed in the ventromedial prefrontal cortex (vmPFC) but moves to the midbrain periaqueductal gray (PAG) nucleus to coordinate survival.
behaviors. In physical settings, the organism moves to maintain the distance ("fear flight"), and fighting is for personal protection or escape ("fear flight"). In psychological settings, the individual adopts defensive protection ("fear flight") by avoiding what the person believes is the problem, using rationalizations and abstractions, and deflecting, excusing, or justifying. For offensive protection ("fear flight"), the individual acts verbally against others with surprise, concentrated action, fast tempo, audacity, blame, accusation, and personal attacks (22, 66).

“We can, however, learn to neuromodulate the behaviors in ourselves or assist and support others to recognize and neuromodulate their threat reflexes (8, 70).”

The threat is a subcortical reaction to existential danger. Known for the “fight or flight” reflexes (68, 69), other threat reflexes include the tonic immobility, and attentive freeze. As it is initiated through the amygdala, the threat is a bona fide reflex as we cannot prevent the initiation of either the affective or motor component (68). We can, however, learn to neuromodulate the behaviors in ourselves or assist and support others to recognize and neuromodulate their threat reflexes (8, 70). Managing threat reflexes are discussed elsewhere (22, 66), but they manifest as:

- "Fight – anger or frustration"
- Flight – avoidance or distraction (searching for equipment is the motor component absent the affective component)
- Tonic immobility – prevents physical movement despite awareness; milder presentations are intense aversion, gastric upset, or nausea
- Attentive freeze – physical freeze with full awareness, the freeze is in the motor component; cognitive freeze with physical activity, the freeze is cognitive from the affective component

The greatest significance of the threat reflexes is their mundane appearance – sick to the stomach and avoiding a decision, anger directed at staff or the situation, diversions for more information, or inability to recall well-known information, as a few examples. In the authors’ experience, the knowledge that these behaviors and cognitions are neurochemically mediated helps in the prevention, management, or termination of the behaviors.

People working in dangerous contexts neuromodulate these responses (8, 22). As HRO has entered healthcare and business management, this seminal characteristic of high-reliability operations has been missed (2, 45).

Inhibitions of Extension

The extension of neonatology asserted effective care over ever more difficult physiology in the liminal zone surrounding a dying baby. Babies and their families benefitted. Extension of care, like HRO, is an ongoing process with new people, disease-physiology interactions, and new families. The organization uses the same HRO methods to achieve, sustain, and extend HRO operations.

Engineered designing to achieve safety, reliability, and resilience for technological systems or socio-technical systems is seductive. It appears clean and capable of preventing or mitigating consequential bad outcomes. The weakness is not compliance from staff. The weakness is from the experience of individual staff facing a confusing situation. They will always act in a way that makes sense to them…locally. This may not make sense to a spectator (2).

“Technological systems become organized by commands from the outside, as when human intentions lead to the building of structures or machines. But many natural systems become structured by their own internal processes: these are self-organizing systems, and the emergence of order within them is a complex phenomenon that intrigues scientists from all disciplines.”

Eugene F. Yates (71)

Socio-Technical Systems (STS). Adding social structure to a technological system, a form of STS does not solve the problem. STS was first described in British underground coal mining with the introduction of technology to mine long-wall segments at one time, by the new “long-wall” method. Until introducing the new technology, lifetime teams of two men worked face-to-face with the “room-and-pillar” technique, which provided social balance. Some mines showed increased productivity with greater cohesiveness and personal along with decreased sickness and absenteeism. Other mines, however, did not. The difference was how the technical management gave miners the security necessary for undertaking new developments (72).

The authors evaluated the outcomes by regarding the long-wall as a technological system expressive of engineering interacting with the long-wall regarded as a social structure with occupational roles. Lost from the room-and-pillar technique was adaptability and responsible autonomy. Mechanization brought new problems:

- intermediate organization from direct face-to-face work
- the lack of recognition of the nature of difficulties
- segmented quality of social organization from a change in scale and spatio-temporal structure

“Disregarded were the dangers and the human shortcomings that followed, the vulnerability of the socially isolated individual, and the magnification of local disturbances.”

Disregarded were the dangers and the human shortcomings that followed, the vulnerability of the socially isolated individual, and the magnification of local disturbances. While leadership “organized by commands from the outside,” the miner’s social “systems become structured by their internal processes.” The resentment and hostility of the miners self-organized for group defense. Technology can create a socially ineffective structure. Yet good management and leadership with close interaction with the staff do produce far better results. We can treat technology as two systems, a technological system, and a social system. HRO works
like that, observed in the organization of the USS Carl Vinson, the aircraft carrier studied by the University of California, Berkeley, HRO study group (41, 45).

**Fear.** Implementation of safety and reliability appears more straightforward with structure, error prevention, and standardization. Other methods address the concern about regulatory or accreditation violations, liability concerns, or financial challenges. The indirect effect is to create situations where damage to the organization from the fear of error or violation is greater than the actual threat. We enact our operations and restraints. Failure from not acting is invisible and becomes part of the organization’s knowledge (50). This is the invisible ecology of fear (73). Reinforcing this fear are the stories told to novices to engender fear and not for instruction, the pedagogy of fear (74).

Quality improvement (QI) auditors create their own type of fear. A former paramedic colleague of the author (DvS) requested a transfer to the EMS QI section of the fire department. His colleagues warned him; the program had a poor reputation. Discussing with the author whether to accept the assignment, the author described Philip Zimbardo’s Prisoner-Guard Study (75). The QI auditors are guards, protecting the department from the paramedics, who became the prisoners. To prevent this from happening, he charged the auditors with the tasks of helping and supporting paramedics. After one year, the members of EMS and the fire department thought highly of the EMS QI section.

People do not self-organize for extension into uncertainty if they work or live in the ecology of fear.

**Disrupting engagement.** Decision-making for the indeterminate problem described above starts with the objective, for example, the airway in the resuscitation ABCs. We should not sacrifice the time necessary to move toward safety to know where we are (soon to be “were”) or identifying antecedent events. Bea describes this approach (above) as interactive - real-time assessment and management of risks. Two unrecognized disruptions to engagement are the category for outliers and the rigor for following rules and protocols. The extension follows engagement. Disrupted engagement means lost opportunity and blocked the extension of neonatology care.

An outlier, to the healthcare practitioner steeped in science, is several standard deviations from the mean. In healthcare, we use statistics, a measure of the past, and probability, a projection into the future. Random and independent, not connected to the present, not useful for the future, we readily disregard the outlier. (Think zebras, a quite dangerous, aggressive equine.) “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,” Bob Bea. Bea had a warning about disregarding outliers:

“That depends on the outliers. This ‘aliasing’ data got NASA into deep trouble with the ‘O-rings’ in low-temperature launches that became apparent during the Challenger disaster. The ‘outliers’ were data from a ‘different population’ (low temperatures that could change the properties of the O-rings...making them brittle). The ‘parent population’ was for higher temperatures that did not result in the embrittlement of the O-rings. Outliers must be carefully treated because they can really hurt...or help you.”

Bob Bea (personal communication)

The expert following the rules. An organization or industry may institutionalize competency rather than proficiency because generalizable principles can be taught to a high-turnover, novice workforce (76). Moving to proficiency requires the use of specifics, the particular, and case reports. It demands more time, training, shared insight, and modeling of senior, more experienced people. Competency-based programs form the rule-based system of Jens Rasmussen’s skills, rules, knowledge (SRK) framework in his ecological interface design system (77). James Reason (78) adapted this framework for his model of error management now used in healthcare. This is almost institutionalization to impair institutional extension.

“Experts continue to develop, and people gain mastery of concepts despite this focus on rule-based systems and rule-based error.”

Experts continue to develop, and people gain mastery of concepts despite this focus on rule-based systems and rule-based error. Though we may master concepts, we never master experience (3). Rasmussen recognized this. Local or special knowledge is the knowledge-based system. In extreme cases where the particular is novel or unexpected

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

Jens Rasmussen (79)

This is how the organization supports extension into novel or adverse environments. But we can now see the problem. An institutionalized rule-based system, developed for the workforce en-acted by the organization (competency-based restraint), and an organization desiring extension into a knowledge-based environment must follow the rules in a knowledge-based situation.

We process the familiar on the right side of the brain and the novel on the left side. The Dreyfus brothers knew this when they studied.
the expert following the rules (80, 81) “True mastery comes when the performer is conscious neither of identifying the situation nor of remembering an action, but rather act spontaneously without necessarily becoming consciously aware of his situation” (81). When the expert operating in this manner, yet required to follow a rule or protocol, will encounter an inappropriate set. This shifts the manner of thought and brain regions. Performance suffers. The expert operates at a lower level than the novice. What has not been explored is motor cognition and the consequences of an expert constrained by the rules.

The organization inhibits initiative. Correlation or association does not mean causation. We have heard this statistical observation used to end a discussion. There are several other forms, “Such results suggest that an error has been made, of an old kind, in arguing from correlation to causation; we cannot argue from Correlation to causation” (82). “The association observable between the practice of cigarette smoking and the incidence of cancer of the lung…has been interpreted…as though it demonstrated a causal connexion between these variables” and “Dr. Bradford Hill while admitting that the evidence of association found by his Unit did not amount to proof of causation” (83). These cited quotations are from Ronald A. Fisher, an inveterate pipe-smoker developer of the Analysis of variance (ANOVA), introduced the null hypothesis, proposed the level of p = 0.05, and developed modern experimental design. In dangerous contexts, sometimes association or correlation is all you have.

“Correlation does not mean causation” is a “thought-terminating cliche,” a type of phrase used to block further analytical thinking. Once someone uses such a phrase, no further argumentation is required by the speaker and no argumentation is allowed by others. It is a form of “loading the language” used during indoctrination processes. Complex problems are compressed into brief, definitive-sounding phrases that can be easily memorized and easily expressed. To others, these phrases cause constriction and linguistic deprivation (84).

To block inquiry and investigation is to impair extension.

What it means to be a Neonatologist

We don’t find meaning; we give meaning. For example, list what you do as a Neonatologist. Include tasks and activities. Adding to the list becomes more difficult as the list grows. When your list has at least seven items, preferably ten, remove the first 3-4 items. The things you think of first are the easiest to think of, not the most important.

The last things on your list...those that are the most difficult to conjure, are what it means to be a Neonatologist. This is where you give meaning to your work. That meaning increases your stress capacity. This is the affective domain.

