

**GBS|CIDP**  
Foundation International

Fall 2013

## *The Communicator*

*Providing Strength Through Support*

### Upcoming Meetings

*Look for details on the web  
or in the mail.*

**October 12  
1:00-3:00 PM**

**LA Area Meeting**  
*Manhattan Beach Marriott*

Speaker:  
**Richard Lewis, MD**

**October 26  
10:00 AM-1:00 PM**

**Long Island, NY**  
*Stoneybrook Hilton*  
**MANAGING YOUR CIDP**

Speaker:  
**David Cornblath, MD**

**Coming this Fall:**  
**Albany, New York**



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be shared with anyone  
outside the Foundation

Contact us online at  
[www.gbs-cidp.org](http://www.gbs-cidp.org)  
or by emailing  
[info@gbs-cidp.org](mailto:info@gbs-cidp.org)



### Ken's Korner

Greetings from the Foundation! In this issue we celebrate many of the accomplishments of the Foundation and our members. You will read about several successful events and programs. Please share any events that you may be having or in which you are participating. We enjoy sharing your successes.

With the fall flu season approaching please read the most current Foundation position on flu shots.

We are very excited to announce that the 2014 International Symposium will be held at a Disney property in Orlando, Florida. Please save the dates Friday, October 31, 2014 through Sunday, November 2, 2014 (starting with our welcoming reception on Thursday, October 30, 2014).

As always, we welcome comments and questions and please know that we are here for you. [info@gbs-cidp.org](mailto:info@gbs-cidp.org)

**Save the dates!**

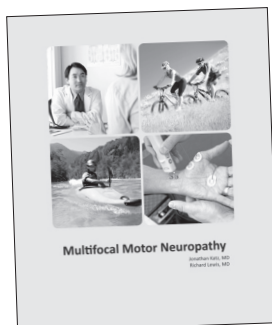
### 2014 SYMPOSIUM

**The 13th International Symposium will be held in  
Orlando Florida at a Disney property**

**Friday, October 31, 2014 - Sunday, November 2, 2014**

**Hotel information and registration materials will be mailed in the spring.**

**Hold the dates!**



**A new and very special MMN  
(Multifocal Motor Neuropathy)  
pamphlet is now available.**

**Please contact the office for your copy.**

We take this opportunity to thank **CSL Behring** for their support in making this newsletter possible through an unrestricted educational grant.

*Printed on recycled paper.*

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**CONTACT US**

International Office  
The Holly Building  
104½ Forrest Avenue  
Narberth, PA 19072

1.866.224.3301

1.610.667.0131

Fax: 1.610.667.7036

www.gbs-cidp.org  
email: info@gbs-cidp.org

## Peripheral Nerve Society (PNS) Meeting

The Peripheral Nerve Society (PNS) meeting was held June 29-July 3, 2013, in Saint Malo, France. The GBS/CIDP Foundation was a proud sponsor. Six hundred and fifty neurologists attended, many of whom presented at the 5 days of workshops and seminars.

We were pleased that Jean-Phillipe Plançon (liaison from Nantes, France) who attended the Berlin meeting and who has been diagnosed with Lewis-Sumner disorder, a variant of GBS, was able to attend. This was very special for Jean-Phillipe because he was actually able to meet the two physicians who identified this variant. How impressive for Jean-Phillip to be pictured here with Richard Lewis, MD and Austin Sumner, MD.



Richard Lewis, MD, Jean-Phillipe Plançon and Austin Sumner, MD

## Centers of Excellence

The following new Centers of Excellence have been approved by the GBS/CIDP Board of Directors:

- Vanderbilt University Medical Center, Nashville, Tennessee
- Cedars-Sinai Medical Center, West Hollywood, California
- Department of Translational Medicine, Milan University, Milan, Italy
- Department of Neurology, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands

**Disclaimer Information** Questions presented in the GBS/CIDP Newsletter are intended for general educational purposes only, and should not be construed as advising on diagnosis or treatment of Guillain-Barré Syndrome or any other medical condition.

