



**GBS|CIDP**  
Foundation International

Spring 2014

## *The Communicator*

*Providing Strength Through Support*

### Upcoming Dates to Note

#### Chapter Meetings

4/12 ~ Indianapolis, Indiana  
4/14 ~ Salem, Virginia  
4/22 ~ Westchester County, NY  
4/26 ~ Columbus, Ohio  
4/26 ~ Spanish Fort, Alabama  
5/10 ~ Albuquerque, NM  
5/17 ~ East Windsor, NJ  
5/27 ~ Westchester County, NY

Contact your local Chapter Liaison  
for upcoming meetings in your area!

#### Walk and Roll Events

5/4 ~ North Central NJ,  
Bernards Township, NJ  
6/22 ~ Greater Philadelphia,  
Wayne, PA

Register on-line at [gbs-cidp.org](http://gbs-cidp.org) :  
Take Action/Community Events



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Your information will not be  
shared with anyone outside  
the Foundation

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### Ken's Korner

Many, many thanks to all of our 2013 supporters! Your generosity directly impacts our ability to serve you, our community, and to remain committed to our four pillars: Support, Education, Research, and Advocacy. See the last page of this issue for an update on each!

2014 brings us the opportunity for a new strategic initiative: IMPROVE COMMUNICATIONS! What does that mean? We are always looking for innovative ways to improve how we communicate with all of you, our constituents. We understand our responsibility as good stewards of every dollar donated and strive to bring you improvements in our communication both efficiently and economically.

You will notice a change in paper in this issue of the *Communicator*. This update does not affect the cost of production, just improves the quality of our publication. As the year moves on, look for additional changes that help us improve our message delivery.

We are in the process of an entire review of our website. This means studying content and presentation for accuracy, up-to-date information, and communication on events like our Symposium and Walk and Rolls.

Electronic communication allows us to deliver information to you more frequently without adding cost! We are not looking to eliminate any means of communication, just provide new vehicles to deliver! If we have your Email address, this year you will begin to receive electronic messages from us.

We remain committed to our mission and grass roots outreach. When we look at how we communicate, we endeavor to preserve our history while reinforcing consistent presentation of GBS|CIDP Foundation International.

I wish you a happy spring and close with four simple "asks".

1. Plan on attending our 13th International Symposium in Orlando, October 31-November 2.
2. Participate and/or volunteer in a Walk and Roll near you!
3. Update your contact information to include your email address so that we can reach you electronically!
4. Participate in GBS|CIDP awareness month this May!

As always, thank you for supporting the GBS|CIDP Communities.

Ken Singleton  
Executive Director

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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## Capitol Hill Presence

Dale P. Dirks and Dane R. Christiansen of the Health and Medicine Counsel of Washington represent the Foundation and the GBS/CIDP community on Capitol Hill continuously working with legislators and federal agencies to advance research, facilitate treatment development, and improve patient care and making progress educating elected officials about GBS/CIDP and the experience of living with these conditions.

Members of Congress want to hear from you, their constituents. Our representatives on Capitol Hill serve as facilitators to connect you with the offices of your legislators. The Foundation can provide interested individuals with legislative briefings on key issues, advocacy training sessions, and all the tools needed to be successful with engaging your House Representatives and Senators. All you need to get started is a desire to improve the lives of affected individuals and a willingness to tell your story. If you are interested in becoming an advocate, please let us know, and we will keep you updated with advocacy opportunities.

Our legislative agenda for 2014 continues the community's efforts to bolster medical research and ensure access to quality healthcare. Grassroots advocates, like you, are asking for increased funding to allow for expansion of the federal research portfolio at the National Institutes of Health, the enactment of a bill to improve private insurance coverage for individuals with complex conditions (The Patients' Access to Treatments Act), and a restoration of physician reimbursement for the tests used to diagnose GBS and CIDP so that no affected individual misses out on an early diagnosis. Please consider joining others to serve as the grassroots voice of the community on Capitol Hill. Contact the foundation office for more information.

