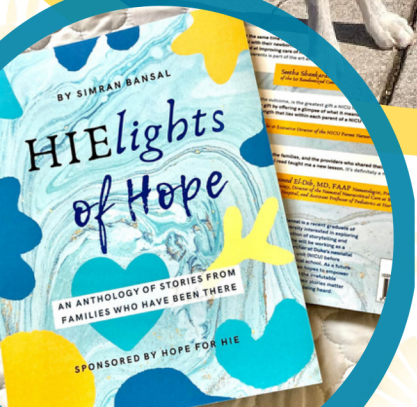


# HOPE for HIE

awareness • education • support

## IMPACT REPORT

# 2022



# A MESSAGE FROM OUR LEADERSHIP

2022 was a year filled with opportunity.

We as an organization upon getting our "feet wet" with growth in 2021, made the investment in further building out our consistency and quality of support programming in 2022.

We were able to onboard a social worker and program manager, bringing depth, quality and consistency to our support programming, and allowing us to dig deep into advocacy opportunities all year, which have led to the ability to partner in research, truly changing the trajectory of quality of life for generations to come.

The burden of HIE continues to be great on the children and families it impacts. We are taking these challenges head on, and could not do this work without your immense support.

We have so much planned for 2023 and look forward to connecting with you.

With Hope & Gratitude,

David Ford & Betsy Pilon



**David Ford**

President, Board of Directors



**Betsy Pilon**

Executive Director

# ORGANIZATIONAL PROFILE

Hope for HIE is the global nonprofit organization dedicated to improving the quality of life for children and families impacted by neonatal and pediatric-acquired Hypoxic Ischemic Encephalopathy.

HIE is a leading cause of cerebral palsy, epilepsy, learning and attention differences and disabilities, and other neurodevelopmental challenges. It has a range of causes, a spectrum of outcomes, and very few therapeutic interventions available to decrease death and disability...

...but that is beginning to change.

Through our accelerated organizational growth and development, we've been able to not only have a seat at the table to bring the unmet needs of our community forward, but create tables for discussion and action.

Our network represents families and providers from over **40 countries, across six continents**, around the world. We are able to facilitate projects and conversations with researchers and clinicians that other groups are not, due to our unique approach and lens as a patient and family support and advocacy organization.

## Through our initiatives, we've been able to:

- Connect more than **8,000 families** to research-backed peer-to-peer support, host online and in-person connections, and distribute over 2,000 care packages to newly diagnosed families and loss families.
- Advocate for improved care, communication and connection for impacted children and families, reducing barriers and gaps.
- Develop comprehensive, accessible, and vetted educational information, addressing health information literacy gaps.

Our work is only made possible by the generous support of our community, our Partners in Hope, community giving, and you.



Platinum  
Transparency  
2022

Candid.



Hope for HIE is committed to the highest integrity for financial and organizational accountability and reporting.

IRS EIN: 46-4038344

[Latest 990 filing](#)

# 2022 WORLDWIDE IMPACT



Connecting families, researchers and clinicians, worldwide,  
since 2010 - connecting 8,000+ today!



## 2022 WORLDWIDE IMPACT BY THE NUMBERS:

HIE impacts **2-3 per 1,000 live births** in developed countries, and even more in low and middle income countries. It is the **second leading cause** of infant mortality.

Hope for HIE grew in 2022 to connect over **8,000 families, researchers and clinicians worldwide** from over 40 countries on six continents through our comprehensive support network, Medical Advisory Board and outreach.

Connected to **over 350 NICUs**, distributing educational materials translated into **seven** different languages.

Over **25,000 individuals** viewed Hope for HIE educational videos.

Over **200,000 individuals** from all over the world accessed Hope for HIE's website.

Over **2,000,000 impressions** were generated from HIE Awareness Month in April, worldwide.

# SUPPORT

## THE PEOPLE BEHIND THE ORGANIZATION IN 2022

### STAFF



**Betsy Pilon**  
Executive Director



**Vanessa Zinke, LCSW**  
Social Worker



**Deanna Bryan**  
Program Manager



**Simran Bansal**  
Program Assistant

### BOARD OF DIRECTORS



**David Ford**  
President



**Becky Detlef**  
Secretary &  
Loss Coordinator



**Matt Kegyes**  
Treasurer



**Crystal Kostick**  
Director



**Amy Cutler**  
Director &  
Medical Advisory Board  
Co-Chair

## PEER SUPPORT MENTORS



Jenifer A.



