

# Child Neurology Foundation Newsletter



Lawrence Brown  
Child Neurology Foundation President



**TWIN CITIES  
MARDI GRAS**

February 16, 2010  
see back page

## Board of Directors

Lawrence Brown, MD,  
*President*

Michael Painter, MD,  
*Past President*

Mark Scher, MD,  
*Secretary/Treasurer*

Anthony Bucci,  
*CEO, MARK USA*

Julie Faneca

Nancy Harris

Phillip Pearl, MD

Catherine Rydell,  
*AAN Executive Dir.*

Peter Saltonstall  
NORD CEO & President

W. Donald Shields, MD

William Trescher, MD

Donna Ferriero, MD,  
*CNS President, Ex Officio*

John Stone, MA,  
*CNF Exec. Director, Ex Officio*

A foundation is a lot like marriage: while it's the passion that gets you to the altar, it is faith and perseverance that keeps you committed. With a generous but limited grant, the Child Neurology Society and many individuals formed the Child Neurology Foundation to support research, education and advocacy in ways that complemented the mission of the CNS.

Ten years, one financial meltdown and the loss of patent protection for most epilepsy drugs later, we are still here with renewed energy. While our Corporate Advisory Board is more vibrant than it has ever been, it is no longer possible to rely to such an extent on the largesse of the pharmaceutical industry. Instead, our efforts have moved in other fundraising directions with an emphasis on "The Circle of 25" (under the national leadership of New York Jets star offensive guard Alan Faneca and his wife Julie) which is aimed at professional athletes and the "Campaign of 25" for other supporters including our friends, colleagues and ourselves.

Beyond fundraising, the CNF has a number of active projects that we hope will resonate with you.

1. The first comprehensive educational program was Infantile Spasms Awareness Week which included a website, brochures and a DVD targeted at pediatricians and the lay public. This effort (sponsored by Questcor) was complemented by a \$30,000 donation for a research project.
2. A similar project will focus on Lennox-Gastaut syndrome (sponsored by Eisai) to be released at the upcoming national meeting in Providence. Look for a needs assessment survey to better understand the current management and how we can better treat and improve the quality of life of our patients.
3. Our advocacy committee is developing a transition manual to help child neurolo-

gists and families prepare developmentally disabled patients for the challenges of adulthood.

4. We are in the early stages leading to an educational course on neurodevelopmental disabilities that will complement the limited training in developmental, cognitive and behavioral disorders experienced by many child neurology residents.

5. One of our important missions is the development of the next generation of child neurologists. A pilot partnership with the Philadelphia Eagles reached nearly 200 medical students at a pre-season game, presenting them with the opportunities of child neurology through the eyes of young, enthusiastic colleagues. Hopefully, similar events will be replicated in other NFL cities next year.

6. We are working with industry and other sponsors to reinstate the summer medical student fellowships.

These and other projects will be possible only with the active support of child neurologists throughout the US and Canada. We are fully supportive of and supported by the CNS; there is no confusion in goals or strategies. Together we are addressing the manpower issues including efforts to provide loan reimbursement for child neurology training, the encouragement of young investigators, improving the quality of life of our patients and partnership with other organizations to advance the field in general. I look forward to your ideas, your enthusiasm and your support. Please contact the foundation at [jstone@child-neurologyfoundation.org](mailto:jstone@child-neurologyfoundation.org)

Thank you,

Lawrence W. Brown, MD  
President

# Leaving a Meaningful Legacy

## *a quick, DIY guide to making a bequest*

Once you have decided to make a charitable bequest for the Child Neurology Foundation, here is the language you need for different types of bequests:

### **General Bequests**

are legacies that come from the general value of the estate, and are made by designating a specific dollar amount, a particular asset or a fixed percentage of your estate to the cause of your choice. General bequest language:

“I give, devise, and bequeath to THE CHILD NEUROLOGY FOUNDATION, the sum of \$?,000 (or a description of the specific asset), for the benefit of THE CHILD NEUROLOGY FOUNDATION and its general purposes.”

### **RESIDUARY BEQUESTS**

are made when you intend to leave the residue portion of your assets after other terms of the will have been satisfied. Residuary bequest language:

“All the rest, residue, and remainder of my estate, both real and personal, I give to THE CHILD NEUROLOGY FOUNDATION, for its general purposes.”