These are also the items that drive the extension of neonatology. They are how neonatology will extend into new worlds and how the Neonatologist gains life.

When a person believes in themselves, they will leave their place of safety and engage the unknown when they know they are supported. Changing a deteriorating problem for the better, knowing their sense of agency helped a struggling baby, seeing life improve...that is where resilience comes from. That is HRO. That is how we extend the care of the Neonatologist to babies and their families. That is how the Neonatologist and the discipline of neonatology gain life.

A tremendous amount of time, effort, and cost are expended teaching healthcare professionals how to develop and ensure reliability, safety, and resilience.

We know that is what they taught you. Let us tell you how it is really done.

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

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!
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?

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

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
Respiratory Syncytial Virus: How you can advocate for babies this RSV season

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

Identify babies at greatest risk

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

Teach families how to protect their babies from respiratory infections

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

Use your best clinical judgement when prescribing RSV prophylaxis

Tell insurers what families need and provide the supporting evidence

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

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:

- 89% treat RSV as a priority, "often" or "always" evaluating their patients
- 71% consider palivizumab "very useful" for reducing the risk of RSV hospitalization
- 71% consider palivizumab "very useful" for reducing the risk of RSV hospitalization

But Parents are Unprepared:

- Only 10% know "a lot" about RSV
- Only 25% believe themselves "very well" prepared to prevent RSV

RSV Education & Awareness can Help

After parents learned more about RSV, they were:

- 61% “More concerned” about their child contracting the disease
- 67% Likely to ask their doctor about RSV

Learn More about RSV at www.infantsearth.org/RSV
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By Jenné Johns

Author | Speaker | Advocate

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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.

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The CE activity explains safe infant sleep recommendations from the American Academy of Pediatrics and is approved by the Maryland Nurses Association, an accredited approver of the American Nurses Credentialing Center's Commission on Accreditation.
AAP Leaders Speak out on Racism Against Asian American, Pacific Islander Children

Monday, May 3, 2021

AAP Leaders urge pediatricians to recognize their own bias and be prepared to care for Asian American families experiencing discrimination.

AAP leaders are speaking out against racism targeting people who are Asian American and Pacific Islander (AAPI) and urging pediatricians to take action. The AAP Board of Directors Executive Committee and Board Committee on Equity penned the perspective piece “Immunizing Against Hate: Overcoming Asian American and Pacific Islander Racism,” which was published today in Pediatrics and lays out members’ concerns about the toll racism is taking on children and their families. “Addressing the pervasive and harmful impact of structural and interpersonal racism on child health is at the heart of the AAP’s Equity Agenda, the goal of which is to assure equitable systems of care that promote optimal health for all children,” said Wendy S. Davis, M.D., FAAP, chair of the Board Committee on Equity. “As we followed the news and heard from our Asian American members about their own suffering and that of their patients, remaining silent was simply not an option. This statement evolved as we sought multiple channels through which we could support our colleagues and the children and families in our care. “At the start of the COVID-19 pandemic, then-AAP President Sara “Sally” H. Goza, M.D., FAAP, warned about the threat of Asian American racism. Those fears have been borne out over the past year with surging rates of discrimination. Hate crimes against Asian Americans rose nearly 150% in 2020, according to a study of police department statistics from 16 U.S. cities. Stop AAPI Hate has documented nearly 3,800 instances of discrimination against people of AAPI descent since March 2020, including verbal harassment, physical assault and online harassment. In addition to enduring racism during the pandemic, people who are Asian, Black and other minority ethnicities are at greater risk of becoming severely ill from COVID-19.” The alarming statistics and the trauma behind them illustrate that America is again waging a battle against two pandemics: COVID-19 and racism,” AAP board members wrote. Pediatricians have seen the impacts of this racism firsthand. “Our Asian American patients tell us that they are afraid to walk or ride the bus to school, go to church, or play outside, as they, too, have been targets of taunts and harassment,” the AAP board wrote. “But even staying inside the home does not protect them. Many children say they have experienced cyberbullying or feel shunned and anxious because of hateful, racist language online. “Racism is a social determinant of health that can take a significant, long-lasting toll on children physically and emotionally. The AAP detailed these consequences in its 2019 policy The Impact of Racism on Child and Adolescent Health and urged pediatricians to address racism in their practices and communities. AAP leaders are renewing their push for pediatricians to examine their own biases and be prepared to care for Asian American families experiencing discrimination. “And we echo and re-emphasize the urgency of Dr. Goza’s call not only to vaccinate children against COVID-19 but also to strengthen our children’s immunity to the virus of hate,” they wrote. “The AAP’s commitment to dismantling racism has been and will continue to be, at the forefront of our highest priorities.”

by Melissa Jenco, News Content Editor

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


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- Receive the SOATT newsletter containing AAP and Section news.
- Access the Section’s Website and Collaboration page – with current happenings and opportunities to get involved.
- Network with other pediatricians, pharmacists, and other health care providers to be stronger advocates for children.
- Invitation for special programming by the Section at the AAP’s National Conference.
- Access to and ability to submit research abstracts related to advancing child health through innovations in pediatric drugs, devices, research, clinical trials and information technology; abstracts are published in Pediatrics.

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

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

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

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

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President Joe Biden on Wednesday promised fast roll-out of the vaccines for adolescents at pediatrician and family physician offices in addition to pharmacies. Some jurisdictions already have announced adolescent vaccination will begin Thursday.

“The vaccine for kids between the ages of 12 and 15 are safe, effective, easy, fast and free,” Biden said. “So my hope is parents will take advantage of the vaccine and get their kids vaccinated.”

Since the pandemic began, more than 1.5 million adolescents ages 12-17 years have been diagnosed with COVID-19 and more than 13,000 have been hospitalized, according to CDC data. The pandemic also has taken a toll on children’s mental and emotional health, social well-being and their educational experience.

Safety
Pfizer and CDC officials reviewed data on safety and efficacy of the vaccine during Wednesday’s ACIP meeting. Pfizer and BioNTech conducted trials in more than 2,000 adolescents ages 12-15 with half randomized to receive the vaccine and half to receive a placebo.

The most common side effects in adolescents were pain at the injection site, fatigue, headache, chills, muscle pain, fever and joint pain, consistent with trials in older teens and adults.

About 6% of vaccine recipients experienced an adverse event, including seven cases of swollen lymph nodes. There were five serious adverse events in the vaccine group (0.4%) including one person with abdominal pain, constipation and neuralgia and others with depression, anxiety and suicidal ideation. None of the serious events were determined to be related to the vaccine and no deaths were reported. There also were no reports of blood clots, serious allergic reactions or Bell’s palsy.

Efficacy
Vaccine efficacy for this age group was 100%. Among just over 1,000 vaccine recipients, there were no cases of COVID-19, while 16 were reported among more than 970 placebo recipients. An immunogenicity analysis in 190 participants also showed their response was even better than the response for those ages 16-25 years.

“I think this will provide protection for 12- to 15-year-olds,” said ACIP member Henry Bernstein, D.O., M.H.C.M., FAAP, professor of pediatrics at the Zucker School of Medicine at Hofstra/Northwell. “It will decrease transmission within their families, and it will contribute to community immunity and allow kids to more safely go back to camps this summer and back to in-person school.”

Vaccine administration
The vaccine will be given to adolescents in two doses 21 days apart, the same as for adults. The need for consent from a parent or guardian will depend on state or local laws.

The vaccine should not be given to anyone with a history of severe or immediate allergic reaction to a previous dose or component of the vaccine, according to the CDC.

Children or adults with a history of multisystem inflammatory syndrome linked to COVID-19 may be vaccinated but should consider waiting until 90 days after the diagnosis of this syndrome.

The CDC updated its clinical guidance for vaccine administration for all ages to say COVID-19 vaccines can be given on the same day as other routine vaccines instead of waiting 14 days. The move is intended to help boost rates of routine adolescent immunizations, which have seen a sharp decline during the pandemic leaving children vulnerable to myriad diseases.

Allowing coadministration of vaccines sparked debate among ACIP members on Wednesday. CDC officials said they based the decision on safety data for administering COVID-19 vaccines alone and years of experience administering other vaccines together. Some ACIP members said they
This holiday season
3,600 families won't be celebrating with their baby.

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Sudden Unexpected Infant Death
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believe more data are needed, specifically on giving COVID-19 vaccines with other vaccines, but AAP policy supports coadministration, which provided reassurance to others.

“In my judgment, the known benefit of COVID vaccination and the known risks of missing routine vaccination combine to justify the modification to the coadministration recommendations to allow COVID and the routine vaccines to be given without regard to intervals,” said David W. Kimberlin, M.D., FAAP, editor of the 2021 Red Book and a liaison to ACIP.

ACIP members said they are excited to see adolescent vaccination begin.

“I think the childhood experience our kids have gone through will have long-lasting consequences that may extend across generations to be honest,” said ACIP member Grace M. Lee, M.D., M.P.H., associate chief medical officer for practice innovation at Stanford Children’s Health. “We don’t really fully yet understand the total … physical health, mental health and educational impact of the pandemic on our kids.”

Resources

- Fact sheet for health care providers
- Fact sheet for vaccine recipients and caregivers
- The AAP will hold a town hall to discuss adolescent vaccination at 8 p.m. EDT on May 13. Register at https://bit.ly/3uGIxzR.
- The CDC will hold a webinar on vaccination of adolescents at 2 p.m. EDT on May 14.
- AAP guidance on providing COVID-19 vaccines to adolescents
- AAP News story “AAP develops coding, billing guidance for COVID-19 vaccine services”
- Information for parents from HealthyChildren.org on preparing children and adolescents for COVID-19 vaccination
- To find a COVID-19 vaccine near you, visit http://vaccines.gov or text your ZIP code to 438829.

Founded in 1930, the American Academy of Pediatrics (AAP) is a professional membership organization of 67,000 pediatricians committed to the optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults. AAP is the nation's leading advocacy organization for children, and the leading source of children's health-related information for pediatricians and their patients. AAP also oversees HealthyChildren.org, the only parenting website backed by pediatricians, and has the largest pediatric publishing program in the world, with more than 300 titles for consumers and over 500 for physicians and other health care professionals, including Pediatrics, its monthly scientific journal, and AAP News, its membership news magazine. For more information on AAP publications, please visit http://www.aappublications.org.

