



GBS | CIDP
Foundation International

Fall 2012

The Communicator

Providing Strength Through Support



GBS | CIDP
Foundation International

TRAVELS THE WORLD

Peripheral Nerve Society Meeting in Rotterdam

The GBS/CIDP Foundation International was proud to support the Peripheral Nerve Society meeting held this year in Rotterdam from June 24th to 27th. Various aspects of GBS/CIDP were addressed by leading authorities. Our international liaisons, Patricia Blomkwist-Markens, Board Member, and Glennys Sanders exhibited at the meeting and distributed our literature (both pamphlets and CDs). Three medical students attended as recipients of a fellowship given in honor of Arthur K. Asbury, Medical Advisory Board.



Glennys Sanders and Patricia Blomkwist-Markens

Letter from Ken Singleton, Executive Director



Our 12th International Symposium is right around the corner. The symposium provides a unique and exciting opportunity for patients, families and doctors to interact.

The staff, many volunteers, Foundation Board and Medical Advisory committee have put in countless hours to ensure an informative and desirable conference. I encourage you to take the opportunity to network, ask questions and take home much information.

This will be my first Symposium and I look forward to meeting as many members as possible. Please feel free to stop me and introduce yourselves. Please travel safely!

HURRY – Get your reservation in for the 12th International Symposium



All brochures have been mailed. Didn't receive yours?

Download the brochure at <http://www.gbs-cidp.org/wp-content/uploads/2012/08/12thSympMailer.pdf> or email the office at info@gbs-cidp.org or call (610) 667-0131 to request your brochure.

October 26 - 28, 2012 ★ Fort Worth, Texas



REMINDER *Looking to keep the spirit of giving alive this holiday season?*

Give the gift of a year-end donation to GBS/CIDP Foundation International.

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

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In each issue of the Communicator we will feature a member of the Board of Directors. For our inaugural article we are introducing Phil Kinnicutt, President of the Board of Directors.

Phil Kinnicutt, Board President

I was in my mid-forties when I was diagnosed with GBS and my wife Annetta and our two kids, aged 4 and 9, were absolutely terrified. Fortunately, I was lucky enough to have a relatively mild case and was out of the hospital in less than a month and back at work in three months.

That was over 25 years ago and since that time I have seen GBS and CIDP in its many forms and degrees of severity and have come to appreciate just how fortunate I really was...particularly since I was afflicted before the advent of Plasmapheresis and IVIG!

It has been a privilege and an honor to be a long-time liaison volunteer in Hawaii and to serve on the Foundation Board of Directors...currently as Board President.

Although I was born and raised in Massachusetts, I have lived and worked in Hawaii for more than 45 years, including a tour of duty in the Navy on board a ship home ported in Pearl Harbor during the Vietnam War.

My career in the 50th State has revolved around marketing and public relations on both the agency and client sides of the business plus some work in the publishing industry. Along the way, I earned an MBA from the University of Hawaii's Shidler School of Business and made time to give back to the community by serving on a number of non-profit boards...many of them related to healthcare.

The Foundation has made tremendous strides in the past few years as we have expanded our efforts on behalf of patients and their families around the world through funding research and being an active patient advocate within the healthcare industry and at every level of the State and Federal Governments in the United States.

In the future, I see us redoubling our efforts on a worldwide basis thanks to the expansion of our international activities and our ability to take advantage of information technology to educate, advocate and communicate with the many thousands of people we serve and those in the medical community who provide the services we need.

I look forward to meeting many of you at our upcoming Symposium in Texas. See you in Fort Worth!

Aloha,

Fundraiser in Estes Park, Colorado

William Shirey raised \$1,731.00 for the GBS/CIDP Foundation by holding a "Sit-In". Participants gathered at St. Bartholomew's Episcopal Church, handed in their "sponsor sheets" and SAT!!! This is the fifth year William has held this event. The total raised: \$7,622. Thank you, thank you! (What a great idea!)

