

Child Neurology Foundation Announces Second Annual Infantile Spasms (IS) Awareness Week

-- CNF also launches IS Heroes Award and names recipient of Logan Infantile Spasms Research Award

MINNEAPOLIS, Oct. 13 /PRNewswire/ -- The Child Neurology Foundation (CNF) announced today the start of Infantile Spasms Awareness Week, an annual event to raise awareness and understanding of infantile spasms (IS) with pediatricians, child neurologists, parents and caregivers.

Over the past year, CNF has developed a website, www.infantilespasmsinfo.org, that provides information on IS from leading child neurologists and shares stories from families coping with this devastating condition. CNF has also developed an educational brochure and DVD.

"Infantile spasms is a very rare, but devastating form of childhood epilepsy," said Lawrence W. Brown, MD, Associate Professor of Neurology and Pediatrics at the Children's Hospital of Philadelphia and President of the Child Neurology Foundation. "It is also a disorder where time is of the essence when it comes to treatment and diagnosis. That's why these awareness efforts are so critical."

As part of IS Awareness Week, Dr. Brown said the CNF has selected Catherine Chu-Shore, MD, of Massachusetts General Hospital as the recipient of the first-ever "Logan Infantile Spasms Research Award."

Dr. Chu-Shore, whose application was reviewed by 10 of the nation's top child neurologists and then selected by the CNF Board of Directors, is focusing her research on the "functional network connectivity" in infantile spasms. The goal of her research is to identify early metrics of altered brain connectivity, which can serve as biomarkers for prognostication and treatment stratification for infants with IS.

"I am very grateful to be the recipient of the Child Neurology Foundation Infantile Spasms Research Award," said Dr. Chu-Shore. "This grant provides me with the opportunity to develop my career as a physician scientist and better understand the mechanisms of pediatric neurologic disease and their impact on functional neurodevelopment."

"Research into orphan disorders like infantile spasms often suffer from a lack of funding," Dr. Brown said. "That is why we are pleased to be able to fund basic research into the causes and consequences of infantile spasms. Our hope is that better understanding of the underlying pathophysiology will lead to new and even more effective treatments."

Dr. Brown also announced that the CNF has launched a new program called IS Heroes, which will include the IS Hero Award.

"The IS Hero Award will recognize a deserving child neurologist and medical institution, nominated by a parent, for making a positive difference in the life of a child with IS," said John Stone, Executive Director of the Child Neurology Foundation. "This is another way we can draw attention to IS and recognize the important contributions made by child neurologists in the care of these infants."

This inaugural year's recipient, being honored for their leadership in promoting awareness and research for infantile spasms, is the Pediatric Neurology Division of the Barrow Neurologic Institute of Phoenix. The

Allen family nominated the team at Barrow after their son, Logan, was treated at Barrow. Logan's seizures were quickly controlled and Logan, now six years old, is developmentally on track with his peers.

Dr. John Bodensteiner, past president of the Child Neurology Society and Professor of Child Neurology at Barrow, said, in accepting the award, "At the Barrow Neurological Institute, our goal is to provide excellent patient care and to find better ways to treat neurological conditions. While we wish every child could have the outcome that Logan Allen had, we know that is sometimes not possible. What is possible is to provide the level of care and commitment from the excellent team of healthcare professionals we have here at Barrow."

The 2010 IS Heroes Award and IS Research Award Ceremony takes place this week at a special luncheon at the Child Neurology Society Annual Meeting in Providence, Rhode Island.

IS Awareness Week, the IS Heroes Award and the Logan Infantile Spasms Research Award are all funded via an educational grant from Questcor Pharmaceuticals.

Infantile Spasms

Infantile Spasms is a severe, ultra-rare form of epilepsy that affects infants, with onset typically occurring during the first year of life in about 90 percent of cases. IS incidence is estimated at approximately 2,000 new cases in the U.S. per year, which can be classified as an ultra-orphan disease. For comparison, orphan disease designation pertains to diseases that affect fewer than 200,000 people.

IS patients experience rapid, characteristic muscular contraction or extensions lasting one to two seconds and occurring in clusters ranging from a few spasms to more than 100 spasms per cluster. Often, in the beginning, the attacks are brief, infrequent and not typical, so it is quite common for the diagnosis to be delayed. Frequently, due to the pattern of the attacks and the cry that an infant gives during or after an attack, the attacks are sometimes initially thought to be due to colic or gastric distress.

About the Child Neurology Foundation

Founded in October 2000, the Child Neurology Foundation was created as the outreach and philanthropic arm of the Child Neurology Society. Members of the CNS include more than 1,300 child neurologists from the United States, Canada, as well as more than 30 other countries around the world.

The Foundation's mission is to advocate for children and adolescents with neurologic and developmental disorders; fund neurologic research of young investigators; promote awareness of career opportunities in child neurology; provide public, professional, and patient education programs; and support the activities and mission of the CNS.

For more information on the CNF, please visit www.childneurologyfoundation.org.

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