

# 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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## "Ask the Experts" Videocast continues through 2021

Our 2021 Ask the Expert Videocast Series kicked off on February 25th with Dr. Peter Donofrio, Chairman of the GBS|CIDP Foundation Global Medical Advisory Board, and Executive Director, Lisa Butler, with a discussion on "Vaccine FAQs from the GBS|CIDP Community." Our panelist answered questions previously provided from members like "Can you explain the differences in the vaccines that are currently available?" and "I have had GBS, can I still need the vaccine?" — plus more. A link to the episode, and all past episodes, can be found on [gbs-cidp.org/asktheexpertsvideocast](https://gbs-cidp.org/asktheexpertsvideocast). Next episode to air March 25th — Movement & Mindfulness for GBS & CIDP.



[Ask the Experts on page 3](#) ▶

## A Nurse & GBS Patient form lasting bond during COVID-19

*Be You, Bravely*

*By a Warrior Nurse named MeiLani*

Last night my brother-in-law asked if we got hazard pay. I said, "No." I then thought about what we do. We go into COVID-19 rooms, with isolation gear, hoping the vent doesn't get disconnected, maintaining isolation techniques so we don't get exposed to COVID-19. We see death a lot.

On my last shift we had 2 people die within minutes. I was so blessed to be able to do the "3 Wishes Program" for both of these families. One family wanted to



GBS patient, Mike Moretti

[A Nurse continued on page 4](#) ▶

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



*We truly miss you and look forward to seeing you soon.*

## Dear Friends,

With three vaccines in circulation, there is real hope on the horizon. When I reflect over the past year, I am continually drawn back to the parallel experience of our community and the past year with COVID19.

As a community, we know firsthand the cycle of a “life-pandemic.” A sudden and unexpected ravaging of the entire “family” system, as well as the patients themselves. We know all too well how it feels to develop strange and debilitating symptoms, rapidly, or over time. We experience the entire range of emotions from the first stage of denial and self-doubt to fear, and eventually, panic when a diagnosis is finally determined. *What in the world is Guillain-Barre Syndrome?* And then, the isolation sets in. The long, long hard work of waiting and the patience with recovery, often with very limited social interaction. We experience moments of stability and movement which offers some hope, *but what will that future look like?*

We have lived a pandemic and I wonder if we are not meant to be leaders in this current world-wide pandemic? Can we draw on our experience, strength and courage to help lead those in our circles through this? I am suggesting that just maybe, we can. I know it’s a stretch but perhaps we can encourage others to continue to be resilient right now. People will say that we shouldn’t let one moment define us, but maybe we should. And as patients and families, let’s allow those dark moments-turned to strength, courage and resolve, absolutely define as the leaders in THIS pandemic that we know we can be.

I often hear people in the current pandemic world ask, “when will we return to normal?” I think our resilience has led us somewhere new. Perhaps to a new normal? But from my own family’s experiences with GBS and from meeting so many of you, I know that if there is anyone who knows how to bravely create a new and wonderful way of being, it is you!

We know we are stronger together and I hope that you have joined us to be together with other champions like you. Please join us in coffee chats, chapter meetings, Ask the Experts, conferences, Walks, all available to you from the comfort of your own COVID-safe respite. And if we are providing you that space to convene, please let us know.

### See yourself as a true pandemic-experienced LEADER!

We truly miss you and look forward to seeing you soon.

Gratefully,

*Lisa*

Lisa Butler, *Executive Director*

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GBS|CIDP FOUNDATION INTERNATIONAL

## COVID-19 VACCINE & GBS

### A Q & A WITH DR. PETER DONOFRIO

(from Ask the Experts, Episode 9)

#### If I got GBS from the flu, should I get the vaccine?

There is no reason to think that the COVID-19 vaccine would make you more prone to have a reoccurrence of GBS. So the answer is yes.

#### If GBS is active or recent, should I get the vaccine?

Yes, you should get the vaccine. If you have GBS recovering the last thing you would want is a natural infection like COVID-19. As you recover you would not want an infection of any type that could disrupt the recovery.