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 the 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 slip 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.

Letter to the Editor

Carol Thomson, the daughter of Edward Papierowicz, who recently passed at the grand age of 85 and was stricken with GBS over 29 years ago, wrote us a wonderful letter. Her nephew's college application essay was read at her dad's funeral – a true testament to his battle and determination dealing with GBS – and we would like to share it with you.

Imagine trout fishing in a picturesque stream in Northern New Jersey on day and the next day laying paralyzed on a hospital bed. This life changing experience happened to my grandfather, or "Grandpop", Edward Papierowicz. Through my Grandpop's journey to a new "normal", I have learned the importance of family support. He has greatly influenced me through his example of determination and courage when faced with life's challenges.

In 1982, before I was born, he was diagnosed with Guillain-Barré syndrome. This is a disorder where the body's immune system attacks part of the peripheral nervous system. Without warning, this disorder took him from a 56 year old able bodied sportstman to a fully paralyzed husband and father of four. After much rehabilitation and determination, Grandpop gained partial movement that enabled him to perform basic life functions. Now he can periodically leave his wheelchair and walk short distances with accommodations for the physically impaired, he can drive a car and lead an 'almost' normal life. His fight back to a normal life is something that I hold in high reverence and what makes him such a great role model to me.

His recovery from the disorder was very painful not only for him, but his family as well. When the syndrome first set in the help and support from his four children and wife was amazing. Taking him to doctor appointments and therapy was now part of everyday life for my grandmother. She and her children quickly became experts at taking care of my Grandpop's needs. Due to the importance family has played in my Grandpop's survival, I am now a person much more in tune with my family life. I regard time spent with my family as a time where I can connect with my past and learn family values. After watching my family physically and emotionally nurse my Grandpop back to a "normal" life, I feel empowered knowing that if I come across a challenge that seems insurmountable my family will always be there for me.

When he first returned home from the hospital, life was pretty rough for my Grandpop. He was unable to do many things on his own and needed assistance for every little chore. However, over time he figured out ways to get things done even with his limitations. My grandfather grew in determination to become independent as each of his grandchildren was born. I vividly remember sitting in a diner next to Grandpop and watching him struggle to get food onto the fork and the food into his mouth. Many times the food would fall and he would begin the process again.

On the surface it was similar to the toddler at the nearby table learning to feed himself, but very different as this was a very proud grown man. As the rest of my family sat there socializing I noted how strong his determination was. This long and sometimes messy process of feeding himself did not embarrass him because he was determined to achieve his goal of becoming self-reliant. As a seventeen year old, my goals often involve my academic or athletic life. I use this example of my Grandpop's determination as I set and accomplish my goals. I especially draw upon this when I go through the repetitive motion of perfecting my golf swing. I refuse to let myself get overly frustrated with the redundant action of my golf swing as I reflect back to my determined Grandpop learning to feed himself again.

Sadly, in 2004 my grandmother passed away. I was not sure how Grandpop would manage. As if losing a spouse wasn't hard enough, he was also physically handicapped. This was a true test of his courage to be self-reliant and accept change. Astonishingly, through his determination, he was able to do many of the things my grandmother did for him around the house. Overcoming another set of obstacles so late in life and so quickly has made my Grandpop more of a hero to me and helped me to accept change. I faced a significant change in my own life upon leaving grammar school. I was one of seventy children who graduated from a parochial school. While the majority of my classmates were continuing on to parochial high school, I was heading to the public high school. The thought of leaving my comfort zone, of being with the same classmates of nine years, classmates that shared the same faith, and entering a freshman class of more than eight hundred students was overwhelming. I knew that my new classmates would be from very diverse ethnic, racial, and economic backgrounds. Entering Naperville North High School on my first day, I drew upon my Grandpop's courage and embraced change. I have become a leader in athletics as a golf captain, in the student body as a Freshman Year Information Leader, and in academics as a teacher's assistant.

