



Welcoming NICU Awareness Month and Transitioning Back to School

September always feels like a full-circle month for our community. NICU Awareness Month is always a bit of a wild ride for those of us who lived it — it gets former NICU parents reflecting on a lot: the ups and downs, the life we thought we'd be living, and the life that's actually unfolded.

This week, that hit close to home for me. I ran into the OB who saved my son Max's life at a school event, right as I was feeling a little overwhelmed myself as the parent of a new freshman. It was so good to see a familiar, comforting face — and to be reminded that if it weren't for her care and quick decision-making, and that of the whole NICU team, I wouldn't have had the chance to be there at all.

That's what [NICU Awareness Month](#) means to families at Hope for HIE: a chance to recognize where so many of our families' HIE journeys began, and to keep pushing on something we talk about often — naming the diagnosis clearly, and making sure full-term babies and their families aren't left out of the NICU conversation.

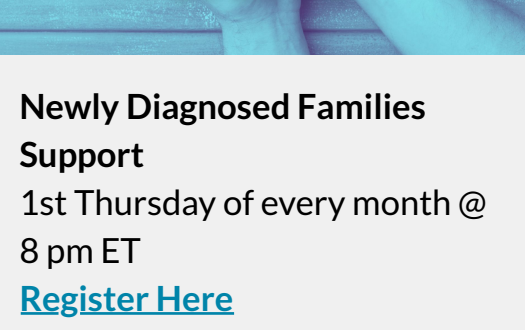
Many of our families are navigating their own layering of transitions this month, [heading back to school](#) and figuring out a new routine. Different season, same truth: you don't have to navigate either one alone.

With hope,



Betsy
Betsy Pilon
Executive Director

Support Hope for HIE



Newly Diagnosed Families Support
1st Thursday of every month @ 8 pm ET
[Register Here](#)

Loss Families Support
2nd Thursday of every month @ 8 pm ET
[Register Here](#)

Navigating HIE with Children 10+ Support
September 14 @ 8 pm ET
[Register Here](#)

Acquired HIE Support
September 16 @ 12 pm ET
[Register Here](#)

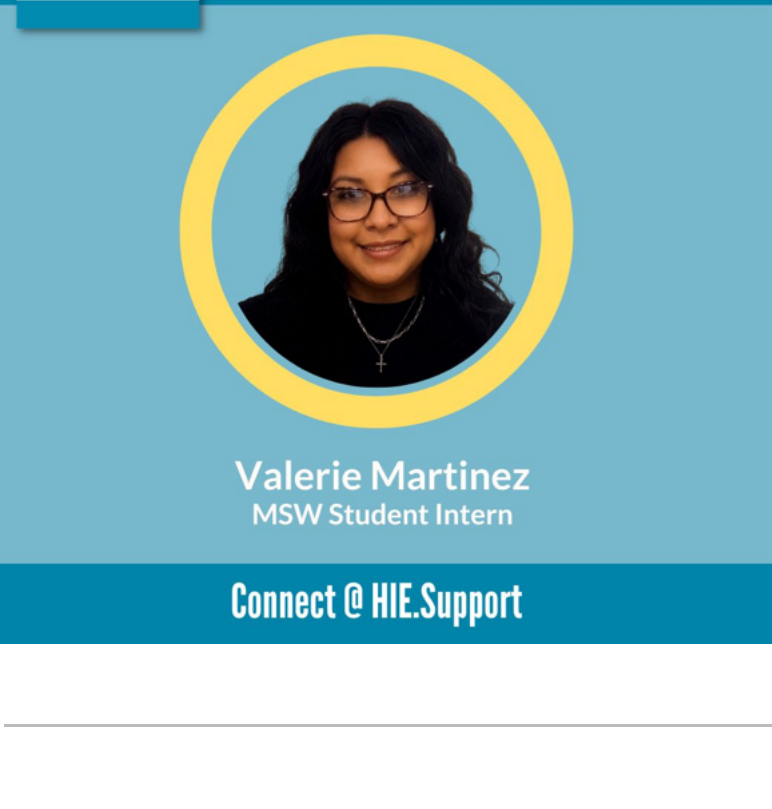
Single Parenting Support
September 21 @ 8 pm ET
[Register Here](#)

Dads & Non-Birthing Partners Support
September 23 @ 8 pm ET
[Register Here](#)

Parent-to-Parent Pop-In Hour
September 24 @ 12 pm ET
[Register Here](#)

HIE & Mild Outcomes Support
September 28 @ 8 pm ET
[Register Here](#)

See all Hope for HIE Events
Support groups, educational Q&As, retreats, and more.
[Event Calendar](#)

