

# 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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## Update from the International Guillain-Barré Syndrome Outcome Study (IGOS)

*Diagnosis and management of Guillain-Barré syndrome in ten steps*

Nature Reviews Neurology: <https://www.nature.com/articles/s41582-019-0250-9>;  
Published Sept 20, 2019. **Explanation of the above referenced article below.** <http://creativecommons.org/licenses/by/4.0/>

**Authors:** Sonja Leonhard, Melissa Mandarakas, Francisco de Assis Aquino Gondim, Kathleen Bateman, Maria Lúcia Ferreira, David Cornblath, Pieter van Doorn, Mario Dourado, Richard Hughes, Badrul Islam, S Kusunoki, Carlos Pardo, Ricardo Reisin, Jim Sejvar, Nortina Shahrizaila, Cristiane Soares, Thirugnanam Umapathi, Yuzhong Wang, Eppie Yiu, Hugh Willison, and Bart Jacobs.

## Previously, no international clinical guidelines

for the diagnosis and management of the Guillain-Barré syndrome (GBS) existed. This was problematic, as clinical presentation and disease course may vary extensively between patients, management can be difficult, and clinicians are often confronted with diagnostic and treatment dilemmas. Furthermore, the incidence of GBS may suddenly and dramatically increase, as was seen recently during the Zika virus epidemic in during 2015-2016 in Latin America and the Caribbean. To

continued on page 4 ►



Morgan, Virginia and Amy (August 24, 2019)

## A Little Support Goes a Long Way, Meet Morgan and Virginia

We are happy to introduce, a friend and advocate, Virginia Vassolotti, and GBS patient Morgan Smith. Virginia reached out to us for support and information after Morgan was admitted to the hospital with a GBS diagnosis. "I went online and started to search and I came across the Foundation rather quickly. And just a phone call later I was speaking with the Founder, Estelle Benson! She was amazing," said Virginia.

Not only was Virginia relieved to find an abundant library of online resources, and a knowledgeable, compassionate ear on the other end of the phone (the founder no less!), but within days a hospital visit was scheduled for Morgan from a former patient and local GBS|CIDP volunteer. Here's what Morgan had to say:

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



*Never before have we accomplished so much in the areas of support, education, research and grassroots advocacy.*

## Dear Friends,

On any given year, in our December issue of the Communicator, I would likely offer “a year in review” and invite you to join us in closing the door and bidding farewell to time well served. However, 2019 has been over-flowing with patient support, volunteerism and inspired collaborations around the world, that it just doesn’t seem appropriate to say goodbye or to close the door on just another year.

Never before have we accomplished so much in the areas of support, education, research and grassroots advocacy. Together, we have broken records in both attendance and fundraising in our National Walk & Roll Program and engaged in over 50 legislative visits in just one day at our annual GBS|CIDP Foundation Hill Day! And over 150 letters were written to Senators and Representatives in May to support the Foundation’s legislative agenda, including HR2905 which would allow Medicare patients to access in home IVIG treatments. Additionally over 1,300 patients attended 76 chapter meetings world-wide. And thanks to the support of our community and industry partners, our Walk and Roll for research funded over \$450,000 in research, marking the highest commitment to research ever in a single year. Last but not least I am so excited to also share that the GBS-CIDP Patient Registry, which launched on February 28, currently has over 1100 patients sharing their journey with healthcare professionals. This access to critical data provides an in-depth understanding of the patient experience and is vital for the pursuit of medical advancements.

And there is no stopping us now!

So I invite you to grow with us from one day, one year, one story to the next. I hope you enjoy meeting our community, in this very special issue, and resting assured that the door will not be closed in 2019 but remain always open as the spring board to the possibility of the days and years ahead. It is truly your spirit and courage that inspire us.

I wish you peace, love, health and happiness this holiday season,

*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 the Foundation.

Contact us online at [gbs-cidp.org](http://gbs-cidp.org) or by emailing [info@gbs-cidp.org](mailto: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](http://gbs-cidp.org)  
**E** [info@gbs-cidp.org](mailto:info@gbs-cidp.org)



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**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.

## IGOS continued from page 1

accommodate for this unmet need and to support clinicians, especially during new outbreaks of GBS, we developed a globally-applicable, simple and practical clinical guideline for GBS.