Taylor R.



Kat S.



Lynn G.



Megan C.



Shawn P.



Jessica C.



Nicole C.



Khadijah H.



Allison M.



Suzi B.



Hope R.



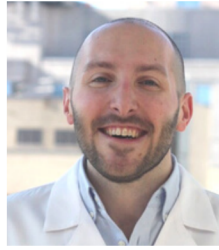
Brady C.

Our Peer Support Mentor program brings trauma-trained members of our community to serve as mentors for those either new to HIE or new to HIE loss. These mentors are available for 1:1 mentorship, and also connect in our 24/7 Facebook-based support groups.

Under the direction of Vanessa Zinke, LCSW, Hope for HIE's social worker, the program launched officially in April 2022, with aims to expand the types of experiences to support in the future.

# MEDICAL ADVISORY BOARD

## NEONATOLOGY



## PEDIATRICS



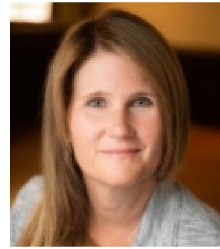
## PED DENTISTRY



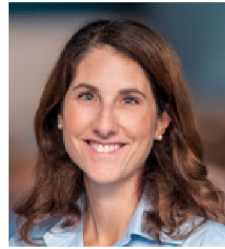
## NURSING



## OCCUPATIONAL THERAPY



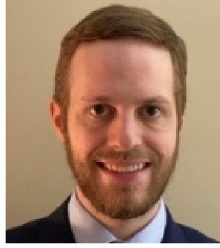
## PALLIATIVE CARE



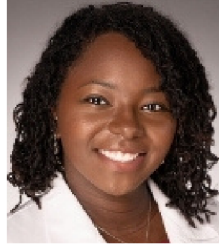
## PEDIATRIC NEUROLOGY



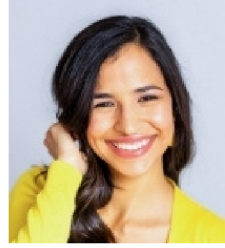
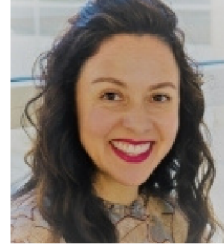
## PEDIATRIC NEUROLOGY



## PEDIATRIC NEUROLOGY & SLEEP



## SOCIAL WORK & COUNSELING



## PHYSIATRY



## PHYSICAL THERAPY



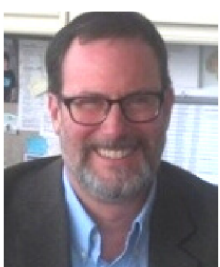
## SPEECH & LANGUAGE THERAPY



## VISION SPECIALISTS



## NEUROPSYCHOLOGY



### THANK YOU!

We want to thank Sue Hall, MD, MSW, FAAP and Adriana Salcido, MSW, for their incredible contributions to our Medical Advisory Board, and as founding members of this group as they transition off the board in 2023.

# 2022 SUPPORT IMPACT: PARTNERS IN HOPE



## Platinum Supporter

ReAlta Life Sciences, Inc. is a clinical-stage, rare disease biotech company dedicated to harnessing the power of the immune system to address life threatening diseases. The Company's EPICC peptides are based on research into the human astrovirus HAstV-1, which causes a non-inflammatory, self-limiting gastroenteritis unique among viruses by inhibiting components of the innate immune system. ReAlta's therapeutic peptides leverage these virus-derived mechanisms to rebalance complement and inflammatory processes in the body. The company's pipeline is led by RLS-0071, which has received IND clearance, and Orphan Drug Designation by the U.S. Food and Drug Administration and European Medicines Agency for the treatment of hypoxic-ischemic encephalopathy (HIE) in neonates. The company launched in 2018 and is located in Norfolk, Virginia. For more information, please visit [www.realtalifesciences.com](http://www.realtalifesciences.com).

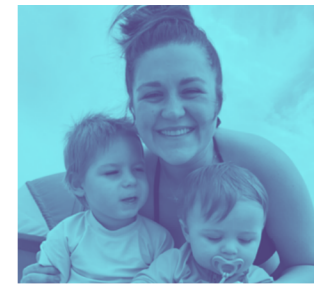
# Medtronic

## Platinum Supporter

Medtronic plc ([www.medtronic.com](http://www.medtronic.com)), headquartered in Dublin, Ireland, is among the world's largest medical technology, services and solutions companies – alleviating pain, restoring health and extending life for millions of people around the world. The company is focused on collaborating with stakeholders around the world to take healthcare Further, Together.