## Walk and Roll 2014 and National Awareness Month Fund Raisers



We are so excited about the interest and support we are receiving for Walk and Roll 2014! Two years ago, Walk and Roll as a nationwide public awareness and fund raising event was a concept. In 2013, the Foundation had three pilot Walk and Roll events. This year, for Walk and Roll 2014, we are expecting more than ten events across the country! We are actively looking for volunteers and participation for locations being planned for:

San Diego, CA	Dallas, TX	New York City, NY	Raleigh, NC
St. Louis, MO	Boston, MA	North Central, NJ	Atlanta, GA
Philadelphia, PA	Pittsburgh, PA	Orlando, FL	Wolcottville, IN

May is National Awareness Month for GBS, CIDP, MMN and variants. This creates the opportunity for anyone interested in spreading the word about these disorders and where to seek help. If you are interested in volunteering for or participating in Walk and Roll 2014, or holding a public awareness event or submitting an article to your local newspaper for National Awareness Month, please contact Bob Nelson, Deputy Director, at bob.nelson@gbs-cidp.org.

**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.

## Meet Our Board Member, Patricia Blomkwist-Markens

### GBS

In the winter of 1990, Patricia Blomkwist-Markens, who holds a legal degree from the University of Amsterdam, spent 4.5 months in the hospital with a severe case of GBS, two months of which she was in the ICU, while ventilator dependent for over a month. Patricia's parents, who were obviously very worried about their daughter, contacted the Foundation and spoke frequently with Estelle Benson over the phone. Estelle assured them that their daughter would get better. Estelle was right; Patricia made a good recovery.



*photography by  
Van Hees Fotografie*

### Dutch support group

While still in the ICU, Patricia was visited by a young woman, who had made a full recovery after having had GBS five years earlier. Patricia's parents had found this young lady and had persuaded her to visit Patricia. That visit made a huge impact and was extremely helpful for Patricia to keep a positive view on her recovery. After the visit, Patricia wondered if there was a support group or patient organization for GBS in The Netherlands and vowed, if there was none, to found one herself. She did, later merging the group into Spierziekten Nederland (the organization for neuromuscular disorders in The Netherlands); and she has been President of the organization's subcommittee for GBS/CIDP from the start.

In that capacity, representing the patients, Patricia sat on the committee that was responsible for developing guidelines (for The Netherlands) for the treatment of GBS, in all phases of the disease. That important work was completed in 2010.

In September, 2011, Patricia was awarded "The Crown" by the Princess Beatrix Muscle Fund, an award in recognition for her work and dedication to patients with GBS, CIDP, and variants.

### International

In 1991, while attending the 2nd International Symposium of the GBS/CIDP Foundation International, Patricia was appointed as liaison for the Foundation for The Netherlands. In later years, Patricia started assisting Glennys Sanders, the regional director for international affairs, in developing the global presence of the Foundation; and soon Patricia was also made regional director for international affairs. Her ability to speak several languages in addition to her mother language of Dutch serves her well in searching for and contacting potential liaisons in all parts of the world. In 2005, Patricia was elected to the Board of Directors of the Foundation and served two years as the Board's secretary, subsequently being elected as Vice-President (for international affairs) in 2013.

Patricia's mission is to make certain that the "international" in the name of the Foundation is validated by identifying liaisons and establishing chapters in as many countries as possible. Patricia looks forward to welcoming many international participants to the 2014 symposium in Orlando.

## International News

Our International presence continues to grow. We now have 57 International chapters and sister organizations representing:



Argentina  
Australia  
Austria  
Belgium  
Bolivia  
Bosnia and Herzegovina  
Brazil  
Canada  
China  
Colombia  
Cyprus  
Ethiopia  
France  
Germany  
India  
Ireland  
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Japan  
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Venezuela  
West Indies  
Zimbabwe



### Our Logo

The four squares represent the four panes of a window which can look very dark when you are challenged with a rare medical condition. The open pane of light and hope represents the Foundation's commitment to support, research, education and advocacy.

## Issues of concern to Patients

*Joel S. Steinberg, MD, PhD, Vice President, GBS/CIDP Board of Directors and member, Medical Advisory Board*

### Diagnosing CIDP

**Question:** It took quite a while to establish that I have CIDP. Is this unusual?

**Answer:** For several reasons, the diagnosis of CIDP can take some time. First, CIDP is rare. Many physicians, especially general practitioners, may have never heard of it. Secondly, the development of sufficient symptoms - slowly evolving weakness of the legs and then of the arms, to suspect the presence of CIDP - usually takes place over months. Because of its rarity, even general neurologists may be uncomfortable making the diagnosis and might rely on a neuromuscular neurology specialist to confirm the diagnosis and oversee treatment. Using a neurologist who specializes in CIDP and similar disorders may be wise, to assure that the diagnosis is correct and the treatments are well thought out. Readers are encouraged to confer with the GBS/CIDP Foundation office or our website for our list of Centers of Excellence. These Centers are chosen because their neurologists have a proven track record of expertise in dealing with CIDP.