Melissa Jenco, News Content Editor

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Gene Therapy Restores Immune Function in Children with Rare Immunodeficiency

Tuesday, May 11, 2021

Experimental gene therapy shows promise as a possible treatment option for infants and children with ADA-SCID
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An investigational gene therapy can safely restore the immune systems of infants and children who have a rare, life-threatening inherited immunodeficiency disorder, according to research supported in part by the National Institutes of Health. The researchers found that 48 of 50 children who received the gene therapy retained their replenished immune system function two to three years later and did not require additional treatments for their condition, known as severe combined immunodeficiency due to adenosine deaminase deficiency, or ADA-SCID. The findings were published today in the New England Journal of Medicine.

ADA-SCID, which is estimated to occur in approximately 1 in 200,000 to 1,000,000 newborns worldwide, is caused by mutations in the ADA gene that impair the activity of the adenosine deaminase enzyme needed for healthy immune system function. This impairment leaves children with the condition highly susceptible to severe infections. If untreated, the disease is fatal, usually within the first two years of life.

“These findings suggest that this experimental gene therapy could serve as a potential treatment option for infants and older children with ADA-SCID,” said Anthony S. Fauci, M.D., director of NIH's National Institute of Allergy and Infectious Diseases (NIAID). “Importantly, gene therapy is a one-time procedure that offers patients the hope of developing a completely functional immune system and the chance to live a full, healthy life.”

People with ADA-SCID can be treated with enzyme replacement therapy, but this treatment does not fully reconstitute immune function and must be taken for life, usually once or twice weekly. Transplants of blood-forming stem cells, ideally from a genetically matched sibling donor, can provide a more lasting solution. However, most people lack such a donor. Additionally, stem cell transplants carry risks such as graft-versus-host disease and side effects from chemotherapy medications given to help the donor stem cells establish themselves in the patient's bone marrow.

The new research evaluated an experimental lentiviral gene therapy designed to be safer and more effective than previously tested gene-therapy strategies for ADA-SCID. This gene therapy involves inserting a normal copy of the ADA gene into the patient’s own blood-forming stem cells. First, stem cells are collected from the patient’s bone marrow or peripheral blood. Next, a harmless virus is used as a “vector,” or carrier, to deliver the normal ADA gene to these cells in the laboratory. The genetically corrected stem cells then are infused back into the patient, who has received a low dose of the chemotherapy medication busulfan to help the cells establish themselves in the bone marrow and begin producing new immune cells.

The experimental gene therapy, developed by researchers from the University of California, Los Angeles (UCLA) and Great Ormond Street Hospital (GOSH) in London, uses a modified lentivirus to deliver the ADA gene to cells. Previous gene-therapy approaches for ADA-SCID have relied on a different type of virus called a gamma retrovirus. Some people who have received gamma retroviral gene therapies have later developed leukemia, which scientists suspect is due to the vector causing activation of genes that control cell growth. The lentiviral vector is designed to avoid this outcome and to enhance the effectiveness of gene delivery into cells.

The results come from three separate Phase 1/2 clinical trials, two conducted in the United States and one in the United Kingdom. The U.S. trials, led by principal investigator Donald Kohn, M.D., of UCLA, enrolled 30 participants with ADA-SCID ranging in age from 4 months to 4 years at UCLA Mattel Children's Hospital and the NIH Clinical Center in Bethesda, Maryland. The U.K. study, conducted at GOSH and led by principal investigator Claire Booth, M.B.B.S., Ph.D., enrolled 20 participants ranging in age from 4 months to 16 years. Most participants acquired and retained robust immune function following gene therapy — 96.7% after two years in the U.S. studies and 95% after three years in the U.K. study — and were able to stop enzyme replacement therapy and other medications. Of the two participants for whom gene therapy did not restore lasting immune function, one restarted enzyme replacement therapy and later received a successful stem cell transplant from a donor, and the other restarted enzyme replacement therapy. The lentiviral gene therapy appeared safe overall, although all participants experienced some side effects. Most of these were mild or moderate and attributable to the chemotherapy that the participants received.

Researchers observed similar outcomes in all three trials, although there were some differences between the studies. Stem cells were collected from bone marrow in the U.S. trials and from peripheral blood in the U.K. trial. In one of the U.S. trials, 10 children were treated with genetically corrected stem cells that had been frozen and later thawed. The two other trials used fresh stem cell preparations. In the future, the freezing procedure — known as cryopreservation — may allow stem cells to be more easily transported and processed at a manufacturing facility far from the patient's home and shipped back to a local hospital, reducing the need for patients to travel long distances to specialized medical centers to receive gene therapy. A trial of the cryopreserved treatment is now underway at the Zayed Centre for Research into Rare Diseases in Children in London, in partnership with GOSH.

For more information about the trials described in the New England Journal of Medicine paper, visit ClinicalTrials.gov under identifiers NCT01380990, NCT01852071, NCT02999984 and NCT01380990. The investigational lentiviral gene therapy, which is licensed to Orchard Therapeutics, has not been approved for use by any regulatory authority.

The research was funded in part by three NIH Institutes: NIAID; the National Heart, Lung and Blood Institute; and the National Human Genome Research Institute. Additional funding was provided by the Cali-
fornia Institute for Regenerative Medicine, the Medical Research Council, the National Institute for Health Research Biomedical Research Centre at Great Ormond Street Hospital for Children National Health Service Foundation Trust and University College London, and Orchard Therapeutics.

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Medical Records Analysis Links Cannabis Use Disorder in Pregnancy to Infant Health Problems

Medical Records Analysis Links Cannabis Use Disorder in Pregnancy to Infant Health Problems

Thursday, April 22, 2021

Study shows babies born to mothers with cannabis use disorder are more likely to have negative health outcomes.

A new study of nearly 5 million live births recorded in California from 2001 to 2012 found that babies born to mothers diagnosed with cannabis use disorders at delivery were more likely to experience negative health outcomes, including preterm birth and low birth weight, compared to babies born to mothers without a cannabis use disorder diagnosis. The analysis, published today in Addiction and funded by the National Institute on Drug Abuse (NIDA), part of the National Institutes of Health, adds to a growing body of evidence that prenatal exposure to cannabis (marijuana) may be associated with poor birth outcomes, and sheds light on infant health one year after birth.

Recent studies have shown the use of cannabis during pregnancy is rising, with some expectant parents reporting using the drug to alleviate nausea and vomiting associated with pregnancy. Medical experts have expressed concern around these patterns

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because an active component of cannabis, delta-9-tetrahydrocannabinol (THC), has been shown to reach fetuses and infants through the placenta and breastmilk, respectively. Further, THC disrupts the normal function of the endocannabinoid system, which has been shown to play a key role in fetal brain development and in pregnancy, including implantation of the embryo in the uterus and maintenance of the placenta.

In the current study, investigators found that among the 4.83 million mother-infant pairs analyzed in the study, 20,237 women received a delivery discharge diagnosis of cannabis use disorder, which goes beyond occasional cannabis use and involves meeting specific criteria for a pattern of continued cannabis use despite negative consequences. Not all people who use cannabis meet the criteria for cannabis use disorder, and in this study, diagnoses were based on self-reported information. Because of this, investigators noted that the actual incidence of cannabis use and cannabis use disorder in the study population were likely much higher than reported.

“While we cannot establish that cannabis use caused negative outcomes in this study, these data reinforce the case for caution around using cannabis during pregnancy,” said NIDA Director Nora D. Volkow, M.D. “Careful analysis of data like these is one way we can responsibly study how cannabis use affects the developing child, all while a natural experiment is playing out across our country in places where cannabis is becoming widely available to pregnant consumers.”

The analysis revealed diagnoses of cannabis use disorders based on medical records at delivery rose from 2% in 2001 to 6.9% in 2012. To assess the correlation between cannabis use disorder and infant health outcomes, investigators compared the mother-infant pairs linked to a cannabis use disorder diagnosis to 40,474 control mother-infant pairs with similar demographics and maternal health factors, including other substance use disorder diagnoses and tobacco use. Infants born to women with cannabis use disorders were more likely than control group infants to be born preterm, have a low birth weight, and be small for their gestational age. These findings were consistent with previous studies in similar populations.

Investigators also analyzed infant death certificates linked to birth records and found that, while infant mortality was rare overall (less than 1% in either group), infants born to women with a cannabis use disorder diagnosis at delivery were 35% more likely to die within a year of birth than control group infants. Analysis of additional health records revealed that infants born to mothers with cannabis use disorders were less likely to be hospitalized within the same year than control group infants, which differs from previous analyses that found a correlation between prenatal cannabis exposure and neonatal intensive care unit admission.

“Because we are looking only at medical records, there is a lot we don’t know about the mothers and infants in this study,” said lead author Dr. Yuyan Shi of the Herbert Wertheim School of Public Health and Human Longevity Sciences at the University of California, San Diego. “But our analysis supports the recommendation that health professionals screen for and address cannabis use disorders in their pregnant clients — to protect both their health and potentially the health of their infants.”

Currently, it is not standard practice for healthcare professionals to screen for cannabis use disorder during pregnancy, nor is it standard to provide counselling on the lack of safety data around cannabis use during pregnancy. Both strategies may be helpful in addition to encouraging pregnant women who use cannabis to discontinue use during pregnancy and breastfeeding and to refer them to treatment when appropriate.

Investigators also analyzed how tobacco use — a confounding factor in previous analyses of prenatal cannabis exposure — impacted infant health outcomes among mothers diagnosed with cannabis use disorders. Compared with infants born to mothers who did not use tobacco, infants born to mothers who self-reported tobacco use were at greater risk of preterm birth and low birth weight, as well as hospitalization and death within their first year. These findings are consistent with previous findings that suggest concurrent tobacco use is common among pregnant women who use cannabis and underscore the importance of analyzing tobacco use and other confounding factors that may occur in cases of cannabis use disorder captured by medical records.

About the National Institute on Drug Abuse (NIDA): NIDA is a component of the National Institutes of Health, U.S. Department of Health and Human Services. NIDA supports most of the world’s research on the health aspects of drug use and addiction. The Institute carries out a large variety of programs to inform policy, improve practice, and advance addiction science. For more information about NIDA and its programs, visit https://www.drugabuse.gov.

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

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**Most Pediatric Spinal Fractures Related to not Wearing Seatbelts**

**Friday, May 14, 2021**

*Seatbelts dramatically decrease the risk of spinal fracture and death*.

