

RARE VIEWS

Infant Health

As the Executive Director of the National Coalition for Infant Health (NCfIH), **Susan Hepworth** is focused on improving the lives of infants and their families through education and advocacy.

NCfIH educates and advocates on behalf of premature infants from birth to age two and provides a variety of advocacy and awareness tools for families and healthcare professionals.



Q. Tell us about the National Coalition for Infant Health (NCfIH).

A. The National Coalition for Infant Health is coalition of more than 300 professional, clinical, community health and family support organizations that advocate for patient-centered care for infants and their families. The coalition envisions safe, healthy infants whose families can access the information, care and treatment their babies need.

Q. Safety in the NICU has been one of your focus areas. What does safety in the NICU mean?

A. Infants – especially those born preterm – are vulnerable. This means that access to the best care in the NICU is critical. Infants are not tiny adults and the healthcare system should not treat them as such. Infants need health care that is tailored to their specific age, weight and condition.

Q. What do you think are the greatest needs in this area and some potential solutions?

A. One of the greatest needs is more research and innovation for new devices and therapeutics developed specifically for this vulnerable population. This will ensure optimal care for infants and reduce risks that can be created by trying to tailor adult devices and medications for these tiny babies. Policymakers can help play a role in incentivizing companies, through a patent extension, for example, to focus their research and innovation on the neonatal population.

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Q. Are there any formalized safety standards or evaluations that specifically assess or rate NICUs?

A. For neonatal intensive care, there is a formal designation process that some states utilize/mandate. It requires units to be surveyed by an outside team of experts to ensure the care they are providing meets the standards of the level designation (Level II, III, or IV) and that there is a robust Quality Assurance and Performance Improvement (QAPI) process in place to ensure the best outcomes for babies.

Q. What are some steps that parents/caregivers can take to feel empowered to be an advocate for their child in the NICU as it relates to safety?

A. Communicating with your child's care team is an important part of being an advocate. Parents and caregivers should never be afraid to ask questions – the more informed you are the better advocate you'll be. The coalition offers resources for parents and providers that can help families navigating a NICU journey. There are also numerous NICU support organizations that are critical to helping families.

Q. What other issues is your organization working on?

A. A few of the coalition's other priorities include access to optimal nutrition, support for the screening, diagnosis and treatment of postpartum depression and post-traumatic stress disorder, and appropriate respiratory care. Overall, the coalition strives to ensure policies support patient-centered care.

Q. How can stakeholders get involved in advocating for optimized care and health outcomes for neonates and their families?

A. Stakeholders can join organizations like the coalition to advocate for patient-centered policies that will improve care for these vulnerable infants. Stakeholders – especially parents and caregivers – can also share their personal NICU experiences on social media to help raise awareness and ensure both the public and policymakers are aware of the challenges facing this population.

Rare Views is an ongoing spotlight series brought to you by Mallinckrodt's Patient Engagement & Advocacy Team.