# 2022 IMPACT: SUPPORT PROGRAM HIGHLIGHTS



Hope for HIE's **SUPPORT PROGRAMS** are at the heart of who we are. In 2022, we made a significant investment to expand the scope, quality and consistency of support programming, while growing our reach and impact of our worldwide comprehensive support network.



## INVESTMENT IN SOCIAL WORKER SERVICES

We were able to onboard Vanessa Zinke, LCSW, to offer support and connection, build consistency, new programming and quality of services offered to our community.

## WEEKLY SOCIAL WORKER-LED SUPPORT GROUPS

Vanessa led weekly video support groups to connect the various demographics we serve, and offer additional high-quality ways to connect.

## PEER SUPPORT MENTORSHIP PROGRAM

Vanessa led weekly video support groups for the various demographics we support in our community, trained **13 Peer Support Mentors** in trauma-informed care practices and officially launched the Peer Support Mentor program for newly diagnosed or new to HIE loss families, connecting hundreds of new families.



## UNITE US SERVICE PLATFORM

Through the generosity of the Child Neurology Foundation, Hope for HIE is now on the Unite Us platform, a comprehensive service referral network making it easier for referrals to be made into our support programming.



## SUPPORT PACKAGES

We made our newly diagnosed support packages more environmentally friendly, and redesigned the contents to bring more cheer during a hard time, as well as securing a new vendor to ensure better consistency reaching our NICU partners.



## BACK TO IN-PERSON EVENTS

We were thrilled to bring back in-person gatherings this year, thanks to the incredible volunteers in our community who serve as regional hosts to help facilitate and plan these events!



## BIRTHDAY CARD PROGRAM

What started as an idea from a parent, has turned into a community effort to celebrate and honor the birthdays of our HIE children -- across all outcomes, and around the world.



## INCLUSIVE VIRTUAL EVENTS

Chef and HIE Dad, Stefano Benso, hosted an all accessible cooking class for our community during HIE Awareness Month!

# SUPPORT IMPACT: 2022 SPIRIT OF HOPE



## Sara Baker Pendleton Mississippi, USA

In early January 2022, one of our members, Lisa Kent, was facing the final moments with her husband, Rob. With no local family to support them, and two little kids, one with medical complexities, Lisa could not get to the hospital without help to be with Rob. She turned to our Hope for HIE community for help, and Sara Baker Pendleton heeded the call.

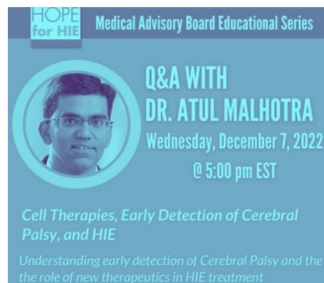
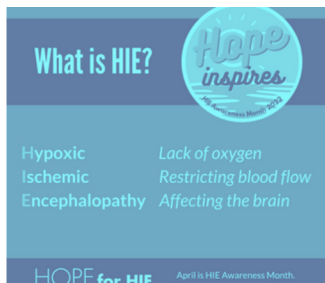
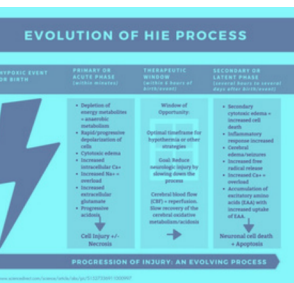
With a three hour drive each way, Sara navigated to the Kent household, allowing Lisa to not only visit Rob and be with him, but have the trust that someone knew how to take care of Peter, their HIE child, and Zachary, their infant son.

Sara has been a long time member of Hope for HIE, sharing her "honey badger" parenting spirit with the community, encouraging others to take chances in creating family memories when faced with difficult medical decisions, recalling a time when she took her daughter, Ansley, to see the New York City ballet before she passed away in 2019. The entire Hope for HIE community knows Ansley as "Diva the Dancing Ballerina", and her legacy continues.

We are honored to have Sara in our community, and she continues to personify the Spirit of Hope for our support community.



