

# HOPE for HIE

awareness • education • support

A photograph of two children in wheelchairs sitting outdoors at night. The child on the left is wearing a bright green t-shirt and a light blue blanket with large brown polka dots. The child on the right is wearing a blue hoodie and a grey blanket. They are both looking towards a campfire in the foreground. The background shows trees and a dark sky. A yellow horizontal bar is positioned above the text.

## 2023 PROSPECTUS FOR FUNDING

# A MESSAGE FROM OUR PRESIDENT

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Since Hope for HIE's founding as a nonprofit in 2014, and originally as a peer support group on Facebook in 2010, Hope for HIE's vision has always been directed at creating connection to improve the lives of those impacted by neonatal and pediatric-acquired HIE.

Through community-building across the ecosystem of care and experiences, we know that we can move mountains together. Our community consistently articulates their unmet needs that fit into our three pillars of focus - Awareness, Education and Support. This direct feedback continues to help us stay focused on the objectives that will transform our community.

Hope for HIE is personal for me. When my own daughter, Scarlett, was born, my wife and I felt a terror like we had never experienced in our life. In our darkest moments, Hope for HIE was there as a guiding light for us in the days, weeks and years ahead in our journey, connecting us to information, resources and peer connections that have significantly improved our whole family healing and processing.

As we build community, we are able to accelerate our mission by engaging a variety of partners and funders to make the world we live in with HIE one that is focused on hope, regardless of the outcome a child may face.

We are eager to learn more about you, your organizational goals, and how we may come together to fully realize the mission of Hope for HIE through strategic partnerships, collaborations, projects and more.

With great hope,

**David Ford**

david@hopeforhie.org

# ORGANIZATIONAL PROFILE

Hope for HIE is the only global nonprofit organization that serves children and families with neonatal and pediatric-acquired Hypoxic Ischemic Encephalopathy.

HIE is the second leading cause of infant mortality worldwide, 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.

Through our accelerated organizational growth and development, we are eager to collaborate with many different stakeholders, bringing our community expertise to advance initiatives that decrease the incidence and impact of HIE,

Our network represents families and providers from over **60 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 organization.

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

- Connect more than **8,500 families** to comprehensive support programs, services and education.
- Become the global advocacy voice of the HIE community - elevating the lived experiences and unmet needs of the HIE community to the forefront to improve equity in research, support, care and communication.
- Convene multidisciplinary stakeholders such as academia, research, clinical care, industry, regulatory, and patient advocacy to advance the cause.

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



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

IRS EIN: 46-4038344

[Latest 990 filing](#)



# NICU CARE & HIE

Neonatal Hypoxic Ischemic Encephalopathy impacts roughly **2-3 per 1,000 live births in developed countries, and 10-20 per 1,000 in low and middle income countries**. It is the second leading cause of neonatal mortality, worldwide, the top cause of neonatal seizures, and a significant cause of lifelong disability. It has many causes and can occur before, during or after birth. There is one therapeutic to show efficacy in this population - therapeutic hypothermia - and it has specific criteria and does not benefit all babies with HIE.

Neonatal HIE falls under the Neonatal Encephalopathy umbrella, and it is typically known around days 5-7 if it is, in fact, HIE vs. a metabolic or genetic non-HIE cause. There is a wide gap of consistency in communication, care and support for HIE families.

There are many factors in this:

- No patient advocacy existed for this population prior to 2013.
- A small percentage of HIE is deemed preventable, yet due to the potential for medico-legal implications, many shy away from naming the diagnosis.
- Funding, resources and research has been focused heavily on prematurity, and NICU support leadership has traditionally been led by families who faced prematurity, creating a culture that prioritizes support by gestational age and length of stay in the NICU.

## AREAS OF NEED

### EDUCATING FAMILIES ABOUT HIE

Families need accessible, consistent, accurate information about HIE, its potential long term impacts, and a confirmed, understood diagnosis of HIE breaking down the complex medical terms.

### DISCHARGE PLANNING

Families need equitable discharge planning to other areas in the NICU. This includes education on seizure risk, identification & elevation, any medical care coming home with feeding, breathing, follow up care, and developmental surveillance/early intervention services.

### IN-UNIT & LONGITUDINAL SUPPORT

Families need the same equitable support offerings as other families in the NICU and beyond, regardless of Length of Stay or perceived outcomes. HIE can have a lifetime of consequences. Peer and licensed support is critical.

