

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

One of the lucky ones.

by **Brenda Perales**

While my journey with Multifocal Motor Neuropathy (MMN) has been an emotional and sometimes frustrating one, I am definitely, *"one of the lucky ones."*

At a long-overdue appointment with my regular doctor to discuss symptoms that I was sure were stemming from problems with my back—and residual side effects from a broken leg—she ordered blood work and an MRI which came back normal. As a result, she recommended I visit a local neurologist.

At that point I began to get really nervous... having a hard time understanding why I was to see a neurologist in the first place, and wondering what further testing might uncover. The neurologist said, *"You don't seem to fit neatly into any box,"* and explained that his primary goal would be to rule out Amyotrophic Lateral Sclerosis (ALS.) He encouraged me to seek an opinion from Dr. David Cornblath at *Johns Hopkins University Hospital*, in Baltimore.

The idea of having ALS can overwhelm anyone, and everything! I was beyond anxious at that point, and wondered, *"How could this be happening to me?"*

My scariest, and also most reassuring moment, happened while I laid still in my hospital bed at *Hopkins*. Dr. Cornblath's tests showed "a lack of reflexes and very slow progression over a long period of time," which caused him to say, *"While many things point to ALS, I am not certain."* I remember covering my face with my hands and bursting into tears while my husband, Michael, sat at the end of the bed in stunned silence.

Dr. Cornblath ordered additional tests, and three months of observation. *"ALS normally*



progresses," he said, *"but MMN usually does not."* We'll see, we thought!

Fearful of a diagnosis of ALS, all I could think about over those last few months was if I would live to see my two sons, Jack and Grant, graduate from high school, marry, and have kids. It all felt so overwhelming!

Fortunately, the tests returned normal—repeat examination had shown no real progression. Thus, Dr. Cornblath thought that a trial of IVIg might be useful.

Three days into IVIg treatment, Michael and I were at Costco when he turned to me and said, *"I didn't hear you coming!"* It took a minute to register what he actually said, then it hit me. My dropped left foot was not flopping and slapping on the floor! I was walking better, and, I had more strength.

Dr. Cornblath was the most surprised of all to see how well I responded to IVIg. A favorable response meant we could finally rule out ALS and prompted my final diagnosis of MMN.

One year later, Dr. Cornblath suggested a switch from IVIg to SubQ. The transition took a few months, and never in a million years did I think I would be able to stick needles (albeit small thin ones) into my own body.

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Nonprofit 501 (c)(3)**Why we walk...**

We've said many times over the years, *GBS/CIDP Foundation* events are all about "Old Friends Meeting for the First Time." Nothing could be more accurate than when talking about our ever-increasing *Walk&Roll* events.

If anyone can relay the emotion *Walk&Rolls* create, it's Jessica McManus.

Jessica, our *Walk&Roll* coordinator, says, "Our *Walk&Roll* program does more than any other to bring together the many people in communities across America who, before participating, felt very alone—many not ever having met another person like themselves who struggle with these rare conditions."



With each walk we are closer to helping to achieve our vision that every person who has been affected by GBS, CIDP, MMN or variants, has convenient access to early and accurate diagnosis, affordable treatments and dependable support services.

I have the privilege of uniting folks who search for 'community.' Our *Walk&Roll* events provide just that—along with community awareness and a goal of garnering financial support from cities and towns throughout the United States.

That is, 'why we walk.' And, as a result, the program is growing at an uncanny rate. As more and more people become aware that GBS, CIDP, or a variants, are right in their backyards—possibly their friends and neighbors—they want to get involved.

Thank you to our many Volunteer Chairs and their teams for your ongoing dedication and support. Each and every one of you make my job more enjoyable, and ultimately, help make the *Walk&Roll* program a success.

I hope to meet you for the very first time, or see you once again, at a *Walk&Roll* event this year. If you need more information, or YOU would like to host an event in 2017, please contact me at Jessica.mcmanus@gbs-cidp.org or call 610-667-0131."

Jessica McManus



NATIONAL RARE DISEASE DAY
2017
FEBRUARY 28

Disclaimer Information Questions presented in The Communicator 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 GBS/CIDP Foundation International. The organization 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 syndromes such as MMN. We respect your privacy.