#### If I got GBS from a vaccine, should I get the COVID-19 vaccine?

If you feel that you developed GBS as a result of the COVID-19 vaccine, first see your primary care doctor who will refer you to a neurologist that can guide you to an accurate diagnosis and appropriate next steps. To date of this interview (2/28/21) there has been not a single report of proven GBS after the COVID-19 vaccine.

#### If I am on immune suppressant, should I receive the vaccine?

Yes, it may not be quite as effective, since your immune system is pharmacologically impaired, but it is still better than no vaccination against COVID-19 at all.



## FOUNDATION GLOBAL MEDICAL ADVISORY BOARD STATEMENT ON COVID VACCINES FOR CIDP AND MMN

*Published on January 21, 2021*

No instances of CIDP or MMN were seen during clinical trials of the two currently available vaccines. Neither the Centers for Disease Control and Prevention (CDC) nor the Food and Drug Administration (FDA) recommends against administration of the Covid-19 vaccine in patients with CIDP or MMN. One must keep in mind that the Covid Vaccine has only been used for 4-6 weeks (as of the publication) outside of the clinical trials and it is too early to offer scientific statements on long-term adverse effects of the vaccine in CIDP or MMN. Even though there is no long term data yet, there is no scientific reason to think that the vaccine will cause problems in those patients with CIDP or MMN. It is suggested to avoid vaccination in the week following IVIg treatment, as this may potentially lessen the effect of the vaccination.

*The J&J vaccine was approved after this article was written but there is no anticipated changes to this statement.*



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](https://gbs-cidp.org) or by emailing [info@gbs-cidp.org](mailto:info@gbs-cidp.org).

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A Nurse continued from page 1

hear his heart murmur so I took our doppler and we could hear it loud and clear. I was able to print the 12 EKG strips and put them in frames for the family, put lights up in the room and have a diffuser with orange/lemon smells. I want to make their last day/minutes with their loved one the most special ever because grief is hard and long (I've experienced heavy grief so I always want to do everything with family.) We support families who can't be at the bedside. We are overworked, stressed with heavy assignments, and are mentally and physically zapped. No, we don't get hazard pay.

A year now into the pandemic and we are now experts in the field of donning on and donning off PPE.

**We are more than just a team, we are family.** We care about each other. Two days ago, I saw a MICU doctor I didn't know, in a room with only a N95. The patient was coughing and had high flow nasal cannula. I knocked on the ICU sliding glass door and told him to come out and please put on a U-shield or goggles with his N95 because of a new policy with patient's on high flow. We take care of each other. New policies change. We are flexible. My leadership teacher Clinton Swaine from Frontier Trainings taught me, **"Adapt. What can I manifest?"** This is how I live my life! Adapting to the ever changing policies with Covid-19 and what can I manifest to make life great and loving for one another?

Last year when my nurse manager Barbara Anderson asked for volunteers to work in the COVID unit, I thought to myself, "Are you crazy, who would ever volunteer?" My nurse manager said 12 RNs did out of 120. I

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**But in the war zone was "living/breathing teamwork, generosity of knowledge, caring, cheering when a patient made it, yelling when a nurse went in a room with no protection to prevent from extubating themselves."**

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said, "I bet none of them had children." She said Rolando did. I immediately called him on the phone to ask why he would risk his life when he had kids. He told me it was the right thing to do. I was so inspired by him. It was that evening that I sat down with my husband and 2 teens (Conlan, 16 and Mieko, 13) to see what they thought. They said in unison, "Go for it Mom."

So there I was making out my will, preparing to die, nauseated, scared, and in scrubs going to work in the COVID unit. It is not what you think. Well, yes, it was and is a war zone. But in the war zone was "living/breathing teamwork, generosity of knowledge, caring cheering when a patient made it, yelling when a nurse went in a room with no protection to prevent from extubating themselves." **I was witnessing and experiencing a type of nursing like no other.** Everyone trained me. I loved working in MICU. We were doing everything together as a team. The more we learned about COVID-19, the more we became the Warriors against it. My first COVID-19 patient was extubated and then reintubated. He was paralyzed by a car accident, age 80. I remember turning the Zoom on for family on the east coast to see him. I zoomed twice that day and twice the next day. I then came to find out the patient died. I called his family to express my sympathies. The son said I put a smile

on his face with my call. He said he will never forget the Zoom calls. I love my patients and families so much. I love my colleagues so much.

