

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.



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150+ Advocacy Champions join forces for GBS|CIDP Awareness Month

Did you know that Medicare part B can restrict your location of care for your IVIG treatments? Or that each year, your voice can influence Congress on important issues such as funding the National Institutes of Health's research into GBS and CIDP?

This May, GBS|CIDP Awareness Month, the Foundation encouraged patients, caregivers, friends and family to learn more about the Foundation's legislative initiatives – which include a bill to create a Medicare Part B Home Infusion Demonstration Project, an “ask” for GBS to be included on the Department of Defense PRMRP list, and increased funding for NIH and CDC. Patients and caregivers were asked to be their own best advocate by joining a letter writing campaign to Congress. And on May 23, GBS|CIDP Hill Day, 32 advocates from all over the US, joined us on Capitol Hill and met with 52 Congressional Offices to ask for support of the Foundation's legislative agenda.

We are pleased to report that within three weeks over 150 letters arrived, representing 37 states. During that very same week, Congressman Blumenauer and Congressman Holding introduced the Medicare Enhancement Act bill that would create the demonstration project in Medicare Part B, allowing CIDP and MMN patients to receive IVIG infusions at home through their Medicare

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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.



We celebrate the strength of familiar voices and the power of community with an unstoppable spirit.

Dear Friends,

This spring I was reminded once again of the power of just a few kind words of support. My dad, 86 years young, had suddenly come down with life-threatening pneumonia which lead to heart-failure. It's been a bit rough for him these past few years, as aging has not been the easiest of transitions, but this new situation was definitely unexpected and very scary for our entire family. I thought of our GBS|CIDP community and how each of you has, at one time or another, walked in these very same shoes of confusion and uncertainty; not knowing what the next day, or even the next hour might bring. I reached out to my niece, who is a Physician's Assistant in the medical field, to consult on all of the new information that was flooding over us – new doctors, new tests, varying opinions and all the while my dad looking so lost and vulnerable, primarily unresponsive much of the time.

But then there was hope. My niece gave me clarity and calmness – she explained the medical terms and what we might expect. She became our rock, our lifeline, as we navigated this complicated new terrain. I thanked her immensely for helping me and she replied, “no worries, that’s why I’m here.”

It struck me that our conversation seemed very familiar. Then I realized that, in fact, it was a conversation that I have not only had many times before with the patients and families we serve, but that I also overhear at the Foundation almost every single day. It made me smile. And I was thankful for the reminder of the important work of the Foundation and how we are a lifeline, and how we, too, offer clarity and calmness in those very dark hours. I hope that you have connected with the many faces, events, and educational materials that Foundation has to offer. In this issue we introduce new faces and new resources. As my family celebrates the recovery of my dad, the foundation community celebrates the strength of familiar voices and the power of community with an unstoppable spirit. I hope you know that providing this support, knowledge and inspiration is our pleasure, and helping you is “why we are here.”

Gratefully,

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 or by emailing info@gbs-cidp.org.

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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.

150+ Advocacy Champions continued from page 1

benefit. The bill was given the number of **H.R. 2905**. A full transcript from the introduction to the House of Representatives can be found at: <https://www.gbs-cidp.org/congress-recognizes-the-month-of-may-as-gbs-cidp-awareness-month/>

We'd like to offer our sincere gratitude to those who participated in the Awareness Month Advocacy campaign this May! We assure you that your voice will be heard and our efforts will continue as our mission gains strength each and every day. If you would like to get involved and be your own best advocate, find out more about our legislative agenda and how to get involved at <https://www.gbs-cidp.org/advocacy/>, or contact Advocacy Manager, Chelsey Fix at Chelsey.fix@gbs-cidp.org.



Top, Vice President of GBS|CIDP Foundation Board of Directors, Matt LaRocco delivers "member advocacy letters" to Congressman Blumenauer. Bottom, Betsy Blake, Merrillyn Macurak, Congressman John Garamendi, Hill Day 2019.

Why I Joined the GBS|CIDP Advocacy Campaign on Capitol Hill

By Brenda Perales

I was diagnosed with Multifocal Motor Neuropathy (MMN), in November of 2013, by Dr. David Cornblath. He referred me to the Foundation, and I looked at their website. I mentioned to him at my next visit that, as amazing as it was, there was not much about MMN, as far as patient stories. So in February of 2016 he asked me to record a patient video for the Foundation website and in Spring 2017, I was featured in the newsletter. I was very excited to bring a face to MMN (and share my new found support in my MMN Facebook group!)

