



Infantile Spasms Awareness Week (ISAW)

Infantile Spasms Awareness Week (ISAW) provides a platform for distributing new research and recognizing exemplary contributions to the treatment of infantile spasms—a rare, but serious form of epilepsy occurring in children, usually under age one.

Because infantile spasms can be mistaken for other conditions or appear subtly, prompt diagnosis and appropriate treatment are critical for the child's best developmental outcome. Most pediatricians will only see one or two cases throughout their entire career, therefore it is very important for health care providers and parents/

caregivers to know and recognize the signs of infantile spasms. Awareness efforts like ISAW bring together advocacy organizations, parent/caregivers, industry, and frontline providers to educate the public about infantile spasms. Held December 1-7, the goal is to increase awareness and understanding of infantile spasms through the distribution of objective educational materials to providers, caregivers, and the public; the announcement of new and useful research and support initiatives; the recognition of exemplary contributions to care; and the declaration to patients and caregivers that *There is help! There is hope!*

Join the conversation on social media using

#ISAW2016

and visit isweek.org

ISAW 2016 Official Partners



INFANTILE SPASMS ADVOCACY FORUM

To kick off ISAW 2016, the Child Neurology Foundation hosted an Infantile Spasms Advocacy Forum with representatives from 14 different advocacy, provider and industry partners, highlighting advocacy opportunities and awareness gaps, along with opportunities within the child neurology community. Attendees included the American Academy of Neurology, the American Academy of Pediatrics, the Child Neurology Society, the Association of Child Neurology Nurses, the American College of Emergency Physicians, the American Epilepsy Society, CURE, the Danny Did Foundation, Lennox-Gastaut Foundation, Global Genes, TS Alliance, Lundbeck, and Mallinckrodt.



ADVOCACY AWARENESS MINI-GRANTS

To spread awareness of infantile spasms, the Child Neurology Foundation has awarded five \$5,000 mini-grants for advocacy awareness projects. The 2016 mini-grant recipients are the American Academy of Pediatrics, American College of Emergency Physicians, Danny Did Foundation, Lennox-Gastaut Foundation, and Seizure Tracker.



BRENDAN MICHAEL HARNETT
INFANTILE SPASMS MINI-GRANT

This year during ISAW, one \$1,000 mini-grant will be awarded to a child with infantile spasms and their caregiver to cover the cost of treatments, therapies, devices, and services not covered by insurance.



2016 INFANTILE SPASMS HEROES
AND HOPE AWARDS

The Infantile Spasms Heroes Award has recognized a healthcare professional and his or her institution for making a positive difference in the life of a child with infantile spasms. The Infantile Spasms Hope Award honors a family that advocates and educates using their own experience parenting a child with infantile spasms. The 2016 winners will be announced during the Child Neurology Society and American Epilepsy Society annual meetings in early December.

ISAW 2016 EVENTS
December 1-7, 2016

December 1	December 2	December 4	December 5
• Twitter chat using #ISAW2016 • National and Local TV and Radio interviews with Dr. Martina Bebin of University of Alabama-Birmingham, Principal Investigator of PReVent Trial • Announcement of mini-grant recipient	• Infantile Spasms Hope Award winner announcement • Tuberous Sclerosis Alliance reception at American Epilepsy Society annual meeting	• Infantile Spasms Advocacy Forum at American Epilepsy Society annual meeting, 12:00-2:00 P.M. CT	• Facebook Live event w/Dr. Bebin • Innovation Pavilion at American Epilepsy Society annual meeting