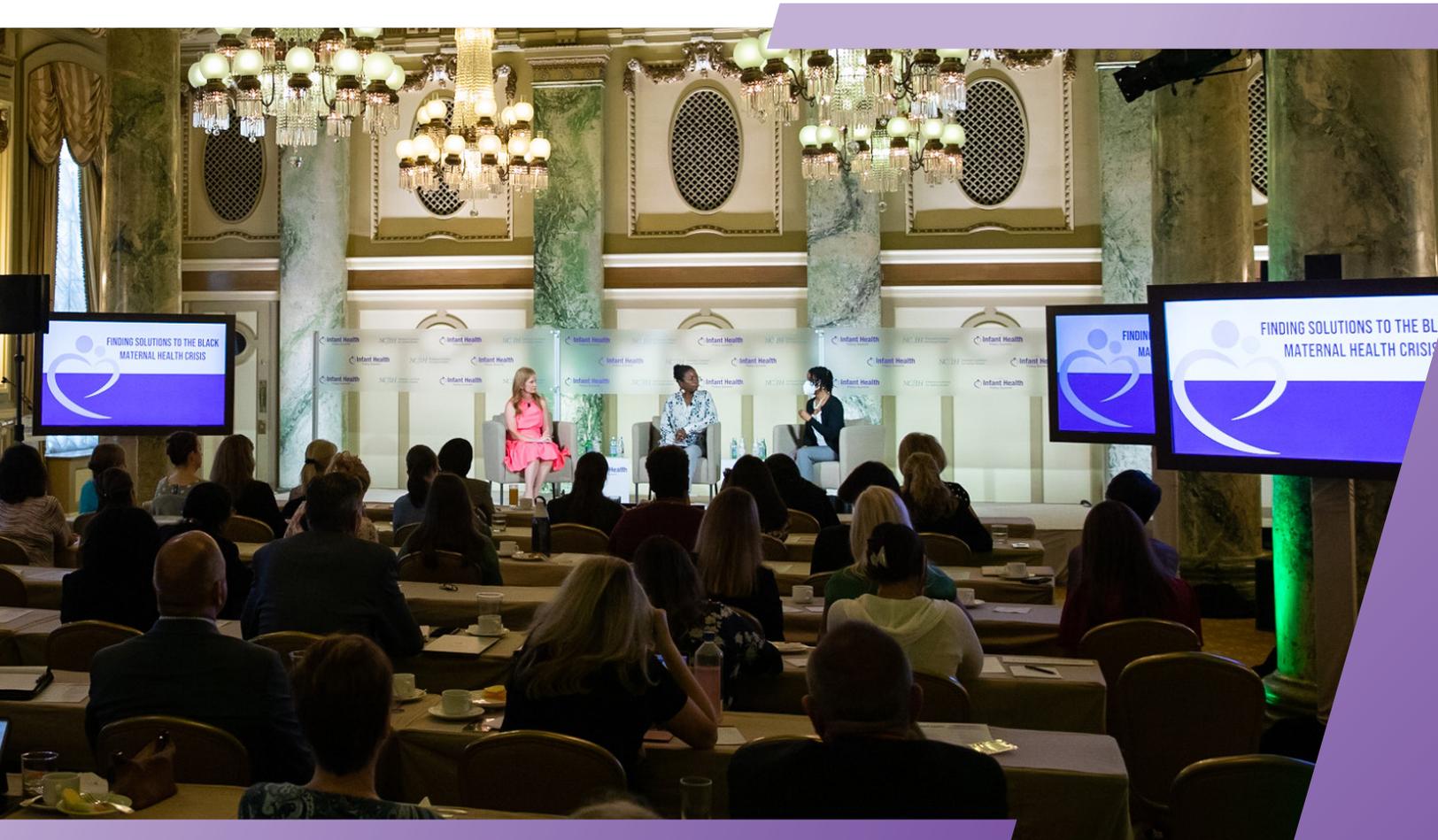


— 2022 —



# Infant Health

## Policy Summit





# Overview

The eighth 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 both in-person and virtually, examined issues such as:

- The Black maternal health crisis
- Donor human milk quality and safety
- RSV preventive interventions
- Drug, formula and product shortages
- Parents as partners in their baby's care

Christy Gliniak, PhD, the communications manager for the National Association of Neonatal Therapists, delivered opening remarks. She called for advocates, parents and other stakeholders to unite in their efforts of promoting infant health.

