

## Sixth Annual Infantile Spasms Awareness Week Scheduled for December 1-7

WASHINGTON, DC: From December 1 to 7, 2020, a coalition of organizations will mark the sixth annual Infantile Spasms Awareness Week (ISAW). The goal of ISAW is to increase awareness and understanding of infantile spasms by offering educational materials to providers, caregivers, and the public; announcing new and useful research and support initiatives; and informing patients and caregivers that help is available. The campaign is supported by the Infantile Spasms Awareness Network (ISAN), a coalition of 31 international organizations that have come together to inform families, physicians and caregivers about the signs of infantile spasms.

Infantile spasms (IS) are a rare, but serious type of seizure, occurring in 1 in 2,000 children, which can cause catastrophic, permanent damage to a child's developing brain. The seizures include repetitive, but often subtle movements — including jerking of the mid-section, dropping of the head, raising of the arms or wide-eyed blinks. The onset of IS peaks between four and six months of age, although these seizures can begin anytime in the first two years. Infantile spasms are often overlooked or misdiagnosed for other conditions, including colic, reflux, or a startle reflex. Worldwide, it is estimated a baby is diagnosed with IS every 12 minutes.

“As everyone navigates the new reality of the COVID-19 pandemic, it's more important than ever for parents to understand infantile spasms are a medical emergency that should never be taken lightly,” **said XXXX**. “The truth is every day there's a delay in seeking a quick diagnosis and prompt treatment increases a child's risk for permanent brain damage, which is why we believe Infantile Spasms Awareness Week is critical to help educate the general public, parents and healthcare providers.”

Because infantile spasms are more subtle than a typical grand mal or “convulsion” seizure, ISAN developed a simple-to-remember mnemonic tool, called ‘*STOP*’ *Infantile Spasms*, 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.

Infantile Spasms Awareness Week includes social media campaigns, national and local media interviews and physician awareness projects.

2020 ISAN partner organizations include: [American Academy of Neurology](#) | [American Academy of Pediatrics](#) | [American College of Emergency Physicians](#) | [American Epilepsy Society](#) | [Association of Child Neurology Nurses](#) | [Be-TSC \(Belgium\)](#) | [Bridge the Gap-SYNGAP](#) | [The Brain Recovery Project: Childhood Epilepsy Surgery Foundation](#) | [Child](#)

Neurology Foundation | Child Neurology Society | CURE Epilepsy | Danny Did Foundation | Duke University Hospital | Dup15q Alliance | Epilepsy Foundation of America | Epilepsy Support Network of Orange County | FamiliesSCN2A Foundation | Global Genes | Hope for HIE | Greenwich Biosciences | LGS Foundation | Mallinckrodt Pharmaceuticals | Mickie's Miracles | National Organization for Rare Disorders (NORD) | RARE Science | Ring14 International | Seizure Tracker | Steunpunt Kinderepilepsie | Tuberous Sclerosis Alliance | The UK Infantile Spasms Trust (UKIST) | Upsher-Smith Laboratories

For more information, follow the hashtag #ISAW2020 and visit [infantilepasms.org](http://infantilepasms.org).

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