

VIRTUAL

— 2021 —



# Infant Health

## Policy Summit



# Overview

The sixth annual Infant Health Policy Summit welcomed health care providers, parents, policymakers, advocates and other stakeholders to explore how policy solutions can improve the health and lives of infants and their families.

This year's event, held virtually, examined issues such as:

- The value of safety and innovation for neonates
- Respiratory syncytial virus and compounding disparities
- Perspectives from the Asian, Black, Hispanic and LGBTQ communities
- The long-term effects of separating mothers and babies during COVID-19
- Nutrition and safety in a growing human donor milk market
- Newborns and rare diseases

Ashley Randolph, a Black mother of three premature babies, president of GLO Preemies and co-founder of the Alliance for Black NICU Families, delivered opening remarks. She called for a reexamination of policies that shape infant care and highlighted what advocates can do to make policies stronger, better and fairer.

“My baby and I did not always get the information, the respect, or the care that we needed,” she recalled of her time in the NICU. “Navigating the NICU after you’ve just come through the enormous stress of a premature birth, that’s difficult for any parent,” Randolph reflected, “but it’s especially hard when you’re met with preconceptions, stereotypes, or judgment from the very system that’s meant to help you.”

Randolph called on advocates to keep working “today, tomorrow and every day, until all infants have the access and the care they deserve.”

The summit, which included a series of panel discussions, individual stories and interviews, was convened by the National Coalition for Infant Health and co-hosted by the Institute for Patient Access and Alliance for Patient Access.



**Ashley Randolph**

*“The challenges I faced were an opportunity to do something more.”*

# Keynote Address

**U.S. Rep. Nanette Diaz Barragán**

*Member of Congress*



For much of the 20th century, stigma has persisted around mental illness generally, with maternal mental health neglected almost entirely. U.S. Rep. Nanette Diaz Barragán wants to see that trend reversed.

The congresswoman used her keynote address to emphasize the importance of repairing prevention and care networks for new moms. Rep. Barragán recently introduced the TRIUMPH for New Moms Act of 2021, a bipartisan bill to create a taskforce across agencies, medical societies, and nonprofit organizations with expertise in maternal or mental health. The taskforce would be chaired by the assistant secretary of the Department of Health and Human Services.

It is critical to reduce disparities faced by moms of color, support policy on maternal mental health, and improve federal, state, tribal, and community partnerships focused on maternal mental health, the congresswoman emphasized. She also highlighted the need to create supportive environments for new moms returning to work.

Rep. Barragán envisions the taskforce coordinating programs, closing gaps, formulating recommendations, identifying appropriate programs and finding federal resources to support new mothers. The

taskforce would also develop a national strategy for maternal mental health and issue recommendations at all levels of government while regularly updating the report to create an ongoing, up-to-date national strategy.

The congresswoman described seeing the lack of federal coordination and strategy every day. Suicide and overdose are the leading cause of death for new mothers, she noted, adding that untreated mental health disorders damage mother-child bonding, most prevalently in communities of color.

**“ One in five women, and three of five women of color, will suffer from a maternal mental health condition. ”**

Rep. Barragán underscored the need for advocacy, explaining that “public sentiment moves the needle.” She told summit attendees that members of Congress need to hear from the “boots on the ground” — reminding them that nothing is as powerful as a personal story.



# Innovating for Infants

This year's summit highlighted an urgent need for policies that promote the development of devices and medications created specifically for infants — and for hospital systems to implement these policies.



## **Mitchell Goldstein, MD**

*National Coalition for Infant Health*

Dr. Goldstein provided an example to illustrate the urgency of needed devices and medications for infants. Early in his career, Dr. Goldstein recalled, he had an infant patient whose oxygen levels were being monitored with an adult oximeter, which didn't work correctly for such small patients. Dr. Goldstein fortunately had access to a trial device developed specifically for infants. With this tool, he could tell that the infant was showing steady improvement.

"This was the first point," Dr. Goldstein reflected, "where I realized how important it was...that we have technology that is specifically designed for the population — in this case, neonates. And this technology for this baby at this time made all the difference."



## **Patricia Bondurant, DNP**

*University of Kentucky HealthCare*

Patricia Bondurant echoed concerns about the scarcity of well-tested, safe and effective medical devices for infants. With the variety of health concerns facing NICU babies, this population is extremely vulnerable to infection. She stressed that more precise measures and dosing are needed, as are tools that address the constantly changing weight and maturation of babies as their stay extends.

Bondurant is leading the way with private-public partnerships to merge life science and digital companies with physical sciences and computer sciences to bring breakthroughs to the NICU. She emphasized the importance of bringing innovators and collaborators "committed to ensuring that all children have access to the right devices to deliver safe care," as well as the need to work with clinicians to improve existing tools.

# Viewpoints

A series of individual perspectives shed light on how parenthood and infant health issues are experienced by different communities.