“Not all babies are born with the same advantages, and not all parents are prepared or equipped to advocate for their child. That’s where we come in,” she explained, emphasizing the need to continue advocating even when there may be challenges. “It requires us to constantly push forward,” she urged, “not letting up until the job is done.”

She called on advocates to increase cooperation to create a better future for infants, citing the summit as a starting point. “It’s a launchpad for advocacy, giving us fresh perspective, new information and valuable insights.”

The Infant Health Policy Summit, which included a series of panel discussions, pre-recorded testimonials and one-on-one interviews, was convened by the National Coalition for Infant Health and co-hosted by the Alliance for Patient Access and the Institute for Patient Access.

# Congressional Update

**U.S. Rep. Alma S. Adams, PhD**

*Member of Congress*



Black maternal health suffered during the COVID-19 pandemic, with barriers impacting Black women's ability to receive quality care. U.S. Rep. Adams urged policymakers and advocates to put aside partisan differences to overcome this crisis.

The congresswomen used her keynote speech to stress the importance of quality care. Black moms face significant disparities at all stages of pregnancy, Rep. Adams explained, from prenatal care to after delivery. Black maternal mortality and morbidity are significantly higher in the United States than other developed countries, the congresswoman pointed out. She also described how families have lost too many Black moms to medical mistakes during or after childbirth.

**“Black women are three times more likely to die of pregnancy-related causes than white women are.”**

To address the challenges that Black women face, Rep. Adams introduced the Black Maternal Health Momnibus Act of

2021, a bipartisan bill aiming to invest in social determinants of health that influence maternal health outcomes. It would also invest in federal programs that address the pregnancy-associated risks of COVID-19.

“We have the policy solutions to this crisis, so there is no excuse for inaction,” the congresswoman said. She requested that policymakers diversify the prenatal workforce and improve data collection.

The congresswoman envisions the creation of a taskforce that works to close the care gap that Black moms face, identifying federal resources to support new mothers among other tactics. She explained that some mothers haven't enjoyed normal prenatal care or moral support from family and friends since the pandemic started.

Rep. Adams urged advocates to speak out against these injustices and push members of Congress to act. “The Black maternal health crisis is preventable,” she reminded summit attendees, noting that, with the right policies, the United States can improve the state of Black maternal health.

# Finding Solutions to the Black Maternal Health Crisis

This year's summit took a deeper look into the root causes of the Black maternal health crisis to identify effective solutions.



## Valencia Walker, MD, MPH

*Nationwide Children's Hospital*

Dr. Walker stressed the Black maternal health crisis is worsened by Black moms' suffering the ongoing effects of racism.

**“It is important to understand that whatever affects the pregnant woman also affects the baby.”**

Health implications to the baby are exacerbated when Black moms suffer from subpar maternal health care, in addition to the stress placed on the mother while dealing with the impacts of racism in everyday life.

“As a clinician, I want them to have the best possible care,” Dr. Walker stated. Fellow providers can fill these gaps in care by partnering with maternal health advocacy groups, reviewing their internal biases and examining the impacts of all social determinants on every mother's health.



## Kanika Harris, PhD, MPH

*Black Women's Health Imperative*

Dr. Harris shared her story as a mom who lost twins at 32 weeks and experienced postpartum depression. Her struggles gave her firsthand insight into the immense difficulties Black mothers face. The way Black women are treated by the maternal health care system may vary, from receiving disrespectful care to clinical inertia to being implicitly blamed for being high risk.

The impacts of racism influence Black mothers' everyday lives. “Either you're succumbing to racism or you're trying to overcome it,” Dr. Harris emphasized. Being at a clinic or hospital doesn't change that fact of life. Policies that support Black mothers, such as trainings that help providers eliminate the harm caused by bias and structural changes in hospitals, are needed to resolve the crisis.



# Redefining the Essential Care Team for Babies



## Michael Hynan, PhD

*Retired Clinical Psychologist*

Dr. Hynan described his experience as a parent whose child was admitted to the NICU. His son's birth significantly altered the direction of his research, and he began studying post-traumatic stress disorder in the parents of NICU babies.

