



Understanding Is Its Own Kind of Hope: October is Health Literacy Month

Entering the world of HIE requires families to learn a new language. From medical jargon, to learning about the medical system, research, advocacy, and more, it's a lot to take in and understand.

We're excited to kick off a new workgroup within our Medical Advisory Board, led by Alexa Craig, MD, our MAB chair, to more systematically focus on building health literacy for our global community, and across the neurodevelopmental timeline, as we continue to build accessible resources for families and the greater community.

Families shouldn't have to guess where to find credible information. But, in a world where misinformation is often pushed by social media algorithms, we continue to ensure our resources are evidence-based, up-to-date, and always focused on empowering families.

Next week, Hope for HIE will be well represented at the Child Neurology Society meeting, October 14-17. Dr. Danielle Barber will be presenting about her life's work in HIE research, in raising a child with HIE, advancing the basic science of neonatal brain injury, and building the HIE registry in her [Phillip Dodge award](#) presentation, and I'll be presenting in a workgroup "Advancing Research Through Storytelling and Family Partnerships".

Through accessible information and meaningful partnerships, we're helping families feel more informed, supported, and confident in the care they navigate and the future they help shape.

Most sincerely,



Betsy
Betsy Pilon
Executive Director

Support Hope for HIE



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

Navigating HIE with Children 17+
October 5 @ 8 pm ET
[Register Here](#)

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

Extended Family Support
October 14 @ 12 pm ET
[Register Here](#)

Navigating More Severe Outcomes Support
October 15 @ 8 pm ET
[Register Here](#)

Work/Life Balance Support
October 19 @ 8 pm ET
[Register Here](#)

HIE & Mild Outcomes Support
October 21 @ 12 pm ET
[Register Here](#)

Navigating Puberty (Girls) Support
October 26 @ 8 pm ET
[Register Here](#)

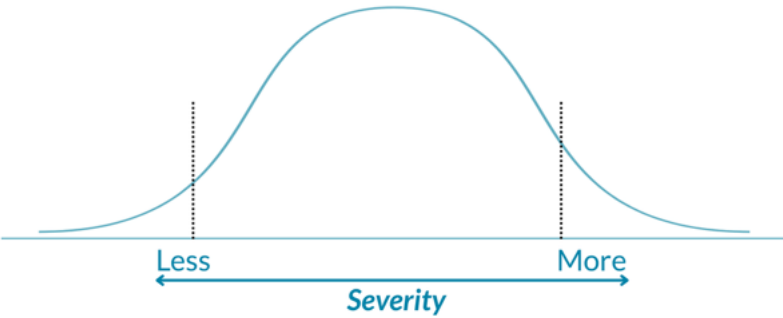
HIE Loss Within the Last Year Support
October 28 @ 12 pm ET
[Register Here](#)

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



HIE & OUTCOMES BLOG SERIES

HIE Outcomes on the Bell Curve: Understanding the Full Spectrum



HOPEforHIE

HIE Outcomes on the Bell Curve: Understanding the Full Spectrum

After an HIE diagnosis, one of the first and hardest questions families ask is what their child's outcome will be, and the honest answer is that HIE doesn't have just one. Outcomes span a broad spectrum, from no identified disability to mild, moderate, or severe disability, to the death of a baby or child, and no single test, age, or percentage can predict where an individual child will fall. This HIE & Outcomes blog series uses the bell curve to explain that full range, why development continues to unfold through childhood, and why doing well and needing support are not opposites.

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DAFs are the most powerful giving tool helping donors give bigger and better.



Learn more

HOPEforHIE

Do you have a DAF? Save the Date for October 8th!

On October 8, people everywhere are increasing the impact of their Donor-Advised Funds by giving together, and we're thrilled to be part of it. If you have a DAF, this is your chance to join a nationwide wave of generosity and support Hope for HIE.

Every grant recommended through your DAF helps HIE families around the globe connect to support.

If you have any questions about donor-advised funds or making a gift to Hope for HIE, please contact our Director of Operations, [Mary Boyle](#).

Let's show what's possible when we give together.

Donor-Advised Funds Giving

MEET THE MENTOR



HOPEforHIE MITCHELLE RAO
Peer Support Mentor

Meet Hope for HIE's Newest Peer Support Mentor

Mitchelle Rao, an HIE mom living in Nairobi, Kenya, is the newest member of Hope for HIE's Peer Support Mentor team, helping more families around the world connect with someone who understands. Mother to 4-year-old Jed, Michelle shares how motherhood reshaped her life and how finding other HIE parents and caregivers led her to want to be that person for someone else. She is now available for 1:1 peer mentorship and will help lead some of Hope for HIE's monthly support groups.

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BETSY PILON '03

LYNNE SHERWOOD WOMEN'S LEADERSHIP AWARD



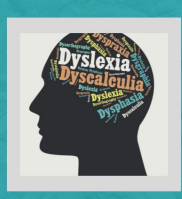
Lynne Sherwood Women's Leadership Award Winner: Betsy Pilon, Executive Director

Hope for HIE Executive Director, Betsy Pilon, was recently awarded the Lynne Sherwood Women's Leadership Award at Alma College's Golden Thistle and Tartan Award luncheon. This alumni award recognizes women whose leadership, service, and professional accomplishments have created meaningful impact in their fields and communities. Her work through Hope for HIE has brought together families, clinicians, researchers, industry leaders, and policymakers to advance education, research, patient advocacy, and systemic change.

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Take Three: Awareness, Education, Support

HIE & LEARNING DISABILITIES



HOPEforHIE

October is **Learning Disabilities Awareness Month**, a time to recognize the learning and attention differences that are common among children affected by HIE. This month, we dive into why identification often comes later, how early support and accommodations can help children thrive, and trusted resources for families navigating school and beyond.

Learn More

KEY TAKEAWAYS



NEONATAL RESEARCH IN CVI: Q&A WITH DR. MUHAMED EL-DIB

In the latest session of our Medical Advisory Board Educational Series, board member and HIE parent **Melissa Akinlawon, MA**, sat down with **Dr. Mohamed El-Dib, MD**, Director of Neonatal Neurocritical Care at Mass General Brigham for Children, to talk about Neonatal Research in CVI. He covered what CVI is, why it matters for babies with HIE, what his team's research is learning about identifying at-risk babies earlier, and what families can watch for and do right now.

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

Learn More

CHILD LIFE SERIES



KEY TAKEAWAYS

HELPING SIBLINGS THROUGH THE NICU

During September's **NICU Awareness Month**, Annie Gunning, Certified Child Life Specialist and Grief Counselor, shared a favorite book and simple, meaningful ways to help big brothers and sisters feel connected to a baby in the NICU.

Explore the [key takeaways](#) and [watch the video](#) at the link below.

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