

FCC TASKFORCE SPOTLIGHT



BETSY PILON
Executive Director,
Hope for HIE
Parent of Max

Meet Betsy Pilon! She serves as both an Organizational Partner with and an Executive Council Family Partner for the Family-Centered Care Taskforce.

How were you personally activated to advocate for and support NICU families?

My son Max was born in 2012 after he stopped moving at 37 weeks. He was diagnosed with Hypoxic-Ischemic Encephalopathy (HIE) with not a lot of answers and a 'wait and see' prognosis. The experience was incredibly isolating - there was no support or advocacy for HIE, the narrative was only preemies go to the NICU, and there was no educational information about the diagnosis. Upon discovering a small Facebook group of HIE families, everyone had a similar story of disconnect and this became a call to action to lend a hand to make a difference with my background in healthcare communication.

How does your organization/company/hospital support NICU families?

Hope for HIE provides comprehensive programming and support services, globally, for families experiencing neonatal or pediatric-acquired HIE, in the NICU and beyond. We have a social worker, child life specialist, and peer support leader on staff and provide accessible, first-language support and educational materials for point of diagnosis.

What are the greatest needs of families in maternal-infant health you observe through your work?

We've come a long way in the last decade, but we still have a long way to go with equity in representation in the NICU advocacy and support landscape. Babies cannot raise themselves and families need support longitudinally. QI unintentionally but systemically often excludes full-term families.

What is your greatest wish in terms of the positive impact the FCC Taskforce members can make together in maternal-infant health?

I'm hopeful that this work transforms outcomes of families and shifts the traditional model to a more equitable, effective model of care to decrease the negative impacts of acute hospitalization.

What insight or advice do you have for healthcare partners who want to implement/strengthen FCC practices in their hospital?

The FCC Taskforce webinars are a good start! FCC is for all babies! Take a look at how diversity and inclusion is more than race or socioeconomic status... look at gestational age, diagnoses, family make up, and engage families intentionally.



What does being part of the FCC Taskforce mean to you personally?

Being a part of the FCC Taskforce is a huge honor for me. The group of NICU All Stars is incredible and it excites me to know that I am part of a group that makes such a difference in NICU family support.

Healthcare partners are... awesome!

NICU & bereaved parents are... BRAVE!



Anything else you want our community to know?

HIE is often painted as 'rare' in the NICU landscape, but it's the second leading cause of infant mortality and lifelong disability worldwide with only one approved, somewhat effective intervention. We are overdue for more representation in NICU QI, research, and support.

