

2024 HIE Awareness Month Toolkit



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

Welcome

WELCOME TO 2024 HIE AWARENESS MONTH!

We come together every April - families, clinicians, researchers, partners, supporters and others in our global community - to spread awareness into the world about neonatal and childhood acquired Hypoxic Ischemic Encephalopathy. This year, the community theme is **TRANSFORMING HOPE.**

Our community is over 10,000 families, researchers, clinicians, and community members strong, across all ages and outcomes, from all over the world, and every day we are so grateful for the many ways we are able to transform the landscape of HIE to build brighter futures for more families.

We know all too well the isolation that can exist for our families. Each of us experienced HIE with our children, and we know when we connect as a community, we are Better Together.

We look forward to sharing the many stories of how not only Hope for HIE has transformed over the years, but the many stories in our community that happen every single day, whether that is online or in-person, redefining the word and concept of hope, day after day.

There has never been a more exciting time for the state of neonatal and pediatric HIE in our lifetime, with promise in research, and greater understanding of maximizing quality of life for more children and families.

We hope you will join us in this effort, and have outlined several ways to be involved this April in the toolkit.

We will continue to update our calendar of events and more tools to be used during April! Please reference HIEawarenessmonth.com for the latest event listing.



Always with Hope,

Betsy

Betsy Pilon
Executive Director

David

David Ford
President

Campaign Program

In 2024, our theme of **TRANSFORMING HOPE** calls our greater community to action. As we transform the state of HIE globally, we need everyone to help -- and every part matters -- whether it's sharing about HIE with friends and family, supporting research, advocacy or our support programs and services, taking part in a local or virtual Hustle for Hope, we can't wait to see everyone's efforts this year!

KEY DATES & EVENTS

- April 1 - HIE Awareness Month Kick-Off
- April 1 - May 15 - Hustle for Hope Events
- April 10 - Super Sibs Day
- April 15 - HIE Spirit Day
- April 20 - HIE Remembrance Day
- April 25 - Grandparents & Family Support Day

MEDIA MATERIALS

- Press release
- Key Messages
- Drop-in Article
- April is HIE Month Proclamation

SOCIAL MEDIA & WEB COMPONENTS

- Sample post language
- Social media banners
- Social media frames & filters
- Sharable facts and images
- Hashtags
- Links

AWARENESS MONTH SWAG SHOP

- Bonfire
- CafePress

OUTREACH IDEAS

ABOUT HOPE FOR HIE



Questions?

If you have further questions about HIE Awareness Month, please contact Betsy Pilon, Executive Director, at betsy@hopeforhie.org

Schedule of Events

Throughtout the month, we'll be adding to our Schedule of Events, and will keep you updated on Hieawarenessmonth.com, and through our social media channels.

KEY DATES & EVENTS

- April 1 - HIE Awareness Month Kick-Off
- April 1 - May 15 - Hustle for Hope 5K virtual events
- April 4 - Newly Diagnosed Family Support Group
- April 4 - HIE Awareness Day
- April 10 - Super Sibs Day
- April 11 - Loss Family Support Group
- April 13 - Hustle for Hope: Virtual Peloton Stack Events
- April 14 - Hustle for Hope: Cherry Hill, NJ area
- April 15 - HIE Spirit Day!
- April 16 - Foster/Adoption Support Group
- April 20 - HIE Remembrance Day
- April 20 - Remembrance Day Event with Julie Keon
- April 20 - Hustle for Hope: Chalfont, PA area
- April 20 - Hustle for Hope: Aurora, CO area
- April 21 - Hustle for Hope: Sparks, NV area
- April 21 - Hustle for Hope: Detroit, MI area
- April 25 - Grandparents & Family Support Day
- April 27 - Hustle for Hope: Seattle, WA area
- April 27 - Hustle for Hope: Alberta, Canada area
- April 27 - Hustle for Hope: Waukesha, WI area
- April 27 - Hustle for Hope: Berwick, LA area
- April 27 - Hustle for Hope: Imperial, PA area
- April 27 - Hustle for Hope: Charlotte, NC area
- April 27 - Hustle for Hope: Quebec, Canada area
- April 28 - Hustle for Hope: Saugerties, NY area
- April 28 - Hustle for Hope: Bristol, RI area



Press Release

FOR IMMEDIATE RELEASE

March 1, 2024

Contact: Betsy Pilon

Email: betsy@hopeforhie.org

Phone: 248-574-8099

When people think of babies in the NICU, did you know over 50% are full-term? Did you also know that a diagnosis called Hypoxic Ischemic Encephalopathy is the second leading cause of infant mortality, worldwide?