I see miracles too. One is patient Mike Morretti (He gave permission to use his real name and his story). He came in with a rare form of Guillain-Barre in April 2020. Paralyzed for months. He was on the verge of giving up and felt doomed for Hospice. I was there the day his wife, Peggy on speaker asked Dr. Vespa, "What are his chances?" Dr. Vespa said, "50% he will walk and live an independent life." Mike looked at me and mouthed over this trach, "I will give it 3 months." That was 7 months ago. He was able to come off the vent and make it to rehab. How blessed was I when his wife Peggy called me and said, "Can you visit Mike?" She was going to be out of town but she wanted him to have company. I went to the rehab twice. From someone vented and giving up to someone talking, sharing conversation, he cared about my life and what I was up to, and I was feeding him my homemade lemon bars, doing range of motion and cutting his nails and giving him a manicure. I've visited him in outpatient rehab, too. I gave him my egg cartons mattress when his wife said he couldn't sleep. He is now walking with a walker. When he was in the ICU there was a picture of him in an apron making pizza. I bet him in ICU that he owes



me a homemade pizza. You know what, that day is coming really soon.

I am so happy that Mike is alive to enjoy his wife and 2 college children. I was there when his children visited. He was not in a good place then. I wanted to be the nurse to be with those kids, to read their dad's lips, to be able to explain all the tubes and let them know their Dad is doing the very best he can at this moment. I am happy Mike is doing so well. It was incredible to work with his wife Peggy, a true patient advocate. Always about what more can we do for Mike's recovery. **It's all about building a championship team.** We UCLA RNs are all about being that kind of team!

My unit is Tier 3. I thought there was no way COVID would ever make it up to us. Right? But it did. In December, and with a vengeance. I was able to take the skills I learned from the COVID unit and teach my unit. We still are caring for COVID patients. Many nurses are scared. It is my ethical duty to educate, support, and be there for my 6 ICU colleagues. We have awesome administration and many resources behind us. I feel safe at work. We are so lucky we have enough PPE right now. I am blessed to be a nurse and just celebrated my 25 years at UCLA. I make posters for the COVID units to keep them inspired. I don't know who really sees them but I want them to know they are loved and supported. My favorite saying is now, **"Be You, Bravely."**



## RARE DISEASE DAY FEBRUARY 28, 2021

In 2020, the world's attention turned to public health matters in light of the COVID-19 pandemic. However, there are still millions in the United States and around the globe living with rare diseases and accompanying life-altering issues that are largely unknown to the general public. On **Rare Disease Day, February 28, 2021**, the Foundation encouraged our community to help shine a light on the challenges faced by GBS|CIDP and variants of the condition such as MMN patients and their families around the globe.

This year, the GBS|CIDP Foundation honored those living with a rare disease by supporting our global community in new and meaningful ways

**"Our mission is to ensure no one, no matter where they reside, faces the challenges of Guillain-Barre Syndrome or Chronic Inflammatory Demyelinating Polyneuropathy, alone."**

—Lisa Butler, Executive Director

### GLOBAL ACTIVITIES INCLUDED:

- First "Spanish Language" Chapter Meeting
- Launch of multi-lingual GBS|CIDP Overview Booklets
- Launch of GBS|CIDP Foundation International (EU) Web Portal, [eu.gbs-cidp.org](http://eu.gbs-cidp.org)



*(Site is translatable into following languages: Czech, Dutch, French, German, Hungarian, Italian, Portuguese, Spanish, Swedish.)*

**For more information on our global efforts listed above please contact Associate Director of Engagement [Kelly.McCoy@gbs-cidp.org](mailto:Kelly.McCoy@gbs-cidp.org).**