**Two thirds of all pediatric spinal fractures, especially in the adolescent population, occur in motor vehicle accidents (MVAs) where seatbelts are not utilized, reports a study in *Spine*. The journal is published in the Lippincott portfolio by Wolters Kluwer.**

“Over 60 percent of pediatric spinal fractures occur in children ages 15 to 17, coinciding with the beginning of legal driving,” according to the new research by Dr. Vishal Sarwahi, MD, of Cohen Children’s Medical Center, New Hyde Park, NY, and colleagues. They emphasize the need for measures to increase seatbelt usage, particularly by younger drivers, and outline the potential trauma that can be avoided through proper seatbelt use.

**Seatbelts save lives... and spines**

Motor vehicle accidents are the leading cause of death amongst teenagers in the United States. Many previous studies have reported rising rates of pediatric spinal injuries, especially in teens aged 15 and older. This new study confirms that MVAs, in fact, cause most spinal fractures in children and adolescents, with high rates of other injuries. Spinal fractures in young patients are also associated with a three percent mortality rate, with many deaths occurring in unrestrained drivers and passengers.

Using the American College of Surgeons’ National Trauma Data Bank, Dr. Sarwahi and his colleagues studied 34,563 pediatric patients (younger than 18 years) who sustained spinal fractures between 2009 and 2014. Many of the patients had multiple spinal fractures, with a total of 45,430 fractured vertebrae.

Overall, teenagers between age 15 and 17 years accounted for about 63 percent of spinal fractures, two-thirds of which occurred in MVAs. These findings show that around the time teens get their drivers’ license, drivers and passengers are at highest risk for MVA resulting in spinal fracture. Fifty-eight percent of the injured patients were male. Pediatric spinal fractures were found to be most common in the South: 38 percent, probably due to a lack of public transport resulting in more vehicles on the road.

The study also shows the impact of seatbelt use on these devastating injuries. “Nearly two-thirds of pediatric spinal fractures sustained in MVAs occurred in children who did not use belts,” Dr. Sarwahi and co-authors write. Without seatbelts, the risks of severe or multiple injuries and death are substantially increased, with a significantly increased death rate from 29.3 percent to 70.7 percent – more than doubled.

Data on seatbelt use was available for nearly 19,000 patients, with approximately two-thirds of patients (65.9 percent) unrestrained. Almost half (44.2 percent) of unrestrained patients in MVAs were teenagers. Despite a larger percentage of MVAs occurring in the South overall, the percentage of spinal fractures from MVAs for unrestrained drivers and passengers was similar across all regions of the United States; approximately two-thirds of all teenagers across all regions – Northeast, Midwest, West, South – involved in MVAs did not wear seatbelts. This demonstrates the universality of teenage risk-taking behavior and identifies at-risk groups for risk modification strategies.

When seatbelts were worn, the rate of spinal fractures was substantially lower for all drivers and passengers. Seatbelt use lowered the risk of death by more than 20 percent. For young patients in MVAs, wearing seatbelts was also associated with lower rates of multiple vertebral fractures, other types of fractures in addition to spinal fracture, and head and brain injury.

While the percentage of drivers wearing seatbelts has risen steadily over the years, adolescents and young adults remain less likely to use these lifesaving devices. Dr. Sarwahi and colleagues discuss targeted approaches using technology and media awareness campaigns to increase seatbelt use among young people, as well as studies showing the importance of societal and cultural norms related to seatbelts. The researchers conclude: “Ensuring our new, young drivers wear protective devices can greatly reduce morbidity/mortality associated with MVA and can help save lives, and spines.”

**Click here to read “Seatbelts Save Lives, and Spines, in Motor Vehicle Accidents: A Review of the National Trauma Data Bank in the Pediatric Population.”**

**DOI: 10.1097/BRS.0000000000004072**

### About Spine

Recognized internationally as the leading journal in its field, *Spine* ([www.spinejournal.com](http://www.spinejournal.com)) is an international, peer-reviewed, b-weekly periodical that considers for publication original articles in the field of spine. It is the leading subspecialty journal for the treatment of spinal disorders. Only original papers are considered for publication with the understanding that they are contributed solely to *Spine*. According to the latest ISI Science Citation Impact Factor, *Spine* is the most frequently cited spinal deformity journal among general orthopaedic journals and subspecialty titles.

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“Even in the middle of taking this course, I could see myself changing the way that I spoke to parents. After taking this course, I am much better at emotionally supporting our NICU families.”

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Family Centered Care is trendy, but are providers really meeting parents needs in the NICU?

Consider the following:

Surveys show hospital support groups are being widely underutilized by parents.

And only 10% of NICUs surveyed connect parents with non-hospital support.

Graham’s Foundation, the global support organization for parents going through the journey of prematurity, set out to find the missing piece that would ensure all parents have real access to the support they need.

See what they found by emailing info@grahamsfoundation.org to request a free copy of the 2017 whitepaper, “Reaching Preemie Parents Today” (Heather McKinnis, Director, Preemie Parent Mentor Program, Graham’s Foundation).

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.

Visit www.GrahamsFoundation.org to learn more.

Fighting for Premature Babies

helping pediatricians prepare to administer the vaccine in their practices. It recently updated its FAQs about COVID-19 vaccines and released new recommendations on how to prepare, how to implement vaccination in pediatric practices and how to get paid for vaccine administration.
**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.

- **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.

**WARNING**

- 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

**PROTECT YOUR FAMILY FROM RESPIRATORY VIRUSES**

- **flu**
- **coronavirus**
- **pertussis**
- **RSV**

**WASH YOUR HANDS**

Often with soap and warm water.

**GET VACCINATED**

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

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Sneeze and cough into your elbow.

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

**STAY AWAY FROM SICK PEOPLE**

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We can help protect each other.

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www.nationalperinatal.org

www.NeonatologyToday.net
In addition to addressing vaccination for children and adolescents on Tuesday, Dr. Bourla said the company plans to apply for full FDA licensure of the Pfizer-BioNTech vaccine by the end of this month for ages 16-85. He also expects to have phase 2 safety data on pregnant women in late July or early August.

Pfizer also is addressing its onerous cold storage requirements and has submitted new data to the FDA that could result in storage at standard refrigerator temperatures for up to four weeks.

Resources
- AAP guidance on COVID-19 vaccines for children
- CDC guidance for clinicians on the Pfizer-BioNTech vaccine
- AAP interim guidance on COVID-19
- To find a COVID-19 vaccine near you, visit http://vaccines.gov or text your ZIP code to 438829.

Founded in 1930, the American Academy of Pediatrics (AAP) is a professional membership organization of 67,000 pediatricians committed to the optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults. AAP is the nation’s leading advocacy organization for children, and the leading source of children’s health-related information for pediatricians and their patients. AAP also oversees HealthyChildren.org, the only parenting website backed by pediatricians, and has the largest pediatric publishing program in the world, with more than 300 titles for consumers and over 500 for physicians and other health care professionals, including Pediatrics, its monthly scientific journal, and AAP News, its membership news magazine. For more information on AAP publications, please visit http://www.aappublications.org.

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The Genetics Corner: Avoiding the Need for Cardiac Transplant - Everolimus Induced Regression of a Cardiac Tumor in an Infant with Tuberous Sclerosis Complex (TSC) Type 2 with Updates on his Progress

June-Anne Gold MD

Case Summary

The patient was prenatally diagnosed with a cardiac tumor; this was attached to the mitral valve. I had suggested during the pregnancy that Everolimus or Sirolimus (mTOR inhibitors) could be given to the mother to reduce the tumor in the fetus. This was only reported in one case previously (1). Parents had declined amniocentesis, so we did not have a molecularly confirmed diagnosis at that time. Cardiac rhabdomyomas are commonly associated with tuberous sclerosis complex types 1 and 2. This is due to a molecular pathogenic variant in either TSC1 or TSC2. TSC1 and TSC2 are in the mTOR pathway, which would lend itself to treatment with the mTOR inhibitors. These fetal cardiac rhabdomyomas usually spontaneously regress during the pregnancy or immediately after birth and do not cause hemodynamic problems. However, larger tumors can cause an obstruction, as in this case, and intervention is then needed.

“Those fetal cardiac rhabdomyomas usually spontaneously regress during the pregnancy or immediately after birth and do not cause hemodynamic problems. However, larger tumors can cause an obstruction, as in this case, and intervention is then needed.”

Other differential diagnoses of rare neonatal cardiac tumors would include Burt-Hogg-Dube (FLCN gene) and Gorlin Syndrome (PTCH gene).

At birth, he was 39 weeks 3 days gestation, born via a repeat caesarian section; birth weight was 4.320 Kg 97th percentile, head circumference was 35.5 cms on the 79th percentile, and length was 53 CMS on the 95th percentile. Apgars at birth were 9 at 1 minute and 5 minutes.

The cardiac tumor was causing the boy to be hemodynamically unstable. The tumor was diagnosed as a cardiac rhabdomyoma by MRI and was impinging the mitral valve, causing mitral valve stenosis, left atrial hypertension, and pulmonary hypertension. Due to the position and severity of symptoms, the cardiac surgeons deemed it not prudent to remove the tumor. It was assessed and thought not to be a viable option due to post-surgical valvopathy. His brain MRI also supported the diagnosis of TSC with brain hamartomas. Genetic testing identified a known pathogenic heterozygous variant in TSC2 c.1832G>A, p. Arg611Gin.

It was thought the best option for him was the recommendation for evaluation for a cardiac transplant. Genetic testing included a SNP microarray which indicated a normal male and a negative methylation test for Beckwith-Wiedemann syndrome.

Due to the severity of the hemodynamic compromise, treatment was initiated at one week of age was with Everolimus (Afinitor®) 4.5 mg/m2/day was started to reach a trough level of 5-15 ng/ml. This level quickly exceeded the dose level needed and was supratherapeutic; this was decreased to 1 mg/m2/day. One week later, the tumor was shrinking, and by one month of administration, the tumor was half the initial size seen at birth. See Images 1 and 2.