Two to three of every 1,000 live births in high-income countries and upwards of 30 per 1,000 live births in low and middle-income countries are impacted by Hypoxic Ischemic Encephalopathy, or HIE, a type of brain injury. More sustain an HIE injury after birth, due to multiple reasons, including near SIDS events. HIE often leads to diagnoses of cerebral palsy, epilepsy, learning disabilities, hearing and vision impairments, ADHD, and other developmental challenges, many not known until years into childhood.

Yet, awareness, funding, advocacy and research has been lacking until Hope for HIE started its advocacy efforts, starting global HIE Awareness Month in 2016 to bring attention and focus to a traditionally underserved population in both neonatal care and childhood services across pediatrics, neurology and in school settings. HIE is not a new problem, but there is great hope for this diagnosis through accelerated research, improved maternal care, and therapeutic development to decrease the incidence and improve quality of life.

During the month of April, Hope for HIE will once again be championing the HIE Awareness Month campaign with many partners across the neonatal and pediatric landscape globally, online, and regionally, to promote awareness, education and, most importantly, support.

The theme this year is Transforming Hope, which aims to share the historical perspective of HIE - the past, present and future - as well as the lived experiences, unmet needs of the community, and incredible stories of the global HIE community which will be shared widely on social media and the Hope for HIE website. The community can join in by using the hashtags #TransformingHope and #HIEawarenessMonth, as well as tagging @HopeforHIE. In addition, Hope for HIE will be hosting many online educational events.

A free, comprehensive toolkit is now available with social media graphics, talking points, event list and infographics at HIEawarenessmonth.com. Please help spread the word about global HIE Awareness Month, to maximize awareness efforts, and connect families to critical peer-to-peer support.

About Hope for HIE

Hope for HIE is the premier global patient advocacy organization for neonatal and pediatric hypoxic ischemic encephalopathy (HIE) dedicated to improving the quality of life for children and families affected by HIE through awareness, education and support. Hope for HIE is a registered 501c3 nonprofit organization, based in the United States, connecting a global community of over 10,000 families, researchers and clinicians.

Key Messages

HIE - Hypoxic Ischemic Encephalopathy - happens in 2 to 3 of every 1,000 live births in high-income countries, 10-30 per 1,000 live births in low and middle-income countries, and more in childhood, but many have no idea what it is.

- HIE stands for Hypoxic Ischemic Encephalopathy, or lack of oxygen from restricted blood flow to the brain. It is a type of brain injury.
- HIE is the second leading cause of infant mortality and lifelong disability, worldwide.
- HIE can cause cerebral palsy, epilepsy (including several rare epilepsies), hearing and vision impairments, learning and attention issues, feeding and GI issues, and other developmental delays and disabilities.
- Most people haven't heard of HIE. Prior to Hope for HIE, there was no central advocacy organization championing the children and families impacted due to disparities in care, communication and connection for HIE families. Equity in NICU experiential messaging continues to be a barrier to awareness and understanding for the general population, as many in the neonatal space have dismissed the lived experiences of non-premature families and conditions.
- HIE babies are typically born very very sick, and many identified as moderate or severe qualify for a specific type of treatment called therapeutic hypothermia or "brain cooling", taking a baby's body temperature to 91 degrees F to slow down the chain reaction of the brain injury.
- HIE can be caused by placental issues, uterine rupture, cord compression, cord issues such as a true knot, placental abruption, maternal infections like COVID, labor that takes too long or is not followed properly. In young children, near SIDS events, near drowning, cardiac arrest and other ways to cause a lack of oxygen cause HIE.
- Outcomes from HIE vary from unaffected/mildly impacted to loss of life, and everything in between.
- There are several promising therapeutics in development, some enrolling patients in clinical trials, that could decrease the impact of HIE, and improve outcomes. Research is accelerating at a rapid pace, and the state of HIE is transforming rapidly.
- Organizations like Hope for HIE are working to improve the quality of life for children and families impacted by HIE through Awareness, Education and Support, connecting with top clinicians and researchers in HIE and newborn brain care to work to decrease the impacts of HIE.

