



Sometimes, caregivers need help that isn't necessarily task-based. Sometimes, parents and caregivers want someone to commiserate with, get advice from, and talk to. In many cases, support groups can fill this void, as they are composed of parents going through the same situation who can provide a perspective that doctors, therapists, or parents of children without disabilities simply cannot provide. As online support groups become more widespread, parents

can more easily find individuals to talk to, though in-person groups still exist.

Parent Support Groups for HIE

The following support groups exist for parents of children with HIE:

- <u>Hope for HIE</u>: A closed forum for parents of children impacted by hypoxic-ischemic encephalopathy; maintains a worldwide presence with country- and state-specific subgroups.
- <u>Newborn Brain Cooling</u> is a closed support group for parents whose children have received hypothermia therapy (brain cooling) as infants.
- BabyCenter has several message boards relating to HIE, including the <u>Children and Babies with Global Developmental Delay</u> board, the <u>Delayed Darlings Group</u> and the <u>Special Needs and Medically Complex Children</u>
- Beautiful Faces of HIE is a closed Facebook group.
- <u>Coping with HIE/CP</u> is an open Facebook group for parents of children with HIE and/or cerebral palsy.



Other Special Needs Parent Support Groups and Resources

Other support groups and resources for more general special needs concerns include:

- <u>Epilepsy.com</u> has a forum available for those impacted by epilepsy.
- <u>CityData has a forum dedicated to helping parents of children with special needs.</u>
- Parents of Disabled Adults is a forum for parents of adult children with disabilities.
- <u>PreemieWorld</u> provides a regular newsletter to point parents of premature babies towards resources, support groups, and certain products to help parents care for their child at home. It also has a Preemie Directory that can point parents towards resources and help for their kids, as well as parent and professional newsletters that track new developments, groups, and resources in the field.
- The Inspire Forums have forums dedicated specifically to parents of preemies.
- <u>March of Dimes</u> seeks to help prevent preterm births.

Often, many larger disability-related organizations such as the Arc_or <u>United Cerebral Palsy</u> will also have resources available for parents to support each other locally. Often, individual blogs, such as <u>CP Daily</u> <u>Living</u>, have listings of individual parent support resources as well.





Infant Loss

<u>Hope for HIE</u> has a resource page dedicated to helping families to cope with the grief and heartbreak that comes with losing a child from complications of HIE.

Note: The HIE Help Center has no affiliation with the above support groups, and aims to provide this listing as an informational resource only. Participation in many of these support groups is closed and limited only to parents of children with a specific diagnosis, making these forums and/or websites safe spaces for parents to freely discuss their child's diagnosis freely.

Want to be posted on our support group listing? Contact us via email at <u>admin@hiehelpcenter.org</u>.

Do you need someone to talk to?

Your child was just diagnosed with HIE and your head is spinning with what may feel like a thousand different things. Questions, medical terms, care plans; it can be difficult to make sense of everything that has happened.

As you start to do your research on exactly what your child's diagnosis means, you may be bombarded with facts, information, and advice regarding HIE, and you may be lost as to where to turn next.

We want to hear your story. HIE Help Center is owned by ABC Law Centers (a birth injury law firm). The intake team at ABC Law Centers is here to listen to every detail of what you and



your family may have gone through during labor and delivery. Although we are not doctors and cannot provide medical advice, our team can provide you with resources specifically tailored to your situation. Our team has reviewed and handled thousands of cases and is trained to recognize if there may have been medical malpractice that lead to your child's diagnosis, and we can advise if taking legal action may be beneficial to you and your family.

Call us at (888) 329-0122 to speak with a member of our intake team.