



GBS|CIDP
Foundation International

The Communicator

Providing Strength Through Support

Working for a future when no one with Guillain-Barré syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), and related syndromes such as MMN suffers alone and that everyone has access to the right diagnosis and the right treatment, right away.

Patient Story

By Tonya Charleston

GBS|CIDP Foundation Liaison, Accokeek, MD

If I were asked before April 21, 2009, “What do you see yourself doing in the next 6 years?” I can assure you that fighting and embracing Guillain Barré syndrome was not on the list.

At the time, I was working full-time, our girls had busy schedules, and my husband was busier than all of us. We loved traveling, crafting, and competitive sports. When I slowed down to relax, you would find me in the perennial garden around our property from sunup to sundown.

Just like a southern summer storm that seems to blow in all of a sudden, life as I knew it just stopped! Initially, I felt run down, but it wasn't that good kind of exhaustion from a perfect workout. It was that lingering fatigue that keeps pulling you down and no matter what you try, your body continues to feel drained.

I finally made an appointment to see my primary physician. I was told to cut back on my daily routine, go to bed earlier and cut out caffeine in the evenings. About three weeks later, I had tingling and numbness in various areas of my body along with severe pain that would interrupt my sleep. I went back to my primary physician a second time. Labs were ordered and I was told to continue reducing my activities, take a multivitamin and add more iron to my diet.

Within 30 days of my initial doctor visit, I had lost 20 pounds and had tingling and numbness all over my body. The pain was so bad I could not sleep. It was definitely something serious. At my third primary physician visit, I was told it might be a thyroid disorder, and that if I got an ultrasound, it



would help with the diagnosis. I was given a prescription and told to hold on to it until I spoke with the doctor the next day.

I called my insurance company's nurse as I was leaving the doctor's office. She could not believe the ordeal I had experienced and sent me a short list of endocrinologists and neurologists in the Alexandria, Virginia area.

The endocrinologist saw me immediately, diagnosed me with Grave's Disease, and began working to get my thyroid function under control. He also advised me that this was not my only issue and sent me to Inova Mount Vernon Hospital for an EMG. In the middle of my EMG, the procedure was stopped due to the horrific pain it caused me. I was led across the lobby to the ER where I was diagnosed with GBS on April 21, 2009. From April 21, 2009 until somewhere around July 2009, I received approximately 20 IVIG infusions. However, there was still something lingering underneath it all, and that concerned my neurologist, so within the next 9 months I was seen by two additional neurologists and a rheumatologist.

At this point I still had pain, tingling, numbness, and fatigue. I was walking with assistance, but struggling to regain my

continued on page 2

In This Issue

Page

- 2** Save the Date! Symposium 2016
- 3** A Letter from the Director
Why I Give
- 4** Autoantibodies in GBS and CIDP
- 8** The Ann Landers Connection
- 9** A Year in Pictures
- 10** Your Gift in Action: Support
- 11** Your Gift in Action: Education
- 12** Your Gift in Action: Research
- 13** Your Gift in Action: Advocacy
- 15** GBS|CIDP Foundation Celebrates 35 Years

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*Non-profit 501(c)(3)**continued from page 1*

Patient Story

independence. My doctors were giving up on me, but I was not giving up on myself. I demanded another opinion. I had to advocate for myself. My independence had been taken from me and I needed it back!

I arrived at Johns Hopkins Hospital on April 27, 2010. I was then diagnosed as having a complex neuromuscular disorder, positive neuronal AChR, chronic fatigue, pain, numbness, tingling, and no reflexes. On July 7, 2010 my thyroid was removed, and within 9 months, I began plasmapheresis treatment every other day through April 22, 2011.

It's been 6 years now, and the tingling, numbness, and pain are a part of my everyday life, but I refuse to slow down. Warmth and massages help me manage the residuals. I have re-engaged in life's activities with our busy science and tech ninth-grader; she loves having me around more. I substitute teach, volunteer, garden when the mood strikes me, and I spread my smile everywhere! I live by the mottos "just do it" and "it is what it is." I am now a GBS|CIDP Foundation Liaison who advocates, educates, and supports those with GBS, CIDP, and other variants. I organize chapter meetings to help patients like me meet one another and learn more about their conditions. I am proud of how far I have come, and I feel gifted to share my story and listen to others tell their stories. There is so much to look forward to—I can't wait to see what is next!