Drop-in Article

Recognizing HIE: A Call for Advocacy

Have you heard of HIE? It's the second leading cause of infant mortality and lifelong disability worldwide. 2-3 per 1,000 live births in high-income countries, and upwards of 30 per 1,000 live births in low and middle income countries, are diagnosed with a type of neonatal and pediatric brain injury, Hypoxic Ischemic Encephalopathy. This diagnosis carries an array of outcomes, from unaffected through loss.

While you may think "preemie" when thinking of the NICU, most HIE babies are typically near or full term, born very ill, and go through a unique NICU experience. HIE has a wide variety of causes - from placental issues to cord compression during birth - and has some pediatric causes like near-SIDS events.

HIE can lead to a variety of additional diagnoses, with the most common being cerebral palsy, epilepsy, learning and attention issues, hearing, vision and feeding issues, and other developmental delays and disabilities.

This April is HIE Awareness Month, and [insert organization name] is highlighting the work of the Hope for HIE foundation to bring worldwide awareness to this type of brain injury advocating for awareness, education and support to the over 10,000 families connecting worldwide, and for equity in care, communication and connection.

We also want to share the stories of the HIE community, and participate in HIE Remembrance Day on April 20th with the online Wave of Light to honor and remember HIE children gone too soon.

The more we know, the better care, communication and connection this incredible community of children and families can expect, bringing improved quality of life, dignity and respect.

For more information, visit **HIEawarenessmonth.com**.

HIE Awareness Month Declaration

DATE]

[ADDRESSEE TITLE] [ADDRESSEE FIRST NAME] [ADDRESSEE LAST NAME]

[ADDRESSEE STREET ADDRESS]

[ADDRESSEE CITY], [ADDRESSEE STATE] [ADDRESSEE ZIP CODE]

Subject: World HIE Awareness Month Proclamation/Letter of Support Request

Dear [ADDRESSEE SALUTATION] [ADDRESSEE LAST NAME],

Hope for HIE, the premier global resource for families whose children have been diagnosed with hypoxic ischemic encephalopathy (HIE), has designated April World HIE Awareness Month. Hope for HIE is a 501(c)3 non-profit registered with the IRS.

I am writing to request a proclamation or letter of support from the [NAME OF GOVERNMENTAL OFFICE OR LEGISLATIVE BODY] acknowledging World HIE Awareness Month on behalf of Hope for HIE and families, like mine, in [YOUR STATE] and around the world that have been impacted by HIE. The goal of World HIE Awareness Month is to increase awareness, education, and support among medical professionals, support providers, legislators, and the public.

HIE is the second leading cause of infant mortality and lifelong disability in the world. Simply put, HIE means the following:

- Hypoxic = lack of oxygen
- Ischemic = restricting blood flow
- Encephalopathy = affecting the brain

When the brain is deprived of oxygen, brain cells are injured. Some may recover, some may die. The most common causes of oxygen deprivation to the brain are low levels of oxygen in the blood or a reduced flow of oxygen to the brain. This can happen in a variety of ways prior to birth, during the birth process, after birth, and during childhood.

HIE has many causes, including placental insufficiency, uterine rupture, placental abruption, true umbilical knots, cord compression, maternal blood clotting disorders, fetal maternal hemorrhage, extremely low maternal blood pressure, trauma during delivery, placental blood clots, shoulder dystocia, cord prolapse, aneurysm rupture, cardiac arrest and near Sudden Infant Death Syndrome (SIDS) events.

The only current treatment that has shown clinical benefit immediately post-injury is therapeutic hypothermia (also known as cooling). Multiple studies have shown a reduction death and disability, depending on severity. Those affected may need other medical intervention to support their organs or to treat seizures as they recover.

Outcomes are wide-ranging. No two children will be the same. The impact of each child's injury is different based on multiple factors, including what parts of the brain were affected and how damaging the insult was to the brain.

- 75-80% survive
- 50-70% experience seizures
- 40-50% develop a permanent developmental disability, such as cerebral palsy, epilepsy, vision loss, hearing loss, feeding issues, cognitive issues, speech delays or global delays

HIE Awareness Month Declaration

I am requesting your support because World HIE Awareness Month is personally significant to my family and me.
[OPTIONAL - INCLUDE A SUMMARY OF YOUR PERSONAL STORY]

Hope for HIE has been an invaluable resource for information and has helped me connect with other families around the world affected by HIE. With your support for World HIE Awareness Month, families will have a better chance of learning about Hope for HIE and other helpful resources more quickly.