**Privacy Policy** In response to many queries: Intrusive practices are not used by the GBS/CIDP Foundation International. It does NOT sell its mailing list nor does it make available telephone numbers! The liaisons are listed in the chapter directory with their permission. Our CIDP and Miller-Fisher Groups share names only after a signed permission is received. We are proud that none of our members has ever been solicited or sent materials other than those concerning GBS. We respect your privacy.

## Welcome to the New Medical Advisory Board Members!



SUSAN T. IANNACCONI, MD, FAAN, is the Jimmy Elizabeth Westcott Distinguished Chair in Pediatric Neurology, Professor of Neurology and Pediatrics at the University of Texas Southwestern Medical Center and Director of Child Neurology at Children's Medical Center Dallas. She specializes in pediatric neuromuscular disease and has been Medical Director for the Dallas Pediatric MDA Clinic since 1991. Her multidisciplinary Pediatric Neuromuscular Medicine clinic serves a population of over 500 children with neuromuscular diseases, including 130 with hereditary neuropathies.

Dr. Iannaccone is known for her work as a clinical trialist for spinal muscular atrophy and Duchenne muscular dystrophy. She was a major contributor for the international consensus statements for standards of care for children with several neuromuscular diseases. She is mentor for a pediatric NMM fellow each year and Program Director of the annual Carrell-Krusen Neuromuscular Symposium.



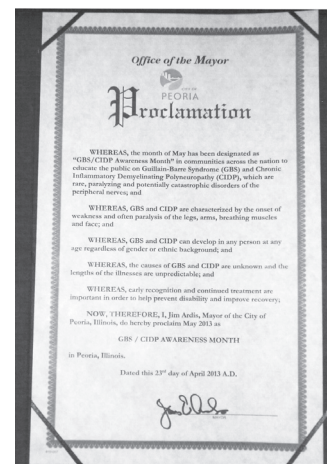
BART JACOBS, MD, did his medical training and residency in Immunology and Neurology at the Erasmus MC. In 1997 he finished a Ph.D. thesis on the pathogenesis of Guillain-Barré syndrome (GBS). Since 2003 he works as a staff neurologist at the Department of Neurology and as a consultant and workgroup leader at the Department of Immunology. Since 2008 he is an Associate Professor of Neurology and Immunology at the Erasmus MC.

His research is focused on the epidemiology, clinics, pathogenesis and treatment of immune-mediated neuropathies, especially GBS. He has a special interest in preceding infections, molecular mimicry, anti-ganglioside antibodies, genetics, intravenous immunoglobulins and predicting outcome in GBS. He has initiated the International GBS Outcome Study (IGOS), a world-wide collaborative study from the Inflammatory Neuropathy Consortium, on the monitoring and prediction of the clinical course of GBS.

Dr. Jacobs is a Member of the Educational Committee Postgraduate School Molecular Medicine, Member of the Educational Committee Master of Science 'Infection and Immunity', and a Board member of the Dutch Neuromuscular Research Center. He is a member of the Dutch Society of Neurology, Dutch Society of Pediatric Neurology, Dutch Society of Immunology, Dutch Society of Glycobiology, International Society for NeuroImmunology, European Neurological Society, Peripheral Nerve Society, and Inflammatory Neuropathy Consortium.

## GBS Awareness Recognized by Proclamations from the following Cities:

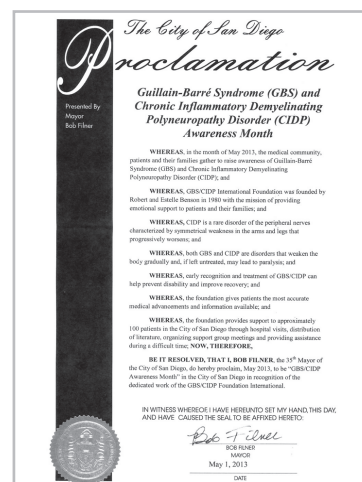
Thank you to Jim Crone (Peoria, IL),  
Liz Russel (San Diego, CA), and  
Rick Forney (Virginia).