At my next appointment with Dr. Cornblath, in December 2018, his first words to me were "What have you done for MMN lately?!" He was always pushing me to get involved. Soon after, Lisa Butler, the Executive Director of the Foundation, contacted me to see if I would speak at a patient summit in Philadelphia. I said yes! And it was the most terrifying and wonderful thing I had ever done.

So why did I decide to join the Foundation advocates for the 2019 Hill Day in Washington DC? Getting to know Lisa Butler, learning firsthand about the amazing programs and services of the Foundation, not to mention all the new experiences it has brought me, gave me the confidence I needed to say yes to Hill Day! After all, if I could get up in front of 200 Pharma researchers, scientists and advocates and share my story, I could absolutely participate in Hill Day! And after seeing the difference sharing my story made at the Patient Summit, I felt like I was now representing the MMN community. I was the face of MMN and I owed it to all those who felt like they had no voice.

I realized I needed to do this for them and then I was really excited!

Also, of course, I truly believe in the legislative agenda! Being 57 and Medicare around



"You never know what you are capable of until you try."

- Brenda Perales

the corner I hope we get the bill passed for in-home IVIG home infusion treatments and, next, we need to get SubQ FDA approved for MMN also approved for Medicare. I feel this is a step in the right direction so we can all live our best lives and have the choices that work best for us.

And like with all the other challenges I have had in my life, I chose to be a survivor. I share all parts of my life, good and bad, hoping just to help one person who may think they are alone. I understand that being out front does not work for everyone and I respect that. There are plenty of things you can do behind the scenes too. For me, advocating for what we deserve, makes me feel like I have a purpose and maybe I have gone through everything for a reason, I was given MMN for a reason. If you are interested in becoming an advocate, push yourself a bit to make that first step like I did. You never know what you are capable of until you try and you just may surprise yourself.

NEW FEATURE!

Introducing “Living Well with GBS|CIDP and Variants”

Integrative medicine puts the patient at the center of the care and addresses the full range of physical, emotional, mental, social, and environmental influences that affect a person's health. This process enhances the ability of individuals, who may be affected by other health conditions, to stay as well as possible while they cope with their condition. In upcoming issues of the Communicator you can look forward to finding practical advice on creating a healthy balanced lifestyle with everyday tips for living well. Dr. Julie Rowin helps introduce our “Living Well” section with the following article on the benefits of mindful breathing.



Dr. Julie Rowin

breathe

By Dr. Julie Rowin

Our breath sustains us. It not only supplies our cells with life-giving oxygen, the mechanical act of breathing itself is intimately connected to our body's basic physiology. With every breath in our heart rate increases and with every breath out it slows.

The modulation of respirations, heart rate, blood pressure and digestion are interconnected through the primitive part of the brain called the brainstem and primitive nervous system called the autonomic nervous system. Most of the autonomic nervous system functions are unconsciously controlled. The distinguishing feature of the breath, however, is that we have conscious control over the speed, depth and flow of our breathing. And, by consciously controlling our breath, we can have far reaching positive effects on other aspects of our autonomic nervous system physiology and our response to stress.

The autonomic nervous system acts like a switch. It is either in ‘rest and digest’ mode or ‘fight or flight’ mode. Consciously slowing and deepening your breathing will ‘flip the switch’ and take you from ‘fight or flight’ to ‘rest and digest’ by slowing your

heart rate, decreasing your blood pressure, improving your digestion and calming your mind.

The stress response and breathing are hard-wired in our nervous system. Someone who has trouble breathing will naturally panic just as someone who has a panic attack will naturally feel short of breath.

Did you ever catch yourself holding your breath during a stressful situation? Most of us spend a good deal of the day with shallow chest breathing and when times get stressful we may even unconsciously hold our breath. It follows that shallow chest breathing and breath holding are associated with increased blood pressure, heart rate and anxiety, while the opposite, deep belly breathing, is associated with decreased blood pressure and heart rate, reduced pain and a calm state of mind.

