## 2020 Infant Health Steering Committee Meeting Held Virtually

Mitchell Goldstein, M.D., Susan Hepworth



The National Coalition for Infant Health is a collaborative of more than 180 professional, clinical, community health, and family support organizations focused on improving the lives of premature infants through age two and their families. NCflH's mission is to promote lifelong clinical, health, education, and supportive services needed by premature infants and their families. NCflH prioritizes safety of this vulnerable population and access to approved therapies.

On July 23, 2020, the National Coalition for Infant Health held its 2020 steering committee meeting. Originally scheduled as an onsite event to coincide with the Pediatric Academic Society meeting in San Diego, difficulties secondary to the COVID 19 pandemic

forced rescheduling the steering committee meeting as a "Zoom" conference call.

The National Coalition for Infant Health (NCflH) is a multidisciplinary coalition of over 200 organizations within the Neonatal, Pediatric, and Perinatal fields focusing on protecting access for

"Join health care providers, parents, regulators, policy makers and advocates for the 2020 Infant Health Policy Summit on September 10. This year's summit will be held virtually because, in spite of the current public health situation, we must continue the important dialogue about issues facing the infant health community and their families."



Infants through age two.

## The National Coalition for Infant Health Advocates for:

- 1. Access to an exclusive human milk diet for premature infants
- 2. Increased emotional support resources for parents and caregivers suffering from PTSD/PPD
- 3. Access to RSV preventive treatment for all premature infants as indicated on the FDA label
- 4. 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 promotes a SANE approach to the care of premature infants:

- **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.

A volunteer steering committee supports the National Coalition for Infant Health, all of whom contribute significantly to the lives of premature infants through work and parenting. Steering committee members represent national nonprofits, academic institutions, and parent organizations, and they provide leadership as well as help to mobilize partners in the field of prematurity.

Following initiation of the Zoom Webinar and "Welcome and Introductions," Susan Hepworth, Executive Director, National Coalition for Infant Health, presented the National Coalition for Infant Health 2020 Year Plan. Steering Committee Member Advocacy Updates were provided by Melinda Elliott, MD, Medical Director, Prolacta Bioscience, Cathy Jackson, Senior Director, Patient Engagement and Advocacy, Mallinckrodt Pharmaceuticals, Dana Harkin, Director of Patient Advocacy, Sobi, Inc., May Lee Tjoa, MD, Director of Medical Affairs, Momenta Pharmaceuticals, and Victoria Niklas, MD, MA, FAAP, Global Medical Unit Head- Rare Diseases Therapeutic Area, Takeda.

A discussion of the plans for the 2020 Infant Health Policy Summit Planning Session followed. Join health care providers, parents, regulators, policy makers and advocates for the 2020 Infant Health Policy Summit on September 10. This year's summit will be held virtually because, in spite of the current public health situation, we must continue the important dialogue about issues facing the infant health community and their families. Registration for the meeting can be accessed on our website (<a href="http://www.infanthealth.org/summit">http://www.infanthealth.org/summit</a>).

The meeting adjourned with a virtual group picture.

The National Coalition welcomes those interested in our activities as well as organizations interested in protecting access for premature infants through age two to visit our website <a href="www.infanthealth.">www.infanthealth.</a> org.

Disclosures: The authors do not have any relevant disclosures.

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## **National Coalition for Infant Health Values (SANE)**

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