This guideline is based on current literature and international expert consensus, presenting a 10-step approach to facilitate use in clinical practice. These 10 steps cover the most important aspects of diagnosis, treatment, monitoring, prognosis and long-term management. Furthermore, tables and figures are provided that give an overview of diagnostic criteria clinical variants and differential diagnoses of GBS. These are helpful resources for busy clinicians, that can be printed and used at the bedside. To complement the paper, we have finalized a web-based resource that presents the information in an easy-to-access online format. <https://rede.tghn.org/gbs-flowchart-sample/introduction-gbs/>

Follow IGOS research news at: <https://www.gbs-cidp.org/support/news/>

## Diagnosis

## 1 When to suspect GBS

- Rapidly progressive bilateral limb weakness and/or sensory deficits
- Hypo/areflexia
- Facial or bulbar palsy
- Ophthalmoplegia and ataxia

## 2 How to diagnose GBS

- Check diagnostic criteria
- Exclude other causes
- Consider:
  - Routine laboratory tests
  - CSF examination
  - Electrophysiological studies

## Acute care

## 3 When to admit to ICU

- One or more:
  - Rapid progression of weakness
  - Severe autonomic or swallowing dysfunction
  - Evolving respiratory distress
  - EGRIS >4

## 5 Treatment options

- Intravenous immunoglobulin (0.4 g/kg daily for 5 days)
- Plasma exchange (200–250 ml/kg for 5 sessions)

## 7 Early complications

- Choking
- Cardiac arrhythmias
- Infections
- Deep vein thrombosis
- Pain
- Delirium
- Depression
- Urinary retention
- Constipation
- Corneal ulceration
- Dietary deficiency
- Hyponatraemia
- Pressure ulcers
- Compression neuropathy
- Limb contractures

## 4 When to start treatment

- One or more:
  - Inability to walk >10m independently
  - Rapid progression of weakness
  - Severe autonomic or swallowing dysfunction
  - Respiratory insufficiency

## 6 Monitoring

- Regularly assess:\*
- Muscle strength
  - Respiratory function
  - Swallowing function
  - Autonomic function
    - Blood pressure
    - Heart rate/rhythm
    - Bladder/bowel control

## 8 Clinical progression

- Treatment-related fluctuation:
- Repeat same treatment
- No initial response or incomplete recovery:
- No evidence for repeating treatment

## Long-term care

## 9 Predicting outcome

- Calculate mEGOS on admission
- Recovery can continue >3 years after onset
- Recurrence is rare (2–5%)

## 10 Rehabilitation

- Start rehabilitation programme early
- Manage long-term complaints: fatigue, pain and psychological distress
- Contact GBS patient organizations

## A Little Support continued from page 1



GBS|CIDP Foundation volunteers, Lynn and Will, visit Morgan in the Hospital

“

“Volunteers from the GBS|CIDP Foundation, visited my friend Morgan in the hospital. I know that made all the difference in her recovery. She was very motivated and in very good spirits after the visit! We are so grateful!”

—VIRGINIA VASSALOTTI

### Q. When was Morgan admitted, and how long until she was diagnosed?

**A.** Morgan was admitted on June 11, 2019 to the NICU at Jefferson University Hospital. She started having symptoms the previous week (June 4) right before she left for vacation to Switzerland with her mom. While in Switzerland, her symptoms got worse and she went to the ER there where they suspected she had Guillain-Barre. Her younger sister, Shelby, a med student also suspected GBS. So Morgan and her mom flew home that Monday, June 10–Tuesday, June 11 then immediately was rushed to the hospital. Luckily, they diagnosed her within a week; I’ve heard stories where it’s taken a lot longer to confirm a diagnosis.

### Q. How did you find out about the GBS|CIDP Foundation?

**A.** Since GBS is so rare, and I had never heard of it, I decided to do some research online when I quickly stumbled upon the GBS|CIDP Foundation International. The Foundation has been a great resource through Morgan’s diagnosis and recovery. The stories of other survivors gave Morgan, her family, and friends hope, knowing she would get better.

### Q. Who visited from the Foundation?

**A.** Lynn and her husband, Will, visited Morgan on Sunday, July 14 while she was still in the NICU. This marked over a month of being in the hospital, a couple days after Morgan had a tracheostomy and gastrostomy, and when Morgan was really down.

### Q. Did the visit help in any way?

**A.** I believe having a former patient visit Morgan was the encouragement she needed. Within four days, Morgan was weaned off the ventilator and transferred to a rehab unit. Since then she’s made constant improvements and is in better spirits. Definitely more motivated!

For more information on volunteer services, or to learn *best practices for connecting with patients and/or hospital visits*, please contact Kelly McCoy, [kelly.mccoy@gbs-cidp.org](mailto:kelly.mccoy@gbs-cidp.org).

You can learn more about Morgan’s journey to recovery here: <https://www.gofundme.com/f/morgans-journey-to-recovery>.\*

\*GBS|CIDP Foundation International does not support fundraising activities for individual patients.



