

*Pre-existing Conditions  
Legislative Update!  
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## CNF Announces New Questcor-sponsored Annual Infantile Spasms Heroes Award



**I.S. HEROES AWARDS  
Presented to:**

*...the Allen Family for outstanding I.S. awareness leadership*

*...the Pediatric Neurology Division of the Barrow Neurological Institute in Phoenix for outstanding I.S. practitioner excellence*

Starting this year, in conjunction with I.S. Awareness Week, CNF will annually recognize one outstanding family who has helped the Foundation raise Infantile Spasms (I.S.) awareness. This year CNF recognizes the Allen family whose son Logan was diagnosed and treated for Infantile Spasms. They in turn have recognized the Barrow Neurological Institute, Phoenix to share in the award.

“It is with great pleasure that our family be given the opportunity to nominate an I.S. Hero. As parents/advocates we feel it's so important to recognize the individuals and organizations that go above and beyond expectations. Dr. Jong Rho and Barrow are just that team. With every great clinician is an organization that supports them. Barrow Neurological Institute is that place. Having had many opportunities to utilize their services and staff we can't thank them enough for their passion and understanding during our difficult time. We are forever grateful to Dr.

Bodensteiner and to the Barrow Institute for working with all of Logan's challenges and providing a place of comfort and support for our family.”

*-Ryan Allen, Logan's father*

“At the Barrow Neurological Institute, our goal is to provide excellent patient care and to find better ways to treat neurologic conditions. And while I gladly accept the I.S. Heroes Award on behalf of our entire team at Barrow, I must commend Logan and his amazing parents, Ryan and Tiffany Allen, who aggressively advocated for their son's diagnosis and eventual treatment.”

*-Dr. John Bodensteiner, past president, CNS*

Questcor is focused on providing prescription drugs for the treatment of rare central nervous system and inflammatory disorders, including infantile spasms.



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# Child Neurology Foundation Newsletter

## From the desk of President Larry Brown

Every pediatric specialty has its share of tragedies, but child neurologists seem to have a corner on the market. Without embellishment, here are just a few vignettes from the last two weeks on the inpatient service at Children's Hospital of Philadelphia.

*A 15 year old football player with such severe whiplash injury (from a knee to his helmet on the practice field) that he suffered prolonged cardiac arrest - unfortunately, in a state that has yet to pass a law insuring adequate first line injury response by coaches and staff.*

*A 4 year old boy with multiple posterior circulation strokes found to have a lupus anticoagulant antibody.*

*A 5 year old girl adopted at age two from India with progressive behavioral issues and new myoclonic seizures; work-up showed CSF measles antibodies confirming the diagnosis of SSPE.*

*But dealing with each of these difficult patients paled in comparison to having to tell young parents of a previously healthy 6 month old baby about the meaning of hypsarrhythmia and infantile spasms... and yes, that birth mark on his thigh is not just a dermatologic curiosity but a marker of a genetic disorder that will likely impact his entire future.*

“infantile spasms awareness  
... just one example  
of projects that embrace  
our tripartite mission of  
research, education and advocacy”

What do any of these stories have to do with the Child Neurology Foundation? Basically, everything.

The CNF is committed to research, education and advocacy as well as efforts to insure sufficient manpower to diagnose and manage all children with neurologic disorders. For this newsletter I would like to focus on the biggest project to date in the ten year history of the foundation. The Infantile Spasms Awareness Project was a pilot program in collaboration with Questcor Corporation to improve public awareness of this devastating form of epileptic encephalopathy that most young parents have never heard of and many pediatricians have never seen since residency, making them unprepared to make an early diagnosis and to refer for immediate treatment. We worked hard to develop a non-commercial educational video and brochure that are still available through the

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## Research Update: Dr. Shellhaas 2009 Shields Award Winner

Newborn infants with hypoxic-ischemic encephalopathy (HIE) and/or seizures are at high risk of death or developmental disabilities, such as cerebral palsy and mental retardation. The reasons for these poor outcomes are not well understood. There is a pressing need for improvement in treatment protocols and new strategies for estimating prognosis for newborns with HIE and for those with seizures.