Peoria, Illinois



Virginia



San Diego, California





## Liaisons Meet in Berlin, Germany

On April 19-21, 2013, a group of liaisons met for training in leading a chapter in their country. Countries represented were: The Netherlands, Turkey, Zimbabwe, Romania, Bosnia/Herzegovina, Germany, Kenya, Spain, Ethiopia, South Africa, France, Belgium, Israel, Nigeria, and Malta. Here are excerpts from some of their letters:



### From Zimbabwe

*I would like to express my profound gratitude to the Foundation for hosting the international liaisons' meeting held in Berlin. The meeting, so to speak, was very informative and after the training I really feel that I am geared for greater heights in terms of helping GBS patients in my country and also be able to impart the gained knowledge to others in fulfilling the Foundation's mission and goals.*

*Chengetai Chinguwa*

### From Nigeria

*On behalf of all GBS/CIDP patients and survivors in Nigeria, represented by GBS/CIDP Nigeria Foundation, I, Babafemi A. Sosanya, hereby sincerely appreciate GBS/CIDP Foundation International's Founding Director Mrs. Estelle Benson, Executive Director Ken Singleton, Officers of the Foundation, Board of Directors and Sponsors for your altruistic love and pure commitment to the course of GBS/CIDP globally.*

*The Nigerian Foundation owes its existence to you and more than that, you united the world in the fight against GBS/CIDP. And so I want to say, whenever you feel discouraged or ever wonder if it's worth the efforts, just remember the countless people you have restored hope and given reason to carry on.*

*If nothing else, you can be sure that these acts of kindness will not be in vain.*

*Thank you so very much,  
Babafemi Sosanya*

### From France

*The exchanges among the various international representatives, the partners of your foundation were of a wealth and an impressive depth. Each evoked in particular freely the experiences with the disease and approached the territorial or cultural specificities.*

*We were also able to measure the important work realized by your foundation with not only for American people but also toward the sick of the whole world.*

*Jean-Philippe Plaçon*

## As the Flu Season Approaches, Here is Our Updated Position on “Flu Shots”

### Vaccines and Guillain-Barré Syndrome

**Summary:** Vaccines are usually safe for most people; their potential benefits usually outweigh their small risks. However there is a lack of data to guide the use of immunizations in former Guillain-Barré syndrome patients. The GBS/CIDP Foundation recommends avoiding immunizations that a Guillain-Barré syndrome patient had received within six weeks of developing their initial symptoms. The decision to receive a vaccination is likely best made by conferring with the primary physician and following guidelines in the product literature.

### History of Guillain-Barré syndrome and Vaccines:

Guillain-Barré syndrome (GBS) is a rare disorder due to damage of peripheral nerves. Major features are weakness, even paralysis and sometimes collapse of breathing. Most patients recover but some are left with long term weakness. Infections commonly precede GBS and are thought to “trigger” GBS through a process called “molecular mimicry.” In this process, the body’s immune defense system attacks an infecting microbe and then inadvertently attacks peripheral nerves that “look” similar to that microbe.

In the fall of 1976 the start of an American vaccination program against swine flu was followed by more cases of GBS in vaccine recipients than would have been expected by chance. This experience raised concerns that future flu or other vaccines might also increase the risk of developing GBS.