Save the date! Symposium 2016

Our biggest symposium yet is coming to beautiful **San Antonio, Texas, September 23rd & 24th!**

Featuring an entirely new curriculum, this symposium will focus on managing your conditions in your daily life, and will be a great way to hear from top doctors, meet other patients, and have fun! Find out more by emailing Kelly.McCoy@gbs-cidp.org and look for posts on our website and Facebook. We hope to see you there!



Hear Our Voices: Stories of Strength and Survival from the GBS|CIDP Community

To members, survivors, and friends: we are working on a compilation of patient stories that we will publish and we want your voice to be heard! If you would like to submit your story (one to two pages in length) please email Kelly.McCoy@gbs-cidp.org your word document (or you can just place it in the body of the email) and please include a photo. We will be accepting stories into the springtime.

We are grateful to the following donors who were omitted from the Foundation Report:

*Patricia Blomkwist-Markens**Charlene M. Wiltshire*

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. We are proud that none of our members has ever been solicited or sent materials other than those concerning GBS, CIDP, and related related syndromes such as MMN. We respect your privacy.

Dear Friends,

What a year! We broke numerous fundraising and awareness records across the board. This year we hosted **80 chapter meetings**, bringing support to over **1,500 patients and families**. We held **18 “Walk and Rolls”** in cities across the country, **raising over \$235,000**. We

With all that we have accomplished this year, one thing has never changed: our commitment to our patients.

recently added our **25th Center of Excellence**, bringing us one step closer to ensuring access to quality care for patients worldwide. At our **35th Anniversary Gala**, we honored Congressman John Garamendi as our Legislator of the Year, and we also introduced the Estelle Benson Volunteer Award, honoring four volunteers for their exemplary work towards each of our four pillars of Support, Education, Research, and Advocacy.

This year we sent out a new email update entitled “Your Gift In Action.” Each quarter we send an update that highlights one of our mission pillars and demonstrates how your donations help us realize our vision. When you give to the Foundation, you are not just a donor, you are a believer. Thank you for believing in us and for your generous contributions this year!

With all that we have accomplished this year, one thing has never changed: our commitment to our patients. We promise that no one will face GBS, CIDP, or variants alone, and our unfaltering dedication to improving the lives of patients and their families in any way we can drives us forward and brings us together as a community. I cannot wait to see what we will accomplish together next year!

Wishing you a joyous holiday season,

Lisa Butler
Interim Executive Director



Why I Give

By Shane Sumlin

GBS|CIDP Foundation Liaison, Shreveport, LA

When I read the Fall 2013 issue of *The Communicator*, I was inspired to try and come up with a local event in my area. I was trying to find meaning and purpose with my diagnosis of GBS. As I explored ideas, I was hitting road blocks until I received a message on Facebook from a high school friend whose son, Austin, needed help. For his senior project, Austin had to host an awareness event and he thought of my story with GBS. Austin came to me with the idea of hosting a “Movie Night,” inviting families to watch a movie while raising awareness of GBS.

The event, in April 2014, was a fun-filled afternoon of games for kids along with tables of information to raise awareness of GBS. Ticket sales, which we sold through social media, were amazing, t-shirts were paid for by local businesses, and the community rallied behind Austin, my family, and others impacted by GBS. We had over 200 people at the event and it was highlighted by a movie that was shown to families at the end of the afternoon.

This event was special in many ways because it showed how a smaller community can host a family event for a great cause such as the GBS|CIDP Foundation. The event raised over \$6,500 and all the proceeds went to the Foundation. For 2015, instead of a second “Movie Night,” I focused all of my efforts towards the Dallas “Walk and Roll” in May!