Update on this patient at two years of age. His last cardiac echo was negative for any tumor presence. He has not had a repeat of the MRI of the brain. This is currently pending, so I cannot comment on the effect on brain hamartomas. I can hypothesize that they will also have reduced in size as this was the initial use of Everolimus in TSC for the Subependymal giant cell astrocytomas (SEGAs) (2)

This patient had three eye tumors, 2 in the right eye and one in the left. Per the most recent ophthalmology review, they have not reduced, so there appears to be no improvement with the treatment. Almost all fetuses with multiple cardiac rhabdomyomas will have TSC. They will often be the presenting feature (3)

Everolimus initiation has been shown to reduce cardiac tumor volume in this patient. A study is needed to ascertain if this treatment will need to be lifelong or if regression could be permanent. The EXIST-1 study supported the hypothesis that everolimus can safely reverse multisystem manifestations of TSC in a significant number of patients (4)

“Everolimus initiation has been shown to reduce cardiac tumor volume in this patient. A study is needed to ascertain if this treatment will need to be lifelong or if regression could be permanent.”

Lessons learned and practical thoughts for the future:

1. Try to make a diagnosis ahead of time if a parent has TSC and a known pathogenic variant, amniocentesis for the TSC familial variant can be offered.

2. It is possible to consider the prenatal medication of the mother with an mTOR inhibitor during the pregnancy. Prenatal initiation of an mTOR inhibitor in TSC confirmed that as well

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as a decrease in tumors, it may decrease the length of post-natal hospital stay and concurrent morbidities.

3. Anticipate the need for genetic testing and test rapidly if the infant is symptomatic to start treatment as soon as possible.

4. Everolimus has been shown to decrease cardiac tumor size in a TSC-related cardiac rhabdomyoma. It is feasible, but the dose-trough response has shown to be inconsistent in neonates.

5. Should we being prophylactic and treat all patients with TSC to prevent the multisystemic effects

References:


Disclosures: The author has no relevant disclosures.

NT
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Common Problems in the Newborn Nursery
An Evidence and Case-based Guide

- Provides practical, state of the art management guidance for common clinical problems in the newborn nursery
- Written by experts in the field in a clear, easy-to-use format
- Utilizes a case-based approach

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Written by experts in their fields, each chapter begins with a clinical case presentation, followed by a discussion of potential treatment and management decisions and various differential diagnosis. Correct responses will then be explained and supported by evidence-based literature, teaching readers how to make decisions concerning diagnosis encountered on a daily basis.

While this guide is directed towards health care providers such as pediatricians, primary care physicians, and nurse practitioners who treat newborns, this book will also serve as a useful resource for anyone interested in working with this vulnerable patient population, from nursing and medical students, to nurses and residents in pediatrics or family practice.

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

For more information, please visit emilyshane.org.
Securing Babies' Access to Life-Saving Medicine

Susan Hepworth

The National Coalition for Infant Health advocates for:

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

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.

“Vaccine-like medications are a welcome tool to protect infants and their families from the torment of a serious RSV infection. Treating these drugs like vaccines will assure more equitable access and save the high costs of treating preventable infections.”

It is one of the most common causes of lower respiratory tract infections in young children and the leading cause of hospitalization (4) among babies less than one year old. The majority of RSV hospitalizations are in healthy infants born at full term.

Most RSV infections produce cold-like symptoms and are easily treated. But the virus can be much more dangerous in some in-

Bringing a newborn baby home from the hospital is a joy like no other. Bringing that same baby back to the hospital for treatment of a life-threatening virus would be a nightmare. Yet, for tens of thousands of parents, RSV makes that traumatic return trip a reality. (1)

While there is no vaccine to prevent the respiratory syncytial virus, “vaccine-like” drugs can protect babies through their most vulnerable years. These drugs, called monoclonal antibodies, deliver protective antibodies by enlisting the body's natural immune system response against infection like RSV. Realizing their potential for all babies means improving their accessibility. That comes down to the question of whether policymakers and insurance companies will cover these medications as vaccines.

If they do, the drugs might be eligible for the national Vaccines for Children Program (VCP). (2) VCP would expand the number of protected children and reduce disparities in access by providing vaccine-like drugs to eligible children at no cost. Such an approach would benefit children insured by Medicaid as well as those who are under or uninsured.

By contrast, if vaccine-like products are treated as traditional medications, they will be more costly for parents and likely harder to get. Most commercial health plans require patients to pay at least a flat co-pay for prescriptions, and uninsured patients are usually responsible for a medication's total cost. It is also common for insurers to limit access through the use of prior authorization. (3) Out-of-pocket costs and insurance barriers will keep kids from reaping the benefits of these preventive medications.

To understand why vaccine-like medications need to be widely available, consider the scope of RSV in America.

It is one of the most common causes of lower respiratory tract infections in young children and the leading cause of hospitalization (4) among babies less than one year old. The majority of RSV hospitalizations are in healthy infants born at full term.

Most RSV infections produce cold-like symptoms and are easily treated. But the virus can be much more dangerous in some in-

NEONATOLOGY TODAY • www.NeonatologyToday.net • May 2021
fants and children. Research cites a greater rate of serious cases in babies from lower socioeconomic groups. (4)

Vaccine-like medications are a welcome tool to protect infants and their families from the torment of a serious RSV infection. Treating these drugs like vaccines will assure more equitable access and save the high costs of treating preventable infections. The net result is lower costs and healthier kids.

References:
3. https://www.youtube.com/watch?v=aibWAPkht0&t=15s

Disclosure: The author has no relevant disclosures.

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Washington, DC 20004
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OPIOIDS and NAS
When reporting on mothers, babies, and substance use

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!

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.
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. 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

nationalperinatal.org/position
www.nationalperinatal.org/Substance_Use

We know that there are barriers that keep pregnant people from accessing care.

We believe that perinatal providers have a duty to help remove those barriers.

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“The definitive work in genetic evaluation of newborns”
- Judith G. Hall

GENETIC CONSULTATIONS
in the NEWBORN

Robin D. Clark | Cynthia J. Curry

- A streamlined diagnostic manual for neonatologists, clinical geneticists, and pediatricians - any clinician who cares for newborns
- Organized by symptom and system, enriched with more than 250 photography and clinical pearls derived from authors’ decades of clinical practice
- Includes “Syndromes You Should Know” appendix, distilling the most frequently encountered syndromes and chromosomal abnormalities in newborns
- OMIM numbers for each condition situate authors’ practical guidance in the broader genetics literature, connecting readers to the most up-to-date references

Comprising of more than 60 chapters organized by system and symptom, Genetic Consultations in the Newborn facilitates fast, expert navigation from recognition to management in syndromes that manifest during the newborn period. Richly illustrated and packed with pearls of practical wisdom from the authors’ decades of practice, it empowers readers to recognize the outward signs and symptoms crucial for an effective diagnosis.

Order now by clicking here.
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.

**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:

<table>
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<tr>
<th><strong>PARENTS</strong></th>
<th><strong>SPECIALTY HEALTH CARE PROVIDERS</strong></th>
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<tr>
<td>Only 18% said parents know “a lot” about RSV, reflecting an awareness level that's roughly half that of the flu.</td>
<td>They treat RSV as a priority, “often” or “always” evaluating their patients (80% doctors; 78% nurses).</td>
</tr>
<tr>
<td>Only 22% of parents consider themselves “very well prepared” to prevent RSV.</td>
<td>During RSV season, they are especially vigilant about monitoring patients for symptoms or risk factors for RSV (98%).</td>
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Clinical Pearl:
A Day in the Life: A Preemie Experience

Catherine Ney, MS, CCLS, Joseph R. Hageman, MD

“Have you, as a clinician, wondered what it is really like to be a premature infant being admitted to the Neonatal Intensive Care Unit? Even after spending time as a patient in the intensive care unit after a cardiac arrest, intubated, then post-operatively following a four-vessel bypass as I did in 2013, I do not think I really know what it is like for a preemie.”

Have you, as a clinician, wondered what it is really like to be a premature infant being admitted to the Neonatal Intensive Care Unit? Even after spending time as a patient in the intensive care unit after a cardiac arrest, intubated, then post-operatively following a four-vessel bypass as I did in 2013, I do not think I really know what it is like for a preemie.

Catherine Ney, my co-author, and colleagues in the Developmental Care Committee have organized an excellent simulation for NICU nurses, neonatal and pediatric nurse practitioners, residents, fellows, and faculty with help from the experts in our Simulation Unit at the University of Chicago. The simulation explores aspects of an admission experience includes admission procedures highlighting the effects of the sensory experience (i.e., sound, noise, taste, smell, light, and positioning). Additional components to effectively simulate the neonate’s experience included the sensation of a weighted positioner on your chest and movement restrictions due to an overly tight swaddle and poor positioning. One of the adults assumes the role of the patient as the providers complete admission tasks with a follow-up discussion regarding the effects on development, potential pathological effects, and how it must feel for the baby.

A comprehensive introduction, led by our Neonatal Nurse Practitioner Chris Eisen, highlights premature development through a developmental care lens that helps focus our participants before their breakout simulation sessions (1,2,3).

Pat Byrnes-Bowen, our physical therapist, explains the stages of development in utero and, as a consequence of preterm birth, what that infant will no longer have an opportunity to experience. As providers in this space, she discusses how we can use various tools and techniques to make the infant’s extraterine life as physically supportive as possible. Pat explains how positioning needs change and how important proper positioning can be to aiding in a successful life as a young child and adult.

Moving through our additional stations, participants discuss taste and smell with Julie Sadowski, Speech-Language Pathologist, and myself (Dr. H). In this session, participants learn about the aspects of development in utero that prepare infants for feeding later and how exposure to noxious smells can interfere with bonding and deter patient’s from positive oral experiences. This simulation allows participants to smell common items used on or near these patients at a high concentration. They are encouraged to smell various containers and identify alcohol wipes, adhesive remover, and perfume. Even in the age of mask-wearing, these smells permeate without losing their potency (6,7).

“As the participants digest these thoughts, the lights are dimmed, and they are encouraged to get comfortable in their chairs with eyes closed as they are about to enter the world of a preemie for a few moments. Recorded sounds are played, starting with a heartbeat track that is layered with common noises on the unit. Participants appear visibly shocked as these noises begin and have thoughtful comments during our discussion”

As participants enter the sound and vision station, they often notice an iPad set up with a decibel reader that is left on throughout the discussion. Catherine walks them through the developmental components of life in utero and the fascinating way the evolution of pregnancy prepares infants for the outside world. For most of our patient population, this natural experience is stripped away as they are thrust into a space that assaults their immature sensory systems. As the discussion moves toward sound, graphs are highlighted with decibel level readings of physical spaces on our unit compared to the recommended level of 45dB’s. The discussion in the room spikes to the mid 70dB range with just one person talking (8-11). As the participants digest these thoughts, the lights are dimmed, and they are encouraged to get comfortable in their chairs with eyes closed as they are about to enter the world of a preemie for a few moments. Recorded sounds are played, starting with a heartbeat track that is layered with common noises on the unit. Participants appear visibly shocked as these noises begin and have thoughtful comments during our discussion.

