



Please join the Infantile Spasms Action Network, in collaboration with Congressman Blumenauer and the Neuroscience Caucus, on **Tuesday, December 5 from 8:30 – 10 am** for an important and highly informative **Congressional Briefing Breakfast**.

The purpose of this briefing is to raise awareness of infantile spasms, the urgent need for accurate diagnosis, current treatments available and research on the horizon to prevent these seizures.

Tuesday, December 5, 2017

8:30 – 10:00 am

(Formal presentations begin at 8:45 am)

U.S. Capitol Visitor Center, Congressional Meeting Room North (CVC 268)

Enter the Capitol Visitor Center (CVC) through the main CVC entrance, located off First Street.

Breakfast provided

Invited speakers include:

- Amy Brin Miller, MSN, MA, PCNS-BC, Executive Director, Child Neurology Foundation
- Shaun Hussain, MD, MS, Assistant Clinical Professor of Pediatrics and Director of the Infantile Spasms Center, University of California, Los Angeles
- Kristie Griess, parent, CEO, Visionary Founder of Mickie's Miracles
- Kari Luther Rosbeck, President and CEO, Tuberous Sclerosis Alliance
- E. Martina Bebin, MD, MPA, Professor of Neurology and Pediatrics, University of Alabama at Birmingham School of Medicine, and Primary Investigator of the Preventing Epilepsy Using Vigabatrin in Infants with Tuberous Sclerosis Complex (PREVeNT) Clinical Trial

If you would like to attend, please RSVP to Stephanie Mucha at smucha@childneurologyfoundation.org or by calling 612-928-6325.

Background Information

Infantile spasms (IS) are a catastrophic form of epilepsy generally affecting newborns before the age of one and in some children, occurring up to age two. IS impacts 1,200 infants per year, and while rare, these seizures can cause long-term damage to a child's developing brain. Infantile spasms are characterized by repetitive, but often subtle movements—such as a jerking of the mid-section, raising of the arms similar to a startle reflex, head bobs, or wide-eyed blinks. IS can happen in clusters, dozens at a time, and in some cases, leading to hundreds of seizures per day if left untreated. IS can result in increased risks for developmental delay, lifelong intractable epilepsy, autism, and even death. Fortunately, treatments are available to help control the spasms.

A collaborative initiative sponsored by members of the Infantile Spasms Action Network, Infantile Spasms Awareness Week (ISAW) is held annually from December 1 to 7, this year in conjunction with the American Epilepsy Society meeting being held in Washington, DC. The goal of ISAW is to increase awareness and understanding of infantile spasms through developing and distributing educational materials to providers, caregivers, and the public; announcing new and useful research and support initiatives; recognizing exemplary contributions to care; and inviting families living with IS to be part of a larger community—many stories with one voice.

Members of the Infantile Spasms Action Network include:

American Academy of Neurology | American Academy of Pediatrics | American College of Emergency Physicians | American Epilepsy Society | Association of Child Neurology Nurses | Bcureful | Belgium TSC | The Brain Recovery Project: Childhood Epilepsy Surgery Foundation | Child Neurology Foundation | Child Neurology Society | CURE Epilepsy | Danny Did Foundation | Dup15q Alliance | Epilepsy Foundation of America | Global Genes | Greenwich Biosciences | Lennox Gastaut Syndrome Foundation | Mallinckrodt Pharmaceuticals | Mickie's Miracles | National Organization for Rare Disorders (NORD) | RARE Science | SeizureTracker.com | Tuberous Sclerosis Alliance | Upsher-Smith Laboratories