## Foundation Board approves funding for largest multi-country CIDP research ever

Chronic inflammatory demyelinating polyneuropathy (CIDP) is such a remarkably heterogeneous disorder — one with diverse presentations, a highly variable disease course, and differing, often unpredictable treatment responses. Neurologist-researchers around the world have established research registries in recent years to prospectively study patients over time. However, according to Foundation GMAB member Dr. Jeffery Allen, “they all collect slightly different sets of data and have slightly different inclusion criteria, and they don’t talk with each other. And even in large countries, the registries don’t include sufficient numbers of patients to address some of the most pressing questions. To really understand the rare immune-mediated disease, we need a worldwide database, so that existing databases can talk with each other, and so that countries that don’t have registries, have a place to [register] their patients,” he said.

This vision, for an international collaboration, is now nearing a reality, with the development of an international registry called the Inflammatory Neuropathy Consortium Base (INCbase). INCbase is an international registry for CIDP patients led by an international collaboration of CIDP experts. INCbase provides a state of the art modular research database that members may use to collect prospective standardized clinical data and, optionally, biomaterials. This infrastructure will allow researchers to perform global and unprecedented collaborative studies. INCbase has a broad scope as evidenced by the currently defined objectives to include:

- To develop a prognostic model to predict short and long-term treatment response in CIDP patients at the start of treatment. To discover clinical, electrophysiological and biological biomarkers for diagnosis and disease activity
- To describe variation in clinical and electrophysiological characteristics of CIDP to define the spectrum and boundaries of CIDP
- To describe short and long-term outcomes at impairment, disability and quality of life levels of (subgroups of) CIDP patients
- To describe physician and patient perspectives on and satisfaction with different treatments that may be used for CIDP, including plasma-exchange and subcutaneous immunoglobulin
- To deepen knowledge on CIDP pathophysiology, including investigating immunological pathways underlying CIDP

The Foundation is proud to support this promising research which involves many of the experts who serve on our Global Medical Advisory Board. For more information and participating sites worldwide see: [www.incbase.org](http://www.incbase.org).

# CIDP CLINICAL TRIAL UPDATE

## Efgartigimod for the Treatment of CIDP

By Jeffrey A Allen, MD

GBS|CIDP Foundation International Board of Directors

GBS|CIDP Foundation International Global Medical Advisory Board



**Chronic inflammatory demyelinating polyneuropathy** Chronic inflammatory demyelinating polyneuropathy (CIDP) is an autoimmune disease that targets peripheral nerves. Standard immune based CIDP treatments include intravenous immune globulin (IVIG), subcutaneous immune globulin (SCIG), and corticosteroids. There is a need to improve CIDP treatments, both by maximizing the currently available therapies and by exploring new and novel ways to combat the disease. One new approach to CIDP treatment that is currently in clinical trials is a class of drugs called FcRn inhibitors.

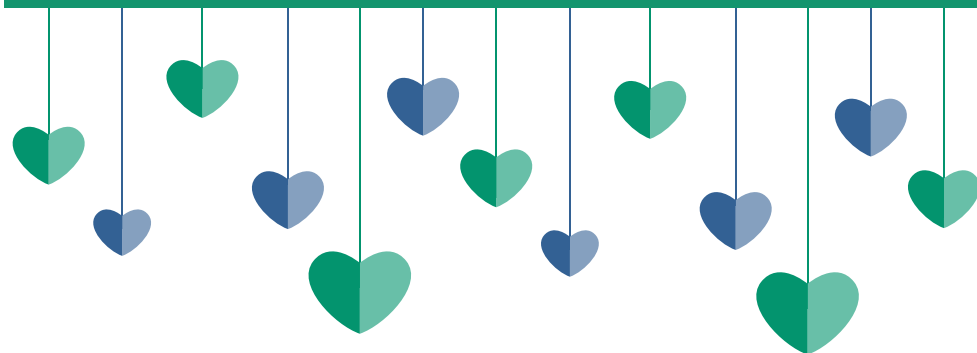
FcRn refers to a receptor that sits on cells within the body that play an important role in regulating immune responses. The weakness and numbness that patients with CIDP experience is thought at least in part to be caused by antibodies that attack peripheral nerves. The FcRn receptor acts like an antibody gateway: some types of antibodies that bind to the receptor are allowed to remain in the circulation while some antibodies that do not bind the receptor are destroyed. By blocking or inhibiting the FcRn receptor antibodies are funneled into the “destruction” pathway, and by eliminating these disease causing antibodies the ongoing immune attack on nerves may be prevented.