### Can Pain Occur with GBS?

**Question:** I am experiencing pain as part of my GBS. I spoke with my family physician who seems to think pain is not part of GBS. What to do?

**Answer:** The outstanding feature of GBS is weakness, the problem that usually prompts a patient to seek medical attention. Yet, pain is a well-known part of GBS for many patients and can even precede weakness, especially pain in the back, thighs, or shoulders. So you may want to discuss the pain issues with your neurologist who may have more experience handling this problem.

### Treatment of Pain in GBS

**Question:** Pain in GBS – how to treat it? My family doctor understands that I am having pain as part of my GBS and if milder pain medicine (acetaminophen or ibuprofen) does not work, is suggesting oxycodone type medications. I am concerned about the risk of side effects, such as constipation and addiction.

**Answer:** You have a very real reason to be concerned. In addition to constipation, narcotics do place a patient at risk for addiction as well as requiring progressively higher doses to be of benefit. These are risks that can often be avoided in treating neuropathic pain, pain caused by damage of nerves rather than a general soft tissue injury. Several medications and other approaches are worthwhile trying to relieve the neuropathic pain of GBS. Applications of warm heat (for example, with a device called a K-pad), topical application of jalapeño peppers as a cream, called capsaicin, in products such as Zostrix®, and some of the modern anti-seizure medications, such as gabapentin (marketed as Neurontin®), (Cymbalta®) and (Lyrica®) have been used, often providing good relief of pain in GBS. Dosing with anti-seizure medications should usually be started at a low dose, increased (doubled) every several days, until relief

is obtained. If drowsiness or dopiness develops, back off the most recent dose increase for several more days so the body can develop tolerance and reduce side effect annoyances.

### Weaning off Treatment for CIDP

**Question:** I have been on treatment for CIDP with monthly doses of IVIG for several months. I can now walk rather well, without much of a trace of weakness or clumsiness. I am wondering just how long I should continue the monthly IVIG.

**Answer:** You may have reached a stage of CIDP where the effect of the disorder on your nerves is diminishing. You may be ready for a slow tapering of treatment dosing. Discuss with your neurologist the possibility of lengthening the time between treatments. Perhaps waiting 6, rather than 4 weeks between dosing may be worth a try, to see if you can do this without much deterioration in your neuromuscular function.

### CIDP Burn Out

**Question:** I have heard of CIDP burning out. Just what does this mean?

**Answer:** In many CIDP patients, their symptoms, weakness, seems to dissipate with time. Just why this occurs is not clear. It's as though the immune mechanisms that cause nerve injury wear out. Even though CIDP is usually recurring, and can last several months, even years, it does often cease, often spoken of as burning out.

### Duration of Formal Rehabilitation Therapy

**Question:** I have been getting physical and occupational therapy for my weakness for several weeks. Now I have been informed that my health insurance will no longer cover this care. I am in a quandary. I still feel that I could benefit from further therapy. What should I do?

**Answer:** This is not an uncommon scenario. Typically most health insurance programs will only continue coverage while there is a measurable improvement in function from week-to-week or month-to-month. As patients improve, the increases in strength and endurance slow down. At some time in this process insurance coverage may be discontinued. There often are good solutions to this situation. A common approach is for the therapist to provide a detailed list of home exercises to perform. The exercises will usually comprise activities that had been performed in a formal rehab program, but without the regimented oversight of a therapist. Exercises such as sit-ups and leg raises with a weight on the ankle will usually require minimal outlay for equipment. They can be performed at home with little, if any, expense. A key to benefitting from a home program is to set aside some specific time during the day to perform them. Listening to your favorite music or watching some entertainment on your TV or computer (e.g., YouTube) can help pass the time while doing the exercises. Continued oversight by physicians, such as a neurologist, rehabilitation doctor (physiatrist), or a family physician is recommended.





This story tells the story of Darren Armstrong, RN at The Queen's Medical Center in Hawaii. Darren is also a newly appointed Liaison in Hawaii.

## Impromptu Wedding Held at Queens

**D**arren Armstrong, RN, is finally back at his job in the Queen's Same Day Surgery Center after a nearly four-month ordeal. "Ordeal" is perhaps too negative a word. Although Darren went through some very worrying and life-threatening times and a long convalescence, he remained remarkably upbeat throughout, and very good things happened along the way.