It has been three years since my grandmother passed, and my grandfather has found the strength to overcome most obstacles. When we visited my Grandpop last summer I was so proud of all the things he could do without assistance and how he was so appreciative of all the little things that I take for granted. He has definitely taught me to be thankful for all the talents I have been given, for me to live in the moment, and discover the good in every experience. Wherever I may be I am sure that my Grandpop's example will be a source of strength and guidance. He has been a model of determination and courage to me and I know I will draw upon these qualities throughout my life.

Christopher Pierson



Letter From a Long-Time Member

Dear Guillain-Barré Syndrome Foundation:

My life with GBS began in July, 1990 when I was 70 years old. A severe case of the flu brought me to the hospital. Fortunately, I was diagnosed with GBS immediately.

No need to write you a book about my hospital experience—chances are you've lived it and you know it.

Today I am 93 years old, residing in an assisted living home, and using a walker. I am in fairly good health.

I would like to share the following expression told to me by my therapist after coming home from a six-month stay in the hospital recovering from GBS:

"Inch by inch, anything is a cinch."

My therapist, a dedicated lady, put me through the mill. After she left, it was exercise, exercise, again and again. I repeat this expression, "inch by inch," and I've applied it to everything I ever did since. It works!

Sincerely, Ed Wissner

PS: Enclosed is a recent picture of me sporting my t-shirt that displays the motto by which I live.

■ ■ Please update your contact information to make sure we have your current email address.

Contact us online at
www.gbs-cidp.org
 or by emailing
info@gbs-cidp.org

Is CIDP always "Chronic"?

Carol Lee Koski, MD, Medical Advisory Board

The diagnosis of Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) is made by the recognition of clinical signs that include progression of weakness and sensory loss in the legs greater than the arms over at least an eight (8) week period with a loss of deep tendon reflexes in the involved extremities. The clinical diagnosis is confirmed by changes in Nerve Conduction Velocities. Although we know of many patients that deal with active disease requiring treatment such as corticosteroids or Intravenous immunoglobulin (IVIG) over decades, increasing information suggests that early diagnosis and aggressive treatment can lead to disease remission and withdrawal from medication in a significant percent of patients. In a future Communicator we will discuss the factors and treatments that can be used to shorten progression and drug dependence.

Immunoglobulin Nursing Society

This year the Immunoglobulin Nursing Society, IgNS, held its first National Conference and Educational Symposium for its members in Orlando, Florida. The GBS/CIDP Foundation International was asked to attend and man a table with information about GBS and CIDP. The purpose of the conference was to provide education and to promote excellence in IVIG treatments to better patient care.

In attendance was the Foundation's Orlando liaison, Ian Harper, as a Guillain-Barré Syndrome patient representative for the conference and he was very well received. He was able to discuss with the nurses and other industry professionals what it is like to be a Guillain-Barré patient and his experience with IVIG. The nurses were eager to hear about GBS from a patient first hand.

Thank you, Ian Harper, for a job well done. The GBS/CIDP Foundation International looks forward to more opportunities for education and industry support in the future.

Fundraisers in Montana

Holly Cannon, our liaison in Montana, held the third Annual GBS/CIDP Golf Outing on June 30, 2012. 50 golfers took to the links for a great round of golf, participating in a four person golf scramble. The day's festivities also included a luncheon and prizes. The total raised was \$5,570.

Holly's daughter, Hailey, a CIDP patient in intermediate school, held a bake sale at her school and through the sale of all those sweets they contributed \$500.

Many thanks go out to the Cannons who continue to work tirelessly on the behalf of raising money for the Foundation, totaling over \$17,500 over the past three years.

Thank you from Estelle Benson

I would like to take this opportunity to thank so many for the hundreds of letters and cards and donations to the Benson Fellowship in memory of my husband, Bob. He is why this organization exists and the outpouring of caring and love reinforces that we are one family.

Thank you again,

GBS/CIDP Awareness Celebrated with Proclamations!