# 2022 IMPACT: EDUCATIONAL HIGHLIGHTS



Hope for HIE's **EDUCATIONAL PROGRAMS** grew in 2022. With an emphasis of making content more meaningful and accessible, we were able to begin transforming many of our education materials into different types of content, to better disseminate research, and work towards translating into the most common languages moving forward.



## ISAN EDUCATIONAL GRANT

We were thrilled to receive a grant to build out additional resources to bring better education to the HIE community and beyond. We have developed an educational module to be used at NICU discharge for all HIE families to learn more about seizures, infantile Spasms, how to elevate concerns to a provider, and help families understand what might be a typical baby movement vs. something concerning that needs medical attention. We look forward to disseminating this further in 2023.



## MEDICAL ADVISORY BOARD EDUCATIONAL SERIES

Our signature monthly MAB educational events continued throughout 2022, on the most impactful topics relevant and elevated by our community.

Each event now also generates additional "key takeaways" that families can access in short infographic and blog formats, in addition to the full video presentations.



## TRANSLATION COMMITTEE

We launched our volunteer translation committee to begin translating our educational materials into the most commonly needed languages, with the hope to complete downloadable content by the end of 2023.

We had over 150 people raise their hand to volunteer!



## UNDERSTANDING HIE AS A CATALYST DIAGNOSIS

We continued to build out resources for families to understand the complexity of HIE through educational content for related diagnoses.



# COMMUNITY HIGHLIGHT

## HIGHLIGHTS OF HOPE: A COMMUNITY CONNECTION TOOL



One of the biggest and exciting things came to fruition in 2022 -- a book of stories from our HIE community -- across all outcomes, globally, from parents and providers. This book is something our community has been dreaming of since 2011.

Simran Bansal, Hope for HIE's inaugural intern, interviewed over 75 members of our global community and turned those interviews into stories in print, eBook and blog formats. The book has sold thousands of copies so far, and has begun distribution in NICUs, PICUs and clinics for HIE families in partnership with various hospitals and clinics.

Simran also had the opportunity to present the book at the 2022 International Newborn Brain Conference, as a featured abstract submission, and included in a talk at the Child Neurology Society annual conference.

## A FEW WORDS ABOUT THE BOOK...



### ERIN BROST, YUKON, CANADA

"Thank you to all the families who contributed their stories to the book! It has been such a comfort for me of such a familiar place of strength and all the many forms that love takes for us as HIE families sometimes loves looks like holding on and sometimes love looks like letting go. With this book, I know we're not alone and you all give me so much strength when I read about your families. I am beyond grateful for this organization it's so professionally and compassionately run and the HIE worldwide community is all rockstars!"



### SEETHA SHANAKARAN, MD: The "Godmother" of Cooling

"Inspiring and at the same time informative, *HIElights of Hope* teaches us how parents of sick infants courageously deal with their newborns' illness. The feedback from parents can advance both clinical care and research aimed at improving care of neonates. This book should be required reading for all trainees. The perspective of parents is part of the art and science of pediatric medicine."

Learn more, and order a copy, at [Tinyurl.com/HIElightsofHope](https://Tinyurl.com/HIElightsofHope)

# 2022 IMPACT: AWARENESS HIGHLIGHTS



Hope for HIE's **AWARENESS** programs are focused on bringing light to and improving the unmet needs of the HIE community. We not only create collaborations, advocacy programs and awareness, but are regularly invited to collaborate as a strong patient advocacy partner by clinicians, researchers, and industry members in the newborn and pediatric brain community.



## 2022 HIE AWARENESS MONTH RECAP

This year's HIE Awareness Month was easily the busiest we've experienced since its inception. The month kicked off at the National Association of Neonatal Therapists conference in Cincinnati, Ohio where Betsy Pilon and Medical Advisory Board member, Dr. Monica Arroyo, presented about HIE to the conference attendees.

Each week had a different theme -- Hope Inspires...Advocacy, Creativity, Support, & Community Connection.

We hosted and participated in over **23** individual events that brought world-class education to our community, the HIE parent perspective to advocacy webinars with the AAP and Vermont-Oxford Network, as well as opportunities for our community to connect and be supported, and we were even featured on TikTok!



### HOPE INSPIRES ADVOCACY

Hope for HIE inspired a parent in Canada to have her local government building "turn teal for HIE" in Newfoundland & Labrador.