On Thursday afternoon, January 13, as *Print Connection* editor Jason Kimura was striving to lay out the next issue of the *Print Connection* to meet deadline, the phone rang. It was Queenie Retuta, a staff nurse on QET 5—Neuroscience. Queenie was wondering if a few photos could be taken at a wedding of another Queen's nurse, Darren Armstrong, at 3:30 pm. A wedding? Today? Yes, a hastily planned one, so sorry about the short notice; but, oh, it would be a great story for the *Print Connection*. Jason wasn't sure. Nevertheless, he grabbed his camera and notebook at the appointed time and headed for the Neuroscience Unit.

The groom, curiously, was as limp as a rag doll and had to be lifted from his bed onto a wheelchair. Soon, people began to arrive. Realizing that there would be no time to talk to Darren before the ceremony, Jason decided he may as well be the wedding photographer. Despite the fact that the wedding was to take place on a hospital building balcony, the arrangements didn't look at all hasty; and no detail seemed to have been forgotten.

There were beautiful flower arrangements, pink roses, two cakes, chocolates, and sparkling cider arranged on a white table cloth on a small table. Thoughtful gifts, complete with personal thank-you notes written by the bride, Miki Kawazu, were given to the *de facto* photographer and other participants before the ceremony began. The ceremony was much more down-to-the-wire than it appeared on the surface, and both the bride and groom seemed not to be the least bit stressed.

After the ceremony was over, Darren told his story. He had arrived at work on his motorcycle at 5:30 am on Tuesday—just two days previously. Darren changed into scrubs and started to get patients ready for surgery at the SDS. The first sign of trouble was that he had difficulty opening alcohol swabs, which was odd considering he was building a house and was in good physical shape. The

weakness continued; so after a couple hours, he called his primary physician, who agreed to see him at lunch. The doctor sent him to see neurologist Anthony Mauro, MD, who straightaway diagnosed Guillain-Barre syndrome and told Darren to get himself admitted. He could still walk on Tuesday night, but by Wednesday, he could not.

Guillain-Barre syndrome is a serious autoimmune disorder in which the body's immune system attacks part of the nervous system, damaging parts of nerves. Most often, the disorder destroys nerve coverings, called myelin sheaths. Demyelination causes nerve signals to move slowly. The nerve damage causes tingling, muscle weakness, and paralysis. The condition gets worse quickly; and patients can even have difficulty breathing and may have to be put on a ventilator.

There is no cure for the disorder; but either a regimen of immunoglobulin therapy, which blocks the antibodies, or plasmapheresis, which removes antibodies from the blood, is given to the patient to lessen the nerve damage. Eventually, the worsening of the symptoms plateaus; and fortunately, myelin sheaths regenerate, although the process can take four to six months, and, in some cases, a year. Ninety percent of people who are afflicted with Guillain-Barre recover completely.

Mostly affecting people between the ages of 30 and 50, Guillain-Barre syndrome often follows a minor infection, such as a gastrointestinal infection, or occurs after surgery. Darren had both, he says, but the cause is unknown. "I've been sick so many times," he said, "but I didn't get it before."

Darren was a travel nurse for eight years, and worked in 17 hospitals in 10 states. He was a traveler at Queen's for three months before becoming a permanent employee three years ago. "It was a little traumatic," Darren admits, finally deciding to settle down at Queen's. An adventurous and free spirit has taken him all over the world—including motorcycling in Asia for three months—and to all 50 states. "I'd spend three months here, three months there to see the world," he related. Hawaii was the last state Darren needed to set foot on to complete his U.S. travel record.

Almost three years ago, he met Miki. At the time, Darren had to move out of his apartment—quickly. He had left the task to the last minute but arranged to rent a room he found on Craigslist. The renter was somehow confused and gave

*continued on page 13*

# Thank you to all the following 2013 donors for your generosity

The Foundation would also like to thank all of the organizations, participants, contributors, and sponsors for special event fundraising.