Ancient practitioners of yoga knew that the quality of breath dictates our state of mind. As Westerners, we are just catching up to this. Breathing techniques that slow the breath, concentrating on prolonging the exhale, change brain waves to the alpha rhythm which is a rhythm correlated with relaxation, positive mood and a reduction

in the stress hormone, cortisol.¹ It follows that breathing exercises are useful in the management of chronic pain.² And learning to regulate the breath can even decrease performance anxiety and improve work performance in children.³

Your breath is free, travels with you, and can be used as a tool anywhere and anytime to calm and elevate your mood and bring you to the present moment. Practice slowing and deepening your breath into the belly (while relaxing and expanding the belly). Next, concentrate on a slow exhale, without strain, with a slight contraction of the belly.

Do this for a few minutes, elongating the breath as much as is comfortable, several times a day, whenever or wherever you are, in a meeting, in your car, in line at the grocery store, in a heated argument. It will ‘flip your switch’, change your life, and improve your health. It is simple, but powerful.

If you need a reminder, put up a ‘breathe’ sign at your workspace or one on your bathroom mirror.

Breathe.

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. *Cogn Emot*. 2017;31(7):1502-1510.

Mindful Breathing Exercises

Breath, well-being and energy are intrinsically connected. Mindful breathing can be performed anywhere and anytime. It's all about bringing yourself to the present moment and focusing on a slower deeper belly breath. Relax and soften your belly. A tight abdomen tends to lead to chest breathing which is stimulating to the nervous system. Here we are looking for a calming effect. The following are a couple of formal breathing exercises to get you started.

EQUAL BREATHING EXERCISE

- 1 Find a comfortable place to sit or lie down, with your feet slightly apart, one hand on your abdomen near the navel, and the other hand on your chest.
- 2 Inhale slowly through your nose to the count of 4, relaxing into and expanding your abdomen
- 3 Exhale slowly through your nose to the count of 4, feeling the gentle contraction in your abdomen.
- 4 Repeat for a total of 5 cycles.
- 5 Increase your inhale and exhale to a count of 5 for a total of 5 cycles.
- 6 You may increase the length of the inhale and exhale by one count every 5 cycles so long as it causes contentment without strain. 3-5 minutes is sufficient to see a calming effect on the nervous system.

Once you feel comfortable with the above exercise, you can try the following, more advanced, exercise.

4-4-8 BREATHING EXERCISE

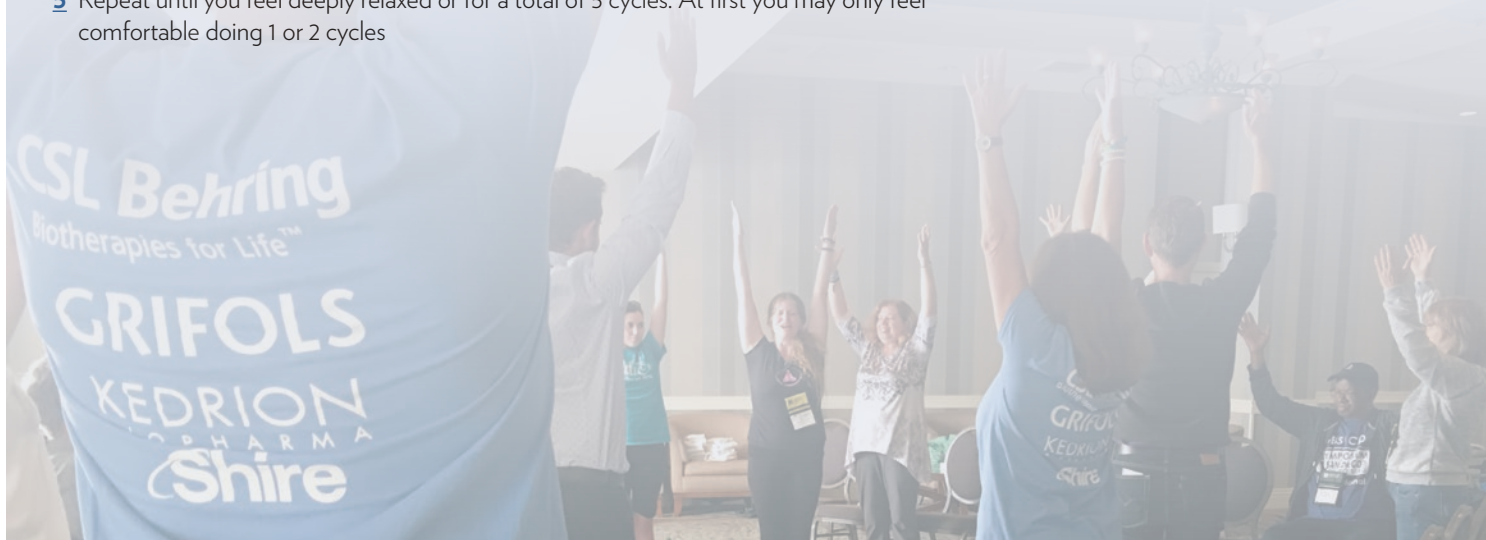
- 1 Find a comfortable place to sit or lie down, with your feet slightly apart, one hand on your abdomen near the navel, and the other hand on your chest.
- 2 Inhale slowly through your nose to the count of 4, relaxing into and expanding your abdomen
- 3 Hold the breath at the top of the inhale for a count of 4 or whatever is comfortable for you, never straining or going outside of your comfort zone
- 4 Slowly exhale through your nose while counting to 8. Gently contract your abdominal muscles at the end of the exhale.
- 5 Repeat until you feel deeply relaxed or for a total of 5 cycles. At first you may only feel comfortable doing 1 or 2 cycles