#### **Bequest (Noun)**

**The transfer of property from an estate to a named individual or organization.**

### **Contingency Bequests**

allow you to leave a portion of your estate to a particular charity if your named beneficiary does not survive you. Contingency bequest language:

“I devise and bequeath the residue of the property, real and personal and wherever situated, owned by me at my death, to (name of beneficiary), if (she/he) survives me. If (name of beneficiary) does not survive me, I devise and bequeath my residuary estate to THE CHILD NEUROLOGY FOUNDATION, for its general purposes.”

### **Specific Bequests**

are made when a particular item or property is bequeathed for a designated purpose. Specific bequest language:

“I give, devise, and bequeath to THE CHILD NEUROLOGY FOUNDATION, the sum of \$?,000 (or a description of a specific asset), for the benefit of THE CHILD NEUROLOGY FOUNDATION to be used for the following purpose: (state the purpose). If at any time in the judgment of the Board of Directors of THE CHILD NEUROLOGY FOUNDATION deem it impossible or impracticable to carry out exactly the designated purpose, they shall determine an alternative purpose closest to the designated purpose.”



The above all presumes that you have made out a will; without one, there is no mechanism in place to make a bequest. Set up an appointment with your financial analyst or attorney to help sensitively guide you through the process.

Contact us with any questions:  
877-263-5430

*The Child Neurology Foundation is a 501(c)(3) nonprofit organization, donations to which are tax deductible to the fullest extent allowed by law.*

# Breaking News . . . .

CNF board-member Julie Faneca and her NFL pro-bowl husband Alan Faneca (Circle of 25 Natn'l chairpersons) delivered 100 CNF fund-raising packets to coaches and players at last month's Pro Bowl.


Senator Klobuchar has just informed us that she will be attending the CNF Mardi Gras. (see page 4)

The proposed health bill contains pediatric-specialty loan provisions that would forgive a portion of education loans incurred by child neurologists. Ask your congress-person to support it.

The CNF-Questcor promotion at the CNS Annual Meeting raised \$30,000 for Infantile-Spasms research.

CNF Mardi Gras sponsors now include:

- Kincaids
- Emotional Mastery, Inc
- Robins, Kaplan, Miller & Ciresi L.L.P.
- Eisai
- Lundbeck
- Upsher-Smith
- Questcor
- with more to come

Stan Hubbard, of Hubbard Broadcasting met with CNF E.D. John Stone and agreed to promote the upcoming Mardi Gras event. 

## 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:



GlaxoSmithKline



Questcor is a biopharmaceutical company focused on providing prescription drugs for the treatment of rare central nervous system and inflammatory disorders. Their efforts are currently focused on the fields of neurology and nephrology, areas of medicine which have significant unmet medical needs. Their main product is H.P Acthar® Gel (repository corticotropin hormone), a naturally-derived formulation of adrenocorticotrophic hormones used in a variety of disorders having an inflammatory component.



Lundbeck is an international pharmaceutical company deeply committed to improving quality of life for persons who have a disease of the central nervous system (CNS). Lundbeck works with research, development, production, marketing and sales of pharmaceuticals worldwide, which target depression, anxiety, schizophrenia and sleep disorders, as well as Huntington's Alzheimer's and Parkinson's diseases.

## 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



# There's Still Time to Help CNF Fundraise

The 1st Annual Twin Cities Mardi Gras will take place on Fat Tuesday, February 16

Tables, seats and sponsorships are still available.

If you can be here as an individual or as a couple we'll provide seats at a discounted



Mardi Gras Honorees  
Drs. Kenneth Swaiman & Phyllis Sher

rate; if you're traveling from out of town, hotel arrangements are available onsite for \$99 per night.

If your clinic or hospital would like to purchase a table, they start at \$2,000 for ten people. Sponsorships are also available starting at \$1,000.

Finally, we still need auction items, gift certificates, vacation getaways, etc.

Please email [jstone@childneurologyfoundation.org](mailto:jstone@childneurologyfoundation.org) or call at 877-263-5430



KARE 11 Anchor  
Mike Pomeranz



Designer  
Christopher Straub



Speed-paint Artist  
Dan Dunn

*address correction requested*

2000 West 98th St, Bloomington, MN 55431

Child Neurology  
Foundation

