

Partnering with Hope for HIE

This guide explains how Hope for HIE partners with international, national, and regional organizations, and what a strong partnership looks like on both sides.

Who we are and why we partner

Hope for HIE is a global advocacy and support nonprofit organization connecting families impacted by neonatal and pediatric-acquired Hypoxic Ischemic Encephalopathy (HIE). It began in 2011 as a parent support group, became a registered nonprofit in 2013, and now reaches over 15,000 families in more than 100 countries.

Our work spans five pillars: Awareness, Advocacy, Education, Research, and Support.

No single organization can meet every family's needs across every health system, language, and culture. Local organizations understand their own systems in ways we cannot. Together we can offer a global network and a trusted evidence base, with local knowledge and presence. We partner so that families everywhere get the best of both.

What we have built

Over more than a decade, Hope for HIE has become the global reference point for HIE families, and the trusted patient-family voice among the clinicians, researchers, regulators, and industry working to improve outcomes. That standing was earned through sustained, rigorous work, and it is what we bring to every partnership.

Community-Centered Support, Available Globally

- A peer support network that began in 2011 and now reaches more than 15,000 families in over 100 countries.
- Comprehensive support services from credentialed staff, free to any HIE family: weekly video support groups, child life services, and social work.
- Family-facing programs, including NICU Welcome Bags for families during therapeutic hypothermia, a global ambassador network, and support to host local events through Hope for HIE.
- Evidence-based educational content, scientifically reviewed with our Medical Advisory Board, to build health literacy and help families make informed decisions.

Awareness and Advocacy

- Founded HIE Awareness Month and built it into an annual global campaign, giving families, hospitals, and professional organizations a shared moment to raise the visibility of HIE.
- Grew an ambassador program that puts families' own stories and leadership at the center of awareness efforts in their communities.

- Advocate for recognition of HIE as a lifelong condition, which means long-term follow-up, developmental and educational supports, and care through the transition to adulthood.
- Champion the inclusion of full-term NICU and HIE families in the institutions, research, and policy discussions from which they have historically been left out.
- Add a unified patient-family voice to coalition advocacy on neonatal, neurology and rare disease policy, and to state and national efforts such as population-based HIE registries.

Driving Research to Reduce Incidence and Improve Outcomes

We don't just take a seat at research tables. We build them.

- Co-leadership, with the Cerebral Palsy Research Network, of a global community HIE registry funded by the Pediatric Epilepsy Research Foundation.
- A community-centered research agenda with clear priorities for new therapies, reducing the incidence of HIE, and improving outcomes.
- Co-authorship of over 40 peer-reviewed research articles, including an international Delphi consensus defining neonatal encephalopathy, analyses from the NICHD Neonatal Research Network, and 2026 papers on family engagement in *Pediatric Research*, *Pediatrics* and *Neurology*.
- Patient-family partnership on international studies across North America, Europe and Australia.

Patient-Family Advocacy with the Clinical and Scientific Community

- Founding member and leader in the Newborn Brain Society, including leadership of its Family Advisory Network.
- Co-founder, with the Newborn Brain Society, of Polar Bear Care, an initiative to increase parental holding during therapeutic hypothermia.
- Leadership and membership in quality-improvement and clinical care bodies, including the Family-Centered Task Force steering committee, the NICHD Neonatal Research Network Community Engagement Panel, the NICU Parent Network, and neonatal and neurology advocacy collectives.
- Invited review of, and contributions to, professional society guidance and international conference programs in neonatal neurology.

Patient-family advocacy in regulatory science and therapy development

- Co-founder of the Neonatal Brain Injury Collaborative, convened under the International Neonatal Consortium, which brings families, clinicians, regulators, and industry together on trial design and biomarkers.
- Patient-perspective input to companies developing HIE therapies and to federal research programs, under clear transparency standards.
- Direct advocacy with regulatory agencies to bridge the identified barriers as a neutral third-party, working to speed up the regulatory process, and shift from “protecting babies from research” to empowering families in research and therapeutic development.

Protecting and Empowering Families

Families reach out at their most vulnerable moments, and they deserve information and support they can trust.