ABOUT Dr. Julie Rowin

Dr. Julie Rowin is a board-certified neurologist, neuromuscular specialist and acupuncturist.

She became interested in Functional Medicine and Acupuncture in 2012 and is currently in private practice in the Chicagoland area. Dr. Rowin has obtained additional board certification in Integrative Medicine and Medical Acupuncture. Her holistic healing approach to the treatment of adult neurological conditions integrates nutrition, acupuncture, mind-body energetics with conventional medical management.





NANCY DiSALVO ELECTED TO GBS|CIDP BOARD OF DIRECTORS

Please join us in welcoming Nancy DiSalvo from Palermo, Italy to the GBS|CIDP Board of Directors! A tireless international volunteer for the GBS|CIDP community since 2013, Nancy has educated and supported numerous patients worldwide. Most recently Nancy held the very first chapter meeting in Italy, with over 50 attendees. Nancy brings a keen sense of cultural differences, combined with a friendly, hospitable and compassionate nature. We look forward to working with Nancy on continuing the mission of the Foundation and serving the GBS|CIDP community.

ANNOUNCING A NEW CENTER OF EXCELLENCE

Beth Israel Lahey Health 
Lahey Hospital & Medical Center

Lahey Hospital & Medical Center
41 Mall Road
Burlington, MA 01805, USA
781-744-8630

FAQ

How does a medical facility become a center 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. The criteria is based on levels of expertise, available treatments, facilities, and research capabilities.

If you are a medical professional, and feel that your medical facility meets these standards and are interested in becoming one of our Centers of Excellence, please contact Special Projects Coordinator, Lori Basiege, lori.basiege@gbs-cidp.org.



HAVE YOU BEEN TO A CHAPTER MEETING?

There's no better way to build a local support network than to attend a GBS|CIDP chapter meeting in your area. In 2019, thus far, Foundation volunteers have hosted 24 chapter meetings with over 500 attendees in total. Additionally, there are over 20 meetings scheduled for the remainder of 2019, with more locations and dates in the works.

Welcome to new chapters...

A BIG thank you to 3 NEW cities hosting their first meetings including Fort Myers, FL, Miami, FL, and Milwaukee, WI!

2019 CHAPTER MEETING DATES & LOCATIONS

6/15	Indianapolis, IN
6/20	Milwaukee, WI
6/22	Staten Island, NY
6/22	Independence, MO
6/29	Tulsa, OK
7/6	King County, WA
7/13	Columbus, OH
7/13	Phoenix, AZ
7/20	Lake Orion, MI
8/10	Sarasota, FL
8/10	Charleston, SC
9/19	Milwaukee, WI
10/17	Milwaukee, WI
10/19	Hackettstown, NJ
11/21	Milwaukee, WI

Find out more information at:
<https://www.gbs-cidp.org/events-calendar/>.

Interested in starting a chapter near you? Contact Event & Outreach Manager, Kelly McCoy, kelly.mccoy@gbs-cidp.org.



An Inside Look at Princeton and Colorado One-Day Regional Conferences

Springtime regionals conferences in Princeton and Colorado Springs brought together a combined 320 attendees including, local physicians, patients, caregivers and loved ones for a day of sharing, learning and connecting.

