



— 2019 —

Infant Health

Policy Summit





OVERVIEW

The fifth annual Infant Health Policy Summit welcomed health care providers, parents, regulators, advocates and other stakeholders to explore how policy solutions can keep infants and their families safe and healthy.

Held in Washington, DC, the event examined issues such as:

- Medical innovation for neonates
- Vaccine hesitancy and outbreaks of preventable diseases
- Respiratory health
- Disparities in the NICU
- Breastfeeding and human milk
- Maternal nutrition
- Tubing safety in the NICU.

Suzanne Staebler, DNP, policy advisor to the *National Coalition for Infant Health* offered welcoming remarks, noting to the crowd that, “We won’t shy away from tough issues and honest policy debate here. Because what’s at stake is too important.”

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

“

We can change the policies that shape these infants’ lives.

”

**-SUZANNE
STAEBLER,
DNP**



BREASTFEEDING & HUMAN MILK



Describing the value of human milk as a “cornerstone issue” for the *National Coalition for Infant Health*, Medical Director **Mitchell Goldstein, MD**, moderated a discussion of how breast milk

benefits the human microbiome.



of necrotizing enterocolitis, explained **Victoria Niklas, MD**, of *Prolacta Bioscience*.

The benefits aren’t always known to parents, however. Bethel-Jaiteh noted that rates of breastfeeding lag

among black families in particular.



Human milk doesn’t just promote “good” gut bacteria but can reduce the risk of lower respiratory infections by 50%, explained **Cynethia Bethel-Jaiteh, DNP**, of the *University of Louisville*

School of Nursing, and lower the risk of GI infections by 59%. It can also reduce the risk



Meanwhile, **Deb Discenza** of *PremieWorld* recalled her own challenges pumping breast milk for her premature daughter, born at 30 weeks gestation, while the hospital intended to give her daughter

formula. She urged parents to speak out about their preferences for their babies’ nutrition.

INNOVATION FOR NEONATES

Getting infants and their families what they need also requires effective public policies. In an interview with **Amy Akers** of the *National Perinatal Association*, the *Food and Drug Administration's Susan McCune, MD*, described the strides that research and regulatory policy have made for neonates. She noted that safety efforts have come a long way, describing morphine-laced “syrup” promoted in the early 1900s for babies with colic or teething pains.

Legislative policies are increasingly designed to promote the development of drugs specifically tested and designed for infants, Dr. McCune explained. She noted the impact of bills like the “Best Pharmaceuticals for Children Act” in 2002, which incentivizes the development of drugs for infants.

But the process is rife with challenges. Only about 40% of studies of pediatric drugs are successful, Dr. McCune noted. She emphasized the role of partnership, encouraging nonprofits and other stakeholders to join alongside regulators and researchers to improve options for treating infants.



TUBING SAFETY & MATERNAL NUTRITION



Infant health, safety and parent education also came to light in updates provided by *National Coalition for Infant Health* Executive Director **Susan Hepworth**.

On the topic of **tubing and connector systems** used in NICUs, Hepworth alluded to hospitals being pressured to incorporate a tubing connector system known as ENFit, which can present **safety challenges** for infants. Hepworth emphasized the importance of thoughtful consideration by hospital systems and NICUs, which should make decisions based on what’s best for their patients. “When patient safety is on the line,” Hepworth emphasized, “hospitals and health care providers need to be fully informed before converting to any new tubing systems.”

Hepworth also addressed new guidelines on pregnant mothers and **fish consumption**. Recently **revised FDA advice** could, Hepworth noted, “help pregnant women confidently add more seafood to their diet, with the goal to have pregnant women eat, on average, as much as six times more seafood than they currently do.” In past years, conflicting messages have led to confusion and left pregnant and breastfeeding women missing out on the benefits that fish offers their developing babies.



RESPIRATORY CARE

Respiratory care is one area where continued policy progress is needed. In a conversation with **Ashley Darcy Mahoney, PhD**, of *The George Washington University School of Nursing*, **Donald Null, MD**, of *UC Davis Children's Hospital* described the improvement he's seen during the course of his career. It can take "a long time" for advances to make their way through, Dr. Null noted, and even then, policy often lags behind.