However, a study of adverse events of flu shots given during the two flu seasons after 1976 showed no increased

risk to develop GBS.<sup>1</sup> A recently published study looked carefully at vaccine recipients over the course of 11 years, 1995–2006, and found no increased risk of developing GBS from influenza or other vaccinations.<sup>2</sup> Other studies suggest only a rare association with influenza vaccine citing an incidence of 1 or 2 excess cases of GBS over expected per million vaccinations.<sup>3</sup>

The risk of a former GBS patient developing GBS again from a vaccination is not known as the complication rate from vaccinations in recovered GBS patients has not been properly studied. Members of the GBS/CIDP Foundation Medical Advisory Board have deliberated on the safety of immunizations for former GBS patients and offer the following guidelines: For the rare person who developed GBS within 4 to 6 weeks of receiving an immunization, it seems prudent to avoid that vaccination in the future. For those whose GBS did not follow soon after a vaccination, there is no reliable data to indicate the risk of developing GBS after a vaccination.

Ultimately, former GBS patients should discuss the pros and cons of receiving a vaccination with their primary physician to evaluate its benefits and risks. Influenza is dangerous, accounting for 40,000 or so deaths each year in the US from complications, especially in the elderly and those with chronic illness (chronic lung disease, diabetes, etc.). The decision about a former GBS patient receiving or declining a flu shot or other immunization should be well thought out. Discussing this matter with the primary physician is likely the best means to access a vaccine’s value.

1. Schonberger LB et al. Guillain-Barré Syndrome: Its Epidemiology and Association with Influenza Vaccination. *Ann Neurol* 1981;9 (Suppl 1):31–38.
2. Baxter R et al. Lack of Association of Guillain-Barré Syndrome with Vaccinations. *CID* 2013;57:197–204.
3. Lasky T et al. The Guillain-Barré syndrome and the 1992–1993 and 1993–1994 Influenza Vaccines. *N Engl J Med* 1998;339:1797–1802.

© Drs. Joel Steinberg, Richard AC Hughes, Carol Lee Koski, David R Comblath; June 2013

## The First “Walk & Roll” Held in the Philadelphia Area

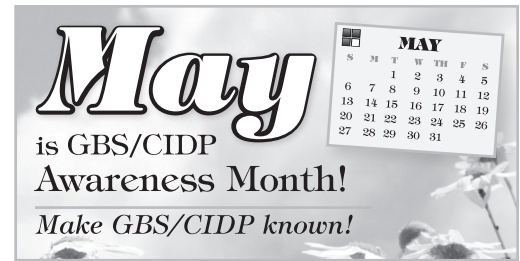
On June 9, 2013, an amazing group of 75 people came together, outfitted in new t-shirts, and the one mile walk began! There were all degrees of recovery, from cane to walker to wheelchair. Applause encouraged Geoffrey Biringer who walked a distance the first time. His wife carefully followed him with his wheelchair “just in case.” How remarkable!



**Look for Walk and Roll Events this Fall in Atlanta and Pittsburgh!**  
If you are interested in having a Walk and Roll for GBS/CIDP in your community in 2014 contact the office at [info@gsb-cidp.org](mailto:info@gsb-cidp.org).

## Fund-raising Activities

A variety of fund-raising activities took place during May's GBS/CIDP Awareness Month. We thank these folks for all they do.



### GBS/CIDP Sit-In

Enclosed are checks and a list of donors to the sum of \$1,541. This is the money raised by the Men of St. Bart's in Estes Park, Colorado. We hope that we will be able to do the "GBS/CIDP Sit-in" again next year.

Sincerely,

William C. Shirey

### Battling the Barré!

I contacted you a while back about an event I was having in honor of my husband who is stricken with GBS. We wanted to bring awareness to the Fayetteville/Fort Bragg, NC area and it was a success. Many had not heard about the disease but by putting on the Zumba event, they were made aware. My group called the Da'Ville Girlz and I would like to donate a portion of the proceeds. I am dropping a money order in the mail today in the amount of \$425. Here is a photo of myself and the Da'Ville Girlz. The community really came out and supported. The event was called "Battling the Barré!"

God Bless and I am hoping this will help with research on this horrible disease.

Stephanie Kegler



### Fashion Show

Another annual Fashion Show featuring beautiful clothing designed by our own Liz Russell in San Diego, CA.

