



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.

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Patient Story

A Letter of Thanks

By Michelle G. Silva

Dear Estelle Benson and Staff,

My name is Michelle Silva. My granddaughter's husband, Sean Young, was diagnosed with GBS in late October 2015. His journey over the last two and a half months has been a very traumatic one, fraught with many complications, as he was diagnosed with a very aggressive variant of GBS.

Sean is a 26 year old young man, with a wife and two small children. At the time of his diagnosis he had been in training at the Police Academy in Fresno, California. He was due to graduate on December 15, 2015. Becoming a police officer was his long held dream. He had also served our country in the United States Air Force for four years.

We are extremely grateful for the GBS Foundation International and for all of your help and support during these months. Your organization immediately guided us to wonderful information about GBS and helped us find experts to consult with Sean's local doctors. Your organization also found Sean a perfect liaison, who is a survivor of GBS. This wonderfully compassionate, caring your man, Kyle Van Mouwerik, drove over a snowy pass for four hours, each way, to visit Sean. Kyle and his family have been such a blessing!

Although Sean is still in ICU, and still very much in the thick of the fight for his life, we are grateful to the many incredible, passionate people in the medical field, who are very engaged in this fight for



Nova visits Sean in ICU.



Kyle Van Mouwerik visits Sean in ICU.

Sean's life and recovery. Here is a perfect example. After two months in ICU and still completely paralyzed from the neck down, Sean's pulmonologist at Kaiser Permanente, Modesto, California, decided it was important to bring some normalcy and special love to Sean. The pictures I've sent are of the first day that Sean's 95 pound German Shepherd, Nova, was allowed to visit his best friend in ICU. It was indeed a wonderful reunion. Nova can visit whenever Sean likes and his presence is also very uplifting and healing for other patients and their families. I am enclosing a few pictures that I hope will bring a smile to your faces and perhaps inspire other doctors to be creative and know when and how to lead with their hearts!

I would like, in closing, to send all of you at GBS Foundation International, our most sincere thanks for the important work that you are all doing. your help and understanding has been our saving grace!

Gratefully yours,
Michelle G. Silva

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Non-profit 501(c)(3)**2016 WALK & ROLL****2016 Walk & Roll****"Old Friends Meeting For the First Time"**

The 2016 Walk & Roll Season Kicks off May 1st in Dallas, Texas! We have a great line up this year and are very excited to be adding many new cities to our roster. There is still time to put together a walk for the Fall!! Please contact Jessica McManus via email jessica.mcmanus@gbs-cidp.org or 610-667-0131 if you would like to host a walk in 2016!

We would like to thank all of our Chairs, Co-Chairs, National & Local Sponsors for their hard work and dedication to this program for a very worthy cause.

The following dates are confirmed for 2016, please visit the Walk & Roll section of our website for more information! We hope to see you walking or rolling in a city near you!

Texas, Dallas ~ 5/1/2016**Tennessee, Knoxville ~ 5/14/2016****Illinois, Chicago ~ 5/15/2016****New York, Newburgh ~ 5/15/2016****New York, Long Island ~ 5/22/2016****California, Los Angeles ~ 5/22/2016****New Jersey, Bernardsville ~ 6/12/2016****S. Carolina, Myrtle Beach ~ 9/10/2016****Pennsylvania, Pittsburgh ~ 9/17/2016****Massachusetts, Boston ~ 10/1/2016****Washington, DC ~ 10/8/2016****Texas, Houston ~ 10/22/2016****Delray Beach, FL ~ 10/29/2016****Washington, Seattle ~ TBD****Philadelphia, PA ~ TBD****Chico, CA ~ TBD****San Francisco, CA ~ TBD****New York, Staten Island ~ TBD****Ohio, Columbus ~ TBD****Georgia, Atlanta ~ TBD**

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,

I am honored to have been appointed as Executive Director of the GBS|CIDP Foundation! I look forward to guiding the organization to greater goals via our pillars of support, education, research and advocacy.

Through my title is new, I am not! My son, Stuart, had GBS at the age of five and a half years old. For 18 years, I was the person who headed the group of young children with GBS and became such an integral part of the organization through my contact with so many families. Stuart is now 19 years old and has become one of our best advocates! GBS has become part of our family not only personally, but now professionally as well.

My tenure started off with a bang! Who would have ever thought that a mosquito causing the Zika virus would bring so much attention to Guillain-Barré Syndrome? We have been contacted by people worldwide wanting to know more. Our official press release appears on page 4. As we speak, members of our Medical Advisory Board are actually in South American countries coordinating research on this curious phenomenon. More information and how we helped secure treatment for these patients will appear in the next issue of the newsletter. In the meantime, check our website for daily updates on the Zika virus and GBS.