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or by emailing info@gbs-cidp.org

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Autoantibodies in GBS and CIDP

By **Eric Lancaster, MD, PhD**

Assistant Professor of Neurology, The University of Pennsylvania, Philadelphia, PA

GBS and CIDP are the most common types of acute and chronic autoimmune neuropathy, respectively. GBS and CIDP are thought to be caused by the immune system. The immune system is extremely complex and has many mechanisms for fighting off a huge range of infections, dealing with bacteria, viruses, parasites, and other foreign materials. As part of this process, the immune system generates special proteins called antibodies. These antibodies circulate through the blood and other tissues, protecting the body from specific infections like measles, the flu, or strep throat. Every day the body makes thousands of new antibodies, selected at random from about a trillion (1,000,000,000,000) possible structures. By selecting the most useful ones for mass production, the immune system has a versatile defence against a huge range of possible infections. Usually there is rigorous quality control to prevent antibodies that could hurt the body from being made. In some autoimmune diseases the immune system makes a mistake and generates antibodies that attack the body; these are called “autoantibodies.” In GBS and CIDP these antibodies are thought to harm nerves.

GBS and CIDP patients often respond to treatments aimed at reducing or neutralizing these antibodies such as plasmapheresis (plasmapheresis is a process for removing antibodies from the blood). IVIG is thought to work by either neutralizing these autoantibodies or by blocking them from causing damage to the nerve, although its exact mechanisms are still not totally clear.

In many antibody diseases such as myasthenia gravis we know the exact targets of the autoantibodies. And in certain groups of patients with GBS or CIDP we can also find specific antibodies. One example is the GQ1b antibody that is found in many patients with Miller Fisher Syndrome, which is considered a form of GBS. But in most patients with GBS and CIDP we do not know what the targets of the antibodies are. One of the most exciting aspects of research into GBS and CIDP is the discovery of a growing family of peripheral nerve targets for these antibodies. This is important for several reasons.

First, the diagnosis of GBS or CIDP can be difficult. Even experts are uncertain with some cases. Once we discover a specific antibody target in an autoimmune disease we can make a test for that antibody. This becomes more and more useful if we can find specific antibodies that account for most of the patients with the disease. Establishing a panel of reliable autoantibody markers would assist in making a rapid and correct diagnosis.

Second, GBS and CIDP are clinically diverse and we do not understand what causes most of this diversity. They may be intermittent or chronic, severe or mild. In some patients there is a highly specific attack on motor fibers compared to sensory fibers or vice-versa. In some patients the muscles of the eyes and face are the primary target of the disease, but in other patients these muscles are spared. Most importantly, patients respond differently to various treatments such as IVIG, steroids, or plasmapheresis. There may be important differences in the antibody responses of various patients that underlie and explain these differences in their symptoms. For instance, do patients with GBS have transient antibody responses and do patients with CIDP have persistent antibody responses? Do some antibodies target a structure on motor nerves and others a structure on sensory nerves? Studying the autoantibodies in GBS and CIDP will unlock the answers to these questions.

Finally, knowing the target of the antibody response may lead to specific treatments. As one example, Luis Querol, Isabel Illa, and colleagues recently reported a small series of patients with CIDP and antibodies to peripheral nerve proteins called NF155 and contactin. Patients with these antibodies had a distinct clinical history: they had a severe form of CIDP that did not respond to IVIG. (This is unusual because IVIG helps most patients with CIDP). They also had a characteristic tremor. These studies led Drs. Querol and Illa to try a different type of treatment, rituximab, in a small group of CIDP patients with these antibodies. In a small group of patients this appeared to help. This may be a glimpse of the future where we may be able to select the correct treatment based on the type of antibodies a patient has.

It will take many years of studies to sort out the role of these different antibodies in the diagnosis of GBS and CIDP. For each antibody we have to determine what clinical picture, if any, it predicts. Some may turn out not to be specific enough to help with diagnosis. But in the long run we can imagine a future where this technology leads to a much more precise way of diagnosing GBS and CIDP. We may start diagnosing patients with “GBS due to antibodies to protein X” or “CIDP with antibodies to target Y.” Finding particular antibody profiles may tell us who is likely to do well with particular therapies and who will require more aggressive treatments. Eventually these antibody studies may allow us to select the best, personalized treatment for each individual patient.