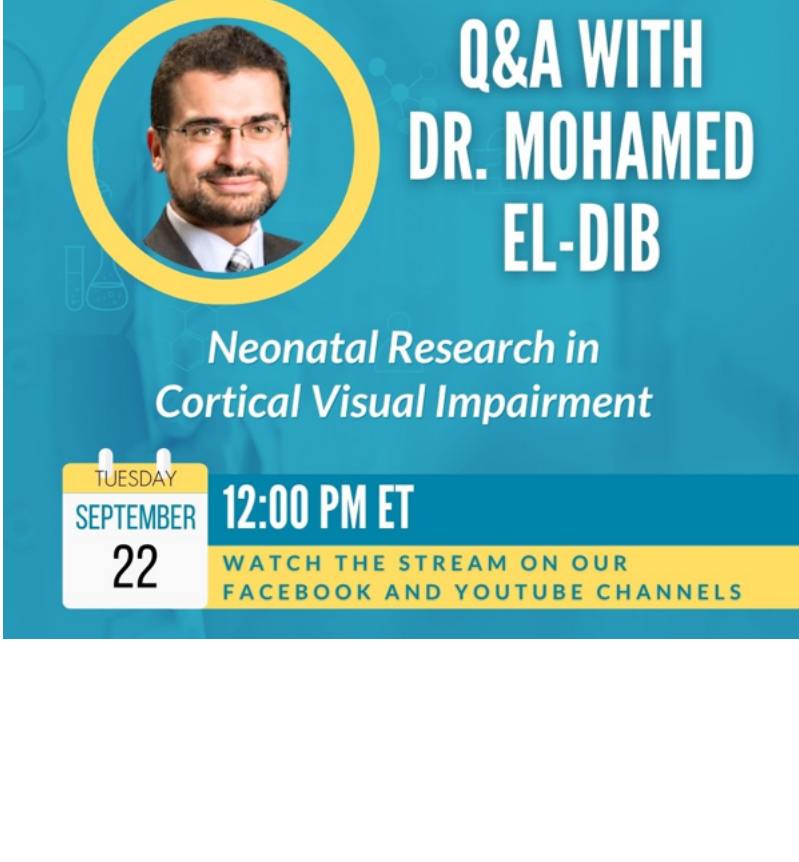


Welcoming Valerie Martinez, MSW Student Intern

Join Hope for HIE in welcoming Valerie Martinez, MSW Student Intern under the direction of Jennifer Schaefer, CAPSV.

Valerie will be with Hope for HIE for two semesters as she finishes her Master's of Social Work at the University of Kentucky and brings the valuable perspective of a NICU parent.

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Medical Advisory Board Educational Series: Neonatal Research in CVI

Hope for HIE's next Medical Advisory Board Educational Series will focus on CVI — a vision condition that develops when the brain has difficulty processing what the eyes see. CVI is particularly relevant for babies who have experienced HIE, and it's a topic many families in the community are navigating without much guidance. Dr. Mohamed El-Dib's research focuses on identifying babies at higher risk for CVI earlier in their care. He will walk through what that research is studying, what it does and doesn't tell us yet, and what early signs might prompt a family to raise vision concerns with their care team.

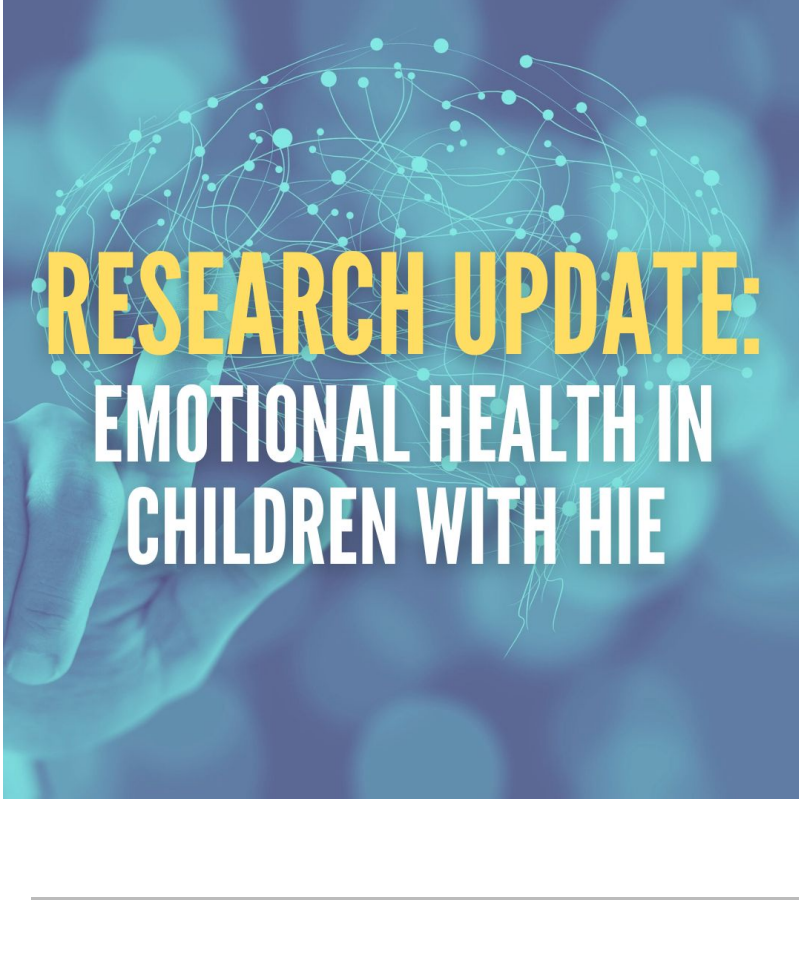
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Hope for HIE Attends the 2026 CVI Conference in Boston

