

Child Neurology Foundation Newsletter



*Joint CNS & CNF
Presidents' Letter
to the Membership*



John B. Bodensteiner
Child Neurology Society President



Michael J. Painter
Child Neurology Foundation President

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Dear Colleague,

Many members of the Child Neurology Society have expressed confusion about the roles and relations of the CNS and the Child Neurology Foundation. They are not sure what the Foundation offers child neurologists or how the Foundation functions. We, as respective Presidents of the Society and Foundation, would like to take this opportunity to answer these questions and concerns.

First, let us emphasize that both the Society and Foundation work together for the common purpose of advocating for child neurologists and the patients for whom we care. The focal point of the CNS is the annual meeting, which has been very successful as a vehicle to disseminate newly emerging scientific information to the membership as well as serving as a forum for discussing many issues of mutual interest. A decade ago the leadership of the Society, however, recognized the need for our profession to fund promising young investigators, foster inter-institutional collaborative research, encourage medical student's interest by supporting summer fellowships, reach out to advocacy groups, and establish a mechanism to interact with our supporters in industry. These were needs beyond the scope of the CNS alone and led to the formation of the Foundation.

The existing shortage of child neurologists, in addition to the need for an increasing supply of new talent to treat many underserved children, was an especially important issue we all appreciated, academically and in practice. The need to increase the visibility of Child Neurology as a profession was recognized as an essential first step to solving this problem. The CNS and CNF continue to address this issue through efforts addressed to medical students, pediatric residents and junior faculty.

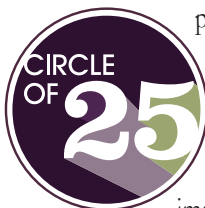
Through the Residency-in-Training Award, the Scientific Award, and the Shields Award, the Foundation has very successfully fostered the careers of some stellar child neurologists. These individuals have been universally successful in achieving further funding following the help these awards provided in getting their research careers started. These child neurologists also serve as visible role models for medical students and illustrate how satisfying a career in Child Neurology can be. Medical students have also been supported with child neurologist-mentored summer scholarships. Unfortunately, due to funding restrictions, the Residency-in-Training award and medical student scholarships are on hold, but these important awards will be reinstated when funding is identified.

The Foundation is very active with parent advocacy groups and its Advocacy Committee works with parents to speak to the need for Child Neurology services. The Foundation's Respite Care Manual is a model of addressing unmet needs and the annual advocacy award serves as an example of the interaction of the field of child neurology and those who depend on our services.

The CNS launched the Foundation with a major grant and many individuals, as well as industry, supported the Foundation at its inception. Changes in the economy as well as pharma guidelines, however, make it clear that the Foundation needs to diversify funding sources. The Society and the Foundation both believe the accomplishments and goals of the Foundation are essential for the future of Child Neurology and support its continued efforts.

The Foundation depends in large part on the participation of child neurologists. While the support for the Foundation is not limited to child neurologists, we hope that the CNS membership understands not only the critical importance of the Foundation's mission, but also recognize that active participation is necessary to convince private individuals, foundations, and industry sponsors. Therefore, we strongly encourage you to show support.

Twenty-five percent of children have issues that are best treated by child neurologists, and we would like to see members of the Society support the "Circle of Twenty



Five", which means a minimum contribution of \$25 per month. Only if we have good participation will these important programs continue.

The success of the Circle will allow the Foundation to continue working for you and you will have the satisfaction of knowing you have contributed to programs that address central issues to our profession.

"the Society and Foundation work together"

We will continue to inform you about the projects and plans of both the Foundation and Society in addition to progress toward a financial plan to insure the viability of both organizations. Please give this request your highest consideration when the Foundation contacts you.

Thank you.

John B. Bodensteiner
Child Neurology Society President

Michael J. Painter
Child Neurology Foundation President



The Child Neurology Foundation is excited to announce its first annual Twin Cities Mardi Gras Event!