# EPILEPSY & HIE

Epilepsy is easily one of the most significant subsequent diagnoses from HIE, and across all outcomes. It is estimated to impact roughly **50-70%** of all HIE cases in some way. Annually, approximately **7,600 babies** are born with HIE in the US, and more acquire hypoxic brain injuries in childhood. **At least** half of those will develop epilepsy at some point.

HIE is known to interrupt the sleep/wake cycle, even for Mild HIE, which can lead to the development of nocturnal epilepsy later in childhood for those who may not have experienced neonatal seizures.



## 50-70%

of all neonatal and pediatric-acquired HIE patients will develop some sort of epilepsy in their lifetime.



## #1 CAUSE

### NEONATAL SEIZURES

Roughly 15-20% will have seizures persist after the neonatal period, and more will have epilepsy develop at some point during childhood.



## LEADING THE RARES



### INFANTILE SPASMS & LENNOX-GASTAUT SYNDROME

HIE is the 2nd leading cause of IS, and the top cause of LGS, both catastrophic rare epilepsies.

### ESES - ELECTRICAL STATUS EPILEPTICUS IN SLEEP

85% of ESES, another rare epilepsy, is structurally caused. It is estimated 80-90% of that percentage is HIE-related.

## Barriers to care:

Lack of education on what seizures look like transitioning from NICU/PICU to home

Neurology sign-offs at age 2/3 make seizure onset in childhood difficult to reenter a medical system.

Lack of global patient registry minimizes the true impact, and epilepsies like ESES are still underdiagnosed.

# CEREBRAL PALSY & HIE

Cerebral palsy is a significant co-morbidity with HIE. It is estimated to impact roughly **40%** of all HIE cases in some way. Cerebral palsy is the most common motor disorder diagnosed in childhood, and has a wide range of impacts. It interrupts the signals between the brain and muscles, which can impact muscle tone - either with hypotonia, or hypertonia and spasticity.

HIE is one of the less common causes of Cerebral Palsy -- only 10-15% of cerebral palsy cases are caused by HIE, which is a shift from the original thought of HIE being synonymous with Cerebral Palsy.

Cerebral palsy may impact oral motor function including swallowing, feeding, and verbal speech. People living with cerebral palsy may require lifelong care, medical equipment, mobility aids, adapted and general transportation services, and accessibility needs in their homes, schools, and community.



## 40%

of all neonatal and pediatric-acquired HIE patients will develop cerebral palsy.

## IMPACT TO QUALITY OF LIFE

### MODERATE TO SEVERE HIE

The majority of cerebral palsy in HIE is associated with moderate to severe HIE classification. It is less common in Mild HIE.

### MOBILITY & INCLUSION

Cerebral palsy may restrict the mobility of someone living with it, which can restrict their community inclusion opportunities, depending on what may be offered.










### COGNITION

Many people living with cerebral palsy have no impact to their cognition, but many will - about 40% - which can add additional need for services and isolate children and families.

# COMMUNICATION

## HOPE FOR HIE'S REACH & COMMUNICATION CHANNELS

With a global network of families, leadership expertise in mass communication, and leveraging available networks, Hope for HIE has cultivated an extensive, multi-channel communication network to disseminate messages and build community.

COMMUNICATION METHOD	REACH	ENGAGEMENT	ANNUAL GROWTH
 <b>HopeforHIE.org Website</b>	100,000+ unique visitors	Above average time spent per user	>10%
 <b>Email Communication</b>	5,500+ contacts	25% open rate	>30% contacts >4% open rate
 <b>Facebook</b>	750,000+ reached	13,500+ followers	>5%
 <b>Facebook Groups</b>	8,500+ members	89% active weekly	>9%
 <b>Instagram</b>	250,000+ reached	6,200+ followers	>17%
 <b>Twitter</b>	250,000+ reached	2,500+ followers	>15%
 <b>LinkedIn</b>	25,000+ reached	1,175+ followers	>40%
 <b>YouTube</b>	10,000+ reached	280+ subscribers	>62%
 <b>TikTok</b>	300,000+ reached	2,000+ subscribers	>75%

# AWARENESS

## HIE AWARENESS MONTH CAMPAIGN

In 2016, Hope for HIE launched the first ever HIE Awareness Month declaring April as the annual worldwide awareness month, and selecting April 20th as HIE Remembrance Day.

