

The Communicator

GBS|CIDP FOUNDATION INTERNATIONAL

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.

IN THIS ISSUE

- 1 GBS|CIDP Foundation International Support Patient Abroad
- 1 Hey doc, are you sure this is CIDP?
- 2 From the Executive Director
- 4 Integrative Neuromuscular Medicine: Neuropathy and Neuropathic Pain
- 5 Centers of Excellence
- 5 2020 GBS|CIDP Symposium
- 6 Medicare and Home Infusion IVIG: What You Need to Know
- 8 Clinical Trials Seeking Patients
- 9 Life after GBS for Youth and Teens
- 10 Chapter Meetings
- 10 Ask the Expert
- 11 2020 Walk Schedule
- 11 Giving Hope to our Global Rare Community for #RareDiseaseDay
- 11 Patient Registry One Year Anniversary
- 11 Australia Chapter Meeting
- 12 Honoring our Very First Volunteer

GBS|CIDP Foundation International Support Patient Abroad

Shaan Lakshmanan, a student from Syracuse University, was studying abroad in London when he had gone on a school weekend trip to Berlin, at which time he developed GBS.

"It was such a scary time," said Tina, Shaan's mother, "at first we didn't know what to do, we had never ever heard of GBS. Our son, Shaan, 22, was on a college trip in Berlin when he developed a loss of strength in first the thighs and then the shoulders. This was on Nov 9 and by Nov 10, he was quite unable to move and needless to say, perplexed about what was happening. Fortunately, he had counsel that admitted him to the Military Hospital (Bunderwehrkrankenhaus) in Berlin where he was diagnosed with Guillain-Barre Syndrome. He was in the ICU and was moved to the neurological ward on Nov 17,



having established that he was under no further respiratory or cardio risk. Fortunately, there was a GBS|CIDP Foundation Chapter meeting in Berlin and we were able to attend. It was so comforting to find others to turn to.

As we started making calls and plans to return to the US, Shaan even got a surprise visit in the military hospital in Berlin from a GBS patient, who just happened to attend a Foundation chapter meeting for the first time the same night that we attended, and when

[continued on page 3](#) ▶

Hey doc, are you sure this is CIDP?

By Jeffrey A. Allen MD, University of Minnesota

It's ok to ask the question.

Whether you've had the diagnosis for a day or a decade its ok to ask. You should ask. Do my symptoms make sense? Are my test results what you would expect for CIDP? Have other explanations been explored? Should I get a second opinion?

It can be hard to diagnosis CIDP. Just as some patients have symptoms for far too long before a diagnosis is made, many others get falsely labeled or misdiagnosed as CIDP. It turns out that over half of all people that carry a diagnosis of CIDP do not have that

condition. Some have other explanations for their neuropathy, some have no neuropathy at all – but the sheer frequency of CIDP misdiagnosis is alarming. It's a hard diagnosis to make in part because there is no single test that can diagnosis CIDP. A clinician arrives at the diagnosis by putting together many different pieces of information, none of which is diagnostic by itself but in the right context and in the right combination can add up to CIDP. The methods used to put these pieces together can be quite variable



[continued on page 3](#) ▶

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



*Your story matters in more ways
than you may even know.*

Dear Friends,

Sharing and listening to stories from others in similar situations is one of the most empowering and healing ways to cope with the ups and downs of a rare condition. Over the years, the Foundation has built a library of stories from every corner of the world. Patients, caregivers, youth, teens, and seniors from a vast range of cultures and communities have contributed to this inspiring and educational collection. In this issue we share a story that crosses borders, connecting our volunteers and experts to a young patient in need, in every possible way. Plus, in this issue, we offer clarity on the, often, complex medicare system and a deeper view of our current advocacy initiative HR 2905. You will also learn how our collective “patient registry” voice is informing our key opinion leaders and medical advisors as they seek quicker diagnosis and advancements in treatments. Last but not least, you will be invited to join us for our 2020 Walk & Rolls, Chapter Meetings, and of course the biggest celebration of patient support, the 2020 Biennial Conference in DC! I encourage you to not only read our newsletter but to take advantage of the many ways to participate in the GBS|CIDP community! Your story matters in more ways than you may even know.