Drs. Kenneth Swaiman & Phyllis Sher

This exciting event will honor Dr. Kenneth Swaiman (the founder of the Child Neurology Foundation and the Child Neurology Society) and his wife, child neurologist Dr. Phyllis Sher. It will be hosted by Matthew Anderson (Manager, St. Paul Kincaid's; President Elect, Bloomington Chamber of Commerce; Director, Mpls. Regional Chamber of Commerce).

This costume/black-tie event will be the place to be on Fat-Tuesday:

- On the menu:
 - ~an elegant French Creole dinner
 - ~authentic jazz
 - ~jugglers
 - ~fabulous decorations
 - ~magicians
 - ~comedy
 - ~signature chocolate martinis
 - ~dancing
 - ~direct video feeds from New Orleans

PROGRAM

- Reception
- Dinner
- Live Auction
- Presentations
- Great Music
- After Dinner Dance

Your Mardi Gras evening of fun starts by calling CNF at 952-641-4466.



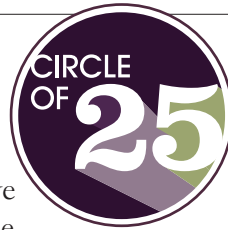
Matthew Anderson

It's About Time

Give to Children's Neurologic Research Now!

- ~ Go to www.childneurologyfoundaiton.org and click on the "CNF Donate" button to make a one-time or a "Circle of 25" monthly gift by credit card.
- ~ If you prefer, send a check to CNF, 2000 West 98th Street, Bloomington, MN 55431

The CNF Circle of 25...



... is banding together the families of professional athletes and celebrities who have children with neurologic disorders to lead the way so other families might have the same access to the quality neurologic care. As one-in four (25%) children in the United States have a neurologic disorder (see table below), we're calling this group the "Circle of 25".

We are excited and honored that Alan Faneca of the New York Jets and his wife Julie are our premier members. Their \$25,000 contribution will help realize these four goals:



Alan Faneca

- ~ raise awareness as to the number of families affected by child neurologic disorders
- ~ raise awareness as to the severe shortage of child neurologists.
- ~ fund the recruitment of future child neurologists
- ~ fund research in the area of child neurology

CNF's CALL TO ACTION

Professional athletes will lead the charge but the Circle of 25 is for everyone.

- ~ Have you been asked by grateful families how they can help? Now you know where to send them.
- ~ If by chance, your grateful family is connected to professional athletics or other celebrity, have them contact the Foundation office.
- ~ Lead by example. Join the Circle of 25 today. See the appeal on the bottom of page 2.

THANK YOU! 

Infantile Spasms (IS) Awareness Week: October 12-18

The CNF proudly announces the creation of Infantile Spasms Awareness Week starting Oct 12 (in conjunction with the CNS Annual Meeting).


The goal is to provide pediatricians, parents and caregivers with objective, educational tools to increase awareness and understanding of



IS. Early diagnosis and treatment can impact the IS prognosis. As part of its mission, the CNF funds scientific research of IS.

Your signature = \$100 for IS research

In 2009, CNF received \$10,000 for an Infantile Spasms (IS) Scientific Fund from Questcor Pharmaceuticals. They also committed to donate more *with your help*.

For those attending the CNS annual meeting, have your photo taken at the Questcor booth (# 25). Then, bring it to our CNF Booth and Questcor will contribute \$50. Sign the photo to double Questcor's contribution to \$100! 