Our medical presenters on March 9th at the Princeton, New Jersey Regional Conference included Steven S. Scherer, M.D. Ph.D., Professor of Neurology at Penn Medicine along with Shan Chen, M.D. Ph.D., Neurologist at Robert Wood Johnson University Hospital. On April 9 in Colorado Springs, Colorado, our team of medical presenters included GMAB member David Saperstein, MD, Neurologist at Phoenix Neurological Associates, and Dianna Quann, MD, Neurologist and Professor at University of Colorado. Both GBS|CIDP medical teams presented the latest in GBS|CIDP research as well as “What to Expect” after a GBS or CIDP diagnosis, and an interactive “Ask the Experts” session with specific questions from attendees.

Additional topics presented at both conferences ranged from breakout sessions for patients based on their specific condition, insurance and advocacy, social work and your circle of care, adaptive living devices for the home, caring for the caregiver, and various sessions on current treatments available.

Additional presenters included, President of our Board of Directors, Jim Crone; Executive Director, Lisa Butler; Maria Illiano Harris PT, DPT, CBIS and Charla Fronczkowski, Master's Degree in Occupational Therapy, from Bryn Mawr Rehabilitation; Dane Christiansen, Vice President of the Health and Medicine Counsel of Washington DC; Jim Romano Director of Government Relations, Patient Services Inc. (PSI), Jane Meier Hamilton, RN, MSN, Partners on the Path, along with industry representatives, Social Workers Briana Kohlbrenner & Kate Ross from University of Denver.



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“It was truly our pleasure to attend the conference. We'll keep up with all the latest news & events from the Foundation from now on! Keep up the fantastic work. You all make a great difference in the lives of many.”

—CAROLINE BIAGI

THESE REGIONAL CONFERENCES ARE MADE POSSIBLE THROUGH THE GENEROSITY OF OUR MEETING SPONSORS: Grifols, CSL Behring, Accredo Specialty Pharma, Argenx, Briova Infusion Services, Kedrion Biopharma, Kroger Specialty Infusion, Option One Pharmacy, RMS Medical Products, Takeda. **THANK YOU!**



MORE OPPORTUNITIES TO CONNECT THIS FALL!

REGISTRATION IS NOW OPEN!

1 INDIANAPOLIS ONE-DAY REGIONAL CONFERENCE

Saturday, September 7, 2019
Embassy Suites by Hilton
Indianapolis Downtown
110 W Washington Street
Indianapolis, IN 46204

2 BOSTON ONE-DAY REGIONAL CONFERENCE

Saturday, October 5, 2019
Boston Marriott Burlington
One Burlington Mall Road
Burlington, Ma 01803

YOUR STORY MATTERS!

A GBS|CIDP Patient Registry Update

The GBS|CIDP Foundation invites you to **join over 800 patients** who have enrolled in the online Patient Registry for patients with GBS|CIDP or variants of the condition. The GBS|CIDP Patient Registry, consisting of patient reported standardized questionnaires, will allow healthcare professionals access to critical, **de-identified** patient data and a more in-depth understanding of the patient experience. This unique collection of data can be critical for the pursuit of medical advancements and development of patient resources. ***Studies of these conditions may take years to finish, but patient reported registries provide power in numbers!*** The Foundation will provide periodic updates and results with the discoveries made possible with this impactful data.

If you are a patient, or the primary caretaker of a patient living with GBS, CIDP or a variant of the condition, we encourage you share your experience, enroll in GBS|CIDP patient registry and play a role in a better tomorrow for GBS|CIDP patients everywhere.



Ask the Expert...

Featuring Dr. David Saperstein



“Ask the Expert” panels at the Foundation’s educational conferences are among the most popular and most interactive sessions. Patients and caregivers have the unique opportunity to submit specific questions and concerns, that are answered live and in-person, by some of the top physicians in the field of peripheral neuropathy. Below are three 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: How can a 72 year old person with slowly progressing CIDP differentiate issues of normal aging – arthritis, fatigue, aches, and pains?

A: The key is to focus on characteristic symptoms of CIDP. This would be weakness in arms or legs, numbness or tingling in the arms or legs, or pain characteristic of neuropathy (such as prickling, burning, or stinging). Also, I would ask if the symptoms you are experiencing are symptoms you have experienced before in association with your CIDP. If symptoms only consist of fatigue and joint pain or aches, I would attribute these to factors other than CIDP.