Looking forward to connecting in 2020 and beyond,

Lisa

Lisa Butler, *Executive Director*



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

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

CONTACT US

GBS CIDP Foundation International

International Office
375 East Elm Street, Suite 101
Conshohocken, PA 19428

T 866-224-3301
T 610-667-0131
F 610-667-7036
W gbs-cidp.org
E info@gbs-cidp.org



EXECUTIVE DIRECTOR

Lisa Butler

FOUNDER

Estelle L. Benson

OFFICERS

James Crone
President

Patricia H. Blomkwist-Markens
Vice-President

Jim Yadlon
Treasurer

Russell Walter
Secretary

BOARD OF DIRECTORS

Joshua Baer
Kenneth C. Gorson, MD
Gail Moore
Shane Sumlin
Nancy Di Salvo

GLOBAL MEDICAL ADVISORY BOARD

Kenneth C. Gorson, MD
Chairman

Bart C. Jacobs, MD, PhD
Vice-Chairman

Jeffrey Allen, MD
Vera Bril, MD
Diana Castro, MD
Peter D. Donofrio, MD
John D. England, MD
Sami Khella, MD
Richard A. Lewis, MD
Robert P. Lisak, MD
Eduardo Nobile-Orazio MD, PhD
Mamatha Pasnoor, MD
David S. Saperstein, MD
Kazim A. Sheikh, MD
Betty Soliven, MD
Maureen Su, MD
Joel S. Steinberg, MD, PhD
Professor Peter Van den Bergh, MD
Pieter A. van Doorn, MD
Professor Hugh J. Willison, MD
MMBS, PhD, FRCP
Eroboghene E. Ubogu, MD
Gil I. Wolfe, MD, FAAN

Nonprofit 501 (c)(3)

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.

Support from Abroad continued from page 1

she heard about Shaan, she went to see him the next day! She was so lovely, so supportive.

The plan was to repatriate him by flight (air ambulance). Luckily we connected with the GBS|CIDP Foundation where Pam, a member of their staff immediately put us in touch with Jim Yadlon and Sheila Blane, regional volunteers from our area in New Jersey. We wanted to admit him at a rehabilitative facility and with all of their help, that is exactly what we did. No time wasted! He was admitted to Kessler Institute for Rehabilitation in West Orange New Jersey, as per the Foundation recommendation.”

Both GBS|CIDP volunteers, Sheila Blaine, Assistant Northeast Regional Manager, and Jim Yadlon, Regional Northeast Manager were inspired by the love and determination of the Lakshmanan family. After visiting Shaan at Kessler, Sheila said, “They are such a lovely family! We had a great visit and conversation with all of them. Shaan appeared to be doing well and is definitely recovering. He never lost breathing ability, thank goodness, but was paralyzed. We got to see him moving his arms quite a bit - he could control the motorized wheelchair and we learned he stood for the first time the day before! They are very happy with the care he is receiving at Kessler. They are also very grateful for the support from the Foundation.”

Jim, having also been affected with GBS at the very same age as Shaan, also visited with the family. He found their positivity quite remarkable. He said, “This is a wonderful family that is a model of support for a GBS patient.”

Currently, Shaan is doing outpatient therapy thrice a week at Kessler. He spends his time painting, reading, applying for jobs in the summer and classes in the fall, and making cute little videos on a social media platform called TikTok (you can find him at hi.this.is.shaan), chronicling his journey to recovery. He hopes to become fully independent and work once summer rolls around as well as return to his classes in London.

For more GBS|CIDP patient stories go to:
<https://www.gbs-cidp.org/support/connect-with-gbs-cidp-community/patient-stories/>

Hey Doc continued from page 1

amongst physicians. Some clinicians are more experienced and some are not – and as a result the diagnosis of CIDP is not always accurate.

There are ways we can do better. Ask your doctor about CIDP diagnostic guidelines. Guidelines are the roadmap to diagnosis. They spell out what symptoms fit with CIDP, what we need to see on the nerve conduction studies, and how other data can influence the diagnosis. They can be helpful to integrate all the information together in a way that gives each piece of data the weight it deserves. Your doctor might say that guidelines are for research. Not true. Modern guidelines such as those published by the European Federation of Neurologic Society and Peripheral Nerve Society (EFNS/PNS) are meant for use in daily clinical practice and can be an invaluable resource to help improve the accuracy of the diagnosis.

Although CIDP can affect different people in different ways, there are certain features that are distinctly unusual for the disease. It’s important to discuss these “red flags” with your doctor as they may suggest a completely different diagnosis. Some “red flags” include:

IS IT CIDP? These “red flags” might suggest something else.		
Symptoms	Nerve conduction studies	Other features
Prominent pain	Absence of clear evidence of demyelination. Ask your doctor to review the guidelines to see if benchmarks for demyelination are met.	Family history of neuropathy
Symptoms all in the feet or legs		Treated with steroids or IVIG and did not have a clear and unquestionable positive response
Symptoms different on one side of your body than the other		Is there a better explanation for the neuropathy, such as diabetes, toxin exposure, vitamin deficiency, or something else
Prominent light headedness, dizziness, passing out, bowel or bladder changes		Your doctor finds that your reflexes are present or even “brisk”
Prominent fatigue without other CIDP hallmarks		

Many patient’s find that getting a second opinion to be a worthwhile endeavor. We encourage all patients to be evaluated by a CIDP expert at least once. If you have any of the “red flag” features a second opinion is especially valuable. A list CIDP centers of excellence can be found at <https://www.gbs-cidp.org/support/centers-of-excellence/>. Doctors at these centers have a special interest in the diagnosis and management of CIDP, and may be able to help work through some of the diagnostic challenges. Most patients with CIDP have marked improvement of their function with treatments such as IVIG and corticosteroids. If you are not having clear improvement in your condition it would be appropriate to have your condition reevaluated at a GBS|CIDP Foundation International Center of Excellence or other specialized center.