One FcRn inhibitor that is currently in a CIDP clinical trial is called Efgartigimod, which is manufactured by the biotechnology company Argenx. Clinical trials are research studies that are performed in people in order to understand if an investigational intervention is safe and effective. There are different stages of clinical trials. Efgartigimod is currently being studied in a phase II and phase III clinical trial. Whereas a phase I trial primarily focuses on drug safety, a phase II trial tries to understand if the investigational drug shows

some signs that it works while also keeping a very close watch on safety. If a phase II trial meets its objectives then the drug will typically move into a phase III trial that aims to more confidently understand if the investigational drug is effective. The Efgartigimod trial will seamlessly evolve from a phase II trial to a phase III trial if no safety issues are observed and if there are signals of efficacy early in the trial.

The Efgartigimod CIDP study (also called the ADHERE study) began enrolling patients in mid 2020 and aims to enroll a total of 130 participants from the United States, Europe, the Middle-East and Asia. Eligible participants will be blindly randomized to either the study drug Efgartigimod or to a placebo compound. Placebo interventions form a basis by which to compare the effects of the investigational drug and are commonly used in clinical trials. Blind randomization means that patients will randomly assigned Efgartigimod or the placebo, and that neither the investigator nor the study participant knows which one they received. Efgartigimod is administered as a subcutaneous injection (an injection into the fat under the skin, often in the abdominal area). Each subcutaneous injection takes about 1 to 2 minutes to administer. Study participants will be treated with subcutaneous Efgartigimod (or subcutaneous placebo) once per week for a total of 48 weeks. Participants in the study are monitored very closely by in person and remote (virtual) study visits. If a patient worsens during the study period then they may be removed from the study in order to receive CIDP standard treatment (usually IVIG) or may be eligible to receive non-blinded Efgartigimod. This clinical trial is anticipated to enroll participants until 2022, and have study results available in 2023. For a detailed list of participant eligibility criteria and participating study locations visit <https://clinicaltrials.gov/ct2/show/NCT04281472>.





## A SALUTE TO THE GBS|CIDP COMMUNITY, ALL THANKUARY (FEBRUARY) LONG!

February, we were excited to share a social shout out to our donors, volunteers, plasma donors, medical pros, and all those who help to support this community! Check out our social posts on all of our social channels #GBSCIDPthankuary, learn more about the power of gratitude & community and join us in celebrating the very special month of Thankuary!



Fundraiser and Walk Chair David Ahrens, Chicago



Plasma donor, Victoria Piccone on right



## 2021 Regional Conference Going Virtual May 15

As the safety and well-being of our community is a top priority, we will be pivoting to a Virtual format for our 2021 Regional Conferences this May 15. The good news? All can attend, no matter where you reside! We will hear from local medical and wellness professionals, and topics of discussion will include: treatment updates, practical daily advice for staying well, vaccine updates and information, current clinical trials, and much, much more. Plus, there will be breakout sessions for those living with GBS, CIDP, or MMN. Registration is not yet open, but please check back at our event calendar in upcoming weeks. We hope to “see” you there!



## PFIZER GETS US FDA APPROVAL FOR PANZYGA TO TREAT CIDP

Pfizer announced that the US Food and Drug Administration (FDA) has approved PANZYGA (Immune Globulin Intravenous) to treat adult patients with CIDP. PANZYGA is the only intravenous immunoglobulin (IVIg) with two FDA-approved maintenance dosing options for CIDP. New FDA approval for IVIg means more options for patients to choose.