## **Wakako Minamoto Eklund, DNP**

*Pediatric Medical Group of TN, Northeastern University*

Wakako Minamoto Eklund, reflecting on the experiences of the Asian community, has found that major language barriers can create a difficult environment for multi-ethnic families. She has seen poor interpretation unnecessarily add to families' strife.

Eklund laid out several policies and tools that could reduce language issues. Those included boosting training so that translation services could guarantee a quality interpreter with proper training to facilitate conversations about medical issues. Eklund also recommended developing go-to resources for translators with common language and medical terms. Better understanding nonverbal cues and changes is also important, since patients may sometimes refrain from asking questions or chatting with providers when language barriers exist. Training providers in nonverbal communication such as smiling, pointing, universal signs and gestures, Eklund noted, could also improve medical interactions for family.



## **Curry Bordelon, DNP, MBA**

*University of Alabama at Birmingham School of Nursing*

Curry Bordelon has run into issues of bias in all areas of his life as a gay man, father and same-sex partner. While in the NICU, he found that the medical providers assumed they were "waiting on mom." Preconceptions about what makes up a family are pervasive, Bordelon said, from the NICU to school forms to pediatric visits.

Many LGBTQ patients and families fear providers disengaging from patients who are different from them or whom they aren't sure how to approach, Bordelon noted. His mission is to teach students and colleagues about bias, both conscious and unconscious, helping them to see that families come in all colors, shapes and sizes.



## **Liliana T. Miramontes, BSN**

*Perinatal Nurse*

It's time to "make sure the workforce is as diverse as patients," said Liliana Miramontes. As a Hispanic, she has experienced bias herself — both as an experienced medical professional and as a patient. Patients may assume she is uneducated, Miramontes explained. They don't want to believe or credit her knowledge, and sometimes they want to talk to the doctor so that the doctor can repeat everything she's already said.

Whether it's having English as a second language or coming from a different educational background, Hispanic people can have different experiences in the world of pregnancy and infant health. Miramontes explained that it is important to educate patients so they can be their own advocates. She is working to get information to patients and help them understand how America's health care system works and what the process is for labor and delivery. More resources in more languages and in more locations, Miramontes noted, would help empower patients and reduce anxiety.



## **Gigi Khonyongwa-Fernandez, BSc**

*Certified Professional Coach*

Gigi Khonyongwa-Fernandez has experienced her share of bias — as a preemie mom who spent six months in the NICU, as a Black woman and as a health care provider. She reflects that the experiences stemmed from both conscious and unconscious bias. She was often overlooked as a medical professional, even assumed to be housekeeping staff in one encounter.

She said that fighting assumptions and having to disprove stereotypes can have an impact on both families and babies. In many cases there is an immediate assumption that a Black family must be incapable of preparing for a child. She explained that providers "actively try to fit you or, shall I say, force you" into a box. This can cause unnecessary trauma and stress, and it also exerts energy on ignorant assumptions rather than focusing on the child. Distrust creates an uncomfortable environment.

When asked how providers can ensure every single baby and family receive optimal care, she said they must keep the conversation going. "We have to get comfortable with being uncomfortable," Khonyongwa-Fernandez emphasized.

# Respiratory Syncytial Virus

As yet another RSV season sets in, policymakers must improve access to health care for underserved communities and ensure more comprehensive coverage for treatment.



## **Megan Jones**

*Iowa General Assembly, The Jones Family*

The mom of four kids, Representative Jones recalled the challenges and heartache of seeing her infant son hospitalized with RSV. An ER visit led to an ambulance ride that “I will never forget,” Rep. Jones explained, which ultimately landed the family at an Iowa children’s hospital. While her son survived, Rep. Jones says the experience has made her family vigilant about RSV precautions.

She urged legislators and advocates to raise awareness about the disease and lack of resources for infant health care in underserved and rural areas.



## **Suzanne Staebler, DNP**

*National Coalition for Infant Health*

Suzanne Staebler explained that, while RSV cases initially dropped amid the masking and sanitizing of the pandemic, a delayed RSV season started much sooner this year. Pediatric beds in many hospitals are full of RSV or COVID cases, she noted.

From a provider’s perspective, she noted, it is hard to watch infants struggle because RSV can be prevented. “Prophylactic treatment for RSV has been available since the late 1990s,” Staebler explained, but restrictive dosing and coverage by insurance companies means that “many at-risk infants are denied treatment.”



## **Martha A. Dawson, DNP**

*National Black Nurses Association*

Martha A. Dawson outlined RSV’s comparatively high impact on the Black and brown communities. She explained that faith-based organizations can be a catalyst for awareness, pointing to similar efforts for adult diseases such as diabetes, stroke and heart disease.

Whether it’s prayer services, women’s retreats or baby showers, Dawson explained, faith communities can have a role in raising awareness about RSV. The health care community is wide, and concern doesn’t — and shouldn’t — stop at the hospital.

# COVID-19 Mother & Baby Separation

Even during a pandemic, separating mothers from their newborn infants can have severe consequences, both short and longterm.



