HOPE for HIE
awareness • education • support

EDUCATING PATIENTS ON

INFANTILE SPASMS

AND HYPOXIC ISCHEMIC ENCEPHALOPATHY

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HIE AND INFANTILE SPASMS

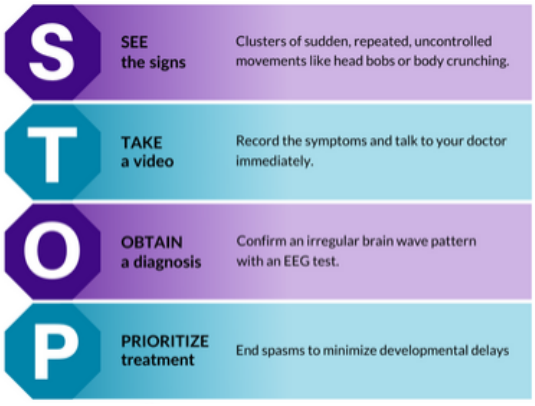
HIE (Hypoxic Ischemic Encephalopathy) is one of the leading causes of Infantile Spasms. While the reported rate of infantile spasms after HIE varies, with anywhere from a few percent to up to one-third of babies being diagnosed with IS, according to studies, it is a significant issue in the HIE community.

As the premier organization serving families of children with HIE, we see families are often unaware of IS, the symptoms, and treatment. For children with Infantile Spasms, quick, aggressive, and correct treatment is critical. Families are often hesitant to begin treatments because they are nervous about the potential side effects, and we want to better help you communicate the importance of aggressive treatments with the families you serve.

PROMOTING AWARENESS

Because this is such a critical issue for so many of our families, Hope for HIE participates in the Infantile Spasms Action Network (ISAN), to bring awareness and education of Infantile Spasms to our community. We appreciate your help in educating your patients on the symptoms of Infantile Spasms and what to do if they suspect their child is exhibiting symptoms.

CNF uses STOP to help promote awareness of IS and the need to seek treatment. This helpful mnemonic device can help spread awareness, and promote quick treatment for IS.



INFANTILE SPASMS OVERVIEW

- Infantile Spasms, also known as West Syndrome, occur in fewer than 6 cases per every 10,000 live births.
- Multiple underlying disorders can be involved with Infantile Spasms, including HIE, metabolic disorders and genetic disorders. HIE is the etiology in about 4 percent of IS cases.
- The rate of epilepsy in children with HIE is as high as 33 percent, with Infantile Spasms making up about 25 percent of epilepsy cases that begin in the first year of life.
- The onset of IS is usually in the first year of life, most commonly between 4 - 8 months. And they typically stop by age 2 - 4 years.
- The seizures often look like a sudden bending forward of the body with stiffening of the arms and legs lasting for 1-2 seconds. Spasms tend to occur upon awakening and often occur in multiple clusters and hundreds of seizures per day.
- It is critical to begin treatment as soon as possible. Ongoing Infantile Spasms have the potential to adversely impact all aspects of brain development. One study showed delaying treatment as little as one week could have long-lasting impacts.
- Standard treatment for Infantile Spasms includes several forms of hormonal therapy, including adrenocorticotrophic hormone (ACTH) or prednisolone),or the anti-seizure medication vigabatrin.