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Ron Bailey	Patricia H. Blomkwist-Markens	Howard Burnette	Neoma Corey	John Dezort	Mark Falbo
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Donna Bankston	Robert Bommer	Tom and Lisa Butler	JoAnn and Charles Courts	Pam and Michael Dobos	John Felps
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Elsa Munoz	Todd Pawlowicz	Robert Reed	Doris Ryan	Gloria Shovin	Louis and Gerry Swiderski
Shawn Murphy	Linda Payne	Scott and Kathleen Rees	Scott and Curtis Rybaczyk	Ashutosh Shukla	Alfred Swindler
Walter Murphy	Kay Payne	Thomas Rees	Deb and Jack Ryder	Sharon and Stan Sielaff	Michael Swirsky, MD
Thomas Murray	Sharon and Joseph Pazak	Louis Regenstein	Margaret Rzeszotarski	Ivan Sievers	Marshall and Tineke Switzer
Marie and Edgar Murray	Margaret Pearce	Linda Reid	Michael Sabia	Christie Silbajoris	Douglas and Jeanne Swope
Thomas and Pamela Murray	Helene Peck	Thomas and Nancy Reiland	Mike Salkner	Mike Silliker	John and Joan Swope
Sally Musso	Julia Peeler	Herman Reimer	Harry Salon	Ira Silver	Jeanne Syarto
Jill Naberhaus	John Peer	James Reinert	Dellene Salvatore	Jeffery Silver	Stan Szczygiel
Rose and Fred Nagao	Gary Peet	Nicholas Reinert	Deanna Samilo	Sondra Silverman	Barbara Szitta
Gary Nagurka	Arline Peeters	David and Nancy Reisig	Theresa and Robert Sanchez	Debra Silverman	Marie Szymurski
Anneliese Nathan	Vicki Pendergast	Lorraine Rella	Patricia Sand	William Simics	Jennifer Tabler
Susan and Steven Nathan	Mary Pepper	David Remy	Evilia Sandall	Delbert Simmons	Catherine and John Tackett
Lori Naumowich	Jesus Perez	Carol Rendro Demmon	Debra Sandt	Beverly Simpson	Anthony Tacoma
Amy Naway	Sandy Perez	Sandra Restino	Elizabeth Sanford	Lu and Altus Simpson	Donald Tallerico
Mary Rae Naylor	Ana Perez	Naomi Retchin	Jose Santiago	Shirley and Glen Sims	Richard Tambor
Pearl Nealis	Nancy Perlow	Alfred and Betsy Rhodes	Rochelle Santopalo	Tommie and Jane Sims	J. Clarke Tankersley
Jounice Nealy-Brown	Carolyn Perry	Richele Ricci	Peter Sarda	Richard Sincoff	Joseph and Marion Tannuzzo
Ralph Neas	Charles and Barbara Peters	Shari Rice	Janey Sarriak	Richard Sindich	Nathan and Kimberly Tate
Douglas Neff	Dorothy Petersen	Ruth Rich	Theresa Sasak	Blanche Singer	Kathleen Tatman
Norman Neiwerth	Thomas Petersen	Gerald Rich		Carolyn Singer	Reva Taylor