Prior to the final discussion, all participants are gathered for a presentation on mindfulness. Working in the health care field and in an intensive care unit demands more than clinical competence. Compassionate care supports a family-centered model but can be hard to sustain amid the daily challenges on our unit, not to mention the global pandemic. Participants are encouraged to explore the use of G.R.A.C.E. to help support their cultivation of compassionate care toward their patients and families and find ways to support their capacity to do so (12)…
We also discuss what the clinicians can do to be more sensitive to the infant's senses and developmental needs, optimize their NICU experience, and minimize the negative effects of this experience.

“We have a debrief and ask them what can be done to improve the experience and have received a lot of helpful feedback to refine the simulation.”

We have had several nurses, NNPs, fellows, and attending neonatologists experience this simulation, and the feedback has been really positive thus far. We have a debrief and ask them what can be done to improve the experience and have received a lot of helpful feedback to refine the simulation.

This is by no means a unique simulation as other NICUs have been doing this for a number of years (Phillips https://www.learningconnection.philips.com/en/course/preemie-day), and Catherine has spoken with clinicians from other units about their programs.

We will continue to refine this Day in the Life simulation and plan to do some follow-up surveys for those clinicians who have been through this to see if it has affected their practice in the NICU. An educational handout with summaries of development and the senses is also provided (Appendix 1) for the attendees.

“We will continue to refine this Day in the Life simulation and plan to do some follow-up surveys for those clinicians who have been through this to see if it has affected their practice in the NICU. An educational handout with summaries of development and the senses is also provided (Appendix 1) for the attendees.”

References


Disclosures: The authors have no conflicts to disclose.
A Day in the Life: A Preemie Experience
Educational Handout
<table>
<thead>
<tr>
<th>Smell</th>
<th>Developmental Facts</th>
<th>Positive Impacts of Dev Care Practices</th>
<th>Negative Impacts in the absence of Dev Care Practices</th>
<th>Ways to Enhance Dev Care Practices</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>• During gestation, the nasal orifices remain plugged until the 6th month or earlier, but then dissolve and allow fetuses to inhale amniotic fluid</td>
<td>• The smell and taste of breast milk on a scent cloth can trigger the cephalic-phase response to help support absorption and digestion while infants are being tube fed</td>
<td>• Exposure to strong stimulants such as disinfectants, detergents, alcohol, etc. has shown decreased oxygenated hemoglobin over the parietal region of the brain</td>
<td>• Rub Purell in all the way before touching infant or entering isolette</td>
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<td>• Flavonoids and odorants in amniotic fluid allow for taste and smell experience and exploration while in utero</td>
<td>• Tactile stimulation combined with odor and flavor stimuli appears to mediate important learning and builds faster oral feeding competence</td>
<td>• Perception and past experiences with the taste and smell greatly influence emotions, psychological well-being, physiological and metabolic processes as well as interpersonal relationships and social associations</td>
<td>• If mother’s milk is not available for olfactory stimulation, vanilla has been shown to also provide a calming effect on infants</td>
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<td></td>
<td>• Preterm infants can both detect and discriminate between different odors as early as 28 to 29 weeks’ gestation</td>
<td>• Research has documented the ability of the positive smell of mother’s milk to calm and organize the infant, as well as improve NNS and draw the infant toward mother’s milk for breastfeeding.</td>
<td>• Avoid wearing perfumes/cologne (by staff or caregivers) as this can interfere with the infant’s identification and response to their own mother’s odor or to the appetitive behaviors to a feeding experience</td>
<td>• Encourage skin-to-skin holding and the use of scent cloths to provide maternal scent</td>
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<td></td>
<td>• The cephalic-phase responses are innate and learned physiological responses to sensory signals that prepare the gastrointestinal tract for the optimal processing of ingested foods. CPRs could be affected by inconsistencies in the associations between sensory signals and subsequent post-ingestive consequences</td>
<td>Long Term:</td>
<td>• Open alcohol wipe, adhesive remover, etc. outside of the isolette</td>
<td>• Avoid wearing perfumes/cologne (by staff or caregivers) as this can interfere with the infant’s identification and response to their own mother’s odor or to the appetitive behaviors to a feeding experience</td>
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<td>• The smell and taste of breast milk on a scent cloth can trigger the cephalic-phase response to help support absorption and digestion while infants are being tube fed</td>
<td></td>
<td></td>
<td>• Vent isolette when cleaning while infant remains inside or try to time cleaning when infant is participating in kangaroo care</td>
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<td><strong>Positive Impacts of Dev Care Practices</strong></td>
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| “All of the processes involved in the development of the structure and function of the human visual system...have a critical period between 20 and 40 weeks’ gestation during which epigenetic events, toxic exposures and inappropriate external stimulation can produce significant alteration in the structure and function of the infant’s visual system.” | Protecting sleep is critical for healthy visual development | Short Term:  
- When quality of sleep is compromised, infants burn extra calories due to stress  
- Excessive and early exposure to intense or flickering light can alter synaptogenesis in the visual and auditory system  
Long Term:  
- Direct ambient light has a negative effect on the development of a preterm infant’s visual neural architecture | Use isolette covers as soon as possible for all infants in isolettes regardless of gestational age  
- Bright lights only as needed for assessments or procedures  
- When possible, shield infant’s eyes from direct, overhead lighting, aiming to exclude the infant’s head unless medically necessary |
| The visual system is not developmentally ready for visual stimulation until birth at term – external visual stimuli is not necessary for visual development | Using indirect light except for procedures when lighting can be used with appropriate shielding of the baby’s eyes |  |  |
| Excess visual stimuli can also interfere with auditory neurosensory development prior to 38 weeks | Standard lighting;  
- 37 to 50 lux during nighttime  
- 192 to 890 lux during daytime  
- EX: phototherapy = 3000 lux |  |  |
<p>| Premature infant has no pupillary reflex below 30 weeks’ gestation and only variable responses until 32-34 weeks |  |  |  |</p>
<table>
<thead>
<tr>
<th>Sound Developmental Facts</th>
<th>Positive Impacts of Dev Care Practices</th>
<th>Negative Impacts in the absence of Dev Care Practices</th>
<th>Ways to Enhance Dev Care Practices</th>
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</table>
| • Through pregnancy, the walls of the uterine lining begin to thin (timed with development of hearing structures/processes) to expose fetus to sound frequencies that are appropriate | • Directed human voice is important – background noise (conversation) does not provide infant with the appropriate stimulation needed for their auditory development. | Short Term:  
• Physiological responses: increased crying, heart rate, blood pressure, decreased oxygen sats, sleep  
• Exposure to even moderate noise levels may delay normal auditory development  
• Noise on the unit masks meaningful sounds (i.e. parent’s voices) needed for normal development | • Keep conversation noise levels down |
| • From 32 weeks’ gestation into the 2nd year of life is a critical period of development. Neural connections are forming and the auditory system is most vulnerable to the damaging effects of abnormal sensory input | • Keeping noise levels low (closer to the recommended 45dB) helps reduces stressful stimuli that increased cortical levels that can alter the makeup of the brain (Mary Coughlin)  
• Engaging infant with a soft gentle voice prior to touching or handling infant (one modality at a time) helps them acclimate better and reduces their stress during interaction. | Long Term:  
• Growth and development delays, hearing deficits, increased LOS, speech delays  
• REM sleep is greatly interrupted which is essential for early brain development | • Close portholes softly and encourage caregivers to do the same |
<p>| • Excessive sound may damage delicate auditory structures and increase the risk of auditory processing discrimination problems | | | • Limit the time the top of the isolette bed is up, as possible |
| • Sensory interference occurs when stimuli are out of sequence or when intensity is inappropriate for the stage of development | | | • Turning off alams as soon as possible |
| | | | • Answer or silences phones as soon as possible |
| | | | • Gather all materials needed before entering isolette for care; this will help avoid raising your voice over to ask others for forgotten materials |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>The pharyngeal swallow of amniotic fluid begins to emerge around week 10-14 weeks PMA</td>
<td>Kangaroo care increases physiologic stability in infant (increased stability of O2, etc.) and stimulates breastmilk</td>
<td>Short Term:</td>
<td>Not only important to avoid/limit negative experiences, but also to provide positive experiences while not overwhelming infant</td>
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<td>Babies will swallow about 600-800 mLs of amniotic fluid a day in the last trimester (premature infants are deprived of this sensory input and experiences compared to the infant in utero)</td>
<td>Non-nutritive sucking on pacifier decreases time to transition from tube to oral feeds.</td>
<td>“Increased exposure to stressors in the NICU has been associated with alterations in neurobehavioral and brain structures at 40 weeks PMA”</td>
<td>Promote skin-to-skin opportunities to allow for taste and smell of maternal milk and skin</td>
</tr>
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<td>The infant in utero has plenty of opportunities to have their hands near their mouth for exploration and calming/comfort, while our NICU babies may miss out on these opportunities</td>
<td>Supportive interventions which assist parents in reading the cues of their infant, and in supporting their infants’ goal strivings has shown improved developmental outcome to 9 years of age.</td>
<td>“…neonates with comorbidities require additional time to show consistent oral feeding skills.”</td>
<td>Identify infant’s engagement and disengagement cues to help parent learn infant’s responses to build competence and confidence and prepare them for infant driven feeding in future</td>
</tr>
<tr>
<td>Non-nutritive sucking develops around 27-28 weeks PMA which will help prepare and build a foundation for later feeding skills</td>
<td>Kangaroo care – studies show skin-to-skin results in MOB breast feeding exclusively and longer than controls</td>
<td>Long Term:</td>
<td>Offer pacifier as tolerated, - can begin offering around 27-30 weeks PMA – per cues. Recommend transitioning to standard/newborn nipple around 32 weeks to allow infant to ready for bottle feeds</td>
</tr>
<tr>
<td>“The processing of the taste and smell sensory environment significantly influences the entire developmental life of individuals from day one…Because of the early development of the smell and taste systems, early associations (positive and negative) can influence thoughts, emotions, and behaviors throughout the lifespan.”</td>
<td>“Although less than 1% of preterm infants required supplemental tube feedings at time of discharge from NICU, more than 50% of parents of NICU graduates report problematic feeding behaviors in their former preterm infant at the age of 18-24 months.”</td>
<td>“…successful feeding is related to maturation rather than feeding experience…the younger the infant is at birth, the longer it takes for that infant to achieve a mature suck pattern.”</td>
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<td><strong>Ways to Enhance Dev Care Practices</strong></td>
</tr>
<tr>
<td>• The womb, with its muscular uterine walls and amniotic fluid, provides continual sensory and kinesthetic input necessary for motor system development.</td>
<td>• From birth, provide containment and body flexion of the newborn utilizing: fluidized positioner, swaddling, weighted positioner</td>
<td>• Abrupt blood flow changes exert deleterious effects on the immature brain and appear to alter its subsequent development</td>
<td>• Avoid extreme cervical rotation positions</td>
</tr>
<tr>
<td>• Swaddling and containment of the infant with general flexion of the extremities and trunk mimics the in utero environment.</td>
<td>• Swaddling can decrease awakenings during quiet sleep and promote longer periods of REM sleep; appears to improve self-regulation, diminished stress response, and a decrease in arousal level</td>
<td>• Tight swaddling has the potential to interfere with normal respiratory effort and may potentially have orthopedic consequences</td>
<td>• Provide flexion, containment and alignment during all caregiving activities</td>
</tr>
<tr>
<td>• Neural pathways for movement and position stimuli are intact as early as 23 to 24 weeks’ gestation with greater discriminatory capacity probably beginning during the 28-32-week gestational time period.</td>
<td>• Swaddling can support Safe Sleep during supine positioning and decrease the risk of sudden infant death syndrome (SIDS)</td>
<td>• Prolonged inadequate support contributes to: asymmetries, atypical alignment, movement patterns which can negatively impact the infant, future motor development through overstretch injuries</td>
<td>• Allow infant to move as would be typical in utero within the containment of the nest or swaddle.</td>
</tr>
<tr>
<td>• Back to Sleep decreased the incidence of SIDS, but this change in sleep position has brought a new set of concerns, including a slower attainment of major milestones... and the development of positional plagiocephaly...&quot;</td>
<td>• Role modelling of appropriate positioning practices to parents and colleagues supports consistent experiences for the infant and their continued development</td>
<td>• Reinforcing arching and retraction through improper positioning prevents hands to midline can contribute to delays in fine and gross motor skills</td>
<td>• Swaddles should allow hip flexion and abduction, not papoose</td>
</tr>
<tr>
<td>• Abrupt blood flow changes exert deleterious effects on the immature brain and appear to alter its subsequent development</td>
<td>• Flat Head Syndrome</td>
<td>• Ensure proper postural support: Physiologic flexion, Head/neck midline/neutral, Shoulder protraction, flexed upper extremities and lower extremities, Hands midline and to mouth, Posterior pelvic tilt, Foot bracing</td>
<td>• Make certain monitors are not pulling on extremities and avoid placing weighted positioners on infants backs or chests</td>
</tr>
</tbody>
</table>
ChildKind Tips