The pathway to getting a diagnosis of CIDP can be frustrating. The symptoms. The tests. The uncertainty. It all adds up – and when that diagnosis is reached it can be hard to go back and ask: Hey doc, are you sure this is CIDP? But it’s ok to ask. Whether you’ve had the diagnosis for a day or a decade, You should ask. We all want to get this right.

INTEGRATIVE NEUROMUSCULAR MEDICINE:

Neuropathy and Neuropathic Pain

Consider the Alternatives

By Julie Rowin, MD



(Article is a continuation from December, 2019 Communicator article — Integrative neuromuscular medicine: Neuropathy and Neuropathic pain: Consider the Alternatives — The following treatment is neither recommended or endorsed by The GBS/CIDP Foundation. As always, we recommend that you consult with your healthcare provider prior to beginning any treatment regimen.)

VITAMINS AND SUPPLEMENTS

There are well-tolerated vitamins and supplements with evidence showing benefit in neuropathy and neuropathic pain. Historically, physicians have avoided recommending nutraceuticals and herbs due to the lack of rigorous federal regulatory oversight of these compounds as well as potential interactions with pharmaceutical agents. These are important concerns.

Nutraceutical treatment should be used under the guidance of a healthcare professional.

Alpha-lipoic acid (ALA) is a naturally occurring fatty acid that can be found in many foods in very small amounts such as yeast, spinach, broccoli, potatoes, and organ meats. It is an anti-oxidant and thought to be protective against free radical damage. ALA in supplement form has been extensively studied and used in Europe for the treatment of neuropathy associated with diabetes. Both IV and oral forms of ALA have been shown to improve symptoms of neuropathy and may help to protect against further nerve damage. It is generally well tolerated but side-effects can include nausea, vomiting and dizziness. A side-effect of IV treatment is low blood sugar.

Acetyl-L-carnitine (ALC) is an amino acid that is naturally occurring in the body. It helps produce energy. As a supplement, it has been extensively studied in Europe in neuropathy associated with diabetes. Studies have shown ALC to improve the pain of diabetic neuropathy. Additionally, there is evidence that it can aid in nerve regeneration. Although generally well-tolerated, there is a potential for gastrointestinal side-effects such as nausea, vomiting or diarrhea.

Omega-3 fatty acids found in foods such as salmon, walnuts and flaxseed are crucial

to nerve health. Myelin, the covering of nerves, is comprised of 70% fats. Essential fatty acids (EFAs) cannot be made by the body and must be supplied by the diet, and EFAs and cholesterol are required for myelin health and function. Omega-3 fatty acids in supplement form have been found to be protective against peripheral nerve damage from chemotherapy and may also improve the nerves' ability to regenerate.

Gamma-linolenic acid (GLA), is an omega-6 fatty acid found in evening primrose oil and borage oil. GLA is an essential component of myelin and studies support the use of GLA to improve nerve function in neuropathy associated with diabetes.

Curcumin is a natural component of turmeric root. It is one of the most widely used and researched natural medicines for pain. Curcumin has been shown to lower oxidative stress, pain, and inflammation as well as have neuroprotective effects.

Vitamin D research has noted an association between low vitamin D levels and the presence and severity of neuropathy in diabetes and after chemotherapy. Vitamin D levels can be monitored by a simple blood test.

Supplementation and brief daily sun exposure as well as foods rich in Vitamin D may be recommended to keep Vitamin D levels within the normal range.

B Vitamins There is scientific evidence to support the use of B vitamins for neuropathy especially when there is a deficiency of B vitamins in the body. Vitamin B12 deficiency is particularly common in the US secondary to diet, medication use, and the reduced vitamin absorption which occurs with aging. Some forms of B vitamins may be better able to be used by the body. These forms are the methyl-folate form of folate, methylcobalamin form of vitamin B12, pyridoxal-5-phosphate form of vitamin B6 and benfotiamine form of vitamin B1. There is clinical trial evidence supporting the use of these B vitamins to reduce the symptoms of neuropathy associated with diabetes. A cautionary note is that very high and sustained dosages of vitamin B6 at greater than 200mg daily may cause toxicity leading to neuropathy.

Pharmaceuticals... Find full length article online at: <https://www.gbs-cidp.org/neuropathy-and-neuropathic-pain-consider-the-alternatives/>

1. Chan AS, Cheung MC, Sze SL, Leung WW, Shi D. Shaolin dan tian breathing fosters relaxed and attentive mind: a randomized controlled neuro-electrophysiological study. Evid Based Complement Alternat Med. 2011;2011:180704. 2. Anderson BE, Bliven KCH. The Use of Breathing Exercises in the Treatment of Chronic, Nonspecific Low Back Pain. J Sport Rehabil. 2017;26(5):452-458. 3. Khng KH. A better state-of-mind: deep breathing reduces state anxiety and enhances test performance through regulating test cognitions in children. ogn Emot. 2017;31(7):1502-1510



WELCOME Duke University and University of Alabama to the GBS|CIDP Foundation International Centers of Excellence

Our Global Medical Advisory Board has set standards for what they consider to be excellent medical centers for the diagnosis and treatment of GBS and CIDP, MMN and related neuropathies. Based on levels of expertise, available treatments, facilities, and research capabilities, these are the medical centers that we can unequivocally recommend as Centers of Excellence. Please join us in welcoming Duke University and the University of Alabama to our esteemed roster of COE's. Find out more at: <https://www.gbs-cidp.org/support/centers-of-excellence/>

NEW!