Janette Taylor Shane Taylor Alonzo Taylor Ellen Taylor William Taylor, Jr. Michael and Kym Tedesco Marilyn and Louis Tedesco Thomas and Dana Tegtmeier Lawrence and Esther Terenzi Lawrence and Susan Terkel Bonnie Termarsch Charles Termini Sarah Terry Gina and Mahesh Thakur Ella Tharp Sally Theiler Howard Thiele Johanna and Michael Thompson Kim Thompson Troy Thompson Norma Thompson Gail Thompson Rosa Thomson J. H. and Aliene Thornton Maria Tibbetts Gerald Tiems Clyde and Carlin Timmons James Tobin Skip and Cynthia Tolle Helga Tomasch Daniel Tomassoni Marie Torrence Jonathan Toumey Judith Towns Joanne Traina Victor Traub Anne Travalia Diane and James Treacy Richard Trebel Ronald Tribble Daniel Trimper Aretta Tronstein Hyla Troxell Cindy Troy-McKee Steve Trudeau	Michael Trudeau Mike Trudeau Kris Trudeau Fred Trudeau Kerry Trudeau Henry and Sandra Tuck Tom Tule Tonya and Perter Turczyn Gail Tuthill Gregg Tuttle Barbara Tymann Chad Uffelman Randy Uffelman Brian Uffelman Ann Uhl Kassandra Ulrich Cheri Uno Madeline Valentine Perkie Van Dusen Richard and Joan Van Gelder Linda Van Grinsven John and Sharon Van Grinsven Pauline and William Van Sickle Cheryl Van Til Karen Van Trump Jeanette Van Wyhe Jim and Claire Vanairsdale George Vandenburg Helen Vanvick Felicia Varlese Fred Vasquez Janet Vaughn Marvin, Sue and Sue Vawter Brenda Velantzas Swathi Veluri Loretta Ventura Vernon Vikingson Roberta Villacres Oscar Villarreal Tim Vinson Lorene Vollmar Paul and Janet Votze Ward and Carole Vreeland Paul and Shermaine Waas Debbie Wade	Daryl Wager John Wagner Pat Waid Jennifer Wainscott Arette Walfield Walgreens Infusion and Respiratory Services Mark Walker Debbi Walker Brenda Walker William Dean Walker Betty Walker Patricia and Jerry Walker Laura Walker Vince and Kathy Wall Michael Wall Esther Wall Gloria Wallace Wallach Foundation Steven and Susan Wallerstein S. Jerome Wallin Helga and Robert Wallner Charlie Walsh Michael Walter LaVon Wankum Patricia Ward Ellis and Irene Ward Beata and Kris Ward Dianne Ward and James Mulholland Barbel Ware Rosamond Warnquist Irene and Robert Warren Ron Warrick Mary Ann Washington Pierre Watiez Harold Watkins Kenneth Watson Ronald and Alice Weagley Kristen Weaver Jack and Ann Webb Brentley C. Weber H. Robert Weddle Hans and Sharon Wehl Elizabeth and Ronald Wehunt Walter Weichel	William Weiland William and Beth Weinberger Laura Weiner William and Joan Weingartner Howard Weintraub Arthur and Arline Weisberger Steve and Linda Weisbrod Robert Weise Syd Weiss Ellen Weiss Louis Welke Becky Wells Kenneth Wells Margaret Wells Mary Welly Allen and Joannie Welshe Marcy Wendrow Edward and Beverly Wentz W.H. and Barb Werling Adele Werneburg Joanne Wernitz Scott Western Arthur and Jane Weston Jo Ann and Roger Wettlaufer Sabrina Whately Robyn Wheeler Linda Wheeler and Eddie Wheeler, Sr. Walt Whelan Jerry and Jusy Whetstone Sarah Whetstone McSweeney D. Lester Whicker Beth and Randall Whipple Denis Whitacre Patricia White Dawn White Valerie Whitfield Gladys Whittenberg Douglas Whittington Elizabeth Widdifield Raymond Wiczorek Nora Wiegerig Marjorie Wilchins Bob Wiley Della Wiley	William Wilkins Harriet and Vern Will Mark and Janet Will Colleen Williams John Williams Ruby Williams Howard and Melba Williams Lana and Mark Williams Glenda Williams Robert and Billie Williams Barbara Willig Lenola Willis Thomas Willis Barbara Willoughby R. Kenneth Willis Bernie Wilson Margaret and Anthony Wilson Nancy Wilson Pamela Wilson Daniel Wilson Karen Wilton Charlene Wiltshire Midge Winchester Bobbie Windhorst Robert Winemiller Geraldine Wingert Richard Winkler Donna Winsor Richard Winter Eugene Winters Thomas Wirth Christa and Richard Wirtz Robert Witt Edna Wittwer Christian Woessner Peggy Wojtowicz Jack Wokutch Walter Wolff Chris Woltman-Cambria Marshall Wong Donald and Helen Wood Patrick Wood Elsa Wood Rose Woodall Paul Woodard	Scott Woodring Kennard and Emily Woods Zorina Woodward Sandy Work Dave and Karen Worrall Kimberly Wragg Mary Wright Norris Wright Vincent and Joyce Wyles Freddie and Nancy Wyndham James and Rachel Yadlon William Yadlon Brian Yakey Jack and Diana Yantis Kevin Yeiser Rowland Yeo Marlene Yoder Mary Yoder Lois York Wallace Young Warren and Sandra Young Stephen Young Timothy Young Ruth Young Linda Zaimis Elizabeth and Christopher Zangara Betty Zaninovich Carol Zaun Suzanne Zeller Gretchen Zens Joe Zeringue Judy Zhang Hazel Ziebell Herbert Zimmerman Sasha Zivkovic Clara Zogg Bep Zonneveld Jeffrey and Ellen Zschunke Carlos Zuniga Joseph and Cindy Zuraw Micheline Zwastetzky
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\*Our apologies if any name has been omitted.

## Impromptu Wedding Held at Queens

*continued from page 2*

the room to someone else. Darren now had only 30 hours to move out. Another [Craigslist](#) search revealed a new listing for a two-week rental at half price. The rental was attached to a house that belonged to the owners of a vacation rental company; and Miki, who worked for the company, was housesitting for them. Darren and Miki became friends, and after about a year, they began dating. "If that lady hadn't rented out my room, or if I hadn't checked [Craigslist](#) at that time, we wouldn't have met," said Darren happily. "It's just the way life works...a little change can change everything."