In 2022, we reached over **three million people** through our various outreach initiatives, selecting the theme of "Hope Inspires." We hosted and participated in over 30 events including educational webinars, our first in-person Hustle for Hope event, and support events for our global community.

We launched additional support programs and partnerships.



**Sponsorship opportunities exist to support HIE Awareness Month initiatives.**

## SPEAKER'S BUREAU

Hope for HIE volunteers and personnel have been guest speakers at Grand Rounds, international conferences, podcasts and symposiums since 2016.



## LEGISLATIVE ADVOCACY

David Ford, Board of Directors President, has coordinated legislative advocacy efforts for the foundation. In 2019, several families attending the Pennsylvania House Resolution 205 and Senate Resolution 75 to recognize April as HIE Awareness Month. He also participated in advocacy meetings with US Senator Patrick Toomey and Brian Fitzpatrick through the Rare Disease Legislative Advocates Rare Across America Campaign.





# AWARENESS

## EPILEPSY, CEREBRAL PALSY, AUTISM, & OTHER RELATED NEURODEVELOPMENTAL CONDITION AND DIAGNOSIS AWARENESS

Hope for HIE regularly develops and participates in campaigns for education and awareness of related conditions and disabilities that are prevalent in our community. We actively advocate for further research and tracking of long term outcomes across the spectrum of severities, as many times some neurodevelopmental differences and disabilities are brushed off as "minor" or "mild", and yet need additional care and coordination.

HIE is also the second leading cause of Infantile Spasms, a potentially catastrophic rare type of epilepsy. Prior to 2019, the HIE community was not included in these efforts, despite its high prevalence. Families often were nervous to push for evaluations and start their children on aggressive treatments.

Hope for HIE received a \$5,000 grant from the Child Neurology Foundation in 2019 and in 2022 to develop educational tools for our community including modules, training programs, and advocacy trainings for our community.



**Sponsorship opportunities exist to support individual awareness events and communication.**

## JUST SAY HIE PODCAST

Monthly episodes are launched sharing the unique stories, outcomes, parent and caregiver-related topics that showcase the breadth and depth of our worldwide community. Available across all podcasting platforms, Just Say HIE also releases Bonus Episodes from our Medical Advisory Board educational series, to bring education and awareness to this newer medium.



**Sponsorship opportunities exist to support the podcast.**

# ADVOCACY

## PARTNERSHIPS TO GO FURTHER TOGETHER

Hope for HIE regularly partners and participates in a variety of collaboratives to move forward the mission of the organization, decrease the incidence and impact of HIE, accelerate research, and convene multistakeholder groups.

HIE advocacy begins in pregnancy with obstetric providers, continues through the NICU and PICU, and out across the many co-morbidities associated with HIE.

HIE is one of the leading causes of non-premature NICU and PICU hospitalizations, yet the disparity in messaging, education and connection for families is a significant unmet need. Through Hope for HIE's involvement with different organizations, we are working to close these gaps and barriers to care, communication and connection.

We believe coming together where commonalities exist better accelerates all missions forward for optimal care and outcomes for families.



# RESEARCH & CONSULTING

## THE GLOBAL PULSE ON HIE - ACCELERATING RESEARCH & DEVELOPMENT

Hope for HIE's leadership and global community have decades of expertise in best practice development for patient advocacy involvement in clinical trials, patient communication, regulatory requirements and insights, and regularly consults and collaborates on various stages of research and development for scientific and therapeutic areas relating to HIE, on both the academic and industry/pharmacological sides.

### CONSULTATION SERVICES:

- Patient-family insights in therapeutic & MedTech development
- Facilitation and access to key opinion leader insights
- Clinical trial design
- Patient-Family Centered core outcome setting and measurement
- Patient-family engagement and communication strategy
- IRB-approved focus group and survey methodology
- Regulatory compliance support

### RESEARCH SUPPORT SERVICES:

- Longitudinal partnership and support for research/product development
- Comprehensive Halo of Support<sup>©</sup> clinical trial model & framework
- Development & facilitation of patient-family advisory councils
- Clinical trial design
- Core outcome setting and measurement
- End-to-end patient-family engagement and communication strategy management for optimal data capture
- IRB-approved consent, focus group and survey methodology
- Study dissemination design and strategy
- Regulatory and commercialization

## HALO OF SUPPORT<sup>©</sup> MODEL



**ALIGN MISSIONS**



**ENGAGED PARTICIPANTS**



**COMPLETE DATA**

# RESEARCH & CONSULTING

## RESEARCH & CONSULTING COLLABORATIONS

Hope for HIE's global community has decades of expertise in best practice development for patient advocacy involvement in clinical trials and regularly consults and collaborates on various stages of research and development for scientific and therapeutic areas relating to HIE with both academic and industry-based innovation in pharmacologic and medical technology/device development, including implementing and licensing Hope for HIE's Halo of Support(tm) framework for longitudinal clinical trials.