The GBS|CIDP Foundation International Center of Excellence Seal of Approval (pictured above) will be re-issued annually to those medical facilities that continue to uphold our standards of excellence in patient care, including expertise in GBS|CIDP, available treatments, facilities, and research capabilities.

GBS|CIDP SYMPOSIUM



BIENNIAL SYMPOSIUM OCTOBER 1-3, 2020

Registration now open!

The Hilton Alexandria Mark Center, Alexandria, VA
Seating is limited to 600 attendee capacity.

2020 SYMPOSIUM JUST 7 MONTHS AWAY!

As always, our symposium is a three-day event consisting of sessions led by our Global Medical Advisory Board physicians and related professionals. Our event will kick-off with a welcome celebration followed by two full days of educational and experiential workshops and presentations for the entire community. On Saturday night, you'll enjoy a closing reception where we announce the location of our next event! If you or someone in your life is living with GBS, CIDP, or related conditions – the symposium is tailor made for you!

WHAT'S NEW FOR 2020 SYMPOSIUM?

We are evolving our programs based on the needs of our community. This year, we will be asking 100 patients to join us on September 30, the day before the conference begins, for a special advocacy day on Capitol Hill! Perhaps you'd like to extend your stay and join us on Sunday, October 4, for the Washington DC Walk & Roll? Stay tuned for more information on the Symposium Capitol Hill Day, the 2020 DC Walk & Roll, and all things 2020 Symposium, in upcoming weeks at: <https://www.gbs-cidp.org/2020symposium/>

New Symposium Features! Including:

- Caregiver Sessions
- Teen/Youth Program
- MMN Track and Dedicated Sessions
- Expanded Global Medical Advisory Board One on Ones
- One on Ones with Integrative Health Specialists
- Multifocal Motor Neuropathy (MMN) Track led by Dr. Thomas Harbo, Neurologist at Aarhus University Hospital – Copenhagen, Denmark, a GBS|CIDP Foundation International Center of Excellence

Continued Programming:

- Separate Tracks for GBS & CIDP Patients
- Emotional Health Sessions
- Zen Den & Integrative Health
- Much, Much More!



MEDICARE AND HOME INFUSION IVIG: What You Need to Know

By Chelsey Fix

Medicare is confusing – that’s a fact! Add the confusing Medicare system on top of a complex treatment for a rare disease, and it’s easy to feel overwhelmed. The Foundation is here to help all of our patients navigate health insurance headaches! For now this article explains the current Medicare situation for our friends living with CIDP and MMN who are on Medicare and want to access home infusion for their IVIG treatments.

LET’S START WITH A QUICK REVIEW OF MEDICARE AND ITS PARTS:

MEDICARE PART A

- Everyone is automatically enrolled in Part A when they apply for Medicare
- Covers hospital costs
- No monthly premium, but there is a high deductible (the amount you have to pay out of pocket before costs are covered)
- Considered part of the “Original Medicare” benefits

MEDICARE PART B

- Everyone is automatically enrolled in Part B when they apply for Medicare, and most people pay a monthly premium for this coverage
- Medicare pays 80% of Medical costs

- You can purchase a Medigap plan (often called a supplemental plan) to cover the other costs, including the 20% “copay” required by Medicare. **The Foundation strongly recommends that people with Medicare purchase a Medigap plan**
 - Note – Medigap plans are not always offered to people under 65 years old. Contact the Foundation for help with this situation.
- Covers doctors’ visits, general outpatient services, and some prescriptions, and is considered one of the “Original Medicare” benefits

MEDICARE PART C

- Medicare Advantage Plans
- Provided by a private insurer that follows rules set by the Medicare office
- Most plans follow the coverage guidelines of Part A and Part B, with some prescription drug coverage benefits
- Advantage plans may be most beneficial to people under 65 years old that are on Medicare because of disability that cannot purchase a Medigap plan
 - However, Advantage plans do not replace Medigap plans for those that can purchase them

MEDICARE PART D

- Distributed by a private insurance company that follows rules set by the Medicare office

- Plans help to cover the cost of prescription drugs; you are responsible for either a flat copay or a percentage of each prescription
- There is no limit on out of pocket costs under Part D, but the plan is designed to help lower costs for prescriptions where possible through something called “catastrophic coverage” (more on that in the table below)

Now the important part – what does it mean if you have CIDP or MMN and want to infuse at home? Currently, there is no benefit under Medicare that specifically covers home infusion. That means that some home infusion providers will work with you if you bought a Medicare Part D plan to provide the service, but they are not obligated to do so.