Q: I developed GBS after my flu shot. Is it safe for me to get a pneumonia and shingles shot/vaccine?

A: An important issue is “when” after a flu shot you developed GBS. Only if GBS develops within 6 weeks of a flu shot or other immunization do we consider it to have potentially caused the GBS. Even if you did develop GBS within 6 weeks of a flu shot, there is no evidence that you are at increased risk for a relapse after a pneumonia or shingles vaccine. Therefore, the final answer is “yes” it is safe for you to get a pneumonia or shingles vaccine.

Q: Is it possible to have had Miller Fisher at birth?

A: While technically possible, this would be an extremely uncommon occurrence. Therefore, I would strongly consider other possible explanations. I am aware of only a single report in the medical literature describing GBS occurring at birth. I am not aware of any reports of Miller Fisher syndrome occurring at birth.



Why I Volunteer

*Spotlight on Southeast Regional Director & Walk & Roll Chair,
Merrilyn Macurak*

It is the Foundation's privilege to work with such a committed and passionate team of volunteers. In this issue, the Foundation would like to draw your attention to a familiar face in the GBS|CIDP community, a woman that has not only joined our mission of excellence with verve and vigor, but who exudes strength and resilience every step of the way.

Meet Merrillyn Macurak!

When did you get involved with the Foundation and what made you want to volunteer?

I became a member in 2007 and started volunteering in 2014. I was so alone on my journey that I wanted to help others. Our doctors don't have all the answers. This is scary, both mentally and physically. Talking with others and sharing our experiences helps to calm the fears of these unknown conditions. I became a Regional Director because I felt it's a way to help a lot more people. I enjoy mentoring and guiding Liaisons and Points of Contact. The Southeast regional team is great group of caring individuals. They care about their patients and communities.

What is your favorite part of the GBS|CIDP Community?

It's hard to pick one favorite. The chapter meetings bring great information from speakers and help the local community's members. I absolutely LOVE the Walk & Rolls. It brings the whole community together to raise awareness and raise funds for research. I also find it a much more relaxed atmosphere for patients, families and caregivers to get to know each other better. We break bread together. Food always makes everything better!

I have made some life-long friendships that I cherish. I love my GBS|CIDP sisters & brothers.

The Biennial Symposia bring the best professionals in our fields of study together for an exciting, fun, educational weekend.

This year I participated in Hill Day in DC. I joined over 30 other advocates, including staff, and was part of the GBS|CIDP Awareness Month effort on Capitol Hill for our CIDP and MMN patients. What an interesting and educational experience! One of the best days ever!

What advice would you give someone who is new to the Foundation?

As a newly diagnosed patient, read the literature, ask questions and know you are not alone.

And to a new Liaison or Point of Contact (POC), be prepared for a very rewarding and healing experience.

What advice would you give someone about their journey with GBS, CIDP or a variant of the condition?

Take it one day at a time. It's okay to have bad day. Celebrate the good days or a milestone. If you want to cry, then cry. If you want to scream, then scream. Recovery is slow and steady. It's a marathon not a sprint. Know you aren't alone on your journey. I would also like to say the staff in the Foundation office are some of the most caring and dedicated people I know. I know I can pick up the phone or email anytime for advice or answers. And so can others in need as well!

VOLUNTEERS NEEDED IN:

Coastal Georgia, West Virginia,
Southeastern Florida, Miami,
Alaska, Hawaii

If you are interested in holding chapter meetings in your area or volunteering for the GBS|CIDP Foundation please contact Kelly McCoy at kelly.mccoy@gsb-cidp.org.



2019 Walk & Rolls Spring into Action!

Why Walk for GBS|CIDP?

Walk & Roll is a great way to raise awareness, show your support, make friends and build a local network. In 2018, we updated the program to the **Walk & Roll for Research**, designating every dollar raised directly to research. In 2018 donations were able to fully fund THREE grants for Research totaling over \$150,000. This year, by increasing our goal to \$200,000, we are taking it one step further, and aiming to fund FOUR research grants! As of the printing of this newsletter today we are half way there! Each walk is one mile closer to overcoming the challenges of living with GBS, CIDP and its variants, such as MMN. Invite your friends, family, neighbors and community to join our mission, walk or roll one mile, and have fun too!