On our journey to ChildKind, here is are tips for easing pain and promoting comfort based on the senses:

- Providing mother’s odor during invasive procedures (i.e. heel sticks) in infants has been shown to reduce reactivity and shorten the return to baseline.

- Try to use bright lights as little as possible and use an eye shield or cloth to cover infant’s eyes.

- Decreasing unnecessary background noises and volume (i.e. conversations, alarms, doors) allows for increased opportunities for babies to experience positive auditory input through human voice (i.e. reading or talking softly at bedside).

- Avoid frequent taping/re-taping around mouth and nose and try to transition from OG to NG, as able, to reduce negative oral sensory experiences.

- Providing swaddling support on non-affected limbs during painful procedures like IV starts can help reduce stress, minimize physiological responses and help infant return to baseline quicker following procedure.
### Comer NICU Noise Levels

<table>
<thead>
<tr>
<th>Sound Source</th>
<th>dB</th>
</tr>
</thead>
<tbody>
<tr>
<td>2nd Floor door entrance</td>
<td>72 (*90+)</td>
</tr>
<tr>
<td>Linen container</td>
<td>74</td>
</tr>
<tr>
<td>ECMO, supply door</td>
<td>65</td>
</tr>
<tr>
<td>HVAC, warmer</td>
<td>62</td>
</tr>
<tr>
<td>Soft closing door, fridge door</td>
<td>68</td>
</tr>
<tr>
<td>Alarm, sink/water, paper towel holder</td>
<td>73</td>
</tr>
<tr>
<td>Rounds</td>
<td>91</td>
</tr>
<tr>
<td>Empty room (4th floor)</td>
<td>51</td>
</tr>
</tbody>
</table>

### Sound Equivalents

<table>
<thead>
<tr>
<th>Sound Source</th>
<th>dB</th>
</tr>
</thead>
<tbody>
<tr>
<td>Closing both porthole doors at the same time</td>
<td>122</td>
</tr>
<tr>
<td>Shutting both cabinet doors near bed space at the same time</td>
<td>114</td>
</tr>
<tr>
<td>Placing infusion pumps on top of incubator</td>
<td>110</td>
</tr>
<tr>
<td>Setting milk bottle softly on top of incubator</td>
<td>96</td>
</tr>
</tbody>
</table>

### Risk of Hearing Damage (OSHA)

<table>
<thead>
<tr>
<th>dB</th>
<th>Hours</th>
<th>Sound Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>90 dB</td>
<td>8 hours</td>
<td>Factory, train</td>
</tr>
<tr>
<td>95 dB</td>
<td>4 hours</td>
<td>Subway noise, motorcycle</td>
</tr>
<tr>
<td>105 dB</td>
<td>1 hour</td>
<td>Chain saw, siren, rock concert</td>
</tr>
<tr>
<td>110 dB</td>
<td>30 minutes</td>
<td></td>
</tr>
<tr>
<td>120 dB</td>
<td>15 minutes</td>
<td></td>
</tr>
<tr>
<td>125 dB</td>
<td>Painful</td>
<td></td>
</tr>
</tbody>
</table>
It is hard to be a Neonatologist who took the path through Pediatrics first, and not use a Dr. Seuss quote from time-to-time. If your unit is anything like ours where you work, I imagine you feel as if you are bursting at the seams. As the population grows, so do our patient volumes. I often quote the number 10% as being the number of patients we see out of all deliveries each year in our units. When I am asked why our numbers are so high, I counter that the answer is simple. For every extra 100 births, we get 10 admissions. It is easy though, to get lost in the chaos of managing a unit in such busy times, and not take a moment to look back and see how far we have come. What did life look like 30 years ago or 25 years ago? In Winnipeg, we are preparing to make a big move into a beautiful new facility in 2018. This will see us unify three units into one, which is no easy task but will mean a capacity of 60 beds compared to the 55 operational beds we have at the moment.

In 2017, we were routinely resuscitating infants as young as 23 weeks, and now with weights under 500g at times. Whereas in the past, anyone under 1000g was considered quite high risk, now the anticipated survival for a

**“Oh the Places you’ll Go”**

By Michael Narvey, MD

Originally Published on: All Things Neonatal

http://www.allthingsneonatal.com

July 13, 2017; Republished here with permission.

Winnipeg Free Press

Sunday, October 5, 1986

Pages 5-16

1986 – Opening of the New NICU at Children's Hospital

**What did life look like 30 years ago or 25 years ago?**

**“Oh the Places you’ll Go,” by Dr. Seuss** (originally published in 1990)

Sign up for free membership at 99nicu, the Internet community for professionals in neonatal medicine. Discussion Forums, Image Library, Virtual NICU, and more...

www.99nicu.org
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).

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!

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 preemies 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:
- 12% of preemies who get NEC
- 5% of preemies requiring surgery to treat NEC
- 30% of micro preemies needing surgery will die from NEC

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%

An Exclusive Human Milk Diet gives vulnerable infants the best chance to be healthy and reduces the risk of NEC and other complications.

Learn more about Neonatal Abstinence Syndrome at www.nationalperinatal.org
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99nicu

NATIONAL PERINATAL ASSOCIATION

Update: CORONAVIRUS COVID-19

According to data published in The Lancet

Pregnancy and the risk of VERTICAL TRANSMISSION

LOW

www.nationalperinatal.org

Time is precious, just like your patients.
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

<table>
<thead>
<tr>
<th>Fish Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>shrimp</td>
</tr>
<tr>
<td>cod</td>
</tr>
<tr>
<td>catfish</td>
</tr>
<tr>
<td>salmon</td>
</tr>
<tr>
<td>pollock</td>
</tr>
<tr>
<td>tilapia</td>
</tr>
<tr>
<td>canned light tuna</td>
</tr>
</tbody>
</table>

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?

Support the Open Letter
Breastfeeding Innovations Team

GET THE FACTS ON FISH CONSUMPTION FOR PREGNANT WOMEN, INFANTS, AND NURSING MOMS.
Letters to the Editor

Lessons learned from an International Summit on Newborn Pulse Oximetry Screening Programs

“This forum was the first in a series aimed at accelerating the adoption of newborn pulse oximetry screening programs in Latin America by establishing a multi-national collaborative.”

On 7-9 December 2020, key leaders in public health, clinical practice, NGOs, and academic health in Latin America (Mexico, Bolivia, Colombia, Peru, Guatemala, Ecuador, Argentina) along with international experts from the United States, Philippines, Mongolia, China, Pakistan, and India, convened at the 1st Latin American Summit on Early Detection of CHD and Secondary Conditions to share knowledge about research, resources, health policies, and evidence-based implementation strategies to equip stakeholders better to improve neonatal health and survival through earlier diagnosis and access to timely interventions.

This forum was the first in a series aimed at accelerating the adoption of newborn pulse oximetry screening programs in Latin America by establishing a multi-national collaborative. The delegates were representing the countries committed to the principles of equitable, bilateral exchange of knowledge and resources to bolster newborn screening, particularly pulse oximetry screening in regions and nations without programs or in the early stages of implementation/expansion.