The Foundation wants everybody to have the choice of where they get their IVIG infusion, regardless of their insurance. That is why we have worked with Congress to introduce HR 2905 – the Medicare IVIG Access Enhancement Act. (Read more at: <https://www.gbs-cidp.org/advocacy/advocacy-priorities/>) HR 2905 will create a law for a “demonstration project”, which is a fancy way of saying that Medicare will let people with Medicare Part B decide to get home infusion if they want to. Meanwhile, the Medicare team will monitor the cost and health of patients, and after 3 years will decide if Medicare should cover home infusion for CIDP and MMN patients forever. It is important to

remember that this is always voluntary for patients – HR 2905 does not force anybody to choose home infusion!

Because Medicare is so confusing, it is natural to be worried about what it would cost to get home infusion through that system. Here's the breakdown of your potential costs in Medicare Part B or Medicare part D:

PRO TIP Timing is Everything

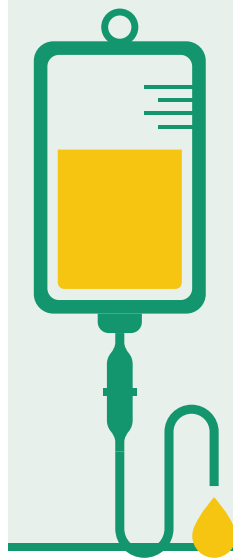
- 1 If you opt-out of Part B OR do not choose a Part D plan, you will be charged late-enrollment fees based on how long you went without those plans.
- 2 If you don't get a Medigap plan or an Advantage plan when you are first eligible for Medicare, Medigap and Advantage are **not required** to give you a plan and may deny you.
- 3 Make sure you purchase what you need when you are first eligible!

As you can see, our goal is to make home infusion accessible in Medicare Part B because it will be more affordable. It is important to note that the cost is lower because Medigap plans cover the cost of everything that Medicare does not cover, and those plans are only available if you are using Medicare Part B. Also, Medicare allows for yearly changes to your coverage, so be sure to track your expenses closely and make changes during the yearly "Open Enrollment" period to find a plan that helps to meet your needs.

We hope this helps you to make decisions about your Medicare coverage and site of infusion care. The Foundation is available to answer any of your questions! In the meantime, we hope that you will visit our Advocacy Action Center to help us make HR 2905 and the demonstration project happen: Go to: <https://www.gbs-cidp.org/advocacy/advocacy-action-center/> and tell your Congressperson to support the bill that will take the first steps towards getting home infusion covered by Medicare Part B!

**For more questions contact
Advocacy Manager, Chelsey Fix
at chelsey.fix@gbs-cidp.org.**

	MEDICARE PART B (what would happen if HR 2905 becomes law)	MEDICARE PART D (only some home infusion providers accept Medicare Part D)
Monthly Premium	Fixed rate: \$144.60/month	Cost varies, Average \$42.05/month
Other costs	Purchase a Medigap plan – \$150/month Medicare Deductible: \$198/year	Deductible: \$435/year Initial Coverage Phase: \$1,005/year Coverage Gap Out of Pocket: \$1,588/year Catastrophic Coverage Out of Pocket: \$9,000/year (estimate)
What is covered by Medicare?	Typical Medicare services & visits, PLUS <ul style="list-style-type: none"> • IVIG drug • cost of nursing for home infusion • cost of equipment for home infusion 	Typical Medicare services, PLUS <ul style="list-style-type: none"> • IVIG drug
Estimated cost paid by patient per year	Approximately \$4,000	Approximately \$13,000
Important points to remember	<ul style="list-style-type: none"> • The cost of a Medigap plan is different for everyone based on where live, your age, and the type of plan you purchase • Many Medigap plans cover the 20% copay typically required by Medicare Part B AND set out of pocket spending limits • This accounts ONLY for the cost of home infusion; your yearly medical expenses may also add to what you spend out of pocket 	<ul style="list-style-type: none"> • When a person is using the "Catastrophic Coverage" feature of Medicare, they will pay 5% of the total cost of each medication until the end of the calendar year. You may pay more or less than our estimate here depending on your IVIG brand, frequency of treatment, etc. There is no out of pocket spending limit. • Some specialty pharmacies offer financial assistance programs to some people, which can help to lower your out of pocket cost; your specialty pharmacy cannot advertise this program so make sure you ASK if they can offer help • There may be other financial assistance programs through Medicare or your state government. The Foundation is happy to help you learn more about one of those programs • This accounts ONLY for the cost of home infusion; your yearly medical expenses may also add to what you spend out of pocket



LOOKING FOR OTHER FINANCIAL RESOURCES?