Dear Friends,

It is a bitter 18 degrees outside my window and the blustery wind has been tossing the falling snow into what looks like more of a blizzard. For those of us who actually “enjoy” snow and crisp winter days, I’m grateful for the winter wonderland in the vista before me.

I am also grateful for you, our faithful donors and partners who can turn even the coldest days into days of warm thoughts by sharing your stories with us here at *GBS/CIDP Foundation International*.

I’ve included several of these stories in this issue of *The Communicator* and I know you’ll find them as inspirational as I do. Stories of people like Brenda, an MMN survivor who came away from her recovery with a much deeper understanding of what support can mean when you need it most. And, Dick, a Liaison from Oregon whose life-mission is to be there for others who are experiencing what he had experienced years earlier.

2017 has begun with not only these blessings, but a host of others I am excited to share with you in this issue. So, grab a blanket. Curl up in your favorite chair, and read about everything that’s been happening at *GBS/CIDP Foundation International*.

Wishing you the warmest of greetings as we anticipate a year of great events.

Speaking of events, plan on joining us in Baltimore on May 6th, or in Chicago, later this year, for our One-Day Regional Meetings. And, keep checking our online *Foundation* events calendar for an upcoming *Walk&Roll* or chapter meeting happening near you.

Sincerely,

Lisa Butler

Executive Director



I've included several of these stories in this issue of The Communicator and I know you'll find them as inspirational as I do.



Calling all teenagers...

Being a teenager is hard enough, believe us, we've all been there...

and being a teenager who also deals with GBS, CIDP or variants, makes that special time of life even more difficult.

We are here to help. Our “Just for Teens” outreach has been designed especially for patients in their teens and for young adults. If you are a teen looking for support, contact us today. info@gsb-cidp.org



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Fax: 1.610.667.7036
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email: info@gsb-cidp.org

Please update your contact information to make sure we have your current email address. Your information will not be shared with anyone outside the *Foundation*.

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

Visit us on Facebook: facebook.com/gbscidp





Meet a new member of our Global Medical Advisory Board: Dr. Jeffrey Allen

Dr. Jeffrey Allen is a neuromuscular specialist and clinical investigator at *University of Minnesota*, Minneapolis, MN.

After completing his residency at *Tufts University*, Medford, MA, and fellowship in neuromuscular medicine at *Harvard Medical School*, Boston, MA, Dr. Allen joined the faculty at *Northwestern University*, Chicago, IL. In 2014, he moved to *University of Minnesota*, Minneapolis, MN, but still holds an adjunct appointment at *Northwestern*.

Dr. Allen's clinical focus is in peripheral neuropathy,

myasthenia gravis, and muscle disorders. He also performs electrodiagnostic studies as well as nerve and muscle biopsies.

He is a member of the *Peripheral Nerve Society* and the *American Academy of Neurology*, and serves on the Inflammatory Neuropathy Consortium (INC) board and Global Medical Advisory Board for *GBS/CIDP Foundation International*.

Dr. Allen's research has focused on improving the diagnosis, surveillance, and treatment of inflammatory neuropathies, including GBS, CIDP, MMN and related neuropathies.

Going that extra mile. from Estelle Benson, Founder

Dear Estelle,

I want to complement you and GBS/CIDP Foundation International for having an Oregon liaison person such as Dick Beukema.

Dick's professional assistance—from his first contact with us in early 2016—has been extremely helpful.

Dick has been in continuous contact with us and he is a strong support as we navigate this extremely difficult journey—dealing with my daughter, Julie's, sudden diagnosis of GBS in November, 2015, which we continue to struggle with today.

During this chaotic time, Dick has reached out to other GBS patients to ask them to contact Julie. They have done just that and shared with her their variety of experiences with this deadly disease... yet survived. Not only does Julie appreciate their kindness, she attributes her positive attitude change to their credit.

Both Julie and I want to convey our thanks to you, and to Dick, in appreciation for his tremendous support.

—Arlie M.

GBS/CIDP Foundation International goes BIG in the Big Apple!

When Lisa Butler, Executive Director, was approached by *Horizon Publishing, Inc.* offering a "once in a lifetime opportunity," she was somewhat skeptical. However, what seemed almost too good to be true actually was true. As a result, you'll find *GBS/CIDP Foundation International* running 120, 5-second spots on ABC's *Good Morning America*'s Big screen in New York City's



Times Square, April 3-9th from 6AM-midnight. We are hoping the added exposure to the *Foundation* will increase awareness to NYC residents and visitors.

