Pediatric RESEARCH

INSIGHTS

Family reflections: hope for HIE

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Pediatric Research (2019) 86:672–673; https://doi.org/10.1038/s41390-019-0460-2

Three words—Hypoxic Ischemic Encephalopathy—entered our lives after the birth of our son Max in April 2012. HIE is a type of brain injury that 2–3 per 1000 live births in the United States experience across many causes, such as placental abruption, uterine rupture, and placental insufficiency, and more hypoxic injuries that happen in childhood due to causes like near SIDS, near drowning, and more.

Max's HIE was caused by the intermittent failure of my placenta that was discovered after he stopped moving when I was 37 weeks pregnant and went into labor and delivery. He was not prebreathing on the ultrasound, and did not have variable heart tones. He arrived via emergency c-section and was immediately intubated and quickly transferred to Henry Ford Hospital in Detroit where he received whole-body hypothermic cooling.

The first 3 days were filled with many ups and downs, heavy sedation, near loss, difficulty with ventilator settings, and the slightest touch would cause discomfort to Max, so we stared at and spoke softly to our new baby. This was definitely not the beginning of our parenthood journey we imagined. However, we had the kindest and most thorough NICU team of nurses and neonatologists guiding us through.

On day 5, we finally got to hold him, after we were told the devastating results of his MRI that showed moderate-to-severe brain damage. Words like "intellectual impairment" and "cerebral palsy" dropped out of the mouths of our neonatologist and pediatric neurologist. We were officially thrown into the world of "wait and see". Wait and see if he will feed. Wait and see if he will open his eyes. Wait and see if he will grow and thrive.

At that time, we were told there were no specific resources for families who had experienced HIE with their children. There were plenty of resources for preemies, but nothing for HIE. We asked if there was another family we could connect with, as surely someone else had experienced this. We were told there was not. After 3 weeks, Max was discharged and we attempted to settle in at home.

Facing uncertainty, we went against medical advice to "avoid Google", and did what any other person with Internet access would do, we searched online. We needed to know "would we be ok?" OK to us was defined as intact marriages, intact careers, and additional children. It was not focused on an outcome.

Fairly quickly, we found ourselves connecting to three other families who blogged about their experience and each one represented their own version of "OK". They referred us to a community gathered online in a Facebook group called Hope for HIE. At that time, there were around 200 families from all around the world, with varying causes, outcomes, ages, and stages. The peer-to-peer support and information sharing was a god send, as we started navigating this unexpected life we were thrust into with people who understood what we were potentially facing.

Max started showing visual concerns around 3 months. He was not tracking like they wanted and his eyes began to turn. He ended up with a diagnosis of delayed visual maturation and eventually alternating esotropia that he received corrective surgery for around the age of 2. Around 6 months old, he was officially behind in his gross motor milestones and by 9 months, a diagnosis of cerebral palsy was given. We began early intervention therapies and saw progress.

We went through 0–3 services, transitioned into Early Childhood Special Education services for ages 3–5, and then made the big leap into K-12. Max has had consistent outpatient physical and occupational therapy over the years, with amazing teachers, physicians, and therapists who have helped him reach his potential. The appointments have become more manageable, and we have definitely settled into our "new normal".

With so much unknown about the placenta, and no clots or obvious issues that could be prevented, we met with a maternal fetal medicine specialist who guided us through a post-HIE pregnancy that resulted in the uneventful birth via repeat c-section of our daughter, Emily, 3 years ago. I had the full support of other mothers who had gone on, despite fear and anxiety, to add to their families and did it!

At age 7, Max is a happy, healthy, hilarious child who is finishing the first grade in a general education classroom. He is a top reader in his class and school, and is succeeding in all other subject areas. He walks with orthotics and has accommodations for his visual, fine, and gross motor challenges. He plays on a baseball team with friends from school, loves superheroes, and races to see how fast he can go down any slide against his sister.

Life with HIE has been a challenge, but not impossible. In fact, because of Hope for HIE, I have been connected to some of the most incredible families I would have never met otherwise. They, and especially their children, have shown that no matter what each may face, there is joy, immense love, and HOPE in each and every story. In 2013, six of us got together for a weekend retreat as moms. We found so much healing that we got all of our families together the next year, as well as starting national and regional retreats to connect more of our community in person. This connection has helped us as parents, but also our kids, as they process how their differences fit into the world around them.

In 2013, several of us parents came together to bring the group founder's vision of a nonprofit to reality. Over the last several years, Hope for HIE has worked on the pillars of awareness, education, and support. With so little information and support previously, we wanted to serve the great need for one global source of peer-to-peer support for families, while also working with the medical and educational community to improve care and outcomes, and generate awareness for HIE.

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Received: 4 June 2019 Accepted: 4 June 2019
Published online: 14 June 2019

HIE is complicated. Because there are different causes, research is needed across a multitude of areas. For one, the sample size of research studies averages 40–50 children. Hope for HIE has grown to serve over 4600 families worldwide, and more are finding us every day. We are partnering with social workers to hand out patient referral materials, we consult on patient educational materials for hospitals, and we are taking part in a project with TREND Community, analyzing the discussions our community has had through Facebook over the last 9 years that we anticipate will identify unmet needs of our community, with the hope to drive additional research and find more therapies and treatments to help our children thrive.

Our community wants to help decrease the incidence of HIE and work with researchers to use our collective brain trust of experiences to help change the world for families whose children experience HIE. There is so much that is not known about the brain, but concepts like neuroplasticity are encouraging. While cerebral palsy and epilepsy are the most common diagnoses to come from HIE, learning and attention difficulties, autism, behavioral challenges, and more are very prevalent and yet do not get as much attention for research and discovery.

To the amazing researchers who are tackling HIE, thank you for your commitment to our children and to those who will end up in the same situation. We look forward to working together. We also appreciate any referrals to the critical peer-to-peer support we offer through our more than 65 subgroups, with many in-person chapters all around the world.