### HOPE INSPIRES SUPPORT

We shared new support resources with our peer mentorship program, and rebranded our NICU support packages with our beautiful watercolor print.



### HOPE INSPIRES CREATIVITY

The HIE community was invited to participate in a fun and accessible cooking class, led by HIE Dad and Chef, Stefano Benso.



### HOPE INSPIRES COMMUNITY

We announced a partnership with ReAlta Life Sciences, as they move a promising therapeutic for HIE through clinical trials in 2023 and beyond.

# AWARENESS IMPACT: FEATURED AMBASSADOR



**Monique Mohan**  
Dubai, United Arab Emirates

Monique Mohan was selected as a 2022 HIE Awareness Month ambassador, and moved mountains to bring awareness to her local community in Dubai, getting the Children's Hospital involved, putting together awareness packages and swag to be handed out, and led efforts to create incredible social media impact videos and content to generate even more awareness.

Monique is the loving and amazing mom to Zach, who experienced HIE at birth. Over the last few years, she has been one of the biggest champions of HIE Awareness in our community, and her creativity and commitment have helped dozens and dozens of families connect into Hope for HIE who wouldn't have heard of it otherwise.



Monique personifies the theme of "Hope Inspires", as she inspires everyone she meets to embrace the beauty around them, even through the difficult times.



# ADVOCACY HIGHLIGHTS

## BRINGING HIE TO THE FOREFRONT OF NEONATAL NEUROLOGY RESEARCH & CLINICAL CARE

Where were we in 2022? EVERYWHERE.



From Portugal to Canada, Australia to India, and everywhere in between, and with the resources to dig further into advocacy, Hope for HIE was represented in 14 different conferences by staff, Medical Advisory Board members, and volunteers.

Some of the most exciting work that came to fruition has been years in the making. We continued our advocacy messaging of inclusion and representation, and was able to continue existing and build new advocacy partnerships that are accelerating research and improvements for HIE children and families, worldwide.



### ELEVATING OUR PATIENT ADVOCACY PARTNERSHIP STRATEGY

At Child Neurology Society's Annual Meeting, the International Newborn Brain Conference, the International Neonatal Consortium, and Grand Rounds presentations, Betsy Pilon presented with leading researchers, federal regulators, and clinicians about the myriad of ways patient advocacy organizations like Hope for HIE can meaningfully collaborate in research, advocacy and awareness.



### REPRESENTING HIE AT AACPDPM

This year, Amy Cutler, Board of Directors member, Medical Advisory Board co-chair, pediatric occupational therapist and HIE mom, was invited to join the American Academy of Cerebral Palsy & Developmental Medicine's Community Council, bringing much-needed representation from our community to this highly regarded organization.



### COOL PRIME: MILD HIE RESEARCH

Led by Drs. Lina Chalak & Natalie Maitre, both Hope for HIE Medical Advisory Board members, a multi-year study has been funded by PCORI to study the comparative effectiveness of therapeutic hypothermia for Mild HIE. Hope for HIE is a funded patient advocacy partner.



### REPRESENTATION IN NICU FAMILY-CENTERED CARE INITIATIVES

While there is still so much advocacy and work to do in the NICU advocacy space, we were invited to join the AAP SONPM Family-Centered Care Task Force after seeing there was no representation of a non-preemie experience. We continue this work to ensure families like ours will receive equitable care and support.

# LOOKING AHEAD

## PRIORITIES IN 2023 AND BEYOND

With solid footing under us thanks to the continued and increased support from our global HIE community, we are eager to get started on our upcoming priorities in 2023. These include:



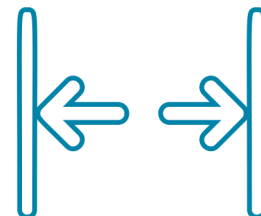
### HEALTH INFORMATION LITERACY

HIE families often feel like they have to learn a completely new language, set of norms, culture and more. With such a complex diagnosis, wide range of impacts, longevity of unknowns, and in the era of misinformation, it is our imperative to help families navigate in productive ways to protect the health and safety of their children and whole family.

We are eager to build out health literacy educational resources beginning in 2023 that will educate and empower families no matter what path their HIE journey will take.

### CLOSING THE GAPS: DEVELOPING A HIE REGISTRY

- While there are several small data warehouses around the world, there is no comprehensive registry that has been built with the partnership of the patients and families it impacts.
- The goal to create a two-part registry: one tracking from HIE birth or event, and two an opt-in natural history registry, will allow researchers to test out hypotheses that can help better understand the full impact of HIE, with the goal to aid in developing additional therapeutics along the neurodevelopmental continuum.