The office is abuzz with activity. Plans are being made for 100 chapter meetings this year, 20-25 Walk-and-Roll events, and, of course, our 14th International GBS|CIDP Symposium being held September 22-24, 2016, in San Antonio, Texas.

What a start! I am so proud of the GBS|CIDP Foundation and what we do! Let me hear from you!

Delighted to be here,

Lisa Butler

Executive Director



I look forward to guiding the organization to greater goals via our pillars of support, education, research and advocacy.

Calling All Teenagers!

A new group is being formed for those of our GBS|CIDP patients who are in their teen years!

From the contacts we have already received, these young people are very proactive and want to really get involved with the organization. Because of their enthusiasm and willingness to help, we are even having special events "Just for Teens" at the upcoming symposium!

Are you interested?

Email us at info@gbs-cidp.org!

Guillain-Barré Syndrome Celebrates It's 100th Birthday!



In 1916, one hundred years ago, Drs. George Guillain and Jean Alexander Barré identified this condition in France during World War I.

A day of "Celebration" will take place in June in Glasgow, Scotland during the meeting of the Peripheral Nerve Society. Presented will be the great strides in research that have taken place over these 100 years and what the next 100 might have in store.

Happy Birthday, GBS!



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

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GBSICIDP Foundation International Update on Zika Virus and Onset of Guillain-Barré Syndrome

NARBERTH, Pa., Jan. 26, 2016/PRNewswire/ -- The GBSICIDP Foundation International and its Global Medical Advisory Board is closely monitoring the suspected link between the Zika virus and the onset of Guillain-Barré Syndrome (GBS).

GBS is a rare inflammatory disorder of the nerves outside of the brain and spinal cord with an incidence rate of 2 per 100,000 individuals. The syndrome is characterized by a rapid onset of numbness, weakness, and often paralysis of the body. It is an autoimmune disorder usually preceded by a viral infection.

Recent reports from Brazil suggest the Zika virus may cause an increase in cases of GBS. According to the United States Centers for Disease Control and Prevention the Zika virus is spreading in Latin America and other countries through mosquitos. The virus includes symptoms of fever, rash, conjunctivitis and headache.

"The reports on Zika virus and GBS now coming from South America follow those from French Polynesia in December 2013," say members of the GBSICIDP Foundation's Global Medical Advisory Board. "We are in touch with doctors in South America and doctors from the CDC who are investigating this now. They have offered whatever assistance is needed given their expertise. At the moment it seems that Zika virus is one of many agents that can lead to GBS, but we eagerly await more information."

The GBSICIDP Foundation International is the preeminent global non-profit organization supporting individuals and their families affected by Guillain-Barré Syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), and related syndromes through a commitment to support, education, research, and advocacy. The Foundation has more than 35,000 members throughout 47 countries and has a 26 member Global Medical Advisory Board comprised of the world's leading physicians in peripheral neuropathy research and patient care.

For additional information, please contact:

Lisa Butler, Executive Director
(610) 667-0131
lisa.butler@gbs-cidp.org
www.gbs-cidp.org

Additional resources:

- Guillain-Barré Syndrome Overview
- Patient story from *The Washington Post*: "I could move my fingers but within days, I'd probably be totally paralyzed."



Questions and answers for common Zika concerns:

Q: I had GBS X years ago, is it okay for me to travel to South America?

A: "Patients should be directed to the CDC website for the most current travel recommendations. There is, as of now, no proven association between a history of prior GBS and developing recurrent GBS upon traveling to an endemic area, as the exact relationship between the Zika virus and any trigger to a first episode of GBS has yet to be scientifically substantiated. Pregnant women (regardless of prior GBS status) are strongly discouraged from traveling to the affected regions."

Q: I had GBS X years ago, am I more at risk to get Zika or GBS again because of Zika?

A: Susceptibility to Zika virus is a function of mosquito exposure in endemic areas, and has nothing to do with having had prior GBS; 80% of patients infected with the Zika virus have no symptoms, and the remainder develop a benign viral syndrome manifest by fever, aches and pains, headache, rash and conjunctivitis that resolves over 7-11 days. Having had a prior episode of GBS should have no bearing on the risk of Zika infection."

What Emergency Physicians Should Know About Guillain-Barré Syndrome

By Joel Steinberg, MD, PhD

Dr. Steinberg is a hospitalist for Cooper University Hospital in Camden, New Jersey. As he was recovering from GBS, he helped found the GBS/CIDP (Chronic Inflammatory Demyelinating Polyneuropathy) Foundation International.