# INTEGRATIVE NEUROMUSCULAR MEDICINE:

## Neuropathy and Neuropathic Pain

### *Consider the Alternatives*

By Julie Rowin, MD

#### What are Symptoms of Neuropathy?

There are many symptoms of neuropathy depending on the type of nerves involved and the distribution in the body. Most commonly, symptoms are in the feet and legs followed by the hands and include symptoms from involvement of the:

- 1. sensory nerves:** numbness, tingling, burning, pain, gait imbalance or incoordination
- 2. motor nerves:** weakness, atrophy in the muscles, cramping and twitching in the feet and calves
- 3. autonomic nerves:** skin color changes particularly on the feet, loss of hair on the legs, light-headedness, sexual dysfunction, changes in urination, changes in sweating and constipation

#### Treatments for neuropathy

It is important to address any root cause environmental factors and medical conditions that are associated with or may be contributing to neuropathy. An anti-inflammatory approach to the treatment of neuropathy includes nutrition, exercise, toxin avoidance and stress reduction in addition to symptomatic treatment for nerve pain and discomfort.

#### Diet and lifestyle

Proper nutrition is crucial for health including the health of the nervous system. Foods to support an anti-inflammatory, neuroprotective life-style include whole foods with a high phytonutrient density, low-glycemic-load, protective anti-oxidants, soluble fiber and high-quality dietary fats. Inflammatory foods such as sugar, heavily processed flour, genetically modified foods, chemical additives and artificial

sweeteners, heavily processed oils and fats, conventionally raised meats and pesticide laden produce are best avoided as they may disrupt normal gut integrity and contribute to blood sugar dysregulation and systemic inflammation.

#### Exercise and physical therapy

Exercise is paramount to health including the health of the brain and peripheral nerves. Studies have shown that moderate to rigorous exercise is protective against health-related conditions associated with neuropathy. In syndromes of blood sugar dysregulation, such as diabetes and metabolic syndrome, sixty minutes of regular exercise 3-4 times per week improved the body's ability to regenerate nerve-endings as shown in biopsies of the skin. Moderate physical exercise is anti-inflammatory, improves gut, brain and nerve health, and contributes to maintenance of a healthy body weight and muscle mass. Always consult with your healthcare professional before starting a new exercise program.

#### Acupuncture

Acupuncture involves inserting very thin needles into acupuncture points which are located throughout the body. Acupuncture has been utilized in the East for centuries and thought to balance Chi, one name for our vital life force energy. In the West, acupuncture is growing in popularity for the treatment of a variety of pain syndromes including neuropathy. A large scientific review revealed the benefit of acupuncture over usual medical care alone for diabetic neuropathy and carpal tunnel syndrome. The positive studies used acupuncture points located near to affected peripheral nerves suggesting that acupuncture has a

direct effect on the nerve tissues. Research also suggests that the effects of acupuncture may in part be due to alterations in brain plasticity. A gentle electrical stimulation is often placed through the acupuncture needles to optimize pain relief. Generally, a course of 6-12 acupuncture treatments, 1-3 times per week is recommended to determine if it will be of benefit. Once benefit is noted, less frequent treatments may be sufficient.

#### Movement based therapies such as Tai Chi and yoga

Tai Chi is a traditional Chinese martial art that has been practiced for many centuries consisting of deep diaphragmatic breathing and relaxation with slow, gentle movements and postures. It is known for improving balance, flexibility and mental focus. Studies of Tai Chi for neuropathy show improved blood sugar regulation, balance and symptoms of neuropathy. Additionally, Tai Chi has been shown to improve immune function in diabetic patients.

Yoga is an ancient practice of body postures, conscious breathing and mental focus. Frequent and consistent practice of gentle yoga has been shown to be beneficial for various neurological disorders, pain, and diabetes in multiple studies. The practice of yogic postures as well as yogic breathing improves the function of the autonomic nervous system including heart function.

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**Vitamins and Supplements...** (article to be continued in Spring 2020 issue of the *Communicator*. Or, find full length article online at: <https://www.gbs-cidp.org/neuropathy-and-neuropathic-pain-consider-the-alternatives/>)

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## Dr. Julie Rowin

Dr. Julie Rowin is a board-certified neurologist, neuromuscular specialist and acupuncturist. She completed her medical school training and Internship in Chicago at Northwestern University Medical School in 1993. She went on to do her Residency and Fellowship training in Neurology, Neuromuscular Medicine and Electromyography at Rush University. She was Assistant Professor of Neurology at Rush University from 1998-2004. Then from 2004-2013, she was Associate Professor of Neurology and founding director of the MDA/ALS Center and MDA Clinics in the College of Medicine at the University of Illinois at Chicago. Dr. Rowin has obtained additional board certification in Integrative Medicine and Medical Acupuncture. She also has training in Ayurvedic Medicine and Yoga. Her holistic healing approach to the treatment of adult neurological conditions integrates nutrition, acupuncture, mind-body energetics with conventional medical management.