Perfusion and oxygenation are pivotal determinants of brain metabolism and may be disrupted in neonates with HIE and/or seizures. Near-infrared spectroscopy provides reproducible, quantitative measures of cerebral blood volume (reflecting perfusion), oxygen saturation, and tissue oxygen extraction, which could represent abnormal brain metabolism. Electroencephalography (EEG) provides the most accurate information about seizure burden and provides important prognostic information in encephalopathic neonates.

Amplitude-integrated EEG has also been shown to have prognostic utility in the first hours after neonatal

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# CNF 2010 Research Award Winners

One of the most important missions of the Child Neurology Foundation is to encourage innovative research by child neurologists, especially those who are early in their careers and who have not yet achieved NIH support. Below are the 2010 CNF Research Award recipients.



## The Shields Research Award

provides two years of funding at \$50,000 per year to support translational or clinical research for a child neurologist early in his/her academic career.

Dr. Charu Venkatesan completed her internship and residency in pediatrics in 2004 and residency in child neurology in 2007 at Children's Memorial Hospital at Northwestern University. In 2010, she joined Dr. Jack Kessler's laboratory to gain expertise in neural stem cell biology.

Dr. Venkatesan's current research interest is perinatal brain injury, particularly hypoxic-ischemic injury. The long-term objective of her research is to identify signaling mechanisms that regulate oligodendrocyte differentiation in the normal and diseased states. The studies funded by the Child Neurology Foundation Shield's Award examine the regulation of oligodendrocyte precursor cell differentiation by 1-integrin signaling pathway.

"It is a great honor to receive the Child Neurology Foundation Shield's Research Award. This award will allow me to explore mechanisms regulating neural stem cell differentiation in healthy and injured neonatal brains. I feel that understanding the factors that regulate oligodendrogenesis in the neonatal brain may lead to therapeutic strategies that harness endogenous neural precursor cells for repair, regeneration and restoration of function after perinatal hypoxic-ischemic injury. Support from the Shield's Award will help advance my career goal of combining clinical and research activities effectively in order to be a successful independent physician-scientist."



## Logan Infantile Spasms Research Award

provides one year of funding at \$30,000 for research specific to Infantile Spasms.

Dr. Catherine Chu-Shore completed her child neurology training at Massachusetts General Hospital (MGH). In 2010, Dr. Chu-Shore joined the staff at MGH in the Pediatric Neurology and Neurophysiology Programs. Dr. Chu-Shore is interested in studying epileptic encephalopathies, conditions in which the epileptic discharges are thought to contribute to the development of permanent cognitive deficits, even in the absence of overt seizures.

The Logan Infantile Spasms Research Award will help Dr. Chu-Shore conduct a study on the effects of the neurophysiologic abnormalities that are present in infantile spasms (hypsarrhythmia pattern on EEG) on the immediate and long-term functional connectivity networks that are simultaneously maturing in the infant brain. The goal of this work is to identify early metrics of altered brain connectivity which can serve as biomarkers for prognostication and treatment stratification for infants with this often devastating epilepsy syndrome. This work will serve to help understand how abnormal neurophysiologic activity during a critical period may affect normal physiologic neurodevelopment.

"I am very grateful for the Logan Infantile Spasms Award. This award 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."



## Scientific Research Award

provides two years of funding at \$50,000/year for work in the field of child neurology. This award recognizes the work of a child neurologist early in his/her career.

Dr. Chris Smyser received his MD from the University of Iowa College of Medicine in 2004. He completed his pediatrics residency at the University of Iowa Hospitals and Clinics and then completed his pediatric neurology residency at Washington University/St. Louis Children's Hospital in 2009.

Throughout his time at Washington University, his initial activities focused on development and optimization of the tools necessary to utilize functional connectivity magnetic resonance imaging (fcMRI) to investigate development of functional cerebral connections in preterm and term infants. The proposed study seeks to expand these efforts to define the impact of white matter injury on emerging functional motor connections in the developing brain.

