STOP INFANTILE SPASMS

The Infantile Spasms Action Network provides the "STOP" mnemonic device to help parents recognize Infantile Spasms and encourage rapid treatment:

S	**SEE the signs**	Clusters of sudden, repeated, uncontrolled movements like head bobs or body crunching.
T	**TAKE a video**	Record the symptoms and talk to your doctor immediately.
O	**OBTAIN a diagnosis**	Confirm an irregular brain wave pattern with an EEG test.
P	**PRIORITIZE treatment**	End spasms to minimize developmental delays

WHERE TO FIND MORE INFORMATION

Hope for HIE participates in both the Infantile Spasms Action Network (ISAN) and the PCORI-funded Neonatal Seizure Registry to promote awareness and education of Infantile Spasms through our outreach and educational efforts to minimize the impact of HIE and Infantile Spasms.

You can learn more at:

hopeforhie.org/infantilespasms

CONNECT WITH US

HIE.support
Outreach@hopeforhie.org
@HopeforHIE on social media

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LEARNING ABOUT

INFANTILE SPASMS

AND HYPOXIC ISCHEMIC ENCEPHALOPATHY

KNOW THE FACTS ABOUT INFANTILE SPASMS

Babies with HIE (Hypoxic Ischemic Encephalopathy) have a higher risk of developing Infantile Spasms (IS), a specific type of epilepsy that requires urgent treatment–ideally within one week of an IS diagnosis. Infantile Spasms most commonly occurs in babies between 3 and 9 months old.

The onset of Infantile Spasms is considered a medical emergency.

- HIE is the second leading cause of Infantile Spasms. Additional causes include other types of early brain injury (e.g., strokes or brain injury from low glucose or preterm birth), abnormalities in brain development (e.g., tuberous sclerosis complex or other brain malformations), and genetic changes.
- The reported rate of Infantile Spasms after HIE varies from a few percent to up to one-third. Most babies with HIE do not develop Infantile Spasms, but it's important to be aware of what they are, what they may look like, and the best way to seek evaluation, diagnosis and treatment with your medical team.
- Risk factors for Infantile Spasms after HIE include neonatal seizures and brain injury on MRI. Children with a more severe clinical course are more likely to have Infantile Spasms.

HOW TO SPOT INFANTILE SPASMS

Most commonly, Infantile Spasms look like a sudden bending forward of the neck with simultaneous raising of the arms and legs lasting for 1-2 seconds and happening in clusters, or many times in a row. Some caregivers may mistake Infantile Spasms for reflux or other harmless conditions.

- Less commonly, Infantile Spasms can include a sudden extension of the body or widened eye opening.
- They typically occur just as the baby wakes up, but can occur throughout the day.
- The movement may be symmetric (the same on both sides of the body) or asymmetric
- Children can have many Infantile Spasms per cluster and many clusters per day, which can add up to hundreds of spasms each day.

FINDING AN EFFECTIVE PROVIDER

If your child is deemed at high risk of developing Infantile Spasms, it is important you work with an effective provider who has experience identifying and treating Infantile Spasms.

Ask questions to your team to see if they do, and if not, who they can refer you to.

QUICK AND AGGRESSIVE TREATMENT IS ESSENTIAL

Urgent treatment, within one week after spasms begin, is important for the best chances of eliminating the spasms. Delaying treatment can impact a child's development
long-term.

- Standard treatment for Infantile Spasms includes hormonal therapy (ACTH or prednisolone) and/or vigabatrin
- Some neurologists may prefer to start with a combination of both hormone and vigabatrin therapy.

WHAT TO DO IF YOU SUSPECT INFANTILE SPASMS

- Contact your primary care provider or neurologist immediately.
- Take a video of the spasms to show the doctor.
- Be prepared to bring your child for an EEG as soon as possible.