PANZYGA was approved by the US FDA in 2018 for the treatment of primary immunodeficiency (PI) in patients two years of age and older and chronic immune thrombocytopenia (cITP) in adults.





As we kicked off 2021 full of hope for the future, we also welcomed a new Congress to Capitol Hill. The 117th Congress first convened on January 3, 2021, and now that they are settled into their role, we believe it is time for the GBS|CIDP and variants community to reach out and introduce our Representatives and Senators to our community and tell them about our priorities! It is so important that the offices of your Members of Congress hear often from you and others from the community so that they understand how important our issues are. If you don't tell them about how they can help improve life for those living with GBS|CIDP or variants, who will?

Now, your Representative and Senators might not have changed, but you can — and should — still reach out! A friendly reminder of the GBS|CIDP community and our priorities is always a good idea.

On the other hand, some Members of Congress might be new, or might have new roles — such as Committee Assignments — and they are eager to hear about how their new position can benefit their constituents — AKA you! If you want to find out if your Members serve on a Committee important to us, you can find the Senate Committee Assignments here: [https://www.senate.gov/general/committee\\_assignments/assignments.htm](https://www.senate.gov/general/committee_assignments/assignments.htm) and the House Committee Assignments here: <https://www.house.gov/committees>.

**PRO TIP:** we often work closest with members of the **Defense and LHHS Subcommittee** and the **Labor, Health and Human Services, and Education, and Related Agencies Subcommittee** of the Senate Appropriations Committee. On the House side, we work with Members of the **Ways and Means Committee** and the **Energy and Commerce Committee**.

So whether you are introducing yourself for the first time or sending a friendly reminder, please send a letter to your Representative and Senators by filling out the NEW version of our Advocacy Action Center. <https://www.gbs-cidp.org/advocacy/advocacy-action-center/>

Once you complete this form, your letter will be emailed to the staff members of your Representative or Senators. If you have any questions, don't hesitate to reach out to [Chelsey.Fix@gbs-cidp.org](mailto:Chelsey.Fix@gbs-cidp.org).

# WELCOME, New Congress!

*If you don't tell Members of Congress about how they can help improve life for those living with GBS|CIDP or variants, who will?*

## VOLUNTEER SPOTLIGHT

## Ray Lopez

*Boca Raton, FL*

The word pivot has been used constantly by various organizations around the world recently, and it is thanks to our amazing volunteers that we were able to pivot, too! One of the volunteers who has helped us continue to support our patient community is Ray Lopez, our Boca Raton liaison. After ten months of recovery from GBS in 1988, Ray knew that the best way for him to help patients like him was to become a local liaison. Throughout his years at the Foundation, Ray has hosted various chapter meetings, educational panels about GBS, and also volunteers at his local hospital. Ray brings his positive outlook on life and enthusiasm for the community to every chapter meeting he hosts. At each meeting, he invites various members of the GBS|CIDP Foundation International community, including friends who he has met Symposia as well as recently diagnosed patients to learn more about various topics related to their diagnosis. COVID-19 has left many feeling alone, and it is thanks to volunteers like Ray that our members can continue to receive a sense of community during this isolating time. Ray's ability to be flexible and his passion for our community has shone bright this year, and we as a Foundation are extremely grateful for the work that he does for our patients and their families. **Thank you so very much Ray!**

*Ray's ability to be flexible and his passion for our community has shown bright this year, and we as a Foundation are extremely grateful for the work that he does for our patients and their families.*



## CIDP Self Infusion Panel Discussion Now Available On-Demand

Want to learn more about a self-infused CIDP treatment option? Watch "Understanding a Self-Infused CIDP Therapy Option" and learn how CIDP patients and their caregivers can understand the differences and advantages of a self-infused Ig treatment that allows greater freedom and flexibility. Program is now available On-Demand at: <https://www.gbs-cidp.org/cidp/treatment-options-for-cidp/> (Registration is required to view program).