Guillain-Barré syndrome (GBS) is a rare and potentially catastrophic paralyzing disorder of the peripheral nerves. It is also known as Landry's ascending paralysis, postinfectious polyneuropathy, and acute inflammatory demyelinating polyneuropathy. The emergency physician is often the first to see GBS patients as the illness evolves. Early diagnosis, or at least suspicion of GBS, is important to provide a better outcome as delayed treatment can lead to unrecognized failing respiration and life-threatening dysrhythmias. Given that GBS is rare, presents with the common chief complaint of weakness, and has no simple diagnostic lab test for its confirmation, it is an easy diagnosis to miss.

GBS Stats and Facts

- It is rare, affecting about 1–2 persons per 100,000 each year.
- Mortality rate is about 3–5 percent, usually from cardiopulmonary complications.
- Approximately one-third of patients will require intubation and mechanical ventilation.
- Up to 20 percent of patients are left with significant, lifelong problems.
- Bradycardia, although rare, can require a temporary pacemaker.

Clinical Features

Here's a list of clinical features to raise suspicion of GBS when a patient presents to the emergency department:

- Relatively new onset of weakness, within a day to three to four weeks.
- Symmetrical weakness rather than unilateral.
- Most typically, an ascending pattern of weakness (eg, a waddling gait; difficulty climbing stairs; difficulty rising from the bed, chair, or floor).
- New pain of the thighs and/or low back; pain can be an early—and even the first—symptom of GBS.
- Early dysesthesias (eg, numbness, tingling, and formications of the feet, hands, and distal limbs—even the face or gums).
- Absent or diminished deep-tendon reflexes, a hallmark of GBS.
- Elevated spinal fluid protein without elevated cerebrospinal fluid cells, another hallmark of GBS.
- Recent viral or other infection (eg, upper respiratory infection, sore throat, diarrhea), seen in two-thirds of GBS patients.

People of any age can develop GBS, from babies to seniors. If you are unsure what's going on, it may be safer to admit the patient and get a neurology consult. A confirmatory nerve conduction study/electromyography study will likely be planned. Urgent diagnosis is important since early treatment with high-dose intravenous immunoglobulins or plasma exchange can often shorten the disease's course if started within two weeks of onset of symptoms. Corticosteroids have not been found beneficial and may even lengthen its course.

References

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Look Who's Walking Now...Houston!

By **Megan McCulloch**

Walk Chair, Houston, Texas

After a long evening at the Houston Medical Center visiting my mom who was recovering from another relapse of CIDP, I felt helpless. When I got home, I checked my mail to find a postcard from the GBS|CIDP Foundation regarding a Walk & Roll in Dallas, Texas coming up in May 2015. I was excited and encouraged to learn about the Foundation's community events to raise awareness and research funding. I was eager to help patients affected by GBS, CIDP and variants receive the cure they desperately need. I excitedly checked the Walk & Roll website to see when a Houston Walk & Roll was scheduled, but I was surprised and disappointed not to see Houston listed as a city hosting a walk. I called the Foundation the next morning to find out why and was told that there was no walk because no one had volunteered to plan one in my city. This was it – it was my opportunity to do something to help my mom and those like her who are afflicted. I simply said, "I'll do it!"

Spoiler Alert – We beat our goal!

I first had to get a planning committee formed. This started with the Foundation connecting me with someone else in my area who was also interested in having a Houston Walk & Roll. From there, the two of us asked our friends and family to also be part of this ambitious committee. We started by picking a place and date, with our biggest consideration being attendance. We wanted to be sure we picked the best day and an inviting venue to attract the walkers we needed to reach our goal of raising \$15,000. The Foundation supplied me with a compilation of tools, including a step by step guide on how to plan and market materials that would be mailed out to the Houston area. I also created a Facebook event page to post updates of the event and the direct link to register to participate in the Walk & Roll. This was a great place to reach those who were not already part of the Foundation. We had people inviting so many friends from all over Texas, and even the surrounding states to the Houston event. One thing we did on our page leading up the event was a week-long trivia game (with prizes!) asking various questions related to the Foundation and facts about GBS, CIDP, and variants. This enabled us to help raise awareness to those that might not have the background on why this walk was so important to our community.

It was essential to the committee that we plan not only



a successful event, but also a memorable one that would appeal to all ages. The committee decided that creating a fun theme for the Walk & Roll would allow our walkers to have fun while at the event. We decided to create a super hero theme to honor the strength of the GBS and CIDP patients. We asked the walkers to come dressed in their best super hero gear - and boy, they did not disappoint - everyone came dressed!