### NEONATAL SEIZURE REGISTRY

Hope for HIE has been a patient advocacy partner since 2019 with the PCORI-funded multi-center Neonatal Seizure Registry project, and subsequent add-on studies, giving insights from our patient-family community, bringing expertise in patient communication strategy to disseminate results.



### HEAL STUDY

Hope for HIE was tapped in to consult on the HEAL study during the final phase of assessment, and the dissemination of results. Many lessons were learned about the need to include patient advocacy input at the onset of the planning.



### REALTA LIFE SCIENCES

Hope for HIE is the patient advocacy partner for the development of a multicenter study for ReAlta Life Sciences' promising therapeutic set to enter multicenter clinical trials in 2023, providing focus groups, core outcome measurement, and the implementation of Hope for HIE's comprehensive Halo of Support(tm) framework for the longitudinal clinical trial.



### COOL PRIME - MILD HIE & THERAPEUTIC HYPOTHERMIA

Hope for HIE is a patient advocacy partner in the upcoming COOL PRIME PCORI-funded comparative effectiveness study for mild HIE and therapeutic hypothermia, convening a patient-family advisory council, study design, communication strategy development and dissemination.



# EDUCATION

Hope for HIE works diligently to provide **EDUCATION** for its global community. Families of children with HIE face many obstacles accessing educational materials that we are working to remove. Health information literacy is one of the most significant issues impacting families, in addition to the lack of connecting families early, naming the diagnosis, and providing educational materials that are written free of medical jargon and available in first use language for our diverse population.

## HIE EDUCATIONAL RESOURCES

Developing educational materials has been a focus since our inception. In 2020, we launched our HIE NICU experience education materials, in conjunction with our Medical Advisory Board. We have been able to translate these into seven languages, with more in the works. This graphic and printable handout has been downloaded now over 500 times since its launch, and over 4,000 pieces of printed pieces across the various translations have been requested and mailed out this year alone.

**Sponsorship opportunities exist to support translation efforts, printing and web design.**

**YOU HAVE PEOPLE.**

We understand and have been where you are right now, and we want you to know that you are not alone.

Know that thousands of families are here for you in your journey, no matter what is ahead.

The HIE NICU experience is unique, and we want to share with you resources that can help you, through our peer-to-peer support network, and in collaboration with your medical team.

We have parents dedicated to connecting with you as a new parent in this journey, and we look forward to getting to know you and your family.

When you are ready, we are here, 24/7, to help you.

**OUR MISSION**

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

**CONNECT WITH US**

**FACEBOOK FORUMS:**  
[Facebook.com/groups/hopeforhie](https://www.facebook.com/groups/hopeforhie)

**WEBSITE:**  
[HopeforHIE.org](https://www.hopeforhie.org)

**EMAIL US:**  
[outreach@hopeforhie.org](mailto:outreach@hopeforhie.org)

**CALL US:**  
248-574-8099

**THE NICU JOURNEY WITH HIE:**  
HYPOXIC (LACK OF OXYGEN) ISCHEMIC (RESTRICTING BLOOD FLOW) ENCEPHALOPATHY (IMPACTING THE BRAIN)

**THE JOURNEY BEGINS**

**BIRTH**  
A baby is born - they may have experienced HIE before or during the birth process. Assessments of APGAR scores, cord blood gases, and a baby's situation are done to confirm suspected HIE and to see if a child qualifies for therapeutic hypothermia.

**NICU ARRIVAL**  
Whether it is within the birth hospital, or through ambulance or helicopter, the baby is transported to the NICU for further assessment and, if appropriate, to begin the therapeutic hypothermic cooling process. Many babies need multiple interventions such as breathing and blood pressure support, an IV in the belly button to administer medications, and will receive neurological diagnostic testing such as EEG, as neonatal seizures are very common in HIE. Medications may be used to control seizures, and keep babies stable and comfortable during cooling. Many hospitals have access to mental health resources in the NICU for families, so be sure the social worker.