"The Child Neurology Foundation Scientific Award will allow me to continue efforts designed to establish fcMRI as an imaging biomarker that identifies infants at increased risk for adverse neurodevelopmental outcomes, allowing targeted intervention and reducing rates of disability in this population. The generous support provided through the award will strengthen the foundation necessary to realize my goal of becoming a successful independent clinician-scientist investigating brain injury and ensuring optimal neurologic outcomes in newborn infants via development and application of novel neuroimaging techniques. It is truly an honor and privilege to receive this esteemed award."

## Breaking News....

The 2011 Twin Cities **Mardi Gras** is Saturday, February 19<sup>th</sup> in Bloomington, MN

**CNF Donor Luncheon**  
Open Invitation:  
Supporters of the CNF are invited to the annual donor luncheon Thursday, October 14th, 2010 Rhode Island Convention Center (RICC) Room #551A. RSVP to [jwright@childneurologyfoundation.org](mailto:jwright@childneurologyfoundation.org)

**Circle of 25 Campaign**  
Chairpersons Julie and Alan Faneca have kicked off the campaign by donating \$25,000

### Yes CNF, you can count on me!

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Volunteer interest  
Make checks payable to: CNF  
2000 W. 98th Street,  
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Donation Amount \_\_\_\_\_

Credit Card Number \_\_\_\_\_

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or give online:  
[childneurologyfoundation.org](http://childneurologyfoundation.org)

or call John Stone  
at 952-486-2845

From the desk of Lawrence Brown con't.

CNF ([www.childneurologyfoundation.org](http://www.childneurologyfoundation.org)) as well as an open unbranded website for the public ([www.infantilespasmsinfo.org](http://www.infantilespasmsinfo.org)).

A unique signing-wall at last year's CNS meeting in Louisville allowed individuals to show their support for more research and allowed us to raise funds for an Infantile Spasms Research Award which will be awarded for the first time in October 2010 at the CNS meeting in Providence. At the same time, our corporate partner Questcor has been so impressed with our efforts that they have agreed to sponsor an annual Infantile Spasms Heroes Award to be presented in Providence to the Logan family and the Pediatric Neurology Division of the Barrow Neurological Institute (Phoenix) in recognition of their contributions to the field. We will also continue to promote public awareness by distributing educational resources - and raising money for additional research - at the upcoming CNS meeting in addition to booths at future national meetings of the American Epilepsy Society, American Academy of Neurology and the American Academy of Pediatrics. Our efforts to promote infantile spasms awareness is just one example of projects that embrace our tripartite mission of research, education and advocacy.

This report may have opened with a few remarkable cases from personal experience. But sports injuries affect millions of children and adolescents; hopefully a future report will include results of educational efforts sponsored by the CNF to minimize this unnecessary epidemic. Pediatric stroke is far more common than anyone ever realized until recently, and we are making headway thanks in part to an early multi-site CNF grant that helped to develop the pediatric stroke collaborative. Failure to immunize remains a world-wide cause of unnecessary and preventable disease and disability. We all have a responsibility for these and other neurologic disorders. Together we can make a difference and the CNF is looking forward to providing the leadership and resources to make it happen.

*Lawrence W. Brown MD*

Lawrence W. Brown, MD  
President

Dr Shellhaas con't.

apnoea. Exciting preliminary data, derived through funding from the Child Neurology Foundation's Shields Research Award, suggest that combining these technologies with formal polysomnography (to assess sleep/wake cycling) in a multimodality neuromonitoring approach, may provide new insight into the pathophysiology underlying brain dysfunction in high-risk groups of newborn infants. We are now analyzing the relationships between neonatal HIE, neonatal seizures, and sleep physiology using state-of-the-art technology, including EEG to assess seizure burden, amplitude-integrated EEG to assess for EEG background changes, polysomnography to characterize sleep-wake states, and near-infrared spectroscopy to evaluate brain metabolism.

Analyzing the interplay between neonatal encephalopathy and seizures, sleep-wake states, and brain metabolism will lead to new understanding of the pathophysiology underlying these disorders and may shed light on the reasons for poor developmental outcomes in high-risk individuals. Results could eventually lead to new, targeted diagnostic and therapeutic strategies.

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### CNF 2011 Award Application Due Dates:

February 25, 2011 Applications for **Swaiman Medical Scholarships**

March 25, 2011 Application for **Shields; Scientific; Logan I.S. Research Awards**