See if you qualify for a low-income subsidy:

- <https://www.ssa.gov/benefits/medicare/prescriptionhelp/>

See if your state offers extra help:

- <https://www.medicare.gov/pharmaceutical-assistance-program/state-programs.aspx>

Learn about when to enroll in each program:

- <https://www.medicare.gov/your-medicare-costs/part-b-costs/part-b-late-enrollment-penalty>
- <https://www.medicare.gov/drug-coverage-part-d/costs-for-medicare-drug-coverage/part-d-late-enrollment-penalty>
- <https://www.medicare.gov/supplements-other-insurance/when-can-i-buy-medigap>

Clinical Trials Seeking Patients

Clinical research studies are scientific evaluations in people, led by researchers and physicians. They can help advance the understanding of a disease and are the most important way for researchers to find out if potential new treatments are safe and effective. Studies like these are needed to be able to make new treatments available to patients.



A CLINICAL STUDY OF ROZANOLIXIZUMAB IN PATIENTS WITH CHRONIC INFLAMMATORY DEMYELINATING POLYRADICULONEUROPATHY (CIDP)

The international My CIDP CHOICE study is currently enrolling CIDP patients to help us understand how effective and safe a new investigational drug, called rozanolixizumab. It is for the treatment of CIDP. Rozanolixizumab is a non-blood product and aims at lowering the levels of immunoglobulins (IgG) in the body, including IgG that are thought to be linked to CIDP.

ABOUT THE STUDY

The study is looking to enroll a total of approximately 34 participants at approximately 24 study sites globally. The My CIDP CHOICE study will last for about 28 weeks (up to a maximum of 40 weeks) for every participant. Some study visits may be conducted at home. Participants for whom the study treatment works well may be able to enroll in a 6-month follow-up study where everyone receives rozanolixizumab (no placebo), provided they meet the entry criteria. Patients interested in joining the My CIDP CHOICE study must:

- Be 18 years of age or older
- Have a definite or probable diagnosis of CIDP
- Have prior experience of discontinuing/reducing their immunoglobulin treatment
- Have been receiving immunoglobulin treatment with a stable dose for at least 4 months.

Find more information on clinicaltrials.gov, search for the identifier NCT03861481 or CIDP01 in the "Other terms" field. If you are interested in participating, contact UCBCares, who can refer you to a study physician in your area. UCB Cares — +1-844-599-CARE (2273) — UCBCares@ucb.com

BAXALTA/QUINTILE CIDP TREATMENT CLINICAL TRIAL

ADVANCE-CIDPTM 1 Study is looking at a potential new treatment (an investigational medication) for patients with chronic inflammatory demyelinating polyradiculoneuropathy (CIDP). The investigational medication is an immunoglobulin (made from proteins found in the body called antibodies) and is given as an infusion under the skin every 2, 3, or 4 weeks.

ABOUT THE STUDY

The study is currently looking for 170 patients at approximately 90 study centers worldwide. Visit clinicaltrials.gov and search for study identifier NCT 02955355 for more information, including a list of participating countries and study centers.

GBS|CIDP Foundation Granted Membership of the National Health Council (NHC)

We are pleased to announce that the GBS|CIDP Foundation International has been granted Membership of the National Health Council. Membership of the National Health Council by voluntary health agencies (VHAs) is contingent upon their meeting the Council's Standards of Excellence. These 38 standards were adopted by the NHC Board of Directors to ensure that VHA members maintain the highest levels of efficiency, accountability, transparency, and public stewardship. The standards cover the areas of governance, human resources, programs, fundraising, finance, accounting and reporting, and evaluation.





Life after GBS for Youth and Teens

by Diana Castro, MD

Despite recovery of muscle weakness in most children, many patients experience persistent fatigue, pain and anxiety/depression. These symptoms can be incapacitating and can affect academic and social development.

The mechanism underlying post-GBS fatigue is unclear. Fatigue can be secondary to stress and psychological factors. Other possibilities are deconditioning due to the lack of physical activity or side effects from pain medications. Exercise programs directed by physical therapists, especially water therapy, have been shown to be useful in reducing fatigue.

Pain is not as common in young children compared to adults, but it can be present in teenagers and young adults. Pain can be neuropathic in origin, often described as burning, stabbing or electric. Chronic pain post-GBS can also originate from the muscles, especially lower back and limbs, or in the joints. Muscle and joint pain can be attributed to immobility, and neuropathic pain may be caused by regeneration of the nerve. It is very important to

keep pain well controlled, as this will allow the patient to continue physical and occupational therapies, which are fundamental in the recovery phase. Medications that can be used to treat neuropathic pain include: anti-seizure medication (gabapentin, pregabalin and carbamazepine) and antidepressant medication (duloxetine, amitriptyline). Muscle pain can be managed with non-steroidal anti-inflammatory drugs (ibuprofen, naproxen), muscle relaxants (cyclobenzaprine) or topical agents (lidocaine patches).

Anxiety and depression are most likely due to the sudden and rapid loss of physical function, often in previously healthy individuals. Early identification and treatment of psychological symptoms is vital in the recovery of patients with GBS. Some of the medication used to treat neuropathic pain can also control symptoms of anxiety and/or depression. Regular psychological support should be part of the overall management.