At the same time, included with this unique advertising package, was an opportunity for *GBS/CIDP Foundation International* to be featured in *Horizon's HORIZON Travel America* magazine and be distributed with *The Wall Street Journal* in Texas and other select southwest markets.

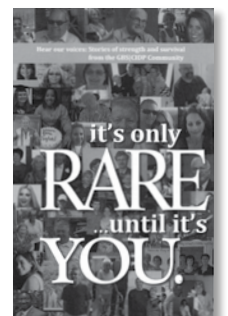
If you happen to be in New York, Texas, or the sunny southwest at that time, take a selfie and send it to us!

Looking for some interesting reading?

You will find a list of the most popular books on Guillain-Barre' syndrome, CIDP, and variants on our website "library," including an exclusive book, *It's Only Rare, until it's You*.

It's only RARE, until it's YOU, is a fascinating collection of real patient survivor stories guaranteed to lift you up in your journey as you discover how others survived their trauma and lived to tell about it.

It's Only Rare until it's You is only available for purchase through the *Foundation*. **Call 610-667-0131 to order your copy today!**



Healthcare Coverage and Access Community Update

by Dale Dirks and Dane Christiansen, Washington Representatives

The fundamental structure and scope of the US healthcare system, including access to various forms of insurance, networks of specialized physicians, and innovative treatment options, has been a hotly debated topic on Capitol Hill since the beginning of the year. The “repeal and replace” of *Patient Protection and Affordable Care Act* (ACA/Obamacare) was a popular campaign promise for the new Congress and the incoming administration. Lawmakers in the House and Senate have been searching for a way to move forward with such an effort since the 115th Congress convened on January 3rd.

The reality is that American healthcare is incredibly complicated and making changes to one part of the system often has an immediate domino effect as well as unintended consequences for other parts of the system. This complexity has greatly slowed the repeal and replace effort as lawmakers search for a path that addresses ongoing issues (such as the rising cost of premiums) while not creating additional or more serious issues. To be clear, the ACA has not been repealed and no one is at risk of losing their insurance coverage as a result of government action during 2017. In fact, the most high-profile proposal working through Congress is a technical repeal of the ACA that maintains the current system for two to three years (at least) while lawmakers work out the specific details of a replacement plan.

The ACA was by no means perfect, but it was a step in the right direction for patients and families facing rare, chronic, and costly medical conditions. While the law made vast changes across healthcare, it also contained narrow protections crafted specifically to prevent medical bankruptcy, involuntary medical divorce, and spending down to qualify for Medicaid. These patient protections are often overlooked in the broader debate, but they disproportionately benefit individuals and families affected by GBS, CIDP, MMN, and variants.

The lack of a cohesive plan and strategy in Congress to reform healthcare has led to the proliferations of numerous, competing proposals. Rather than evaluate each proposal for its various individual merits and drawbacks (and none of them are currently patient-centered,) Congress simply needs to ensure any serious repeal, replace, or repair effort includes the following “four pillars” of patient protection.

In this regard, please consider reaching out to the offices of your Members of Congress, educating them about the unique needs of this community using your personal story, and asking them to support the pillars below. *GBS/CIDP Foundation International* can support and assist you in your outreach, and please contact Lisa Butler, Executive Director, lisa.butler@gbs-cidp.org, if you are interested in making your voice heard on this important issue. Your personal outreach is incredibly important and your legislators will welcome your input as they try to make difficult decisions.

Community message to Congress as lawmakers consider changes to healthcare:

- First and foremost, the community has the right to review any replacement plan and judge whether it adequately addresses the needs of patients before the current system is repealed. Do not repeal the ACA until the replacement plan has been vetted by stakeholders.
- Secondly, there are critical patient protections with bipartisan support that must be part of any modifications to the healthcare system. The following four pillars are absolutely essential to patients and their families, and must be included in any serious proposal moving forward.
 - **Pillar 1: Prohibit pre-existing condition discrimination.** Individuals must be able to equitably access comprehensive healthcare coverage regardless of their health status, diagnosis, and/or related factors.
 - **Pillar 2: Prohibit lifetime and annual caps on insurance benefits.** Any individual that purchases healthcare coverage must not be able to outspend that coverage and expose themselves to additional, unaffordable fees.
 - **Pillar 3: Allow children to stay on family coverage until age 26.** Families with affected members face unique and serious financial challenges. Therefore, prolonged stability is essential.
 - **Pillar 4: Limit out-of-pocket costs for patients.** Enacting and preserving no-nonsense restrictions that cap out-of-pocket costs is the best way to keep coverage equitable and accessible to everyone.