If you are interested in planning or sponsoring a Walk & Roll near you, contact Walk & Roll Program Manager, Jessica McManus, Jessica.mcmanus@gb-cidp.org.

WALK & ROLL AT LINCOLN MEMORIAL AND REFLECTING POOL IN WASHINGTON, DC

Thank you to Walk Chair Tonya Charleston, her amazing team of volunteers, and to over 150 Walkers and Rollers from across the Washington, D.C. region (and beyond) who gathered together on April 27, for the third year, for a one-mile walk and celebration like no other! Adding to the excitement, over \$16,900 raised goes towards the GBS Grants & Research Program.

CHARLESTON WALK & ROLL ROCKS ON!

The 2nd Charleston Walk & Roll took place on April 13th, chaired by Mindy Hester and a team of tireless volunteers! Over 50 enthusiastic attendees raised more than \$4,000 more for GBS|CIDP research! Thank you to each volunteer, participant and sponsor who made this day possible!

CLOVIS BREAKS ITS OWN RECORD!

On March 9, for the second year in a row, at Dry Creek Park in Clovis, California, GBS volunteer and Clovis Walk Chairman, Robert Vasquez hosted his second exciting Walk & Roll fundraising event with a record-breaking 320 walkers in attendance! Thus far the event has raised almost \$12,000 to support GBS|CIDP research. Congratulations to all for this outstanding achievement!



2019 WALK & ROLL SCHEDULE (TO DATE)

6/1	Twin Cities, MN
6/2	Philadelphia, PA
6/9	New Jersey
6/22	Houston, TX
9/7	Myrtle Beach, SC
9/14	Staten Island, NY
9/21	Pittsburgh, PA
9/22	Columbus, OH
9/28	Portland, OR
10/12	San Francisco, CA
10/19	Raleigh, NC
10/26	Phoenix, AZ
11/2	Fort Myers, FL
11/16	Nashville, TN
TBD	Seattle, WA
TBD	Dallas, TX

1320 WALK & ROLLERS
REGISTERED &
COUNTING

CHECK OUT MORE WALK PHOTOS:



[gbscidp](#)



[gbscidp](#)



[gbscidpfoundation](#)



GBS|CIDP 2019 Research Grant Funding Announced

Your Donations in Action

The Foundation fills an important need in the GBS, CIDP, and related disease research arena by offering seed money for research that may lead to NIH funded projects. As determined by the GBS|CIDP Foundation Global Medical Advisory Board, thus far, the 2019 Research Grants, totaling \$340,000, will be awarded to the following research studies:

KARISSA GABLE

Duke University

PROJECT: Pathogenic Th17 cell pathology in CIDP

SYNOPSIS: Evidence from our lab, supported by the medical literature, suggests that T helper cells producing IL-17 (Th17) are important mediators of inflammation in CIDP. We propose to deeply characterize pathogenic Th17 cell populations in CIDP and determine the effects of Th17 targeted therapy for this disease. Treatments for CIDP have not advanced significantly in many years and new treatment approaches are needed.

EDUARDO NOBILE-ORAZIO

Milan University, IRCCS Humanitas

PROJECT: A randomized controlled trial with Rituximab versus placebo in patients with chronic inflammatory demyelinating polyradiculoneuropathy (CIDPRIT): support for an additional dose of Rituximab after six months of therapy

SYNOPSIS: In this study, immunoglobulin therapy will be continued for six month after initial rituximab therapy to allow rituximab to become effective. We originally proposed the same protocol shown to be effective in another immunological disease (rheumatoid arthritis) with rituximab at the dose of 1000 mg intravenously versus placebo on day 1 and 15 after randomization. After reconsidering the results of the rituximab trial in arthritis rheumatoid where its efficacy was significant after 24 weeks but declined at week 48, with proposed an amendment to our Ministry of Health to add a further 1 g dose of rituximab or placebo 6 months after the initial therapy, one week after IVlg suspension (see attached revised protocol). This decision took into account the fact that the

primary end-point of the study was the different proportion of patients relapsing within 12 months after therapy initiation. This amendment was approved without further financial support for the additional therapy.