I'd appreciate an opportunity to visit with you to personally thank you, share more about our story, and talk with you about how much your support for means to families like mine.

Please contact me at [PHONE NUMBER] or [EMAIL ADDRESS] to let me know if you have questions or need additional information.

Sincerely,

[YOUR NAME]

[YOUR STREET ADDRESS]

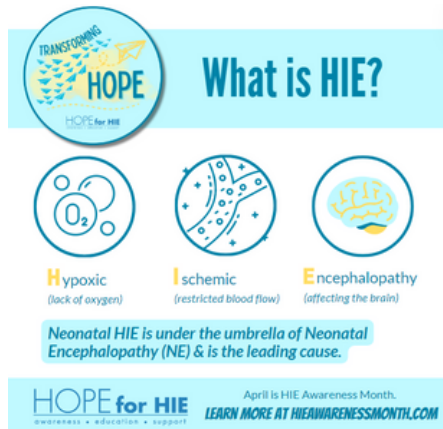
[YOUR CITY], [YOUR STATE] [YOUR ZIP CODE]

Ph: [PHONE NUMBER]

Social Media Tools

Social Media Graphics

A collection of downloadable graphics and templates are available at **HIEawarenessmonth.com**, or shared from Hope for HIE's public Facebook page - Facebook.com/hopeforhie.



Hashtags

- #HIEAwarenessMonth
- #TransformingHope
- #HopeforHIE

Social Media Channels - Follow, Like, Share @HopeforHIE

- **Facebook:** Facebook.com/hopeforhie
- **TwitterX:** Twitter.com/hopeforhie
- **Instagram:** Instagram.com/hopeforhie
- **YouTube:** Youtube.com/c/hopeforhie
- **LinkedIn:** Linkedin.com/company/hopeforhie
- **TikTok:** TikTok.com/@hopeforhie



Links

- HIEawarenessmonth.com
- HopeforHIE.org

Social Media Tools

Sample Posts

- April is #HIEAwarenessMonth! This year's theme #TransformingHope focuses on the many ways the state of HIE is transforming -- the past, present and future -- giving HOPE, across the many definitions, to the global HIE community. Learn more and download the free #HIEAwarenessMonth toolkit at Hieawarenessmonth.com.
- It's #HIEAwarenessMonth and we're sharing our #TransformingHope toolkit! HIE is the second leading cause of infant mortality and lifelong disability, worldwide, impacting 2-30 per 1,000 live births. This month brings attention to the global HIE community and how the state of HIE is transforming, across all outcomes. Learn how we can improve care, communication and connection to improve quality of life for children and families facing HIE to build brighter futures.
- This year's #HIEAwarenessMonth highlights how the concept of HOPE transforms through action, community, creativity, connection and support. With educational and community events, resources and advocacy, we're showing what can be done when we come together and work to best support families, accelerate research, and celebrate the stories of the global HIE community.
- You can support #HIEAwarenessMonth in April by sharing tools from the HIEawarenessmonth.com toolkit, getting involved as a volunteer on the Hope for HIE volunteer hub (HopeforHIE.org/volunteer), through our Hustle for Hope events, through advocacy and awareness! Let's show families in the global HIE community how much we support them!

Facts to Share

- What is HIE? H - Hypoxic (Lack of Oxygen), I - Ischemic (Restricting Blood Flow), E - Encephalopathy (Affecting the Brain)
- HIE is the second leading cause of infant mortality and lifelong disability, worldwide.
- HIE has a wide range of outcomes. Outcomes range from unaffected/minimally affected to loss of life, with anything and everything in between.
- HIE can be caused before, during and after birth. Placental abruption or other placental issues, uterine rupture, fetal-maternal hemorrhage, shoulder dystocia, cord compression and cord issues, maternal infections like COVID, mismanaged birth, near SIDS and cardiac arrest are just a few causes.
- HIE is the leading cause of neonatal seizures, and a top cause of many types of epilepsies including Infantile Spasms, Lennox-Gastaut Syndrome, DEE-SWAS/Electrical Status Epilepticus in Sleep, and others.
- HIE can cause other conditions. Cerebral palsy, epilepsy, vision and hearing loss, speech delays, learning and attention issues, feeding issues and global delays and disabilities are just a few of those conditions.
- Babies and children who experience HIE are typically very, very sick at the time of injury, or very soon after. Many experience seizures, floppy muscle tone, have a lack of respiratory effort, have absent reflexes and need various forms of life support to stabilize them.
- Treatments specific to HIE are currently limited to therapeutic hypothermia, which has become the standard of care for most moderate to severe-presenting neonatal HIE in high-income countries, but more therapeutic discoveries are in the pipeline, with some enrolling babies in clinical trials.
- Hope for HIE provides comprehensive support programs and services to a worldwide network of over 10,000 families, and has been accelerating advocacy and research through collaborations in the neonatal and pediatric neurology landscapes to decrease the incidence and impact of neonatal and pediatric-acquired HIE since 2010.