CHARITY NAVIGATOR
Your Guide To Intelligent Giving

For more information about our score on *Charity Navigator*, visit charitynavigator.org/index.cfm?bay=search.summary&orgid=10284

The importance of saying “Thank You.”

by Lisa Butler

I had the pleasure of speaking with a first-time donor the other day to thank her for her generous gift. I also asked her, “Why, of the thousands of charities you can choose from, did you choose to donate to us?”

After sharing with me that her husband had been diagnosed with GBS after a bout with West Nile Virus in 2016, her reason was quite clear. She said, “I found out about the Foundation from a Facebook friend and I wouldn’t have called you back were it not for the fact that your organization has proven so professional.

You are number one in my book.”

—Julie K.

A special note.

GBS Foundation,

Twenty-four years ago, at age 55, my husband was diagnosed with GBS two weeks after receiving a flu shot. He was in the hospital for 4 months, including therapy, but continued to have therapy for months after coming home.

His recovery was magical...a lot of work, but he returned to normal health, which not many do. We thank you for what you do for GBS patients. We enjoy your newsletter so very much. Included is a check to help with your organization.

—Nelda B.

GBS/CIDP Foundation International named to the 2016 Classy 100

Recognized as a consistently growing nonprofit organization, *GBS/CIDP Foundation International* has been ranked #10 of the top 100 nonprofits using *Classy*, an online fundraising program for social enterprises.

Classy 100

Classy recognizes organizations who’s scores ranked highest in monthly revenue growth using *Classy*; year-over-year growth using *Classy*; and overall revenue size on *Classy*.

Classy is the world’s leading fundraising platform for social enterprises with the goal of solving social problems more effectively and efficiently. Since launching in 2011, *Classy* has helped more than 3,000 social enterprises including *Oxfam*, *World Food Program USA*, and *National Geographic* to raise hundreds of millions of dollars.

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Patient Story

Saying I was a bit nervous would be an understatement!

Today, the positives of SubQ—which make me feel close to normal again, or as I like to say, “my new normal,”—clearly outweigh the negatives of IVIg.

So, why do I think I was one of the lucky ones? Of course, not having ALS is at the top of the list. But, it is only one of many reasons:



- Most people with MMN see about four or five different specialists before being diagnosed—I saw only one.
- A lot of people with MMN are misdiagnosed as having ALS, but I was only under that terrifying cloud for a few months.
- There are only a handful of neurologists that really understand—and specialize in—MMN. I was referred to an amazing physician practicing at one of the finest medical institutions in the world who is comfortable and familiar with the idea of prescribing SubQ. He worked with me until we got it right. He worked with my insurance company to insure coverage. He restored my quality of life and allowed me to regain my independence.
- I am one of the 5% of people managing a rare disease that has an FDA-approved treatment.
- Most importantly, along with my wonderful husband, Michael, and terrific sons, Jack and Grant, I have a supportive and loving family of friends who are always here for me, including Cindy, my terrific at-home nurse, and all of my MMN Facebook friends.

Three years after this whole ordeal began, I still wake up every day feeling incredibly thankful. So, how could I not be “one of the lucky ones?”

First One-Day Conference in Fort Lauderdale breaks new ground for *GBS/CIDP Foundation International*

Our biennial International Symposia has been a hallmark at *GBS/CIDP Foundation International* since its inception.

The 14th International Symposium held in San Antonio, TX, in September of 2016 drew a record attendance. The three-day event offered fun, fellowship, and was jam-packed with exciting presentations from many of the world's most renowned neurologists and healthcare professionals. "*The best symposia ever,*" we heard!

Our members/patients know how important it is to have easy access to the most current information regarding their conditions. They also recognize the opportunity our symposia offer them to interact with knowledgeable healthcare professionals along with the many other individuals who struggle with the same rare conditions they do. Many have expressed that two-years is too long to wait for the opportunity to attend.

To address those concerns, and several others, *GBS/CIDP Foundation International* has introduced a series of geographically-diverse One-Day Conferences for 2017.