A year-and-a-half later, Darren had purchased property in Kailua and was in the process of building a house, mostly by himself, but also with a contractor's help. He says he learned how to do it from books, friends, and from watching professionals. Miki was also expecting a baby, but the couple had not yet planned a wedding. "When I got Guillain-Barre, I decided it would be safer to do it sooner," says Darren. He asked Miki to marry him that Tuesday night and told Queenie, who suggested they could have the wedding at Queen's. She got the minister and "had all these ideas about how it could be done." Planning in earnest began on Wednesday. Ludy Lemus, RN, of SDS, served as wedding planner, got a cake, and set everything up. Auntie Jo [Josephine Montecillo] of Housekeeping helped with dressing up the table and chairs, and Rhea Morales, SDS unit secretary, got the bouquet.

Meanwhile, Miki went to the Department of Health to find out what they needed to do to get a marriage license. The DOH normally requires individuals to appear in person and had to be assured the groom was of sound mind.

Because Darren couldn't go there, they agreed to come to Queen's but needed a letter from Dr. Mauro. They needed a notary public, a power of attorney, an advance directive. A hundred other details needed attention. Stephen Wong, RN, cleaned out the fridge for the food; Lisa Coins, PT, took care of video; MD's Bradley Hall and Tim McLaughlin were the clean-up crew, Riri Anguay-Samson, RN, QET 5, helped with the initial planning and marriage license; Nico Pascua, QET 5 unit secretary, made a wedding sign; many others pitched in to take care of a myriad other issues.

On Thursday, the exact time wasn't set until an hour before the wedding. The DOH lady came at 2:30 pm and the minister got lost; but the wedding took place at 3:30 pm. Later, Darren said there was no time for a bachelor's party, so MDs Bradley Hall, Greg Morris, and he told risqué jokes. He also joked (truthfully) that his wedding night was spent with his anesthesiologist, Alan Tanaka, MD. After Queen's, Darren went to Rehab Hospital before convalescing at home. Miki gave birth to their daughter, Kaimiloapono Maxine Haru Kawazu-Armstrong on March 10. At the time, Darren could drive and felt normal sitting, forgetting he was still weak—until he got up. He has since made a full recovery and is not only back to work but also finishing the house he was working on before he got sick.

"There are so many great people here," said Darren. "What a difference it makes when people are so supportive. I love working here. I've got a great job with amazing coworkers." For Darren Armstrong, there is no longer trauma in settling down—just a lot of blessings.

## Planning Your Estate

While it is never too early to plan your estate, it can be too late! Also, if you have already created an estate plan, you may at some point need to make a change because of changes life brings, such as a new marriage, a divorce, the birth of grandchildren, and so forth. Estate planning should be an ongoing process, not an event.

Four documents every person should have in his or her estate plan include a will, a durable power of attorney, an advance directive, and a letter of instructions. While these documents do not require an attorney for their creation, using an attorney can be very helpful in providing advice on estate and tax-saving strategies which can ensure your final wishes are clear and carried out.

If you are ready to begin an estate plan or need to review and perhaps make a change in your existing plan, it is an opportunity to make a philanthropic gift that could last forever. Please consider remembering our mission and the impact we have in your estate plan.

For more information, please call Ken Singleton at (610) 667-0131.

## Liaison Activity

**Together, we have much to share  
and many to serve.**

Our deepest thanks to all of our Liaisons and Regional Directors. Your dedication supports our grass-roots mission that no individual will suffer in isolation!

**We welcome the following  
new Liaisons:**

Bridget Hamilton - Dubuque, Iowa  
Merrilyn Macurak - Conway, South Carolina  
Gina Sharpley - Egg Harbor Township, New Jersey  
Judy Jetson - Weaverville, North Carolina  
Darren Armstrong - Hawaii  
Sharon Klaschka - Hawaii  
Kathy Donaldson - Australia

**We thank the following for  
their years of service:**

Audrey Brucker Nancy Roberts  
Rev. Langston Logan Kathie Pomykala  
Ron Owens \*deceased Pam Wrobel

## SAVE THE DATE!

*13th International Symposium*

**October 31- November 2**

*Walt Disney World, Florida*

**Disney's Coronado Springs Resort, Lake Buena Vista, FL**



**Keynote Speaker: Bart C. Jacobs, MD**

*"The Alphabet Soup of Inflammatory Neuropathy"*

Don't miss this unique opportunity to meet the industry's most qualified professionals as they present on the following: *(list not final)*