## Classic, Simple Yoga Pose for Lowering Stress Response

### *Viparita Karani- Legs up the Wall Pose*

We all hear about the links between stress and disease. This technique practically guarantees a calm nervous system within 10-15 minutes. Let your own body's built in reflexive responses aid you into relaxation. This traditional yoga posture is known to flip the switch from the sympathetic nervous system (fight or flight) to the parasympathetic nervous system (rest and digest).



### VIPARITA KARANI-LEGS UP THE WALL POSE

Dr. Rowin's personal favorite for stress reduction and immune system balance

### DIRECTIONS (see picture ▶):

Lie down on the floor in a quiet room (or with your favorite meditation music) with your legs up the wall and a bolster under your hips (or use 2 thick blankets at least six inches thick, about 10 inches wide to support your hips in entirety) placing it length wise against the baseboard. Sometimes it can be challenging to get into position. You may find it helpful to look at the attached diagram. Settle your back on the floor aligning your spine perpendicular to the wall. Bring your hips as close and square to the wall as possible without causing discomfort. Make sure you are comfortable and warm and that you have a small blanket under your head so that your chin is slightly lower than your forehead. When you feel comfortable, close your eyes. Take some deep breaths while expanding your belly. Let your body have the sensation of sinking into the floor...the weight of the world falling away. When you have felt the shift (typically 10-15 min) slowly and gently bring your legs into your chest, rolling to your side, gently removing the bolster and rest for a few breaths in fetal position before slowly sitting up. Notice any sense of ease and renewal.

It is a great posture for the transition from work to home, or anytime you feel under stress. This traditional yoga posture (Viparita Karani) has been known for centuries to balance the nervous system. We know now that it works by shifting the hypothalamic-Pituitary-Adrenal (HPA) axis from "fight or flight" to "rest and digest." It does this by pooling blood in the upper chest region where there are blood pressure sensitive (barosensitive) receptors that are sensitive to the stretch of the blood vessels. These baroreceptors send a message to your brain to slow the heart rate and reduce blood pressure as well as activate the rest and digest response and restore the body to a state of muscle relaxation and mental calm. This technique relaxes the physiology of the body which reflexively leads to relaxation and quieting of the mind.

## VACCINES AND GUILLAIN-BARRÉ SYNDROME

*A word from our Global Medical Advisory Board*

Vaccines are usually safe for most people; their potential benefits usually outweigh their small risks. However, there is a lack of data to guide the use of immunizations in former GBS patients. For the rare person who developed GBS within four to six weeks of receiving an immunization, the Foundation advises to avoid the same immunization in the future. The decision to receive a vaccination is likely best made by conferring with the patient's primary physician and following guidelines in the product literature.







## A Walk & Roll for Research Year to Remember



Thus far in 2019, we've raised over \$240,000, in peer-to-peer donations, with over 2,500 Walk & Rollers participating from coast to coast! That's enough to fund 5 research grants in the upcoming year! A BIG thank you to our teams, affected patients, families, friends, industry partners and all of the communities that stepped up, stepped out and supported this amazing cause. And thank you to our Walk & Roll chairpersons for making this a record-breaking year!

## FIRST VIRTUAL WALK & ROLL...LIVE! #gbscidpVIRTUAL

The Foundation's very first **Virtual Walk & Roll** was an opportunity to come together, **online**, wherever you live, to walk & roll with us and raise money for GBS|CIDP research! On November 16th, friends and medical experts in the GBS|CIDP community joined in from around the globe for a 30-minute Virtual Walk & Roll & educational program... live! Check out the program on the Foundation's Facebook page or Youtube channel! Interested in connecting with other GBS|CIDP virtual walkers? Join our Virtual Walk Facebook Group. Stay tuned for 2020 program link this spring. Need more info? Go to Virtual Walk FAQ.



## 265 Patients & Caregivers attend 2019 Regional Conferences in Boston and Indianapolis

Rounding out our 2019 regional conferences, over 265 patients and caregivers attended the Boston and Indianapolis Regional Conferences. Keynotes and updates regarding the latest research were delivered by GMAB members, Robert Lisak, MD in Indianapolis and Ken Gorson, MD in Boston, followed by educational presentations including navigating health insurance, understanding current legislation affecting GBS|CIDP and variant community, and an interactive "ask the experts" breakout session whereby patients could connect directly with GBS|CIDP medical experts. The Boston Regional attendees enjoyed a new session on assistive devices presented by *Permobil*. Our list of expert presenters included Michal Vytopil, MD of Lahey Hospital and Waqar Waheed, MD, of the University of Vermont (both medical facilities are deemed GBS|CIDP Centers of Excellence). Additional presenters also included Betty Soliven, MD, Jim Romano of Patient Services Inc. (PSI) and Dane Christiansen of the Health and Medical Counsel of Washington DC. Stay tuned for more information on Regional Conference locations for 2021.