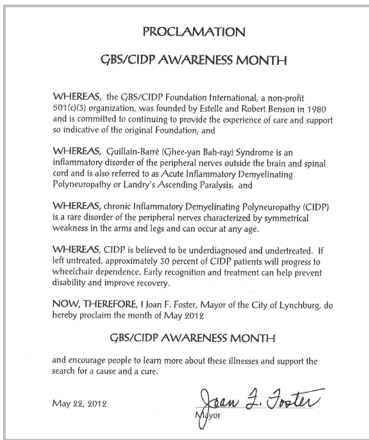
Thanks to liaison Rick Forney of Hardy, VA and Rose Gallegos of Fairview, NM!



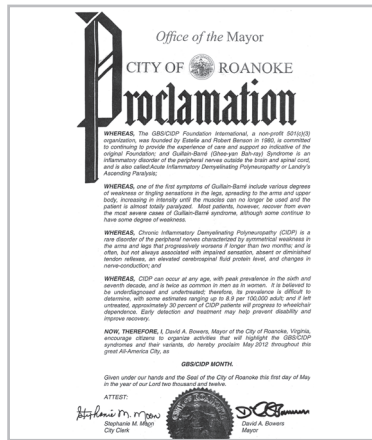
Rocky Mount, VA



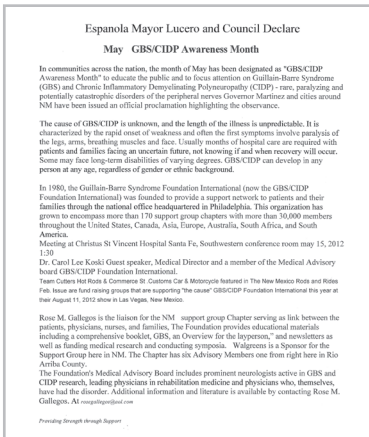
Bedford, VA



Linchburg, VA



Roanoke, VA



Española, NM



Española, NM

Local Brings Awareness

Three days after Lake Delton resident Emily Knapp noticed tingling and numbness in her hands and feet she went to the ER to get checked out.

Knapp was initially diagnosed with myositis, inflammation of skeletal muscles.

She woke up the next morning with numbness in her knees and found it hard to walk. When she returned to the ER, she received the same diagnosis.

"Later that afternoon I had a doctor appointment which left the doctor questioning what was happening. I was scheduled to have an MRI the following day and blood test a day after the MRI.

"By that night, I was unable to move. My parents decided to drive me to the ER at UW Madison, where doctors had no question about my diagnosis. I was diagnosed on March 23, 2010 with Guillain-Barré Syndrome," Knapp said.

Guillain-Barré Syndrome, GBS, and Chronic Inflammatory Demyelinating Polyneuropathy, CIDP, are rare, paralyzing and potentially catastrophic disorders of the peripheral nerves.

Knapp said during treatment she was paralyzed from the neck down, on life support for five and a half weeks and placed in a medically induced coma for three weeks.

"Once I was taken off of the comatose medication, I was left the ability to nod yes and no which made communication easier. Communication was accomplished using a letter board, since I had no movement to write," Knapp said.

Following further treatment Knapp was moved to the inpatient rehabilitation unit where she stayed for an additional two weeks. She returned home after 58 days and continued full-time physical and occupational therapies.

"Today, I am proud to announce I am 100 percent recovered and have mild residual weakness in my face and feet," Knapp said.

Knapp is now the Wisconsin liaison with the GBS-CIDP Foundation International, an organization working to raise awareness and provide a support network to patients and their families.

Earlier in the week she met with Kay Mackesey, Lake Delton clerk, treasurer and coordinator, and Nancy Holterm, Wisconsin Dells City Clerk/Administrative Coordinator where she received proclamations from the village and city designating May as GBS/CIDP Awareness Month.



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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 poly-neuropathy. 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 experiences that others might not understand. To have a teenage GBS'er pen pal, write, call or e-mail to 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/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.