**COOLING PROCESS**  
If a baby meets the criteria to be cooled, they will be placed either on a cooling blanket, wrap, or head cooling cap for 72 hours at around 91°F. This is to slow the body down and focus the body's healing on the brain. If you are unable to hold your baby during cooling, talk to your team about other ways to make memories, bond and care for your baby during this part of the journey.

**MRI DAY**  
After a child is rewarmed, or if they did not go through cooling, a MRI is typically done around day 5, although it may be done earlier or later, depending on the circumstances. MRIs can show the NICU team where the brain may have experienced injury or damage. MRIs do have limitations, and it is our recommendation that they are not taken as a "set in stone" use of prognosis. As they are a picture in time, and due to how babies brains develop, they may not show all impact. HIE has a wide range of outcomes.

**FIRST HOLDS**  
While some hospitals have made it possible to hold your baby during cooling, if they are cooled, many babies are not stable enough. The first hold is a keystone moment for families, and may happen right after cooling, or the following few days or week, depending on the stability and tolerance of each baby.

**NICU DISCHARGE**  
At last, it is time to discharge from the NICU. Each NICU has its own criteria, and discharge procedures. Babies typically have to be able to get safe and consistent nutrition whether by breast, bottle or tube, and meet other medical milestones. Most families are required to take infant CPR classes, and families should be connected to follow up primary and specialist care appointments, early intervention services, social/emotional support for the family to process this time, and learn about the signs of seizures or other difficulties HIE babies are at risk for.

**POST-NICU SUPPORT**  
Connecting with peer-to-peer support, ideally in the NICU or after the baby goes home can improve mental health and the parenting experience. Connecting with other families who have gone through the unique HIE NICU experience can empower parents to further understand, process, and accept the situation they have been through. In-person NICU support groups through hospitals are also very helpful. And, through early intervention, many parent groups can be helpful to understand risk factors and other nuances to this journey.

**NICU DURATION**  
Depending on the baby and their clinical course, they will be working hard to recover from the initial trauma of HIE. Families should be encouraged to attend daily rounds with the team. Some babies may be able to feed at the breast or using a bottle, and some may need a feeding tube placed through the nose to the stomach. If a baby's suck/swallow/gag reflexes are absent or weak, a g-tube can be surgically placed in the abdomen, and allow the baby to safely transition home. Many babies will need supplemental oxygen for a period of time, and work on decreasing their need over time.

**HOPE awareness • edu**

**WE'RE ALL IN FOR YOU.**

# EDUCATION

## HOPE GOES LIVE! EDUCATIONAL EVENTS

Utilizing the ability to "go live" with the online Hope for HIE community, we regularly host several informational sessions. Some are parent-led, some are a part of our Medical Advisory Board Educational Series.

### Some topics we have covered:

- Augmentative and Assistive Communication
- Common Feeding & Swallowing Issues
- HIE and Seizures
- HIE Awareness Month
- School Advocacy Tips
- Medical Advocacy Training
- Infantile Spasms Q&A
- Transitions of Care
- Sleep Issues and HIE



***Sponsorship opportunities exist to co-sponsor these events.***

## PEER-TO-PEER SUPPORT TRAINING

Hope for HIE provides trauma-informed care training for all organizational volunteers partnering with members of our Medical Advisory Board.

Our peer-to-peer support network is the hub of activity and connection in our community and we want to ensure we are utilizing best practices for our volunteers, over 75, who manage and facilitate our peer support programs.



***There is a sponsorship opportunity to fund training for our volunteers***

# SUPPORT

Hope for HIE's **SUPPORT** comprehensive support programs and services are focused connecting families and empowering parents through credentialed provider and peer support, across the age and outcome continuum, connecting to local resources for additional support. The heart of who we are is the spirit of connection and community. We emphasize equity, accessibility and cultural competence, with a goal of integrating the principles of trauma-informed care.

## HOPE FOR HIE PEER SUPPORT NETWORK

Hope for HIE provides individualized support through 100+ topic, location and outcomes-based forums connecting over 8,500 families worldwide. Under the supervision of our part-time social worker, Hope for HIE's Peer Support Mentor program connects and supports families, initially focused on those new to the diagnosis of HIE, and those facing HIE loss. These mentors go through rigorous training, coaching and follow up.

