

VIRTUAL

— 2020 —



# 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:

- Late preterm infants
- Respiratory syncytial virus and COVID-19
- Isolation and disruption during COVID-19
- Vaccines
- Disparities in infant health
- Congenital gut disorders
- Human milk.

Julian Nixon, a NICU dad and director of Diversity & Inclusion Student Services at Clemson University, offered welcoming remarks. "We may be scattered across the country, and we may be virtual," Nixon noted, "but, with this group, we are hardly alone." Nixon described the event's attendees as standing "shoulder-to-shoulder on policies that make every family's journey and every child's health a priority."

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.



**Julian Nixon**

*"We may be virtual, but we are hardly alone."*

# Keynote Address

**U.S. Rep. Kim Schrier, MD**

*Member of Congress*



With the sustained risk of COVID-19 combining this fall with other seasonal viruses like the flu, vaccines are as important as ever for infants and their families. U.S. Rep. Kim Schrier, MD, a pediatrician and author of the [VACCINES Act](#), used her keynote address to emphasize the need for childhood immunization.

Rep. Schrier expressed concerns about the growth of anti-vaccination sentiment online, noting that [30%](#) of Americans have said they would not get the COVID-19 vaccine even if it were free of charge. She urged policymakers and advocates to help build trust in science and data.

Rep. Schrier's comments are timely. During the COVID-19 pandemic, many children have missed their well-child exams and gotten off of the standard immunization schedule for infectious diseases like measles, mumps and polio. Rep. Schrier said schools must insist that children's vaccines are up to date, even if school is online.

***“None of us want to go back to a time with meningitis, pertussis or measles.”***

She emphasized the many ways patients can safely receive care during COVID-19. Rep. Schrier reiterated that hospitals are safe, and described how some pediatricians have set up tents or offered drive-by vaccination clinics to help keep children and communities healthy. For patients who might not want to travel, Rep. Schrier noted, telehealth allows them to see health care providers remotely.

Rep. Schrier, who takes pride in being the only woman doctor in Congress, reinforced that scientific, evidence-based messaging from medical professionals is crucial for changing the public's perception on vaccinations.



# Late Preterm Infants



## **Susan Hepworth**

*National Coalition for Infant Health*

When people think of preterm infants, they often think of tiny and fragile babies. That is not always the case, explained Susan Hepworth of the National Coalition for Infant Health. Hepworth noted that late preterm infants, those born between 34-36 weeks, might appear to be in good health even if underlying health challenges tell a different story.



## **Erin Sundseth Ross, PhD**

*University of Colorado School of Medicine*

Erin Sundseth Ross, PhD, explained that preemies have an underdeveloped neurological system, which can affect their muscle tone, sleeping, ability to stay awake and eating. About 40% of late preterm infants will struggle with feeding problems, as will up to 60% of babies born at 34 weeks.



## **Viveka Prakash-Zawisza, MD**

*National Perinatal Association*

New mothers can face an enormous amount of stress when their babies won't eat. Viveka Prakash-Zawisza, MD, said that educating families on the risks and complications of having a late preterm baby could help, as could standardizing care for this special group of infants. "Care can vary from hospital to hospital because this population of babies has not been very well understood," said Dr. Prakash-Zawisza.

Feeding disorders have often been overlooked or dismissed but, starting next year, a standalone diagnosis from the Centers for Disease Control and Prevention will help allow them to be properly diagnosed.

# Isolation and Disruptions Due to COVID-19

COVID-19 has made it difficult for infants and their families to receive care.



## **Mitchell Goldstein, MD**

*National Coalition for Infant Health*

Mitchell Goldstein, MD, said infants' families are constantly in a state of confusion because hospital and NICU rules can change frequently. Dr. Goldstein noted that NICU visitation restrictions can be severe, increasing stress on new parents. Should one parent be COVID-positive, the entire family might be barred from visiting their hospitalized infant altogether.



## **Rebecca L. Cypher, MSN**

*Association of Women's Health, Obstetric and Neonatal Nurses*

Rebecca L. Cypher, MSN, echoed concerns about gaps in vaccination, especially during the COVID-19 pandemic, noting that the problem is global. She shared that, "The likelihood that a child born today would be fully vaccinated by the age of five is less than 20%."



## **Christine Tester**

*Hand to Hold*

Christine Tester stressed the importance of infant well-checks to make sure children stay healthy. She also emphasized the need for mother well-checks. Tester said, "New mothers cannot be taking care of a newborn if they are not able to perform the most basic levels of self-care."

Tester concluded by explaining, "If anything good has come out of this, I think it's the fact that the mental health conversation has been brought to the forefront...not just in the NICU setting, but overall."

# RSV & COVID-19: Double Trouble

As COVID-19 continues to run its course, a panel explored the overlapping threats of COVID-19 and respiratory syncytial virus, or RSV.



## **Suzanne Staebler, DNP**

*National Coalition for Infant Health*

Like the coronavirus, RSV symptoms start off much like a common cold: runny nose, fever, nasal congestion. Most people can recover in a week or two, but RSV can increase health risks for infants, making it harder for them to breathe. Staebler explained that there is no definite link between COVID-19 and RSV, but that the infants at risk for RSV are the same patients at high risk for severe COVID-19.