### EXPAND SUPPORT RESOURCES

- **Child Life Services** are a comprehensive, holistic approach to helping children and families cope with medical life, in both a hospital and home/community setting.
  - Traditionally, these services are not offered everywhere, and we think this needs to change.
  - We will onboard a Certified Child Life Services (CCLS) professional to support the HIE community, and bring additional, accessible child life resources to families.
- **Hospital Ambassadors** are key individuals for many NICUs and PICUs, providing a local resource to hospitalized families from point of diagnosis forward.
  - We will launch a pilot program of 5-10 ambassadors, with a comprehensive training program, mirroring the success of our Peer Support Mentor program.



# FINANCIAL SUSTAINABILITY

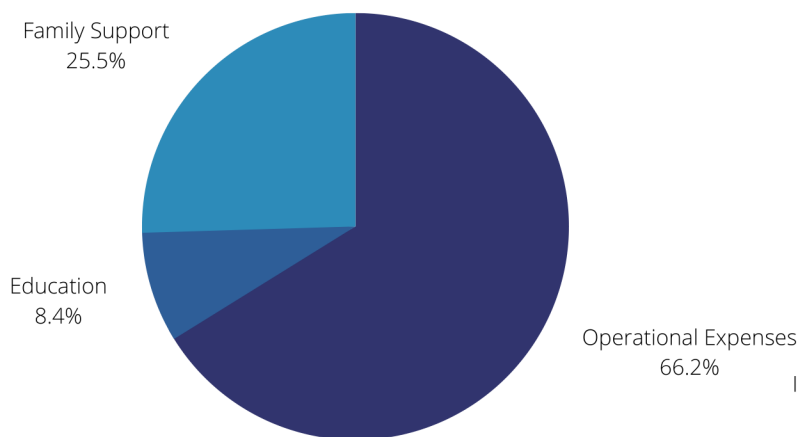
## 2022 FINANCIAL HIGHLIGHTS

Hope for HIE's Board of Directors made a significant decision to invest in building out our support resources in 2022. We were able to onboard and contract a social worker, program manager, and virtual assistant to build in high-quality programming and consistency, that leads to better support, advocacy and community outcomes.

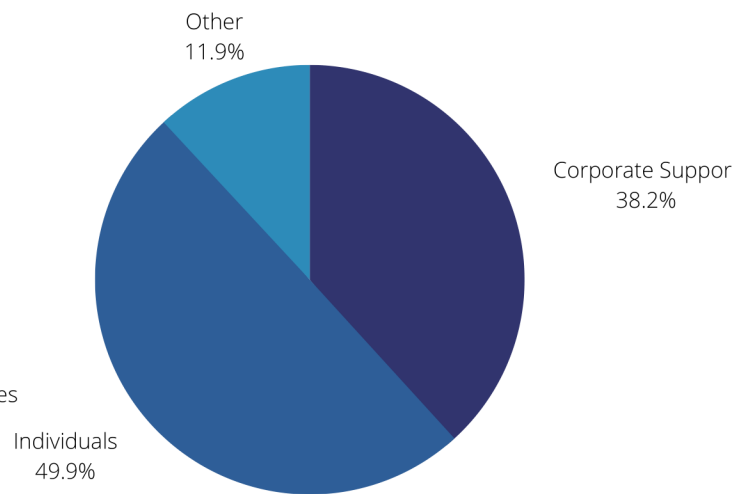
Key highlights:

- Over **\$180,000** raised from donor contributions and fundraising activities
- Nearly **\$50,000** spent on family support, outreach, awareness, and education
- Net assets of **\$282,000** as of December 31, 2022

## 2022 EXPENSES



## 2022 REVENUE



**YEAR ENDED DECEMBER 31, 2022**



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## HOPE FOR HIE'S ORGANIZATIONAL MISSION:

To improve the quality of life for children and families impacted by neonatal and pediatric-acquired Hypoxic Ischemic Encephalopathy through Awareness, Education & Support.

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We want to, from the bottom of our hearts, thank everyone who has contributed in any way to support our organization as we continue on this significant growth curve accelerating our mission through our programs, partnerships, and resources.

**HOPE** for **HIE**  
awareness • education • support

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