## **Marisa DeMis**

*Patient Advocate*

When Marisa DeMis' newborn was diagnosed with a congenital heart defect, she found herself facing unanticipated challenges in the NICU. COVID restrictions prevented immediate family members from coming to the hospital. Though DeMis' husband was allowed to visit, DeMis found herself thinking about how postpartum depression and PTSD could have affected her — and could affect other women who were isolated in the hospital after giving birth.

She now strives to educate and advocate so that other families can avoid similar barriers.



## **Ruth Davidge, RN**

*Neonatal Nurses Association of Southern Africa*

Ruth Davidge relayed related challenges in South Africa. While national policy supports zero separation for full-term babies, sick and small babies are separated from COVID-positive mothers for at least two weeks. In private hospitals, many NICUs are closed to all “visiting” mothers and fathers.

Davidge alluded to studies reporting that “kangaroo care,” even with mothers positive for COVID, outweighs the risks of the illness and reduces mortality in low-weight babies. “The mother’s presence is essential and not a ‘nice to have,’” she concluded.



## **Johanna Kostenzer, PhD**

*European Foundation for the Care of Newborn Infants*

Dr. Kostenzer has spearheaded bi-weekly calls with parent advocacy organizations globally to learn about emerging issues and the impact of COVID-19 restrictions on infants and families. These conversations allowed her to ask questions of different fields relating to the family side of care — issues with depression, breastfeeding, skin-to-skin contact, mental health changes and communication.

Among 2,100 parents in 65 countries, 20% experienced separation of parents and infants, demonstrating that the experience was not just anecdotal. Based on these findings, Dr. Kostenzer calls for a zero-separation policy. She said policymakers must provide inclusive and family-centered care, pandemic or not.



# Antibodies & Rare Diseases

Antibodies are tricky. While some can help health issues others can cause or worsen them for pregnant women and their developing babies.



## **Kenneth J. Moise, Jr., M.D.**

*Dell Children's Hospital*

Dr. Moise explained that antibodies often pass through the placenta into the developing baby — but some can cross and attack. This leads to conditions such as hemolytic disease of the fetus and newborn and congenital heart block. Certain antibodies are commonly tested in pregnancy, but some are rarer and not routinely tested.

Unfortunately, treatments for these diseases are few and can take a toll on an expectant mother. Treatment for hemolytic disease of the fetus and newborn, for example, involves multiple blood transfusions throughout the pregnancy. Dr. Moise emphasized a need for innovation to treat these rare diseases and allow patients to have better outcomes in their overall health.

“Science could have a big impact,” he emphasized.



## **Suzanne E. Shores, CNM, FNP, MSN**

*UPMC Magee Women's Hospital*

Suzanne Shores stressed that maternal vaccines convey exposure to infants, which provides antibodies to fight illness. In utero, antibodies pass from mom into baby and provide some protection for common diseases.

In other cases, antibodies produced by the mother's body can cause complications. Signs and symptoms of abnormality are seen in screening tests and in later pregnancy can show up in ultrasounds as atypical development. Given widespread shortages of advanced health care providers, advanced practice nurses and midwives can play a critical role, especially in rural areas, for risk assessment, assisting in detecting disease and offering preventive care.

It's a collaborative effort, Shores noted, among caregivers, specialists and the family.

# Donor Human Milk

Human milk can offer a variety of lifesaving benefits, but how can policymakers ensure that donor human milk is safe for the infants who need it?



## **Martha A. Dawson, DNP**

*National Black Nurses Association*

Martha Dawson explained that there is no standard of testing and screening human donor breast milk. Practitioners have requested that the FDA clarify plans for safety regulations. “Our nurse leaders really became acutely aware of the different methods for the screening and testing of human milk,” she said, as well as a “lack of consistency and best practices in the industry.”

Human donor milk is a tool for the most vulnerable patients, and infant mortality from complications of prematurity can be lessened with the benefit of human milk. But without clearer guidance from the FDA, Dawson explained, donor milk could be “an accident waiting to happen.”

“We must be proactive to protect infants,” Dawson urged attendees.



## **Scott Eaker**

*Prolacta Bioscience*

As chief operating officer of a company that offers a full line of human milk and human milk-based products for the nation’s NICUs, Scott Eaker offered insight on the issue. The “growth of the human milk industry,” he explained, “is absolutely a net positive, requiring... a huge increase in the amount of milk collected and processed.”

While human donor milk is a lifeline for mothers who cannot produce enough breastmilk on their own, or whose infants require more calories, the market also introduces questions of safety and quality. Eaker reiterated that the FDA needs to address breastmilk as a “novel product” for regulation. It’s also essential that families know the hallmarks of quality and safety of the supply, from donor selection and donor testing to milk testing. Eaker said that the FDA should step up oversight and inspections, which can be encouraged through interest and calls from policymakers.

# Audience Overview



TOTAL  
ATTENDEES

**386**



PAGE  
VIEWS

**801**

## ATTENDEE BREAKDOWN



**NCfIH** National Coalition  
for Infant Health

Protecting Access for Premature Infants through Age Two



Institute for  
Patient Access



Alliance for  
Patient Access