**“ Trauma is real and can have long-lasting effects. ”**

There are avenues to mitigate families' distress, however. Including mental health professionals in the NICU is an important first step, Dr. Hynan emphasized. The main focus of any approach to infant health should be focusing on the family's health, rather than simply placing the baby in isolation. Parents play an integral role as members of that baby's care team, and NICUs should recalibrate with that in mind.



## **Wakako Minamoto Eklund, DNP**

*Council of International Neonatal Nurses*

Wakako Minamoto Eklund discussed the pandemic practice of separating babies from COVID-positive mothers and imposing restrictions on contact with family. It became normal, and thereby comfortable, for many health care professionals to keep parents and the babies separated. In Europe and the United States, however, many hospitals are working to eliminate that separation.

**“ Parents should be defined as essential caregivers. ”**

She also spoke in favor of letting parents be with their children in the NICU and other health care settings.

Language and cultural barriers also present a challenge in the United States, Eklund explained. Nurses and hospital staff may speak to families less if there is not a shared language or if parents are not fluent. The lack of communication can worsen social isolation that many families already experience. She suggested that translators who encourage families, in addition to providing both medical updates, can help bridge this divide.



## **Nicole Nyberg, MSN**

*Novant Healthcare*

Nicole Nyberg described how the hospital protocols established during the pandemic have created a space where providers now expect parents to be less present. But separation can have lasting effects for families, she explained. Babies lose out on early skin-to-skin contact and initial bonding experiences with their parents, which can impact their development.

Parents should be allowed into the NICU and other hospital spaces, Nyberg made clear. “They will do skin-to-skin care. They will begin to bond, which we know positively affects the neurodevelopmental outcomes of the baby and the family unit as a whole,” Nyberg explained.

# The State of RSV Prevention

**Joseph Domachowske, MD**  
*SUNY Upstate Medical University*



Joseph Domachowske, MD, spoke on the impact of respiratory syncytial virus and what is being done to combat the virus' burden.

RSV is the leading cause of hospitalizations for infants under the age of one in the United States. Despite the virus' devastating impact, RSV and its burden aren't well known outside of the health care community. And, as Dr. Domachowske explained, there have been no new treatment options since 1998. The drug introduced then, palivizumab, has become more difficult for babies to access in recent years.

Preventing RSV continues to be a challenge. Maternal immunity can provide some protection but having RSV once does not significantly protect against contracting it again. For now, parents should take commonsense precautions, such as regular handwashing and frequent cleaning of surfaces and toys, to protect infants from RSV.

Monoclonal antibodies may be the solution health care providers and advocates have been searching for, Dr. Domachowske explained. This technology is being developed to create a preventive intervention that would provide infants and young children with viable protection from RSV.

Including these monoclonal antibodies in the Vaccines for Children program would ensure that all children can access this critical intervention.

***“ We have the potential to change the landscape of RSV. ”***

He encouraged summit attendees to advocate for monoclonal antibodies when approved to be broadly accessible.

# The Direct & Indirect Impact of RSV

**U.S. Rep. Bruce Westerman**  
*Member of Congress*



U.S. Rep. Westerman outlined the multifaceted impact of RSV, sharing his own family’s experience with the virus.

When Rep. Westerman’s one-month-old son became ill and had to be hospitalized, the experience shook his entire family. While at the hospital and relying on health care providers to care for his ill son, the congressman felt “anxious and helpless,” he recalled.

**“ Money becomes secondary when your child’s life is on the line. ”**

Rep. Westerman also remarked on the financial burden of RSV for many families. The drug used to treat his son while hospitalized was not covered by insurance, forcing his family to pay out of pocket.

Rep. Westerman also acknowledged that not all families could afford to pay for medications out of pocket.

One way policymakers can address the burden of RSV is through continued research, Rep. Westerman highlighted. He explained that the diseases that receive the most funding are those that appear in the public eye.

Though RSV is common, Rep. Westerman observed, it does not receive much media attention.

The congressman noted that federal funding for disease research and development of an RSV treatment would be important moving forward.

# Ensuring Donor Human Milk Quality & Safety



## Liesl Sheehan

*Prolacta Bioscience*

Liesl Sheehan highlighted the importance of donor human milk, which provides valuable nutrition for infants.