It is worthwhile to remember that most patients will have significant, if not, total recovery. Medical team, family and community support are essential in assuring the best possible outcome.



DR. DIANA CASTRO JOINS YOUTH, TEEN AND YOUNG ADULT PROGRAM (YTA) AS MEDICAL ADVISOR

We are excited to announce our volunteer YTA Medical Advisor Dr. Diana Castro. Dr. Castro is a pediatric neurologist from UT Southwestern Medical Center, a member of our global Medical Advisory Board as well as a frequent presenter at GBS/CIDP Foundation symposiums and events. Welcome to the YTA program Dr. Castro! Are you a teen, parent of a child, or a young adult with GBS, CIDP or a variant?

If so, contact meg.francescangeli@gbs-cidp.org, to learn more about our new YTA program.

2020 CHAPTER MEETINGS FROM COAST TO COAST



Join us for patient support and education in your area. Contact kelly.mccoy@gbs-cidp.org for more information or find our event calendar at: <https://www.gbs-cidp.org/events-calendar/>

2.29.2020	Boca Raton, FL	4.4.2020	Tampa, FL
2.29.2020	Sydney, Australia	4.7.2020	Dallas, TX
3.7.2020	Albany, NY	4.11.2020	Charleston, SC
3.7.2020	Minneola, FL	4.11.2020	Buffalo, NY
3.14.2020	White Plains, NY	4.25.2020	Long Island, NY
3.21.2020	Phoenix, AZ	5.2.2020	Albuquerque, NM
3.21.2020	Annapolis, MD	5.2.2020	Conway, SC
3.28.2020	Alexandria, VA	5.3.2020	Greenwich, CT
4.4.2020	Oak Ridge, NJ	5.16.2020	Syracuse, NY
4.4.2020	Hackettstown, NJ	6.6.2020	Miami, FL

INTERNATIONAL PATIENT MEETING:

Barcelona, Spain

Wednesday, April 22, 2020

17:30 – 20:30

Meliá Barcelona Sky

Contact Kelly McCoy at kelly.mccoy@gbs-cidp.org for more information.

Ask the Expert...

Featuring David Saperstein, MD



ARE RELAPSING GBS AND CIDP THE SAME THING? IF NOT, HOW ARE THEY DIFFERENT?

In most cases, distinguishing between GBS and CIDP is very straightforward. However, there can be times where the lines get blurred and the distinctions can seem too subtle.

Most cases of CIDP are steadily progressive, meaning symptoms continue to get worse without treatment. Some cases of CIDP are “relapsing and remitting”, meaning that symptoms flare-up, subside and flare-up again with or without any treatments being given. The flares seen with CIDP are usually not as rapid or pronounced as those seen in GBS. However, some patients who actually have relapsing-remitting CIDP can initially be thought to have GBS. The diagnosis of CIDP is ultimately made because their symptoms repeatedly come back weeks or months after treatment for GBS. Another clue to the diagnosis being CIDP is that these patients often improve much more rapidly than patients with GBS.

There is a very rare subset of GBS patients who will experience discrete relapses that occur years apart (often this can be quite a large number of years). Each episode is similar: symptoms come on abruptly and progress to the worst point over a couple of weeks. Even with treatment, such as IVIG, recovery usually takes many months. This group of patients can be considered to have “relapsing GBS” as opposed to CIDP.

Walk & Roll Volunteer Spotlight



Meet Nancy and Allen Minton

“Our first in-person Foundation event was the San Diego Symposium,” said volunteer Nancy Minton, as we recently spoke with her about why she supports the Foundation. On Saturday evening of the Symposium the Foundation announced that we were getting very close to our Walk & Roll goal of \$150,000. Nancy stood and walked straight over to the Walk Program manager, “wait I’ll be right back with my check book!” she said. Their significant contribution helped the Foundation to achieve its Walk & Roll goal of funding three new research grants! As a former GBS patient, Nancy was very inspired by the Symposium activities. “I was so moved by the whole event, so much support and information, it was the least we could do. Allen and I know that GBS/CIDP Foundation is a small organization but uses the donations it receives wisely. For me personally, I love to see all that the Foundation does to increase research and educate doctors about treatments and proper protocols. By donating to the Foundation, I know that I am making someone’s journey with these rare conditions more bearable than it was when I was diagnosed years ago.” ***Please join us in acknowledging the kindness, generosity, and support of members, Allen and Nancy Minton.***

2020 Walk and Roll Schedule, 16 and Counting!

The 2020 Walk & Roll schedule is LIVE! Walk & Roll is a great way to raise awareness, show your support, make friends and build a local network. Sign up for a walk near you TODAY and get started fundraising for RESEARCH.

When we updated the program in 2018 to the Walk & Roll for Research, we had no idea how the community would respond.

Designating every dollar raised by you to go directly to research. YOUR donations have been able to fully fund **SEVEN grants for Research, totaling almost \$400,000**, since its inception.

This year, by increasing our goal to **\$300,000**, we are taking it one step further and aiming to fund **SIX** more research grants!