This initiative was led by the team from the BORN Project in Mexico, Newborn Foundation, and yielded three main learnings. First and foremost, newborn screening, including newborn Point of Care (POC) Screening for Congenital Heart Diseases (CHD) and secondary conditions, is an essential tool in achieving an earlier diagnosis, referral, and timely intervention – preventing morbidity, mortality, and disability associated with delayed or missed detection of critical health conditions. Newborn pulse oximetry screening has been added to the routine universal screening panel (RUSP) in the United States and a growing number of countries worldwide. As part of a public health program, CHDs have been assessed to affect 9 per 1,000 live births; approximately one-quarter of those children have critical conditions (CCHDs) requiring surgical intervention in the first weeks or months of life. CHD is the most common and deadly birth defect, accounting for 3 percent of all infant deaths and more than 40 percent of all deaths due to congenital malformations. Higher birth rates in low and middle-income countries, such as Mexico, increase disease burden in all parts of the world. Thus, it is vital to use lower-cost tools such as pulse oximetry in countries where the health systems lack economic resources to identify and treat babies with critical medical conditions.

In addition, the forum participants realized we should advocate from both medical education and in partnership with public health and civil societies, to impact the education and promotion of these projects at the population level, to provide the requisite data and frameworks for policymakers to create and implement mandated policies that for routine, uniform, and equitable screening. Screening should be a key component of public health systems in all countries, prioritized at the government level through policies, medical education, and public education. It is important to leverage technologies that complement newborn screening, including the essential need for data collection and reporting, linking medical centers in the same country and specialized care centers for congenital heart diseases, and other conditions associated with hypoxemia in newborns – allowing seamless collaboration to optimize care and services for families impacted.

Secondly, there is an urgent need for partnership and collaboration between the public and private sector, at the local level, the country level, and between countries. This association has been successfully demonstrated in other regions worldwide and can be modeled for the Latin American collaborative. The BORN Project (Birth Oximetry Routine for Newborns) has been implemented across more than 210 hospitals in 12 countries – utilizing a framework of a hub and spoke pilot programs with robust data collection and routine briefings to public health officials to gain buy-in and ultimately accelerate the adoption of routine screening and standards of care. Additionally, when implementation hurdles are lower in private sector facilities, there should be pathways to inform and support program implementation within the public hospital system. The collaborative as a body agreed that public health mandates must include the private sector and adhere to regulatory requirements that ensure equitable adoption of screening for all newborns. Other international efforts (Pan African Workshop on Newborn Screening and the Asia Pacific Region Collaborative), the Every Breath Counts Coalition, and SDGs 3 (Health and Wellbeing) and 17 (Partnership for the Goals) show that international coalitions and partnership-based initiatives are essential to addressing continued gaps in neonatal health.

Finally, as in every Public Health intervention, there is a need for greater connectivity between early diagnosis, care, and outcomes. Real-time data collection systems aim to improve and assure the quality standards of care. Additionally, data allows stakeholders to have updated information for research aims, algorithm improvements, and optimization of screening as a tool to improve health outcomes. It is critical to bridge the gap between screening as an early identifier and ensuring these babies are guided to the follow-up testing and care required. Telemedicine and care across institutional and geographic borders will be essential tools to realizing this need, while governments and funding agencies must rally around the infrastructure needs to ensure every baby requiring life-saving treatment can access it. Unify the results and even improve the public health case definitions. Depending on where a baby is born, these improvements may be local, national, and even international – built on a backbone of electronic information exchange and collaboration. Stakeholders must build routine connections with other data sources, including public health medical systems, and agree upon data to be collected and pathways to data-driven decision processes.

In conclusion, the convening bodies believe that by establishing this formal Multi-national Collaborative and signing onto the foundational “Queretaro Declaration,” the participating members will advance sustainable, scalable systems that can benefit additional countries in Latin American and beyond.

References:
1. Empowering Newborn Screening Programs in African Countries through Establishment of an International Collaborative Effort - in an effort to explore new knowledge,
and to develop meaningful collaborations for improving child health the First Pan African Workshop on Newborn Screening was convened in June 2019 in Rabat, Morocco.

2. Consolidating newborn screening efforts in the Asia Pacific region - Carmencita David Padilla, Bradford L. Therrell, Jr. and on behalf of the Working Group of the Asia Pacific Society for Human Genetics on Consolidating Newborn Screening Efforts in the Asia Pacific Region

Oscar San Roman Orozco¹,
Isidro Gutierrez Alvarez²,
Annamarie Saarinen³,
Patricia Ledesma³,
L. Alejandra Guzman Esquivel³,
Brenda M. Perez².
¹ Applied Global Public Health Initiative, School of Global Public Health, New York University
² BORN Project Mexico, Newborn Foundation, MX.
³ Newborn Foundation, MN, US

Dear Dr. Orozco:
The importance of the BORN (Birth Oximetry Routine for Newborns) project cannot be overemphasi-zed. As you pointed out, CHD is the most common birth defect and is usually implicated in less than ideal outcomes. Although these screening efforts began in the United States, thanks in no small part to one of your co-authors, universal screening is rapidly becoming worldwide.

The partnership that you speak of is critical in the application of this technology. As you elegantly pointed out, this partnership must transcend all boundaries regardless of socioeconomic or geopolitical considerations. However, screening and identification of CCHD must be coupled with an effective program to treat and, if possible correct those lesions (1) that would otherwise lead to significant morbidity and mortality, especially in areas of the world where strife is rampant. We must intervene for those most at risk.

Telemedicine and care relocalization must be promoted not only at the level of the individual country but by the region and the world. In this day of highly sophisticated cardiac interventions, it is inexcusable for us not to be able to provide access to all. (2)

I applaud your efforts to effect this change and look forward to great strides in the care of all patients with CCHD. It is my sincere hope that the World Health Organization will adopt and prioritize BORN so that we can achieve an optimal result.

References:

Sincerely,

Mitchell Goldstein, MD

Editor in Chief

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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.

### Erratum (Neonatology Today April 2021)

Neonatology Today is not aware of any erratum affecting the April, 2021 edition.

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

### 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: Respiratory Syncytial Virus and African Americans

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Caucasian Babies</th>
<th>African American Babies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prematurity</td>
<td>11.6%</td>
<td>18.3%</td>
</tr>
<tr>
<td>Breastfeeding</td>
<td>58.1%</td>
<td>50.2%</td>
</tr>
<tr>
<td>Low Birth Weight</td>
<td>7.3%</td>
<td>11.8%</td>
</tr>
<tr>
<td>Siblings</td>
<td>60.1%</td>
<td>71.6%</td>
</tr>
<tr>
<td>Crowded Living</td>
<td>1%</td>
<td>3%</td>
</tr>
</tbody>
</table>

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.

READ

NPA’s statement: **BLACK LIVES MATTER**
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Las nuevas mamás necesitan acceso a la detección y tratamiento para la depresión posparto.

1 de cada 7 madres afronta la depresión posparto, experimentando:
- Llanto incontrolable
- Sueño interrumpido
- Ansiedad
- Desplazamientos en los patrones de alimentación
- Ideas de hacerse daño a sí misma o al bebé
- Distanciamiento de amigos y familiares

1 DE CADA 7 MADRES AFORTA LA DEPRESIÓN POSPARTO, experimentando.

DEPARTAMENTO DE SALUD Y SERVICIOS HUMANOS.

La salud de la madre
La capacidad para cuidar de un bebé y sus hermanos

PARA AYUDAR A LAS MADRES A ENFRENTAR LA DEPRESIÓN POSPARTO

LOS ENCARGADOS DE FORMULAR POLÍTICAS PUEDEN:
- Financiar los esfuerzos de despistaje y 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 posparto
- Conectar a las mamás con una organización de apoyo
Upcoming Medical Meetings

Pediatric Academic Society Virtual Meeting
Phase 1: April 30 - May 4, 2021
Phase 2: May 10 - June 4, 2021
https://www.pas-meeting.org/pas2021-virtual/

22nd Annual International Perinatal Bereavement Conference (IPBC)
May 12 - 15, 2021
Pregnancy Death and Infant Loss Alliance (PLIDA)
Chicago, Illinois
https://www.plida.org/ipbc-2021

44th 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/

42nd 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

Specialty Review in Neonatology
Feb 21-26, 2022
San Diego, CA
www.specialtyreview.com

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With over 900 beds in four hospitals, we operate some of the largest clinical programs in the nation. We also offer the only Level I Regional Trauma Center and Children’s Hospital in the Inland Empire servicing the largest county in the US. We lead in many areas of excellence; pediatrics, cardiac services, cancer treatment and research, mental health, chemical dependency, and other essential clinical disciplines. All this adds up to endless possibilities for our patients and for you.

The Neonatal Intensive Care Unit (NICU) at Loma Linda University Children’s Hospital is committed to providing high-quality, family-centered care with our highly skilled, multi-disciplinary neonatal team. Our unit has 84 licensed beds for the most critically ill infants and a new Tiny Baby Program focusing on improving survival and outcomes of extremely low birth weight infants (<1000g at birth). As one of the only level 3 tertiary centers in Southern California, we are equipped to provide the highest level of care for the most complex disorders. We have subspecialists in all medical and surgical areas that are available at all times and are supported by hospital staff with technical, laboratory, and service expertise.

At Loma Linda University Health, we combine the healing power of faith with the practices of modern medicine. We consist of a University, a Medical Center with four hospitals, and a Physicians Group. These resources have helped us become one of the best health systems in the nation.

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https://www.nc3rs.org.uk/arrive-guidelines
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NT

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 Larry Tinsley, MD, It is a quilt that depicts a Samurai. Our Bird for this month is provided by Elba Fayard, MD who provides us with "Pelicans in Flight."

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

NT

Manuscript Submission: Instructions to Authors

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

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

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

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

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

6. An abstract may be submitted.

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

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

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

10. Only manuscripts that have not been published previously will be considered for publication except under special circumstances. Prior publication must be disclosed on submission. Published articles become the property of the Neonatology Today and may not be published, copied or reproduced elsewhere without permission from Neonatology Today.

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 • www.NeonatologyToday.net • May 2021
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.

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**Presented by:**

NICU Parent Network

* Visit nicuparentnetwork.org to identify national, state, and local NICU family support programs.

* The information provided on the NICU Baby's Bill of Rights does not, and is not intended to, constitute legal or medical advice. Always consult with your NICU care team for all matters concerning the care of your baby.

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