### Car Calendars

Car Calendars sold by Karen Pacheco, daughter of liaison Rose Gallegos of New Mexico, raised \$1,000!

### Spring Musical

Enclosed is a donation check for \$1,000 raised by the Burr and Burton Academy's cast and crew of our 2013 spring musical "Little Shop of Horrors." This donation is in honor of our good friend Denis Rice who is now in the ICU of Dartmouth in New Hampshire, slowly recovering from this disease.

Thank you for the amazing work you all do!

Jim Raposa



### Golf Tournament

Thank you, Holly Cannon of Montana, for another successful golf tournament. \$5,000 was raised!



## Another Art Soiree Scores Success!

Hannah Blanton, liaison in Charlotte, North Carolina, hosted her traditional Art Soiree on May 2, 2013. A record amount was raised as a result of the sale of beautiful original art!

Thank you, Hannah, and your wonderful volunteers!



## News from the Plasma Protein Therapeutics Association

**PPTA to Launch International Plasma Awareness Week (IPAW)  
October 13-20, 2013**

PPTA and its member companies are pleased to sponsor International Plasma Awareness Week.

The event will be held annually and is designed to:

- Raise Global Awareness about source plasma collection.
- Recognize the contributions of plasma donors to saving and improving lives
- Increase understanding about lifesaving plasma protein therapies and rare diseases.
- In spearheading this global effort, PPTA has coordinated efforts, designed promotional materials, issued communications to various stakeholder, secured Proclamations from State Governors and managed media relations. The Association has also developed a toolkit for participants to use including posters and banners in various sizes and multiple languages (English, French, German, Spanish, Italian and Czech), radio ads, and press releases.

Member companies are actively planning events including donor appreciation celebrations at plasma collection centers, open houses and tours for patients, community leaders, the media, and more.

Together we are bound by a common goal - to save and improve lives. IPAW serves as a catalyst for sharing that mission and our many contributions to helping patients throughout the world.

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## DIRECTORY

*Check the enclosed chapter directory and contact the chapter nearest you. In addition, our "subgroups" are listed below.*

- **"CIDP" Group**  
For those with a diagnosis of chronic inflammatory demyelinating polyneuropathy. Please identify yourself to the National Office in order to be put in contact with others around the country.
- **Children with GBS**  
Call Lisa Butler, 215-628-2771  
670 Penllyn Blue Bell Pike  
Blue Bell, PA 19422  
Son, Stuart had GBS at 5 1/2 years old
- **Children with "CIDP"**  
For children diagnosed with chronic inflammatory demyelinating polyneuropathy. A separate registry has been created. Please contact the National Office for details.
- **Group for Having GBS Two Separate Times**  
Please call the National Office for contact with others.
- **Miller Fisher Variant Group**  
Please call the National Office for contact with others.
- **Wheelchair Limited Group**  
Please call the National Office for contact with others.
- **AMSAN Group**  
Please call the National Office for contact with others.
- **A Teenage Pen Pal Group**  
Arielle Challander, 231-946-7256  
413 Shawn Drive  
Traverse City, MI 49684  
E-mail: GBSTeenPenPal@hotmail.com  
Arielle had GBS in 2006 at age 13. She is willing to share her experiences so others might understand. To have teenage GBS'er pen pal, write, call or e-mail Arielle.
- **Pregnant Women with GBS**  
Robin Busch, 203-972-2744  
264 Oenoke Ridge,  
New Canaan, CT 06840  
Robin has offered to share her experience with GBS which came about during her pregnancy. We have many such cases and reassurance from someone who has gone through this is needed support.
- **Bereavement Group**  
A group for anyone who has lost a loved one due to GBS/CIDP complications. Please contact: Bereavement Group at the National Office.
- **The "Campy" Group**  
Those whose GBS onset was identified as a result of the campylobacter bacteria. Numbers to be used for research purposes.