HIE Awareness Month Swag

Are you swagged out with your favorite merch?

Purchase HIE Awareness Month apparel and gifts

- **Adult & Kid Apparel**

- Bonfire: <https://www.bonfire.com/store/hopeforhie/>

- **Infant & Toddler Apparel, Stickers, Car Decals, Drinkware & More:**

- CafePress: <https://www.cafepress.com/hopeforhie/17384837>



Outreach Ideas

What can I do to support HIE Awareness Month?

Help spread the word about HIE on Social Media

- Join our #HIEAwarenessMonth #TransformingHope campaign.
- Share your connection to HIE, or what you appreciate about the HIE community
- Put **HIEawarenessmonth.com** in the bio of your Instagram or TikTok profile
- Link to posts on Facebook, Twitter, Instagram, LinkedIn, TikTok and other platforms to **HIEawarenessmonth.com** and tag @HopeforHIE so people can access the different tools and messages.
- Use our social media frames and stickers on Facebook, Instagram, and TikTok.
- Use the hashtags #HIEawarenessmonth, #HopeforHIE and #TransformingHope so we can track reach

Start a Facebook or Instagram Fundraiser

- Facebook Fundraisers (<https://www.facebook.com/fund/hopeforhie/>) are a quick and easy way to share awareness, your connection to HIE, and more.
- You can also add a donation to an Instagram post or story sticker.

Get your local community involved

- Participate in the annual Hustle for Hope Virtual or In-Person 5K. Sign up at [HopeforHIE.org/hustleforhope](https://www.hopeforhie.org/hustleforhope) and encourage your colleagues, friends and family, too.
- Print off any resources and share with your medical and educational teams and talk about the importance of serving our families - or - order an awareness kit!
- Email this toolkit to your friends and families, or refer them to **HIEawarenessmonth.com**.
- Think about other community groups that may benefit from learning about HIE, or Hope for HIE, and getting involved to better support HIE families in your community.

Get your employer involved

- Let them know that April is HIE Awareness Month and share why HIE is an important topic to you
- Offer speaking on the subject about your experience and connecting with any applicable employee groups.
- See if your employer matches donations

Purchase HIE Awareness Month apparel and gifts

- **Adult & Kid Apparel**
 - Bonfire: <https://www.bonfire.com/store/hopeforhie/>
- **Infant & Toddler Apparel, Stickers, Car Decals, Drinkware & More:**
 - CafePress: <https://www.cafepress.com/hopeforhie/17384837>



About Hope for HIE



THANK YOU for your interest and involvement in making 2024's HIE Awareness Month a success!



Get to know Hope for HIE

Hope for HIE is the global patient advocacy and support organization for neonatal and pediatric-acquired Hypoxic Ischemic Encephalopathy. It was started in 2010 as a small Facebook support group by three parents of children with HIE who connected online. It was founded as a nonprofit in 2013, confirmed in 2014, and has grown from a hundred families to now connecting and supporting over 10,000 families worldwide in 2024.

We have an all-volunteer Board of Directors, small but mighty staff, a myriad of volunteers, and a multidisciplinary Medical Advisory Board of the top clinicians, researchers and therapists dedicated to improving the quality of life for children and families impacted by HIE through Awareness, Education, and Support. We are actively engaged in several research projects with the hope of advancing therapeutic discoveries for those impacted by HIE.

We are supported by our incredible community, Partners in Hope corporate support, and grants to help implement the programs and services aligned with our mission.

We believe that we are #BetterTogether when we can come together to reduce disparities in care, communication and connection from the very beginning of the HIE journey, finding and creating spaces to connect with other organizations, research collaborations and collectives.

Learn more at HopeforHIE.org and thanks for being a part of our community!

Ideas?

If you have ideas about next year's HIE Awareness Month, or other ways to partner to move our mission forward, please contact Betsy Pilon, Executive Director, at betsy@hopeforhie.org