The Ann Landers Connection *(as told by Judith L. Macor)*

After the first weeks of my husband George's onset with Guillain-Barré syndrome in December 1984, I realized that his recovery would be a long process. He was not able to have the treatments that are now available to current GBS patients (plasmapheresis and IVIG) and the paralysis would take longer to leave his body.

George is a graduate of the University of Notre Dame, so I knew of the "family" relationship of the University with her alumni and I thought a request for prayers for his recovery would be appropriate. I sent a note to Father Theodore Hesburgh, then the president of Notre Dame, indicating my concerns and request. In addition, I asked how public awareness of GBS could be promoted. He said that he would speak with his good friend Eppie Lederer, the author of the syndicated column *ANN LANDERS*. I provided him with necessary information related to the fledgling support group that was started by Estelle and Bob Benson of Wynnewood, Pennsylvania. Bob had been a victim of GBS and I had been given a pamphlet about the illness.

My initial phone call to the support group connected me with Dr. Joel Steinberg, the author of the pamphlet. He was very patient with the many questions that I had about

GBS, giving me insight into the weeks and months ahead in George's recovery.

Days later, I received a phone call from "Ann Landers" telling me that she had mentioned GBS in an upcoming column. She graciously asked how I was doing. I immediately sent a note to Father "Ted," thanking him for his help.

I received another phone call, this time from Estelle, regarding the impact of the column. Estelle said that the post office had contacted her about some mail, the quantity being too much for the normal postal delivery. To Estelle's surprise, a "special delivery" truck arrived with several bags full of hundreds of letters related to GBS.

George's recovery was slow and incomplete, leaving him with limited mobility, but he was able to return to his position as an aerospace engineer. He worked for an additional fifteen years before retiring. Also, he and I were privileged to serve on the GBS Board of Directors for several years, witnessing the growth of the "support group" to the GBS/CIDP Foundation International of today. As George likes to say, "Estelle and Bob Benson made the medical community aware of Guillain-Barré syndrome."

*Walkers at the Dallas Walk and Roll**San Francisco, CA Chapter Meeting**Myrtle Beach Walk and Roll**New Liaisons at Liaison Training in Philadelphia**Roanoke, VA Chapter Meeting**Oklahoma City Walk and Roll**Jackson, TN Chapter Meeting**St. Paul, MN Chapter Meeting**Paint Night Pittsburgh**New York Walk and Roll**Cbris' Crusaders at Boston Walk and Roll**Dallas, TX Chapter Meeting**Houston Walk and Roll**Liaison Liz Russell and Board Member Marilyn Tedesco**Regional Directors in Washington D.C.**Dubuque, IA Chapter Meeting**Philadelphia Walk and Roll*



YOUR GIFT IN ACTION: GBS | CIDP SUPPORT



Philadelphia, PA Liaison Training and Chapter meeting

The GBS|CIDP Foundation creates and nurtures a global network of volunteers, healthcare professionals, researchers, and industry partners to provide those affected with GBS, CIDP, or related variants such as MMN with support. For 35 years, the Foundation has never lost sight of its original mission that no one will ever again be alone as a GBS or CIDP patient. In 2015, the Foundation's support programming has grown exponentially through:

- 18 "Walk and Rolls," with over 1600 participants and almost 200 teams coming together to raise awareness and funds for the Foundation
- 80 Chapter Meetings nationally, with informative speakers and Q&A sessions where patients and caregivers can bond with others locally
- 165 international liaisons, trained to inform and encourage any patients in need of support, ensuring no one with GBS or CIDP feels alone
- 53 Points of Contact, who provide support through hospital visits and are available to assist anyone looking for help
- On September 23rd and 24th, 2016, the Foundation will host its 14th International Symposium in San Antonio, TX. The Symposium is informative, fun, and an amazing opportunity for patients around the world to meet and build connections throughout the community. For the first time, the Symposium will focus on "Life After Diagnosis."