September is CVI Awareness Month! Hope for HIE was proud to exhibit at [Perkins School for the Blind's](#) 2026 CVI Conference, "The Collective Power of Us," held July 19–21 in Boston. Hope for HIE's Program Coordinator, Allison Moise, attended all three days on behalf of HIE families and connected with Dr. Mohamed El-Dib, neonatologist on our Medical Advisory Board. Dr. El-Dib and his team at Brigham and Women's Hospital, in partnership with the CVI Now team at Perkins School for the Blind, are [advancing research on early detection of CVI](#).

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Emotional Health in Children with HIE: What New Research Shows

Most follow-up care after neonatal hypoxic ischemic encephalopathy (HIE) has focused on motor outcomes, like cerebral palsy, epilepsy, and on some early childhood cognitive development. A new scoping review, published July 29, 2026 in the *Journal of Perinatology*, asks a different question: what happens to a child's emotional health after HIE and are we watching closely enough for it?

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Become a Hope Maker

A gift to Hope for HIE helps families access support from the NICU through childhood, adolescence, adulthood, and bereavement. Families like Stephanie, pictured here with her son Jake at our 2026 Family & Community Conference, who have utilized Hope for HIE's resources since Jake was just a baby. Today, Stephanie gives back as a peer support mentor, helping newer families feel less alone.

Your donation gives tangible moments of hope and support for families through peer connection, social work and child life support, clinical research, advocacy, and awareness.

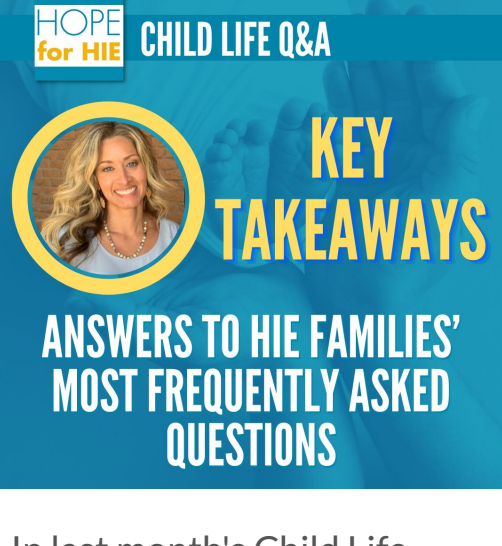
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Take Three: Awareness, Education, Support



September is **NICU Awareness Month**. The NICU is a place no parent expects to be, yet for many families in our community, it's where their journey with HIE begins. Those early days can bring uncertainty, questions, and unexpected challenges, and the experience can feel overwhelming at times. NICU Awareness Month is an opportunity to recognize these experiences, honor the resilience of families, and highlight what matters most — honesty, clear information, and the reassurance that families are not alone.

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In last month's Child Life Q&A, Annie Gunning, Certified Child Life Specialist and Grief Counselor, answered the questions we hear most often from our community, the ones that come up again and again in messages, comments, and one-on-one calls.

Explore the [key takeaways](#) and [watch the Q&A](#) at the link below.

Learn More

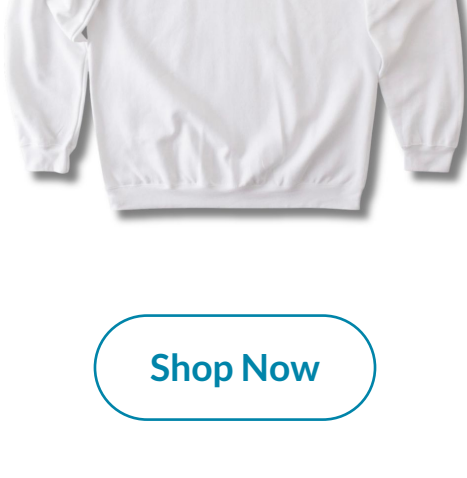


Housing comes up constantly in conversations across the HIE community; how to organize the space you already have, when to renovate, when to move, and how to plan for a future you can't fully predict.

In this Peer Perspective Series panel, three HIE parents, Motti Eisenbach, Quanteria Williams-Porche, and Sarah Bell shared what housing and home modification have looked like for their families.

Explore the [key takeaways](#) and [watch the Q&A](#) at the link below.

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