A. JUNG-JOON SUNG

Seoul National University College

PROJECT: Development of New Biomarkers Using Immune Cells Profiling and T-cell Specific Sequencing

SYNOPSIS: In this study, immunoglobulin therapy will be continued for six month after initial rituximab therapy to allow rituximab to become effective. We originally proposed the same protocol shown to be effective in another immunological disease (rheumatoid arthritis) with rituximab at the dose of 1000 mg intravenously versus placebo on day 1 and 15 after randomization. After reconsidering the results of the rituximab trial in arthritis rheumatoid where its efficacy was significant after 24 weeks but declined at week 48, with proposed an amendment to our Ministry of Health to add a further 1 g dose of rituximab or placebo 6 months after the initial therapy, one week after IVlg suspension (see attached revised protocol). This decision took into account the fact that the primary end-point of the study was the different proportion of patients relapsing within 12 months after therapy initiation. This amendment was approved without further financial support for the additional therapy.

BETTY SOLIVEN

University of Chicago

PROJECT: Exploring possible role of TGR5 and FXR in autoimmune neuropathy

SYNOPSIS: There is increasing evidence that diet and gut microbiome regulate the immune function via changes in short chain fatty acids and other metabolites, but also via altering the bile acid composition in the host. These microbially generated secondary bile acids are signaling molecules that interact with multiple host bile acid receptors. For this pilot study, we plan to focus on a G-protein-coupled bile acid receptor 1 (GPBAR1, also known as TGR5), and type 2 nuclear receptor called farnesoid X receptors (FXR), both of which are activated by bile acids and are implicated in the control of the immune system. Both TGR5-selective agonist and FXR-selective agonist have been shown to modulate the function of monocytes and

macrophages, but their effects on lymphocytes have not been as well-elucidated. The goal of this pilot study is to investigate our hypothesis that altered expression or function of TGR5 or FXR could contribute to the pathogenesis or disease progression in Guillain Barré syndrome (GBS) and chronic inflammatory demyelinating polyradiculoneuropathy (CIDP).

H.G. (RUTH) HUIZINGA & BART C. JACOBS

Erasmus MC, University Medical Center

PROJECT: Neuromuscular ultrasound (NMUS) parameters as diagnostic and prognostic biomarker in chronic inflammatory demyelinating polyneuropathy (CIDP)

SYNOPSIS: Antibodies (Abs) to gangliosides play a key role in the pathogenesis of a proportion of patients with Guillain-Barré syndrome (GBS). Although these Abs have been characterized extensively, little is known about the cells that produce these Abs. We have recently demonstrated that plasmablasts, precursors of plasma cells, are elevated in the peripheral blood of one-third of the patients with GBS and that dominant B-cell clones can be identified. Moreover, preliminary data indicate that isolated plasmablasts can be cultured in vitro and secrete anti-ganglioside Abs. Further studies are required to substantiate these findings.

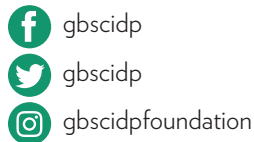
IGOS

The Foundation continues to support the International Guillain-Barré syndrome Outcome Study (IGOS), a worldwide prospective study, conducted by the Inflammatory Neuropathy Consortium (INC). IGOS aims to define biomarkers for disease activity and recovery and to develop prognostic models to predict the clinical course and outcome in individual patients with Guillain-Barré syndrome (GBS).

GUIDELINES FOR STANDARDS OF CARE

The Foundation supports the development of two international guidelines, being developed by the European Academy of Neurology (EAN) and the Peripheral Nerve Society (PNS), one for the "Diagnosis and Management of GBS," and one for "Diagnosis and Management of CIDP." We expect to produce up-to-date international guidelines for GBS and CIDP, and believe that these guidelines will be not only of interest to doctors but will be of benefit for all patients with GBS and CIDP.

CHANGE SERVICE REQUESTED



SUPPORT EDUCATION RESEARCH ADVOCACY SUPPORT EDUCATION RESEARCH ADVOCACY

MARK YOUR 2020 CALENDARS!

We are delighted to announce that the 16th GBS|CIDP International Patient Symposium will be held
October 1-3, 2020 at the Hilton Mark Alexandria, Virginia!



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

DIAGNOSED WITH MMN?

Dominick Spatafora
dominck@dvsconsultants.com

MILLER FISHER VARIANT GROUP

Please call us for contact with others.

CHILDREN WITH GBS

Lisa Butler, 610-667-0131
GBS|CIDP Foundation International
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

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 us 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 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.**