The One-Day Conference format was implemented to be able to offer the same, high-quality, information as our biennial symposia, but on a regional basis and at three convenient locations across the country, Fort Lauderdale, FL, Baltimore, MD, and Chicago, IL.

The first conference, held on March 4 in Fort Lauderdale, FL, was well-attended and blended the expertise of our Global Medical Advisory Board with local resources. Of no surprise, attendees were quite outspoken about the high quality of the presentations and their ability to "*meet old friends for the first time,*" another *GBS/CIDP Foundation International* hallmark.

Our second and third conferences are scheduled for Saturday, May 6 at the Inner Harbor in Baltimore, MD, and on Saturday, September 23, in Schaumburg (Chicago,) IL. If either of those locations are convenient for you, plan on joining us. And, don't forget to think ahead to October of 2018 and mark your calendars for our 15th International Symposium in San Diego, CA.

NORD and Oregon State University sponsor "Rare Disease Support Study."

What is the study about?

In partnership with the *National Organization for Rare Diseases*, Oregon State University is releasing the first large-scale study about the information and psychosocial support needs of people living with rare disorders.

The purpose of this research study is to assess these needs from the perspectives of people living with a variety of rare disorders, to find similarities and differences across disorders. To ensure that results reflect the diversity of the rare disease community, it is crucial that as many people living with a rare disease as possible take part in the study.

Who is eligible to participate?

You must be an adult or the age of majority in your state, be able to communicate in English, and have a rare disease or disorder, or undiagnosed rare condition. Caregivers who do not have a rare disorder themselves are NOT eligible to participate at this time.

A disease is generally considered rare if it affects fewer than 200,000 individuals in the United States or fewer than 1 in 2,000 in Europe.

A list of rare diseases can be found here: www.rarediseases.info.nih.gov/diseases/browse-by-first-letter.

Because rare disorders are discovered and prevalence estimates change frequently, you may participate even if your disorder does not appear on the list.



What would I do as a study participant?

There are two ways to participate.

1. You can follow this link, www.bit.ly/2hWZLr2 to take a 40-minute online survey about your experiences and share your information and support needs related to your rare disorder (paper forms are available by request.) If it is physically difficult to respond, someone may enter your responses for you.
2. During the survey, you can opt to sign up for a second study which involves an online focus group about the information and psychosocial support needs with others with rare disorders. You must participate in the survey in order to be eligible for the focus group, but the focus group study is not required to participate in the survey. You will be paid \$20 for participating in the focus group.

What will OSU do with study findings?

OSU will send a summary of results to all participants. To help NORD, rare disorder organizations, and healthcare professionals meet the needs of people with rare disorders, results will be shared through reports, conference presentations, and scientific publications.

Sign up to participate!

For more information, contact Kathleen Bogart, researcher. kathleen.bogart@oregonstate.edu or 541-737-1357.

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CHANGE SERVICE REQUESTED

INTRODUCING

2017 One-Day Regional Conferences

These, one-day, regional, chapter meeting/mini-symposia will bring local physicians, patients, families and caregivers together in three convenient locations:

FORT LAUDERDALE, FL (closed)
Saturday, March 4, 2017

BALTIMORE, MD
Saturday, May 6, 2017

CHICAGO, IL
Saturday, September 23, 2017

Please visit gbs-cidp.org to see photos from our 14th biennial Symposium 2016 in San Antonio, TX

SAVE THE DATE!

Join us in San Diego for our 15th biennial Symposium, November 1-3, 2018

Directory

Refer to the enclosed chapter directory to 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 us for contact with others.

Children with GBS

Lisa Butler, 610-667-0131
GBS/CIDP Foundation International
Email: lisa.butler@gbs-cidp.org
Son, Stuart, had GBS at 5 ½ years old

Children with CIDP

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

Looking for a 20-Something Contact?

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

Teenagers with GBS and CIDP

For teens ages 12 to 18 with GBS or CIDP to connect with one another, share stories, and support each other. This group is also open to teenage children of patients. Contact us to find out how to join!

International 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.

Advocacy

If you are interested in advocacy activities on a federal, state, or local level, contact us to sign up!

Be sure to inform us if you have been diagnosed with one of the following. This will add your name to condition-specific communications.

AMAN
AMSAN
Anti-MAG
Campylobacter
GBS X2
Miller Fisher
MMN