## BIENNIAL SYMPOSIUM OCTOBER 1-3, 2020

Registration Opens January 1, 2020  
The Hilton Alexandria Mark Center  
Alexandria, VA

## GBS|CIDP SYMPOSIUM



### IT'S ALMOST TIME TO PLAN YOUR TRIP TO DC!

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 Tracks & Dedicated Sessions
- Expanded Global Medical Advisory Board One on Ones
- One on Ones with Integrative Health Specialists

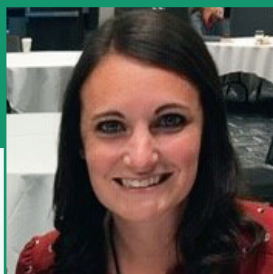
#### Continued Programming:

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



### ANNOUNCING SYMPOSIUM 2020 KEYNOTE SPEAKER, CONGRESSMAN JOHN GARAMENDI

We are proud to announce our Keynote speaker; Congressman John Garamendi, a United States Representative & GBS|CIDP Foundation International's Legislator of the Year in 2015. John, with his own personal connection to GBS, continues to be a Champion for GBS and the GBS|CIDP Foundation.



## NEW PROGRAMMING FOR YOUTH, TEENS AND YOUNG ADULTS (YTA)

My name is Meg and I am excited to announce that I will be leading the Youth/Teen and Young Adult Program at the GBS|CIDP Foundation International! I am thrilled to start this program and help kids, teens and young adults who are coping with GBS, CIDP or a variant condition, connect with one another and realize they are not alone. I am encouraging youths (8-12), teens (13-18) and young adults, (19-27) to consider attending our 2020 Symposium in Alexandria, VA, where we have programs specifically designed for different age groups. Can't make the symposium in 2020? Not to worry, we will have plenty of helpful resources on our website as well as other events specifically designed for your age group. If you are a teen or a young adult and would like to volunteer and take this program a step further, please reach out to me at [meg.francescangeli@gbs-cidp.org](mailto:meg.francescangeli@gbs-cidp.org). Looking forward to connecting with you!



## 1,400 GBS|CIDP CHAPTER MEETING ATTENDEES FIND SUPPORT IN 2019!



2019 was a record breaking year for our chapter meetings with 1,400+ attendees and more meeting locations than ever before! We have also hosted chapter meetings in NEW cities including: Italy, Milwaukee, Long Island, Richmond & Boise. A very special thank you to our chapter liaisons for hosting these meetings and to all that attended! We hope to bring new cities to our calendar in 2020 so stay tuned! Have questions about our chapter meeting program? Contact [meg.frangescangeli@gbs-cidp.org](mailto:meg.frangescangeli@gbs-cidp.org).

## INTERNATIONAL ANNOUNCEMENT:

### Sydney, Australia Chapter Meeting

**Saturday February 29, 2020**

**9:00 am**

**Four Points by Sheraton Sydney  
Central Park**

**Registration is FREE.**

Find out more at [www.gbs-cidp.org/events-calendar/](http://www.gbs-cidp.org/events-calendar/)

### Volunteer Development Meeting

We are excited to announce that we will be hosting a volunteer development meeting in Sydney, Australia for our Asia/Pacific region volunteers on February 28th & 29th of 2020. As you may know, we hosted this event in Amsterdam in 2017 for our European & African volunteers with great success. We will be making this programming permanent, and will focus on the different 'regions' of the globe. We will also be hosting a Sydney chapter meeting while we are there! For questions contact Kelly. [mccoy@gbs-cidp.org](mailto:mccoy@gbs-cidp.org).

If you live in Mexico, South America, Central America and the Caribbean, we will look to host this event in 2022 in your region.



## Ask the Expert...

Featuring Dr. David Saperstein



Below are two questions regarding GBS, CIDP and MMN, from attendees at our Colorado regional meeting, "Ask the Expert" panel. The answers are provided by Dr. David Saperstein, a member of the GBS|CIDP Foundation's Global Medical Advisory team (GMAB).