## **Crystal Baker**

*Patient Advocate*

Crystal Baker remembers the frightening details of RSV all too well. She shared her son Cameron's story of RSV, when flu-like symptoms were compounded with a 60% reduction in Cameron's ability to breathe. He was rushed to the emergency room, but because of COVID-19, Baker was not allowed in the back of the ambulance with her son. The hospital also allowed only one parent to visit at a time, increasing isolation and anxiety for parents.

Scenarios like Cameron's can be avoided through the use of preventive treatment called palivizumab, but insurers often deny access to the treatment. Staebler said, "Insurers often think they are saving money... but when you have an infant who is hospitalized, sent to a doctor's office and had a NICU stay, those all increase the risk and cost." Staebler encouraged policymakers to improve access to preventive RSV treatment.



## **Amanda Conschafter**

*Alliance for Patient Access*

Panel moderator Amanda Conschafter outlined [data](#) from the Institute for Patient Access highlighting how frequently preemies are denied insurance coverage for preventive RSV treatment, despite the virus' threat to infants with fragile immune systems and underdeveloped lungs.

# Health Disparities

Another panel discussion explored reducing health disparities for Black infants and their families by embracing patient-centered care.



## **Michal A. Young, MD**

*Howard University College of Medicine*

Michal A. Young, MD, urged health care providers to “listen to your patients.” Women in general are dismissed more frequently by medical professionals, Dr. Young explained. She also noted that hospitals and their NICUs must meet families where they are.

One important step can be staffing the hospital with diverse health care providers. Dr. Young referenced a recent [report](#) that Black babies are three times more likely to die if their health care provider is white. Dr. Young said, “This is an opportunity for the greater community to understand the kinds of...bias that costs us our health and our lives.”



## **Jenné Johns, MPH**

*Once Upon a Premie Academy*

Jenné Johns, MPH, shared her personal experience with racial bias when she was in the NICU with her son. She said her biggest advice for providers is to continue to actively participate in racial disparities courses and conversations.

Johns encouraged fellow parents, “Talk about what you’re experiencing mentally and emotionally and unpack how those stressors may be impacting you, because at the end of the day, especially as premie parents, our babies need us.”



## **Ashley Randolph-Cooley**

*Alliance for Black NICU Families*

Ashley Randolph-Cooley described her new organization’s goal of combatting racial health disparities by listening to the voices of the families who have been the most impacted. The organization’s goal is to support and empower families in the NICU. Members are predominantly Black parents of premature NICU infants who have experienced racial inequity.

# Congenital Gut Disorders & Human Milk

Congenital gut disorders are rare birth defects that usually result in intestinal obstruction. That obstruction can cause a multitude of problems, including feeding challenges.



## **Katie Trudo**

*NICU Parent*

The challenges of congenital gut disorders are familiar to Katie Trudo, a NICU parent who learned at a 20-week ultrasound that her son Camden had a congenital gut disorder. Fortunately, Camden recovered after 16 days in the NICU. Other families who have an infant with a congenital gut disorder can spend an average of four-six weeks in the NICU.



## **Heidi E. Karpen, MD**

*Emory University/Children's Healthcare of Atlanta*

Panelists explored the benefits of human milk - "medicine, not just nutrition." Human milk can have particular nutritional value for infants with congenital gut disorders.

As Heidi E. Karpen, MD, noted, infants who were fed mostly breastmilk left the hospital 10-20 days sooner than infants who were not. This makes a huge difference for families wanting to take their child home. It can also help contain medical costs. The infants who consumed breast milk also had a decreased risk of infections.

Gut disorders often require multiple medical procedures, which can be especially challenging for newborns, explained Dr. Karpen.





## Martin L. Lee, PhD

*Prolacta Bioscience*

Martin L. Lee, PhD, emphasized the value of human milk for babies with gut disorders. “Human milk is the best medicine and the best nutrition for babies born premature, and of course, for babies born at term.” Whether through breastfeeding or with the help of donor human milk, Dr. Lee emphasized, “it’s incumbent upon us to make sure that every baby gets fed in the best way possible.”

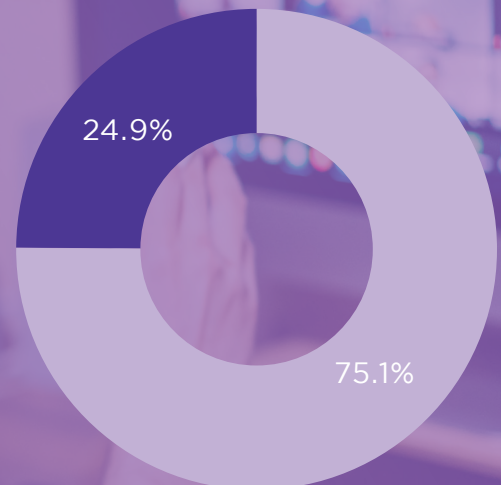
To learn more about topics discussed at the summit and the National Coalition for Infant Health’s policy priorities and advocacy initiatives, visit [www.infanthealth.org](http://www.infanthealth.org)

# Audience Overview



**TOTAL ATTENDEES**  
**416**

## COUNTRY BREAKDOWN



● Returning Visitors  
● New Visitors

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

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*IfPA* | Institute for  
Patient Access

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*AfPA* | Alliance for  
Patient Access