Contact jessica.mcmanus@gbs-cidp.org for more information.

2020 WALK & ROLL SCHEDULE

3.7.2020	Clovis, CA
3.28.2020	San Diego, CA
4.11.2020	Charleston, SC
5.2.2020	Denver, CO
5.30.2020	Twin Cities
6.7.2020	Philadelphia, PA
6.13.2020	Houston, TX
6.13.2020	San Francisco, CA
6.14.2020	New Jersey
9.12.2020	Pittsburgh, PA
9.12.2020	Myrtle Beach, SC
9.12.2020	Chicago, IL
9.12.2020	Staten Island
10.4.2020	Washington, DC
10.24.2020	Raleigh, NC
10.24.2020	Phoenix, AZ



Giving Hope to our Global Rare Community for #Rarediseaseday



The first Rare Disease Day took place on February 29 (leap year day). Because this is rare, only every four years, it became synonymous with rare diseases – as “rare disease day” itself. Of course, in between, it is celebrated on February 28th. The main objective of Rare Disease Day is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients’ lives. This year we are not only celebrating our one-year anniversary since the launch of our Patient Registry, but the GBS|CIDP Foundation International also took part in several RDD activities around the globe!

PATIENT REGISTRY ONE YEAR ANNIVERSARY

The Foundation is pleased to report on the data that we have collected during the 1 year time period since launching this registry! So far, more than 1,200 people have created a profile in the GBS|CIDP Patient Registry. The data reported in the below link represents the responses collected from the 518 people who have taken surveys within the registry, though not every person responds to every question. Also, people who have joined the registry are from all over the world; almost 60 respondents in the registry come from countries other than the United States, including Australia, Germany, Greece, Israel, Japan, Nicaragua, Kenya, and more!

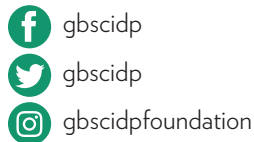
Go to <https://www.gbs-cidp.org/support/news/> and see our very first Patient Registry Annual Report. Interested in joining? Enroll today: <https://www.gbs-cidp.org/research/gbscidp-patient-registry/>

LISA, KELLY, AND MEG AT GBS|CIDP FOUNDATION CHAPTER MEETING IN AUSTRALIA!

As we walked into our first Asia/Pacific volunteer development meeting, the room was filled with 20 of our most dedicated volunteers eager to expand their knowledge about GBS, CIDP, and variants. Dr. Gareth Parry, Dr. Jeff Allen, and Dr. Stephen Reddel joined us in informing the volunteers of updated research, clinical trials, and treatments, in hopes of bringing more knowledge back to the patients in their area. The day was wrapped up with a volunteer training, where we guided the volunteers on how to reach more patients with GBS, CIDP, and variants. The following day, we were greeted by 60+ individuals at the Sydney, Australia Chapter Meeting. The day was filled with individuals not only learning more about their condition, but building connections with one another. Our time spent in Sydney, Australia was unforgettable!



CHANGE SERVICE REQUESTED



SUPPORT EDUCATION RESEARCH ADVOCACY SUPPORT EDUCATION RESEARCH ADVOCACY



HONORING OUR VERY FIRST VOLUNTEER!

by Founder, Estelle Benson

Ellen Burr was a longtime neighbor and friend to myself and my husband Bob. She was there to witness day by day the many stages of GBS. When the first support group met and became the seed of what is now our International Foundation, Ellen was there to help. She even assembled volunteers at a nursing home where patients stamped and sorted newsletters for us. Ellen was actually our very first volunteer, from day one, and still champions our mission along the way. Lisa Butler and I were so pleased to present her with a certificate acknowledging her years of dedication. Thank you Ellen!

CONTACTS AND RESOURCES FOR ALL STAGES OF LIFE WITH GBS|CIDP & VARIANTS

DIAGNOSED WITH MMN?

Brenda Perales
brendajp62@icloud.com

MILLER FISHER VARIANT GROUP

Please call us to connect with others.

CHILDREN WITH GBS

Lisa Butler, 610-667-0131
GBS|CIDP Foundation International
lisa.butler@gbs-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@gbs-cidp.org. For more information on our youth, teen, and young adult (YTA) programming contact meg.francescangeli@gbs-cidp.org.

LOOKING FOR A 20-SOMETHING 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 meg.francescangeli@gbs-cidp.org to find out how to join!

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 Advocacy Manager Chelsey Fix, chelsey.fix@gbs-cidp.org.

INTERNATIONAL OFFICE

610-667-0131

DO YOU HAVE A VARIANT

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
- GBS X2
- Miller Fisher
- MMN

**WE ARE A
SUPPORTIVE ALLY
ON AN UNPLANNED
JOURNEY...**



**ENSURING NO
ONE IS
TRAVELING
ALONE...**



**BUILDING A
PATIENT-CENTERED
COMMUNITY OF
HEALING...**



**TO HELP
YOU ON YOUR
WAY TO A NEW
NORMAL.**