Erin Thatcher of the *PPROM Foundation* knows that all too well. The mother of fraternal twins born prematurely, Thatcher described the impact of respiratory syncytial virus on her daughter, now 7, who still battles asthma-like symptoms from the disease. The effects of RSV "can last for years," Dr. Null explained.

The panel spoke about American Academy of Pediatrics [guidelines](#) from 2014, which had the

effect of reducing the number of infants who receive RSV prophylaxis. Of those guidelines, Thatcher noted, "I wish they'd look at long-term outcomes...the policies are not taking into account what's happening to families."





KEYNOTE ADDRESS

Keynote speaker and *CNN* anchor **Alisyn Camerota** told her own story of prematurity, NICU care and motherhood, highlighting many of the day's themes.

Camerota recalled how a routine prenatal check-up at 30 weeks turned life changing when her doctor announced that she'd need to deliver her twin daughters within 48 hours. A rare condition was preventing one baby from receiving sufficient nutrition through the umbilical cord.

As Camerota explained, this was just one of the challenges she faced. Before her pregnancy, Camerota had struggled with infertility. After her daughters were both safely delivered and in the NICU, she faced breastfeeding challenges.

Camerota described attempting to pump breastmilk for days with no results. When she told her doctor she was ready to give up, he advised, "Give it one more day." The next day, Camerota recalled, she produced her first drops of milk.

Camerota highlighted the importance of perseverance for parents of preemies and hailed NICU staff as "angels on Earth."





VACCINE HESITANCY

As legislative efforts to curb preventable disease outbreaks unfolded in real time, the Infant Health Policy Summit took up the issue during a panel discussion entitled “Vaccine Hesitancy.” **Daniel Salmon, PhD**, of *Johns Hopkins University School of Medicine* and **Mary Koslap-Petraco, DNP**, of *Stony Brook University School of Nursing* debunked widespread myths that have led to a rise in vaccine exemptions – and fueled outbreaks of preventable diseases. Topics included **autism links**, government overreach and misinformation about vaccine ingredients.

Confusion on these and other ideas have led to a rise in vaccine hesitancy among parents – and resulted in new laws in both California and New York to reduce vaccine exemptions that aren’t medically justified.

Both Salmon and Koslap-Petraco emphasized the importance of empathizing with parents who are concerned about vaccines. They also described the value of telling stories about immunizing their own children.

“I say, ‘I have six children,’” Salmon explained of his conversations with parents, **“They’re all vaccinated according to the schedule because that’s the best way to protect my children.”**

Salmon and Koslap-Petraco also noted the importance of educating parents about the potential impact of vaccine-preventable diseases like measles, rubella and hepatitis B.



NICU DISPARITIES

Good communication with parents of young children was also a central theme in a panel discussion about how to build patient-centered NICUs.

DeShay Rice-Clansy, MSW, of Atlanta's *Grady Health System* and **Brigit M. Carter, PhD, RN**, of *Duke University School of Nursing* described how the different demographics being served by NICUs can present strikingly different needs. One mother delivering her baby at Grady Hospital, Rice-Clansy recalled, had only a second-grade education.

Other families faced challenges as stark as homelessness, mental health issues, substance abuse and sex trafficking.

These hospitals and their NICUs must meet families where they are, explained **Suzanne Staebler, DNP**, of *Emory University*. That includes staffing the hospital with diverse health care providers. But that's not always easy. As Bridget Carter, PhD, of Duke University School of Nursing explained, the rate of diverse providers is "phenomenally low."

The National Coalition for Infant Health sponsored a diaper drive in conjunction with the summit, collecting more than 2,000 diapers for the Greater DC Diaper Bank. Learn more about the National Coalition for Infant Health's policy priorities and advocacy initiatives online at www.infanthealth.org.



NCFIH National Coalition
for Infant Health

Protecting Access for Premature Infants through Age Two

www.infanthealth.org



Institute for
Patient Access



Alliance for
Patient Access