# Mindfulness for Neuropathy

By Dr. Julie Rowin, A publication from Dr. Julie Rowin's Blog Post found at: [julierowinmd.com](http://julierowinmd.com)

Neuropathy is a disruption in the communication between the nerves in the extremities and the brain, leading to abnormal sensations or pain and difficulty with muscle control or balance. A mindfulness practice offers benefits beyond what is conventionally offered as treatment for neuropathy.

## HERE'S WHY:

- ▶ Mindfulness is the state of active, open attention to the present.
- ▶ It is a state of observing one's thoughts, feelings and surroundings without judging them as good or bad.

## WHY PRACTICE MINDFULNESS?

Twelve weeks of mindfulness meditation showed these benefits in clinical trials:<sup>(1, 2)</sup>

- 1 Reduction in chronic pain
- 2 Improved mood (anxiety and depression)
- 3 Reduced need for pain medications
- 4 Decrease in perceived stress
- 5 Improved daily function
- 6 Improved perceived quality of life
- 7 Increased brain mass and improved cognition and memory<sup>(3, 4)</sup>

## HOW TO PRACTICE MINDFULNESS?

There are many ways to practice mindfulness:

**In stillness:** breathing exercises, prayer, chanting, meditation, mindful journaling or

**In movement:** yoga, tai chi, nature walking meditation

## WHAT IS YOUR MIND DOING?

- ▶ According to the National Science Foundation, the average person has about 12,000 to 60,000 thoughts per day. Of those, 80% were negative, and 95% were exactly the same repetitive thoughts as the day before.
- ▶ 85% of what we worry about never happens

It is common to experience a fear of being alone with one's thoughts, especially as a beginner to mindfulness practice.

### Try this:

- ▶ Sit comfortably on a chair with your back straight and your feet on the floor.
- ▶ Set the timer for 2 minutes
- ▶ Focus your attention on your breath. Don't try to change it. When your mind wanders away from the breath, gently bring it back to focus on the breath.
- ▶ Witness whatever arises without reaction. The practice is not trying to get rid of the thoughts, feelings or sensations that arise, but to form the correct relationship to them. By being present and aware to the thoughts, feelings and sensations that arise, but not reacting to them, i.e. not putting your energy into them, the brain begins to rewire naturally.

- ▶ Accept what is. Sometimes a pain or discomfort will draw your attention away from the breath. Acknowledge this.
- ▶ Remember that mindfulness meditation is a lifetime practice. You will gain benefits from the process itself. It is not about reaching some goal or achieving something.

## MAKING THE TIME TO MEDITATE IS ANOTHER COMMON OBSTACLE.

Just 10 minutes of mindfulness meditation per day has been shown to:

- ▶ Increase brain grey matter and improve cognitive functioning
- ▶ Improve anxiety, depression and pain
- ▶ decrease emotional reactivity
- ▶ improve immune function
- ▶ improve memory and attention

Choose a mindfulness-based practice that is right for you and do it at least 10 minutes every day. You **CAN** do it. It's all in the practice.

### REFERENCES CAN BE FOUND AT:

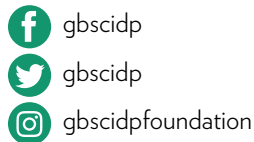
<https://www.julierowinmd.com/post/7-reasons-to-practice-mindfulness-for-neuropathy>



*“Mindful meditation is not about reaching some mystical state. It is actually not about doing anything. It is about realizing what your mind is already doing and dropping it.”*



CHANGE SERVICE REQUESTED



SUPPORT EDUCATION RESEARCH ADVOCACY SUPPORT EDUCATION RESEARCH ADVOCACY

## DON'T MISS 2021 CALENDAR OF EVENTS

Don't miss upcoming opportunities for education, support, and local community building. Our event calendar includes both online and offline opportunities. Events include local patient meetings, regional conferences, coffee chats, symposia...and more. Check out our Calendar at <https://www.gbs-cidp.org/events-calendar/>.



## 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 to connect 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). For more information on our youth, teen, and young adult (YTA) programming contact Meg.Mains@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.Mains@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](mailto: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.**