- Patients with GBS, CIDP, MMN
- Diagnosis and Pathogenesis of GBS, CIDP, MMN
- Current/Future Outcomes of GBS, CIDP, MMN
- Physical and Occupational Therapy
- Fatigue and Pain Management
- Children and Young Adults with Inflammatory Neuropathy
- Immunizations and Vaccinations
- Emotional Issues for Patients and Caregivers
- Exercises in Your Chair
- Human Sexuality for Males and Females
- Current Research
- Treatment with IVIG and Plasma Exchange
- Anesthesia and Patients with Inflammatory Neuropathies
- Ask the Experts (by popular demand, an additional session has been added)
- AND: Don't miss this opportunity to participate in our largest to date Walk and Roll event on Saturday!

**Welcome and congratulations to our newest  
addition to our Centers of Excellence:**

**Milan University**

**Humanitas Clinical and Research Center, 2nd Neurology**

We are interested in expanding our resources and adding to our Centers of Excellence. Contact Camille Yee at the Foundation to learn more.

## We love to hear from you!

Please send us your stories, "Letters to the Editor," and questions for the Medical Advisory Board.

Our summer issue has always been the Medical issue. We would love to publish your questions and concerns! Look for profiles of our experts!

Direct your inquiries to Lisa Butler in the Foundation office at [lisa.butler@gs-cidp.org](mailto:lisa.butler@gs-cidp.org).

## The Foundation proudly reports dedication to our four pillars: ADVOCACY . . . EDUCATION . . . RESEARCH . . . SUPPORT

### Advocacy

#### Capitol Hill Day 2014!!! April 30-May 1st, 2014

Join us for our second annual day on Capitol Hill in Washington, DC, an exciting opportunity to meet members of congress and to help advocate for our mission! (contact Lisa Butler in the Foundation office to participate; space is limited).

#### Some of what we will advocate for:

- Advance medical research.
- Facilitate the development of innovative therapies.
- Improve patient access to quality care and treatment options.

#### Specific Current Advocacy Effort:

- Increase NIH funding to \$32 billion and expand the GBS|CIDP research portfolio.
- Continue to build support for H.R.460 and potential Senate companion legislation.
- Seek another reimbursement increase from CMS for EMG and also for NCS.

### Education

For the first time, our 13th International Symposium will feature individualized sessions for GBS, CIDP and MMN.

We are rewriting, redesigning our website for current, accurate, relevant information.

Our brochures have now been translated in traditional Chinese. Check the website for a complete listing of translations.

#### We continue to work closely with:

- NORD: National Organization of Rare Diseases
- PPTA: Plasma Protein Therapeutics Association
- PSI: Patient Services Incorporated.

We have cultivated strong support with several IVIG infusion companies who can provide assistance in product identification, dosage, outcomes, and insurance issues, thus empowering patients with knowledge.

### Research

In 2013, the Foundation went over the 1.5 million dollar mark to fund research.

#### In 2013, We awarded three grants focusing on:

1. Guillain-Barré Syndrome in low-income countries and participation in IGOS.
2. Alpha-1- antitrypsin as a novel therapy for CIDP.
3. Lentivirus transduced dendritic cells expressing VIP for the treatment of CIDP.

2014 grant requests have been received and will be announced this summer.

The Benson Fellowship has been established to fund Peripheral Neuropathy. Its purpose is to encourage philanthropic support to help address the challenges of the condition. The applications are open worldwide.

The IGOS study continues: International GBS Outcome Study. The study now has 367 patients in over twenty countries.

### Support

The Foundation office receives over 60 inquiries for information, WEEKLY.

We have 141 US Liaisons.

We have 60 Liaisons in Canada and International.

We invite over 13,000 patients and caregivers to Chapter meetings annually.

In addition to our paper newsletter, this winter we sent over 3,000 Electronic newsletters.

On Facebook, we see over 1,500 hits weekly with over 4,500 "likes."

We maintain a list of 250 Neurologists in our 50 states . . . we also maintain contacts for equipment assistance, financial assistance and IVIG coding and reimbursement.

Centers of Excellence, 18 and growing.



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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 placed on the CIDP list for special mailings, etc.
- **Children with GBS**  
Lisa Butler, 610-667-0131  
GBS-CIDP Foundation International  
Email: [lisa.butler@gbs-cidp.org](mailto:lisa.butler@gbs-cidp.org)  
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  
4313 Shawn Drive  
Traverse City, MI 49685  
Email: [ariellegiggles@gmail.com](mailto:ariellegiggles@gmail.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.