- **Standing up to predatory legal marketing.** Some law firms publish content made to look like neutral family resources, in order to recruit HIE families as clients. Hope for HIE has filed formal complaints against about a dozen firms since our founding. We do not accept law-firm sponsorship or advertising, and we help families recognize when a "resource" is really a sales channel.
- **Guarding against misinformation.** We correct inaccurate or overstated claims about HIE, prognosis, and unproven therapies, and hold every resource we share to a clinically reviewed standard.
- **Transparency with industry.** Our industry relationships follow clear standards, with funding disclosed, so families always know who supports what they are reading.
- **Safe, moderated community spaces.** Our online groups are governed by trust, privacy, and affiliation policies. Our community is never used as a recruitment pool for outside platforms, firms, or commercial interests.
- **Empowering family leaders.** We train and support parents to serve as advocates, ambassadors, peer mentors and research partners, so that families shape decisions rather than just react to them.

These relationships took years of trust and resources to build. It is why we take partnership seriously, and why we protect how the Hope for HIE name is used.

Our partnership principles

1. **Families come first.** Every partnership should help families in your community more than either of us could alone.
2. **Value flows both ways.** Each stage of partnership names what each organization contributes. We grow our commitments together as shared work takes shape.
3. **Complement, don't duplicate.** You lead on your health system, language, and local needs, and co-lead where established relationships exist. We contribute our global network, research voice, and established resources. Neither of us rebuilds what the other already does well.
4. **We want to extend the Hope for HIE brand to help you succeed.** We will consider partnerships that extend the Hope for HIE brand into local communities, as we often already have relationships we can co-build.
5. **You can stay independent.** Partners keep their own governance, identity and decision-making, in line with local regulations.
6. **Credit and accuracy go together.** When we adapt our materials, we credit each other and hold shared content to the same standard of accuracy.
7. **Trust is built in stages.** Every new relationship starts in the same way, no matter who founded the organization. This keeps our approach fair and consistent for everyone.

Pathways to partnership

Partnerships grow through three stages. Every organization begins as Connected. Moving to the next stage happens by mutual agreement once shared work is underway, usually after six to twelve months.

Stage	What Hope for HIE offers	What we ask of partners	How the partnership can be described publicly
Connected	Access to our public resources; an introductory call; a listing in our international organizations directory; referrals of families in your country or location.	An overview of HIE care and support in your country (follow-up, services, benefits); a named contact; referring families to our global community	"An independent organization listed in Hope for HIE's international directory"
Collaborating	Permission to translate or adapt specific materials, with attribution; regular check-ins; participation in collaborative and Hope for HIE-led projects including HIE Awareness Month.	Sharing translated or localized materials back for families in your language; country insights for awareness campaigns; co-hosting at least one family event or webinar a year	"In collaboration with Hope for HIE" on the specific co-produced items
Affiliate	Use of program models (such as our NICU Welcome Bags) under agreement; a co-branded Awareness Month toolkit; joint funding and research opportunities; advisory support	An annual set of shared outcome measures; participation in joint research or data efforts harmonization efforts where appropriate; an active seat on the Alliance Council; agreement to our shared standards	"Affiliate member of the Global HIE Family Alliance" with the Alliance member mark (to be built)

Contributions are sized to each organization's capacity. A newly formed, volunteer-led group and an established, institution-backed group will contribute differently, and both are equally welcome.

What partners bring

The strongest partnerships start with a concrete contribution from each side. When we talk, we'll ask which of these you could offer:

- **Reach:** connecting families, clinicians, or hospitals in your region to the global HIE community.
- **Local knowledge:** expertise in your health system, policies, or language, such as translations or a country resource guide.
- **Evidence:** data, registry participation, or research collaboration that strengthens what we know about HIE.
- **Shared work:** hosting an event, leading a working group, or moderating a language-specific support group.
- **Shared voice:** joining coordinated advocacy and awareness efforts.

We will be just as clear about what Hope for HIE contributes. Our aim is a partnership where both organizations, and most of all families, are better off.

Accurate, vetted information

Families make real decisions about their children's care based on what we share. That is why any content associated with Hope for HIE, whether our own, adapted, or co-produced, must meet one shared standard.