## SUPPORT SERVICES - ENSURING ACCESS TO OUR GLOBAL COMMUNITY

Hope for HIE recognizes the significant burden that trauma causes from experiencing life-threatening hospitalizations and acute care needs of HIE children experienced by parents and caregivers.

Yet, these support services are often difficult to access, many times they are not offered to HIE families, or there is significant disparity in availability of these services beyond acute care settings, yet the need is significant.

Trauma can and does impact parent and caregiver mental health and often manifests as PTSD, anxiety and depression. For the best outcomes of HIE children, we need healthy parents.

Hope for HIE's commitment to providing access to credentialed support providers is unparalleled and essential. We have brought on both a part-time licensed Social Worker and part-time certified Child Life Specialist. These specialists help provide comprehensive support for families, opening access to mental health referrals and support, full family programming, consultation for hospitalizations, bereavement and loss support, and additional programming to improve the whole family quality of life.



Vanessa Zinke, LCSW

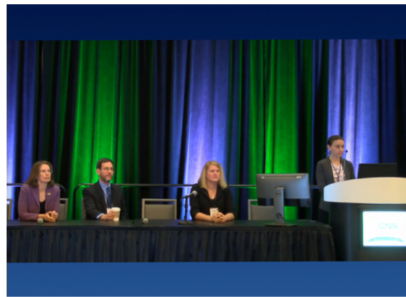


Annie Gunning, CCLS

***There is a sponsorship opportunity to fund our social worker and child life programs.***

# SUPPORT

## ORGANIZATIONAL SUPPORTS



### BOARD OF DIRECTORS

Hope for HIE's Board of Directors is comprised of talented professionals who have a familial connection to HIE, and include diverse experiences both professionally and across the range of outcomes of HIE.

### STAFF

Hope for HIE employs a full time Executive Director, part-time program manager, social worker, child life specialist, and interns.

### MEDICAL ADVISORY BOARD

Hope for HIE's Medical Advisory Board brings together **over 35** of the top worldwide multidisciplinary researchers and clinicians to counsel, collaborate with, and bring their expertise to the HIE community. We are able to facilitate conversations in this space that lead to better collaboration among treating clinicians, emerging research, and allow for an energizing space to connect.

### COUNCIL OF ADVISORS

Hope for HIE's Council of Advisors comprises of the most highly engaged families, donors and community members in the HIE community. Members are offered training to become active members of our Speaker's Bureau and are available to speak on behalf of the organization at conferences, webinars, panel discussions, research projects and more.

### PARTNERS IN HOPE

Hope for HIE engages corporate support and sponsorship. Those who participate in the Partners in Hope program receive dedicated recognition, terms and conditions, and mutual benefit outlined in established gift agreements.



# SUPPORT

## HOPE FOR HIE RETREAT PROGRAMS

Hope for HIE's connections are best made when families meet in person. We have been hosting retreats for our community since 2015. We host a biennial Mom Conference, biennial regional family retreats, in-person overnight and family meet ups, where the goal is to be surrounded by people who are in the same community. The magic is when siblings connect, when HIE kids can connect, and when all family dynamics can feel supported and loved.



## BIENNIAL MEGA MOM CONFERENCE RETREATS

We host a biennial retreat for moms to unwind, connect, and work towards improving their mental health through a blend of group connection and support sessions, and opportunities to network, socialize and facilitate individual connections. These are typically held at a hotel and conference center.

## REGIONAL COMMUNITY MEET UPS

We host regional day and overnight events for our community throughout the year. These are typically hosted by local families, and may include playground meet ups, parent night out events, sibling playgroups, or overnight meet ups.



## HOPE FOR THE HOLIDAYS GIVEAWAY PROGRAM

Since 2016, we have directly given back nearly \$100,000 in goods and services that are directly geared at improving the quality of life and family time for our HIE children and families. Sometimes this is a piece of equipment that helps children access more typical kid experiences, sometimes it is a gift card for carry out to ensure families are fed on those difficult therapy days. We provide these to our worldwide community, and work to ensure families are equally eligible to receive, no matter their worldly circumstance or location.

