

**FOR IMMEDIATE RELEASE**

**November 27, 2019**

***Fifth Annual Infantile Spasms Awareness Week to Educate Public on Infantile Spasms***

*MINNEAPOLIS, Minnesota* — From December 1 to 7, 2019, a coalition of organizations will mark the fifth annual Infantile Spasms Awareness Week (ISAW). The goals of ISAW are to increase awareness and understanding of infantile spasms; to share research and support initiatives; and to declare to patients and caregivers that help is available and hope exists. The campaign was established by the Infantile Spasms Action Network (ISAN), a collaborative advocacy group of 30 international organizations that have come together to inform families, physicians and caregivers about the signs of infantile spasms.

Infantile spasms (IS) is a rare disease that affects 2 to 3 babies per 10,000 live births. The spasms are classified as seizures, and are usually found in infants under 12 months, with symptoms first presenting from birth to six months. The condition is caused by activity in a baby's brain and includes repetitive, subtle movements—such as jerking or “crunching” of the mid-section, uncontrolled head movements, raising of the arms or wide-eyed blinks. It is typically misdiagnosed as colic or reflux, or just seen as a child's typical reflex development.

Because the seizures in IS present more subtly than the convulsions in a typical grand mal seizure, ISAN developed the ‘STOP’ Infantile Spasms mnemonic to help people remember what's most important when recognizing the disease's subtle symptoms:

- ◆ **See the signs:** clusters of sudden, repeated, uncontrolled movements like head bobs or body crunching
- ◆ **Take a video:** record the symptoms and talk to your doctor immediately
- ◆ **Obtain diagnosis:** confirm an irregular brain wave pattern with an EEG test
- ◆ **Prioritize treatment:** end spasms to minimize developmental delays

“What I would always suggest to families is that if you feel like something is wrong, pay attention. Infantile spasms starts with very subtle signs,” says Amy Brin, Executive Director and CEO of Child Neurology Foundation. “But pretty significant changes are going on in the brain, with major seizure activity, and can have a devastating impact on a child's neurological development if left untreated. It's important when families recognize something is wrong, that they act and feel empowered in their relationship with their clinician to come forward with their concerns.”

For more information, visit [www.infantilespasms.org](http://www.infantilespasms.org) or follow the hashtag #ISAW2019.

ISAW 2019 includes social media campaigns directed to the public and parents, and activities at the American Epilepsy Society annual meeting in Baltimore.

Partners in the ISAN Network: [American Academy of Neurology](#) | [American Academy of Pediatrics](#) | [American College of Emergency Physicians](#) | [American Epilepsy Society](#) | [Association of Child Neurology Nurses](#) | [Assertio](#) | [Bcureful](#) | [Belgium TSC](#) | [The Brain Recovery Project: Childhood Epilepsy Surgery Foundation](#) | [Bridge the Gap - Syngap](#) | [Child Neurology Foundation](#) | [Child Neurology Society](#) | [CURE Epilepsy](#) | [Danny Did Foundation](#) | [Dup15q Alliance](#) | [Epilepsy Foundation of America](#) | [FamilySCN2A Foundation](#) | [Global Genes](#) | [Greenwich Biosciences](#) | [Hope for HIE](#) | [LGS Foundation](#) | [Mallinckrodt Pharmaceuticals](#) | [Mickie's Miracles](#) | [National Organization for Rare Disorders \(NORD\)](#) | [RARE Science](#) | [RING 14 International](#) | [Seizure Tracker](#) | [Tuberous Sclerosis Alliance](#) | [The UK Infantile Spasms Trust \(UKIST\)](#) | [Upsher-Smith Laboratories](#)