### Q: Do you have any recommendations for ongoing problems with cramps in hands, legs, and feet?

**A:** Cramps can be a bothersome problem in people with GBS, CIDP or other neuropathies. No one is certain why cramps occur in this setting, but damage to nerves seems to make them more irritable and more likely to fire, therefore sending signals to muscles and making them contract. Not being well hydrated can aggravate cramps, so, at a minimum, you should take care to stay well-hydrated. Gently stretching the muscles that get cramps can also help. Beyond these interventions, there are no "proven" remedies that help cramps. Some people find ingestion of vinegar or pickle juice beneficial for cramps. There is actually research that suggests that by stimulating nerves in the throat vinegar can trigger relaxation of cramps. It is unclear that supplements containing magnesium or potassium are useful for most patients. In some cases, where cramps remain bothersome despite trying simple measures, medications can be tried. These include muscle relaxants like baclofen or anti-seizure medications like gabapentin.

### Q: How can you tell it's time to stop IVIG?

**A:** Research over recent years has clearly shown that a number of patients with CIDP can successfully stop IVIG or other treatments. Unfortunately, we do not as yet have good ways of predicting who will do well with this. If someone has been stable on IVIG (meaning symptoms are neither improving nor worsening) for at least 6 months, it is reasonable to consider making a change to IVIG. In consultation with the physician managing your CIDP you could pursue one of three options: stop IVIG, gradually decrease the dose given each infusion, or spread out the time period between infusions. No one is sure which strategy is best. The most important thing is to stay in close contact with your physician so that changes can be made quickly if you start to worsen after changing IVIG.

Most insurance companies are requiring that physicians document attempts to get patients off IVIG so you can expect this topic coming up in your follow-up appointment.

An important point that is often overlooked is that if you have never clearly improved from treatment with IVIG, then an assessment of whether you can come off treatment should definitely be performed.



## ARE YOU A MONTHLY GIVING PARTNER?

Monthly giving partners enable the foundation to plan continual opportunities, month after month, for families and individuals to connect and build vital support networks, as well as speak directly with medical experts in the field of peripheral neuropathy. And monthly giving partners ensure the sustainment and growth of GBS|CIDP online educational library and continuation of our publications, placing the latest news, research and resources into the hands of those who need it most. Plus monthly giving partners enjoy the ease of a one-time transaction for their monthly donation and the reassurance that they or their loved one will receive the services and connections they need for an entire lifetime.

For more information contact  
Madeline.Miller@gbs-cidp.org

## 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](https://clinicaltrials.gov) and search for study identifier NCT 02955355 for more information, including a list of participating countries and study centers.



## Volunteer Spotlight

### *Rockie Kephart Raises Awareness in ER, Rehab, Hospitals & More*

Meet Rockie Kephart, a tireless GBS|CIDP volunteer, who is bound and determined to make GBS|CIDP, and variants of the condition, well understood and “top of mind” in medical facilities throughout her home state of Colorado, and beyond.

“After attending the Colorado regional meeting, and seeing how much the Foundation has to offer, I decided to become a volunteer. At first I thought I might just hold a few chapter meetings, but then something happened that made me realize there is much work to be done in other areas for GBS|CIDP community as well, particularly in Colorado. I learned of two people who came to one of our top hospitals, with classic signs of GBS, (for a second time in their lives, which is highly unusual), that were both misdiagnosed. The misdiagnosis led to very difficult situations for these patients. My heart went out to them. I thought, **we need some awareness raising in our medical facilities**. So I decided to pursue a different way of getting my feet wet in the area of volunteering for the GBS|CIDP community.

I recalled that when I was in ICU with GBS, the doctors tried to learn about the condition through me! They had very little experience with the condition. And I recalled how I found out about the Foundation. I saw a pamphlet on a bulletin board, when I was doing outpatient rehabilitation – as simple as it sounds, it was just amazing. It was a lifeline.

**So I decided to start there. I contacted Kelly McCoy from the Foundation staff and she sent me some pamphlets and “know the symptoms of GBS” posters, and off I went.**

I was a little nervous about just showing up at the medical facilities without notice so I tried to call and schedule meetings, with little success. In fact, I feel it wasted several weeks. I decided to just march in, and apologize later. It turns out many of them said “What else do you have, sure we’ll put them up!” All of the nurses and doctors were very receptive. **Since April of this year, I have marched into 37 different hospital emergency rooms!**

For the hospitals in outlying towns on the western slope and southern part of the plain, I sent them materials with a handwritten note. Plus, I also make sure that wherever I go in life, I try to talk about GBS, CIDP and the Foundation to whomever will listen. I sat next to a physical therapist on the plane during my recent trip from Denver, and he was very interested in learning more! I love what I am doing for GBS|CIDP patients and the Foundation. I dedicate the time I can, but truthfully I feel there is such a need it could really be full time work! Recently I was asked by the Foundation if I would like to visit the local Grifols plasma center and meet the donors too. I said yes and visited the center last week. I thanked the donors – some were military, some were volunteers. They all were very appreciative to speak with me and learn about the conditions of GBS and CIDP. I made sure to tell them “I wouldn’t be here if not for you.”