1. **Evidence-based.** Claims reflect current clinical consensus and cite their sources. Emerging or investigational therapies are clearly labeled as such.
2. **Clinically reviewed.** Medical content is reviewed by a qualified clinician before it is published through our established Medical Advisory Board workgroup.
3. **Accurate in translation.** Translated medical content is checked by a clinician fluent in that language, or verified by back-translation, as well as a family member fluent in the language.
4. **Dated and maintained.** Each resource shows when it was last reviewed and is re-reviewed at least every two years.
5. **Transparent.** Authors, reviewers, and any industry funding are disclosed.
6. **Correctable.** If either organization finds an error in shared content, it is corrected or withdrawn within 10 business days, and the other organization is notified.

When you adapt one of our resources, we'll work with you on a joint review. Translation and simplification can change medical meaning without anyone intending it, and a quick shared check protects families and both of our reputations.

Using the Hope for HIE name, materials and logo

We're glad to see our resources reach more families. So that families always know who stands behind what, we ask partners to follow these guidelines.

Use	Connected	Collaborating	Affiliate
Refer families to Hope for HIE	Welcome	Welcome	Welcome
Describe Hope for HIE as a "partner"	Not yet	For specific co-produced items	With agreed wording
Display the Hope for HIE logo	Not yet	On co-branded items we approve together	Alliance member mark; the Hope for HIE logo with approval
Name Hope for HIE in a grant or funding application	Not yet	With a signed letter of support for that application	Under a signed agreement
Adapt our programs or materials	Not yet	Specific items, with credit and joint review	Under a program agreement
Speak on behalf of Hope for HIE or quote our team	With approval	With approval	With approval

Credit line for adapted materials. Use *"Adapted with permission from Hope for HIE (hopeforhie.org)"* on content that keeps its medical meaning or has passed joint review. Material inspired by our work but independently developed should not carry our name, and there is a clear line of "inspired by" and plagiarism. It's important to understand international intellectual property laws regarding content, trademarks, and copyright. Hope for HIE is an internationally registered and recognized word mark, and therefore use must be approved.

Your independent work. Your own content, programs and fundraising are yours. Please don't suggest they are endorsed by Hope for HIE unless we have agreed to that in writing.

The Global HIE Family Advocacy Alliance (forming)

Hope for HIE is convening a network of HIE patient-family organizations from around the world. Members stay independent and work together on the things that are stronger when coordinated:

- **HIE Awareness Month:** a shared theme, a multilingual toolkit, a coordinated launch, and a combined picture of our global reach.
- **Education:** a shared library of reviewed resources, each credited to the organization that created it, plus webinars that rotate host countries and time zones.
- **Family support:** warm hand-offs for families who move or seek care across borders, shared training for peer mentors and moderators, and common safety and privacy standards for online groups.

How it works. Hope for HIE serves as convener and coordinator. An Alliance Council with one seat per member organization sets shared priorities each year. Working groups are chaired by member organizations on a rotating basis.

Membership. Members sign a short charter covering accuracy, privacy, attribution, and funding transparency. Each member contributes at least one thing a year, such as a translation, a hosted event, country insights, or chairing a working group. There are no dues in the first year. If you're interested in joining as a founding member, let us know in your reply.

How to get started

1. **Reply with the intake form available on our website:**
https://hopeforhie.org/communityaffiliationpolicy/#submit_a_resource_or_partnership_request
2. **Introductory e-mail.** We'll connect with you about moving forward a partnership. Questions will be sent to be answered before an introductory meeting (see questions below).

Intake questions: These will be sent to you after reviewing your intake form submission.

1. Registration status (registered nonprofit, in process, or informal group)
2. Who leads the organization? Please include the role of parents or people with lived HIE experience.
3. Which families do you serve, and what do you offer or plan to offer?
4. How are you funded? Please include any support from industry, legal, or commercial sources.
5. Who reviews your medical content?
6. What would you most like to do with Hope for HIE?
7. What could your organization contribute to a partnership? (See "What partners bring.")
8. Named contact and preferred time zone for meetings

Contact: [partnerships email]