One of the tools the Foundation gave me was a sponsorship packet with all the details a company needed to make their decision to sponsoring our event. This made the conversations with companies effortless and allowed us to get two sponsors in addition to the national sponsors, totaling \$3,000 towards our goal. We also had many companies want to give in-kind donations, such as gift certificates to their restaurants and hotels. We did not want to turn these donations down, so we opted to host an onsite raffle during the walk with these items to help raise additional funds. Once word got out we were hosting a raffle, additional donated items came flooding in, including jewelry, an autographed baseball, Super Hero Build-A-Bears, and gift baskets. One of most memorable donated items was a photo booth that matched our theme where the walkers could capture their memories that day all dressed up (there was rarely a time when people were not using the booth).

Waking up the day of the event with a looming storm from Hurricane Patricia on its way, everyone on the committee wondered just how the day would go. To our surprise, it was beyond our expectations! We started the day at just under 100 registrations and fundraising at \$13,500 - so close to our goal! We kept a fundraising thermometer posted that we updated throughout the walk in hopes of reaching our goal of \$15,000. We had so many additional people come and register on site (134 total registrations!), I had to postpone my welcome speech to allow everyone to check in (and buy raffle tickets) before we kicked off the event. After waiting as long as I could, and

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Look Who's Walking Now...Houston!

\$40 short of our goal, I welcomed everyone to the event. I ran through how the event would go, giving the option to stay under cover since it was raining and announcing where we stood on fundraising. Once it was announced we were \$40 short, we immediately had two people with \$20 bills walk up and make the donation we needed. I broke down in tears at how inspiring the Houston community was in coming together, and how fulfilling it was to see our goal met in front of those that need it most. And if that was not moving enough, everyone still walked in the rain to show their support! The committee, volunteers, and I were so taken back by the fellowship that day. We never realized just how meaningful hosting the first Houston Walk & Roll would be.

"The 2015 Walk & Roll was not only well organized, it was extremely family friendly and inspirational. I am so glad I was able to attend and support this organization. The park location was also a big plus to the event."

– Kathy, Victoria, TX

"The Walk & Roll was overwhelming and inspiring to be surrounded by so many people in my same situation; it can feel so lonely at times and to see and be a part of the crowd was such a wonderful feeling. I am so thankful for these events being put together. It is one thing to have a digital community, but I will never forget the feeling of walking up to the pavilion and seeing so many people gathered together for our cause."

– Lisa, Austin, TX

"The support from the Foundation and the experience of the Walk is one that will stay with me forever on this journey of life. Being sick is not easy, but having a community who bands together makes the battle worth fighting. Despite the weather trying to bring us down, it was an overall success. My family and friends enjoyed it so much and look forward to next year!"

– Leanna, Sugar Land, TX

Even after the event was over, people continued to donate money to the Houston Walk & Roll until we reached a phenomenal final total of \$19,841. All our sponsors have expressed their anticipation of and commitment to the 2016 Houston Walk & Roll. Being part of this incredible event was a fantastic experience. I cannot express enough how grateful I am to have received that postcard when I did. I may not be able to cure GBS or CIDP, but I am delighted that I found a way to support a cause that could one day find cure for those afflicted.

Like to attend Megan's Houston Walk? It will be held on October 22nd at Eldridge Park at 1:00 pm! Stay tuned for more details to follow and additional dates for our fall walk season!



SAVE THE DATE!!

Join us at our 14th International Symposium in San Antonio, Texas!

Kickoff Welcome Reception September 22, 2016

Sessions-Friday, September 23rd & Saturday, September 24th

Registration is now open!

Enjoy our new curriculum - 'Life After Diagnosis'

Topics Include:

- **Current research on GBS, CIDP, MMN, & Variants**
- **Management of residuals, pain & fatigue**
- **Santo Garcia's famous Chair Aerobics**
- **Holistic Medicine & Alternative Therapies**
- **What is Stem Cell?**
- **Emotional Health & Mindfulness**

Presenters include our Global Medical Advisory Board and local professionals.

'Meet your family' at our receptions, 'get togethers' and our closing Fiesta Celebration!

Coming? Register online NOW at:

www.gbs-cidp.org/symposium/symposium-registration/

Travel expenses & hotel accommodations not included in registration fee

Hotel can be booked for the Hyatt Regency San Antonio 210-222-1234

(Mention GBS | CIDP Symposium for discounted rate!)

Questions or to register over the phone:

Call us at 610-667-0131 or email Kelly.McCoy@gbs-cidp.org

Don't forget to submit your story for our upcoming book *Hear Our Voices!*

Please email Kelly.McCoy@gbs-cidp.org for more info!

Deadline is May 15th.

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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.**

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MMN**