If you are interested in volunteer opportunities, educational materials, or have other questions for the GBS|CIDP Foundation please contact [info@gbs-cidp.org](mailto:info@gbs-cidp.org).



## GBS CIDP Foundation International Earns Coveted 4-Star Rating from Charity Navigator

For the 7th consecutive time, the GBS|CIDP Foundation International has earned 4-Star Rating from Charity Navigator, Conshohocken, PA (December 4, 2018) – GBS|CIDP Foundation International's strong financial health and commitment to accountability and transparency have earned it a 4-star rating from Charity Navigator, America's largest independent charity evaluator. This is the 7th consecutive time that GBS|CIDP Foundation International has earned this top distinction.

## GBS|CIDP Faces in Different Places

### 2019 IgNS CONFERENCE, LAS VEGAS, NV

The GBS|CIDP Foundation International is committed to spreading awareness of GBS, CIDP and variants, to healthcare professionals that provide service & support to our community. In October of 2019, Kelly McCoy and Lori Basiege connected with Ig Nurses at the IgNS Association annual meeting! #gbscidp #IgNSnurses #motivationmonday



### 2019 AMERICAN ACADEMY OF NEUROMUSCULAR AND ELECTRODIAGNOSTIC MEDICINE (AANEM), AUSTIN, TX

Lisa Butler and Maureen Neville spread awareness about the GBS|CIDP Foundation International's research grant program and Centers of Excellence, to the neuromuscular electro-diagnostic medical community at AANEM conference 2019, in Austin.



### GBS|CIDP SELECTED FOR NORD SUMMIT POSTER SESSION

Due to our successful efforts in the area of CIDP advocacy in 2019, not to mention the support and enthusiasm of our volunteers, GBS|CIDP Foundation International was selected to participate in the expansive poster session at National Organization for Rare Disease (NORD) summit 2019. Our poster entitled "Building Community Through Newly Launched Advocacy Program" was co-authored by Advocacy Manager Chelsey Fix, Director of Marketing and Communications Maureen Neville, and Executive Director, Lisa Butler. The poster offered highlights of our journey to, currently, 19 official congressional signatures on proposed bill HR2905. Learn more at: [gb-cidp/advocacy](http://gb-cidp/advocacy).



## INTRODUCING GBS|CIDP FOUNDATION'S NEW CFO, LAURA BLAIR

Please join us in welcoming Laura Blair as the new CFO of GBS|CIDP Foundation International. Laura comes to us following a 15-year career as Finance Director for Habitat for Humanity of Bucks County. She has a demonstrated history of working in non-profit organization management and offers a wide breadth of expertise in all aspects of finance and human resource leadership. Laura is a CPA and has a Master of Public Administration (MPA) focused in Nonprofit Management from New York University. She lives in Ambler, PA with her husband and 2 children. Her favorite way to spend the day is a trip to NYC with her family to see a Broadway play (*but not a musical*)!



# Year-End Advocacy Update

By Chelsey Fix

2019 has been a whirlwind of advocacy activity! We launched a new toolkit, a new Advocacy Action Center, reintroduced a Medicare IVIG Access Enhancement Bill, and moved our legislative priorities forward. Kudos to all of your hard work!



## 2019 ACHIEVEMENTS IN ADVOCACY ON THE HILL

### Historic Community Involvement in Advocacy!

In 2019, 52 advocates from the GBS|CIDP community traveled to Capitol Hill, along with staff, to advocate on important issues to the community. We also had 153 advocates write letters to their Representatives and Senators during GBS|CIDP Awareness Month to raise awareness of the issues facing the community and more than 110 advocates use the Advocacy Action Center to write letters to their Representative in Congress, specifically asking them **to co-sponsor the HR2905**.