Though donor milk is a source of infant nutrition, it does not receive the same level of scrutiny from the Food and Drug Administration as infant formula does. Sheehan explained that there are multiple risks with donor milk, including the cleanliness of the breast pump, the health and habits of the donor mother, and the normal risks of bacteria developing through the pasteurization process.

In addition to introducing safety concerns, a lack of oversight can also make it more difficult for infants to access donor milk because Medicaid won't cover the expense. "We need the right level of scrutiny to increase access," Sheehan explained.



## Sandra Sullivan, MD

*University of Florida*

Fragile infants and babies in the NICU are often the recipients of donor milk, and any contaminants could worsen their condition.

***“ The bar for safety should be set for those extremely fragile tiny humans. Everyone else is safer by default. ”***

Without proper FDA oversight, milk banks and hospitals are left to establish their own safety standards, Dr. Sullivan argued. This can lead to a patchwork of rules that introduce the possibility of gaps in quality. Regulations, Dr. Sullivan summarized, must strike a balance that enables access while also protecting babies' health.



# Drug, Formula & Product Shortages Impacting Infants & Children



## Suzanne Staebler, DNP

*Emory University*

Suzanne Staebler talked about how shortages – from nursing to medications to supplies – impact care in medical settings like the NICU.

Even when there is a shortage, patients must still be treated, Staebler emphasized. It is up to providers to find a way.

***“ We have to work creatively and collectively to figure out how to not compromise care, but to get what we need for the patient even if we are in short supply of something. ”***

Staebler also applauded the work of many physicians and nurses who regularly find a workaround. Policymakers have an important role to play as well, she highlighted, in curbing the impacts of shortages.



## **CAPT Valerie Jensen, USPHS (Ret.)**

*U.S. Food and Drug Administration*

Capt. Jensen focused on the events that lead to drug shortages. “The root cause of shortages really deals with quality, whether that be the quality of the manufacturing site or the quality of the product,” she explained.

The pandemic had a unique impact on shortages, Jensen noted, describing how the high demand for vaccines undercut the production or availability of other life-saving drugs. Jensen suggested that risk mitigation plans may be a valuable option to help curb the effects of shortages.



## **Susan Mayne, PhD**

*U.S. Food and Drug Administration*

Dr. Mayne discussed the Food and Drug Administration’s actions to address infant health-related shortages.

To combat the highly publicized shortages of infant formula, the FDA worked closely with manufacturers at home and abroad to ensure families have access to nutrition for their babies.

**“ The FDA works with manufacturers to ensure that stringent safety and nutrition standards are implemented and carried out. ”**

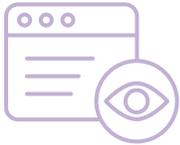
Along with providing the public with educational information about the formula shortages, Dr. Mayne noted, the FDA encouraged the diversification of formula manufacturers to prevent future shortages.

# Audience Overview



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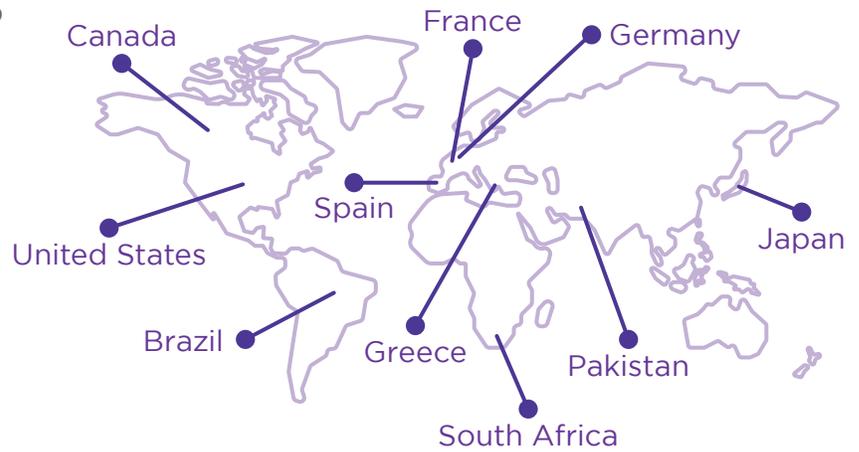
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## ATTENDEE BREAKDOWN



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



Alliance for  
Patient Access



Institute for  
Patient Access