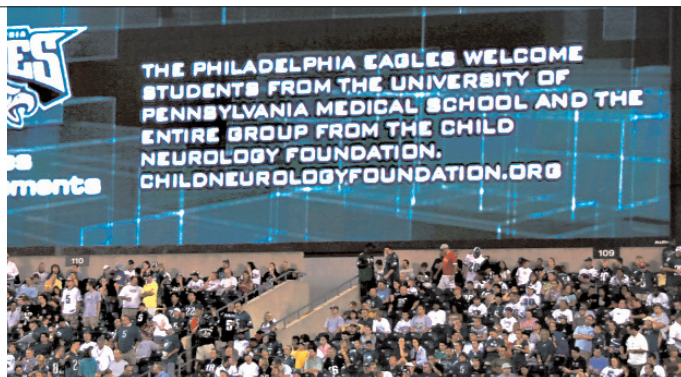
Frequency of Neurologic Disorders in Children	Neurologic Disorder	Source of Information	Rate	Number of Children Affected
	ADD/ADHD	NINDS & CHADD	1 in 20	4,756,000
	Aphasia	NINDS & NAA	1 in 250	325,000
	Ataxia	NINDS & Nat'l Ataxia Foundation	1 in 10,000	7,500
	Autism	CDC	1 in 150	529,000
	Barth Syndrome	Barth Syndrome Foundation	1 in 400,000	200
	Cerebral Palsy	NINDS	1-2 in 50,000	3,000
	Down Syndrome	NINDS	1 in 800	99,000
	Dystonia	Dystonia Foundation	3 in 10,000	2,400
	Epilepsy	NINDS & Epilepsy Foundation	1 in 250	326,000
	Seizure	NINDS	1 in 20	4,750,000
	Headache/Migraine	NINDS & AAFP	1 in 5 (adolescents)	7,250,000
	Multiple Sclerosis	National MS Society	13 in 100,000	10,000
	Rett Syndrome	IRSF	1 in 10,000 (female births)	4,200
	Stroke	NINDS	3 in 50,000	4,750
	Tourette Syndrome	NTSA	1 in 250,000	320
	Williams Syndrome	Orpha.net	1 in 20,000	4,000
	All Disorders		1 in 4	18,071,370

USCB statistics; US Total Pop. under 18: 79,266,475 CDC - Center for Disease Control and Prevention; NINDS - National Institute of Neurological Disorders and Stroke; CHADD - Children and Adults with Attention Deficit Disorder; NAA - National Aphasia Assn; AAFP - American Academy of Family Physicians; EF - Epilepsy Foundation

Philadelphia Eagles: 1st CNF Pro-Team Sponsor



In August, the CNF hosted more than eighty 1st- and 2nd-year medical students to attend a pre-season game. In addition to donating the tickets, the Eagles provided bus transportation where the students viewed our child neurology introduction video and were able to hear from (and ask questions of) local child neurologists Drs. Amy Waldman and Rob Avery.



To cheers from the 100+ medical students, the Philadelphia Eagles put the CNF name "In Lights"

Corporate Board Advisory Members



The Corporate Advisory Board (CAB) is organized and administered by the Child Neurology Foundation, with full participation by the Child Neurology Society and its membership.

Membership is comprised of professional relations representatives, product managers, marketing managers, and public affairs and education representatives from pharmaceutical, medical device, and related industries who have mutual interests in working with child neurologists.

Each Newsletter will feature two of our CAB members:



Upsher-Smith Laboratories, Inc.

6701 Evenstad Drive, Maple Grove, MN 55369
753-315-2000 www.upsher-smith.com



Since 1919, Upsher-Smith Laboratories, Inc. has grown into one of the world's top pharmaceutical companies. This growth is due to our company's quest for Excellence through Innovation. Upsher-Smith develops, manufactures, and markets an array of products that advance human health. Today, the father-son team of Ken Evenstad, Chairman of the Board, and Mark Evenstad, President and Vice Chairman, remains committed to leading the company on its mission to improve people's lives through innovative pharmacotherapy.

Eisai Inc.

100 Tice Blvd., Woodcliff Lake, NJ 07677
201-692-1100 www.eisai.com



Eisai, Inc., a human health care company, offers clinical research, formulation research, clinical supply manufacturing, and pharmaceutical production services. The company also provides its products in various therapeutic areas, such as neurology, gastrointestinal disorders, and oncology/critical care. In addition, it provides pharmaceutical products for oncology treatment. We give our first thought to the patients and their families and contribute to increasing their benefits.

CNF Mission

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, &
patient education programs

Support
the activities & mission of
the Child Neurology Society