### HR 2905 – The Medicare IVIG Access Enhancement Act

Thanks to the many letters sent to Members of Congress this year, we can boast 16 cosponsors for this important bill that takes the steps to create coverage in Medicare Part B for home infusion of IVIG for CIDP and MMN patients. Here is the current list of cosponsors:

- Rep. Blumenauer, Earl [D-OR-3]
- Rep. Holding, George [R-NC-1]
- Rep. Butterfield, G. K. [D-NC-1]
- Rep. Kelly, Robin L. [D-IL-2]
- Rep. Garamendi, John [D-CA-3]
- Rep. Sewell, Terri A. [D-AL-7]
- Rep. Marchant, Kenny [R-TX-24]
- Rep. Davis, Susan A. [D-CA-53]
- Rep. Kelly, Mike [R-PA-16]
- Rep. Luria, Elaine G. [D-VA-2]
- Rep. Evans, Dwight [D-PA-3]
- Rep. Matsui, Doris O. [D-CA-6]
- Rep. Smith, Adrian [R-NE-3]
- Rep. Price, David E. [D-NC-4]
- Rep. Kind, Ron [D-WI-3]
- Rep. Susan Brooks [R-IN-5]
- Rep. W. Lacy Clay [D-MO-1]
- Rep. Brian Fitzpatrick [R-PA-1]
- Rep. Julia Brownley [D-CA-26]

If your Congressperson's name is on this list, make sure you thank them with an email, tweet, or phone call. If they are not on this list, send them a letter by visiting our Advocacy Action Center (or emailing Chelsey Fix [Chelsey.fix@pbs-cidp.org](mailto:Chelsey.fix@pbs-cidp.org) for other creative ways to get in touch with their office). We will continue to work with key Senators (meaning ones that serve on the Finance Committee) in the hopes of adding a Senate Companion bill.

### State Advocacy off the Hill

So far, we have 5 (and counting) volunteers working with their state governments to make changes that will improve life for the GBS|CIDP community. Advocates in Louisiana, Indiana, North Carolina, Arizona, and South Carolina Are coming together to make their voices heard and be a part of our statewide advocacy network. Coming in 2020 – more state government advocates and possibly state-level Hill Days!

### Department of Defense Research Grant Fund Includes GBS on list for 3rd Year in Row

Advocacy efforts of the GBS|CIDP Foundation have influenced the US Senate to name Guillain-Barré syndrome as an eligible condition on the Department of Defense peer-review medical research panel. The addition allows researchers access to the more than three billion dollars set aside for the program. The Peer Reviewed Medical Research Program, established in 1999, has supported research across the full range of science and medicine, with an underlying goal of enhancing the health and well-being of military service members, veterans, retirees, and their family members.

### Foundation GMAB member Kazim Sheikh, MD, awarded DOD grant for study in Immune Neuropathy

#### Principal Investigator

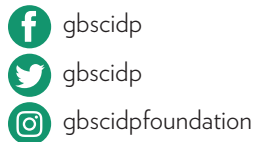
Kazim A. Sheikh, MD of Texas University, Health Science Center at Houston was **awarded** \$1,699,402.00 through the DOD Grant fund in (FY) 2017.

#### His study topic is:

Defining Final Common Pathogenetic Pathway of Endoneurial Inflammation and Nerve Injury in Models of Immune Neuropathy.



CHANGE SERVICE REQUESTED



SUPPORT EDUCATION RESEARCH ADVOCACY SUPPORT EDUCATION RESEARCH ADVOCACY



## SHOW US YOUR GBS|CIDP WRISTBANDS!

This year the foundation has given out **over 6,000** GBS|CIDP Foundation awareness wristbands. If you've been keeping up with all of our travels—we're sure that's no surprise! But we're curious, where have they ended up? We would like to challenge you to **Show Us Your Wristbands!** Snap a photo with you showing your wristband and share it with us! Tag us on social media, email it to [maureen.neville@gbs-cidp.org](mailto:maureen.neville@gbs-cidp.org). We will be sharing our favorites on all of our channels so be on the lookout! #gbscidpwristbands

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

### DIAGNOSED WITH MMN?

Brenda Perales  
[brendajp62@icloud.com](mailto:brendajp62@icloud.com)

### MILLER FISHER VARIANT GROUP

Please call us for contact with others.

### CHILDREN WITH GBS

Lisa Butler, 610-667-0131  
GBS|CIDP Foundation International  
[lisa.butler@gbs-cidp.org](mailto:lisa.butler@gbs-cidp.org)  
Son, Stuart, had GBS at 5 1/2 years old

### CHILDREN WITH CIDP

For children diagnosed with CIDP  
contact Holly Cannon whose  
daughter, Hailey, has CIDP.  
[holly.cannon@gbs-cidp.org](mailto:holly.cannon@gbs-cidp.org)

### LOOKING FOR A 20-SOMETHING CONTACT?

Kyle Van Mouwerik  
[kyle.vanmouwerik@gbs-cidp.org](mailto: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](mailto: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, local level,  
contact Advocacy Manager Chelsey Fix,  
[Chelsey.fix@gbs-cidp.org](mailto:Chelsey.fix@gbs-cidp.org) to sign up.

### 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.**