***There is a sponsorship opportunity to fund Hope for the Holidays giveaway programming - either monetarily or in-kind products.***

# SUPPORT



## 2023 BIENNIAL MOM CONFERENCE RETREAT - MAY 4-7, 2023

We are excited to once again bring our community together after an almost three year hiatus due to the global pandemic. Traditionally, every two years, we host a mega Mom conference retreat. This year we will be in St. Pete Beach, FL. Sponsorships are available at varying levels.

LEVELS OF SUPPORT	OPPORTUNITY DETAILS			INVESTMENT
<b>PRESENTING EVENT SPONSOR (LIMIT 3)</b>	Recognition on all in-person, printed and online materials	Opportunity to provide information in swag bags	Onsite sponsorship banner/signage	<b>\$10,000</b>
<b>SWAG BAG SPONSOR (LIMIT 1)</b>	Logo on swag bags, tshirt	Opportunity to provide information in swag bags	Online recognition of sponsorship	<b>\$5,000</b>
<b>SESSION SPONSOR (LIMIT 1 PER SESSION)</b>	Printed 7 foot tall pull banner at session	Printed recognition in program	Dedicated social media post across Hope for HIE channels	<b>\$2,500</b>
<b>BREAKFAST/ LUNCH SPONSOR (LIMIT 1 PER SESSION)</b>	Printed sponsorship table signage (8.5 x 11) at meal	Printed recognition in program	Online recognition of sponsorship	<b>\$1,000</b>
<b>T-SHIRT LOGO SPONSOR (LIMIT 10)***</b>	Medium-sized logo on back of t-shirt	***Sponsorship must be confirmed one month out from event	Online recognition of sponsorship	<b>\$250</b>

# SUPPORT

## NEWLY DIAGNOSED FAMILY PACKAGES

In 2019, we were able to launch our Newly Diagnosed family support packages, containing comfort items for baby and family. With these packages, we are also able to enclose educational materials in translated languages.

Each Newly Diagnosed Family Support Package costs roughly \$25, including shipping.



## HOSPITALIZATION SUPPORT PACKAGES

Since 2014, we have been sending custom support packages to families facing difficult and extended hospitalizations.

This year, we are hoping to launch HOPE, the bear of comfort, and a blanket program to give the greater community an opportunity to send a bit of HOPE to HIE families, no matter what they may be facing.

Each bear will cost roughly \$25, including shipping.



## LOSS SUPPORT FOR FAMILIES

For families facing the unimaginable heartbreak of loss of their child, we offer comprehensive support and memorialization.

Immediate loss support costs roughly \$125-150 per family, and loss keepsakes are roughly \$15 per family.



## SIBLING SUPPORT PROGRAM - SUPER SIBS

Siblings of hospitalized infants, medically complex children, and HIE loss are often in need of specific support. Through our Child Life Specialist, we are excited to launch our new Super Sibs program.



Costs are roughly \$20/sibling for a welcome kit, ongoing activities and support.

**Support programming and packages can be sponsored in desired quantities and recognition.**

# SUPPORT

## HUSTLE FOR HOPE 5K - RUN, WALK, ROLL

2020 was the year to begin large-scale virtual events, and Hope for HIE, while not anticipating COVID shutting the world down, launched its first international event.

Year over year, the event grew exponentially in participation and in fundraising to support the organization to nearly 500 participants worldwide in 2022. We are hosting 8 in-person events across North America in 2023, with additional interest for future years.



## 2023 HUSTLE FOR HOPE SPONSORSHIP LEVELS

### PRESENTING SPONSOR (limited to 3): \$10,000

- Have "Presented by Your Company (or brand)" added with race name and logo.
- Acknowledgement on race shirt.\*
- Acknowledgment of your support on the Hope for HIE and event website, as well as in the race packet.\*
- Acknowledgment in event-related emails and social media campaign.
- Complimentary race entry x 10
- Ability to include 1 piece of company material or company branded swag item in race packets\*

### RACE BIB SPONSOR (limited to 1): \$5,000

- Logo on custom designed race bib.\*
- Acknowledgement on race shirt.\*
- Acknowledgment of your support on the Hope for HIE and event website, as well as in the race packet.\*
- Complimentary race entry x 6

### RACE SHIRT SPONSOR (limited to 1): \$5,000

- Special Acknowledgement on race shirt.\*
- Acknowledgment of your support on the Hope for HIE and event website, as well as in the race packet.\*
- Complimentary race entry x 6