Thanks to your donations, this is possible.

This is YOUR GIFT IN ACTION!

YOUR GIFT IN ACTION: GBS | CIDP EDUCATION



The GBS|CIDP Foundation is committed to bringing patients and their families the most relevant, up-to-date information on their conditions as possible. We have a number of initiatives that enable us to share what we know with you all. Each Chapter Meeting features a medical professional as a guest speaker with an “Ask the Expert” session. In 2015 we launched the “Managing Your CIDP” series presented by members of our Medical Advisory Board. This informative lecture series, delivered in seven US cities this year, helps CIDP patients understand the history, diagnostic protocols, and treatment strategies of CIDP. Be sure to check out the Events Calendar on our website for the full list of upcoming community events!

The Foundation has produced a number of informational videos on a variety of topics including adult GBS, pediatric GBS, CIDP, MMN, and our Centers of Excellence. We recently released two brand-new “whiteboard” videos—GBS 101 and CIDP 101—aimed to help patients and their loved ones understand these complex conditions in an accessible, easy-to-understand way.

Our website is packed with valuable information, including the recent addition of pages on anti-MAG and MMN, relevant clinical trials, and other additional resources. You can check out our “Recently Added” feature on our homepage to keep up-to-date on all of our new additions!

We know that it can be hard for some to attend our events in person, so coming in 2016, we will be hosting a series of hour-long webinars. These webinars will be designed to bring the best possible information on a variety of pertinent topics to you from the comfort of your own home, and can be enjoyed by patients around the world. All webinars will be posted to our website and YouTube channel after the event. Stay tuned for more information!

This is YOUR GIFT IN ACTION!



GBS|CIDP
Foundation International

YOUR GIFT IN ACTION: GBS|CIDP RESEARCH



Our Benson Fellow, Ruth Huizinga, isolating white blood cells from a patient with GBS. Her research aims to understand the causal relationship between preceding infections and anti-neuronal antibodies.

In the past 11 years, the GBS|CIDP Foundation has invested over \$2,000,000 in sponsoring over 30 research grants! This year the GBS|CIDP Foundation was able to award four research grants as well as the first-ever Benson Clinical Research Fellowship and Mazawey Fellowship. Researchers led by Dr. Isabel Illa at Hospital Santa Creu-Sant Pau in Barcelona, Spain, are looking to identify different genetic subgroups of CIDP. In Bangladesh, where the incidence rate for GBS is much higher than the global average, Dr. Zhahirul Islam and his team are working on developing new outcome measures for GBS patients in low income countries. At the University of Chicago, Dr. Betty Soliven is investigating how different types of immune cells contribute to disease severity in CIDP patients. Dr. Pablo H. H. Lopez in Argentina is attempting to better understand the signaling pathway involved in neuron growth inhibition.

It is our mission to improve the quality of life for individuals and families affected by GBS, CIDP, and related syndromes such as MMN. The Foundation provides researchers with funding so that we can identify the causes of these conditions, discover treatments, and find a cure.

This is YOUR GIFT IN ACTION!

YOUR GIFT IN ACTION: GBS | CIDP ADVOCACY



Advocacy Action Committee in Washington, DC

The GBS|CIDP Foundation structures partnerships to engage in advocacy at the federal, state and grassroots levels to advance our vision and mission with legislators and government agencies. In 2015, the Foundation is supporting the following legislation:

- *Accelerating Biomedical Research Act* (S. 318/H.R. 531), this bill seeks to systematically increase funding for the National Institutes of Health, which will expand research portfolios on various conditions (including GBS, CIDP, MMN).
- *American Cures Act* (S. 289/ H.R. 2104), this bill seeks to systematically increase funding for all medical research programs and activities across the federal government (including the Veterans Administration and the Department of Defense).
- *The Patients' Access to Treatments Act* (H.R. 1600), this bill seeks to ensure patient access to innovative treatments by reducing high out-of-pocket costs associated with coinsurance requirements through private insurance plans.
- *Part D Beneficiary Appeals Fairness Act* (S. 1488/H.R. 2624), this bill would allow Medicare Part D participants to have relief from high out-of-pocket costs for innovative treatments by allowing beneficiaries to formally request an exception from cost-sharing requirements.

The members of our Advocacy Action Committee meet with their local representatives to discuss political initiatives that both directly and indirectly benefit patients with GBS, CIDP, and variants. Our efforts are focused on supporting legislation that improves patient access to care, insurance issues, and research funding. Thanks to your donations, this is possible!

This is YOUR GIFT IN ACTION!

GBS|CIDP Foundation Celebrates 35 Years

On November 4th, 2015, the GBS|CIDP Foundation welcomed almost 400 patients, families, doctors, legislators, and industry partners to celebrate our 35th Anniversary at the beautiful Andrew W. Mellon Auditorium in Washington, DC. We honored Congressman John Garamendi as our Legislator of the Year for his work in advocating for our conditions in Congress. We also introduced the Estelle Benson Volunteer Award, honoring the following individuals for their contributions to our four pillars:

Kassandra Ulrich: Support

Kenneth Gorson, MD: Education

David Cornblath, MD: Research

Stuart Butler: Advocacy

Thank you to all who joined us, and we look forward to making the next 35 years as successful as the first!



Congressman Steny Hoyer



Ralph Neas - Dinner Co-chair



Emcee and Congressman Steny Hoyer and Congressman John Garamendi with Ralph Neas



*For the Pillar of Support:
Honoree Kassandra Ulrich of Ohio with
Estelle Benson, and Dr. Joel Steinberg*



*Legislator of the Year,
Congressman John Garamendi*



*For the Pillar of Research:
Honoree Dr. David Cornblath*



*For the Pillar of Education:
Honoree Dr. Kenneth Gorson*



*Santo Garcia,
GBS|CIDP Board President*



*For the Pillar of Advocacy: Honoree Stuart Butler
with Congressman John Garamendi*



GBS Staff Lori Basiege and Anna Yankelev



Liaison Jon Toumey and Board Members Ginger Crooks and Jim Crone



Estelle Benson and Chris Healy



The Honorable Larry LaRocco and Dr. Joel Steinberg



Santo Garcia and Mitchell Benson



Dr. Jeffrey Gerland, Honoree Dr. David Cornblath and Agnes Gerland



Congressman John Garamendi and his wife Patti Garamendi



Estelle Benson and Julie Birkhofer, PPTA



Dr. Deborah Galinas, Dr. Carol Lee Koski and Carol Dagney



Lisa Butler, Paul Perreault and Ann Bullinger

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Directory

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

Diagnosed with MMN?

Contact: Dominick Spatafora
dominck@dvsconsultants.com

Miller Fisher Variant Group

Please call the National Office for
contact with others.

Children with GBS

Lisa Butler, 610-667-0131
GBS|CIDP Foundation International
Email: lisa.butler@gb-cidp.org
Son, Stuart had GBS at 5 1/2 years old

Children with CIDP

For children diagnosed with CIDP
contact Holly Cannon whose daughter
Hailey has CIDP.
Holly.cannon@gb-cidp.org

Looking for a 20-Something Contact?

Contact: Kyle Van Mouwerik
kyle.vanmouwerik@gb-cidp.org

Teenagers with GBS and CIDP

We are launching a new online
support forum for teens ages 12 to 18
to connect with one another, share
stories, and support each other.
This group is also open to teenage
children of patients. Contact
Anna.yankelev@gb-cidp.org
to get involved.

National Office: 610-667-0131

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.

Advocacy

If you are interested in advocacy
activities on a federal, state, or
local level contact Anna Yankelev
at the international office.
Anna.Yankelev@gb-cidp.org

**Be sure to inform the International
Office if you have been diagnosed
with one of the following. This
will add you to condition-specific
communication.**

**AMAN
AMSAN
Anti-MAG
Campylobacter
GBS X2
Miller Fisher
MMN**