### GOLD LEVEL SPONSOR: \$1,000 (limited to 10)

- Acknowledgement on race shirt.\*
- Acknowledgment of your support on the Hope for HIE and event website, as well as in the race packet.\*
- Complimentary race entry x 2

### SILVER LEVEL SPONSOR: \$500

- Acknowledgment of your support on the Hope for HIE and event website
- Complimentary race entry x 2

### BRONZE LEVEL SPONSOR: \$250

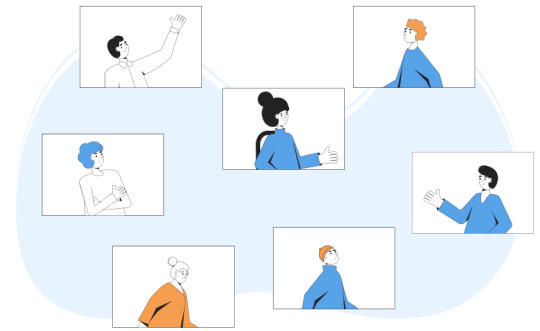
- Acknowledgment of your support on the Hope for HIE and event website

# SUPPORT

## HOPE FOR HIE COMMUNITY CONFERENCE

April 2024 we will be hosting our first Community Conference bringing together families from around the world, with medical, educational and research experts to support, collaborate and educate on the latest treatments and therapeutics in HIE.

Some of the hottest topics in HIE include etiological research, vision, cerebral palsy, dystonia, epilepsy, learning disabilities, family care and mental health support.



## 2024 COMMUNITY CONFERENCE SPONSORSHIP LEVELS

### PRESENTING SPONSOR (limited to 1): \$30,000

- Complimentary registrations (5) to all events, including scientific briefings, parent panels and multidisciplinary problem solving sessions
- Logo placement on website and signage
- 1 sponsored email to registrants
- Acknowledgement via social media
- Ad placement in event program: full page
- Recognition in opening remarks

### SCIENTIFIC BRIEFING SPONSOR (limited to 1 per session): \$10,000

- Complimentary registrations (3) to all events, including scientific briefings, parent panels and multidisciplinary problem solving sessions
- Logo placement on website and signage
- Acknowledgement via social media
- Ad placement in event program: half page

### SUNSHINE OF HOPE SPONSOR (non-exclusive): \$1,000

- Complimentary registrations (1) to all events, including scientific briefings, parent panels and multidisciplinary problem solving sessions
- Logo placement on website and signage
- Acknowledgement via social media
- Ad placement in event program: 1/8 page

### MULTIDISCIPLINARY ROUNDTABLE SPONSOR (limited to 1 per session): \$10,000

- Complimentary registrations (3) to all events, including scientific briefings, parent panels and multidisciplinary problem solving sessions
- Seat at the table to participate in topic discussion
- Logo placement on website and signage
- Acknowledgement via social media
- Ad placement in event program: quarter page

### TECH TALK PARTICIPATION (limited to 3 per session): \$5,000

- Complimentary registrations (3) to all events, including scientific briefings, parent panels and multidisciplinary problem solving sessions
- Seat at the table to present your new tech product during applicable roundtable session
- Logo placement on website and signage
- Acknowledgement via social media
- Ad placement in event program: quarter page

# SUPPORT

## PARTNERS IN HOPE PROGRAM

Hope for HIE offers a variety of ways for corporate entities to support and partner with our organization to accelerate our mission and mutual objectives. Through this recognition program, we are able to tailor to the specific mutual benefits of those participating to further their own organizational messaging and reach and sustain Hope for HIE's mission.

LEVELS OF SUPPORT	PLATINUM \$25,000+	GOLD \$10,000	SILVER \$5,000	BRONZE \$2,500
Recognition as <b>Partner in Hope</b> on Hope for HIE website, social media, and annual report. First access to other sponsorship opportunities.	✓	✓	✓	✓
Logo and messaging featured in spotlight sections of eNewsletter	✓	✓	✓	
Recognition during our Hope Goes Live events	✓	✓		
Recognition and speaking opportunity during our Executive Summit	✓			

## SPONSORSHIP OF SPECIFIC PROGRAMS OUTLINED

Hope for HIE's programs, events, and service lines are available for corporate sponsorship and support. Please contact the organization for more specific availability and details.