

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.



Meet Hero Crystal Sada, a Warrior in Every Sense of the Word

By Barbara Gatti



Crystal Sada, 3 time Walk & Roll Chairperson, Staten Island

"I would like to honor my friend, Crystal Sada who was diagnosed with CIDP in 2014. She is a warrior in every sense of the word. She has had many setbacks which only make her fight harder to walk again and have a normal life. Even though she could have let this illness bring her down to a dark place, she remains upbeat and has become a champion for all CIDP patients. She has led the Walk and Roll fundraiser on the Staten Island boardwalk since being diagnosed and has raised awareness and money toward advancing research for this debilitating illness.

Since January 2018 she has recently been readmitted into the hospital for the 3rd time, having experimental blood treatments and heading for another stay in rehab. One cannot admire this courageous woman, and her wonderfully supportive husband, Jai, more. I am praying for a miracle to bring our hero Crystal back to a quality of life! Crystal is not only a crystal, but a rare diamond!"

More "Honor Your Hero" stories at: gbs-cidp.org/support/honor-your-hero-stories/

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GBS|CIDP Awareness Month a Big Success!

35,000 MEMBERS = 35,000 HEROIC STORIES TO TELL

Caregivers, friends, family members and patients, enthusiastically joined us this past May, for GBS|CIDP Awareness month! We received over 100 Hero Stories and shared many of them on our website and social media, reaching far beyond our membership community. But it's never too late to tell us about your life with GBS|CIDP or a variant of the condition. Sharing a story is the most meaningful way to raise awareness and inspire patients around the world. Please support the GBS|CIDP Foundation by making a donation and/or share your story with us. Send your story to Director of Marketing & Communications Maureen Neville, mneville@gbs-cidp.org.

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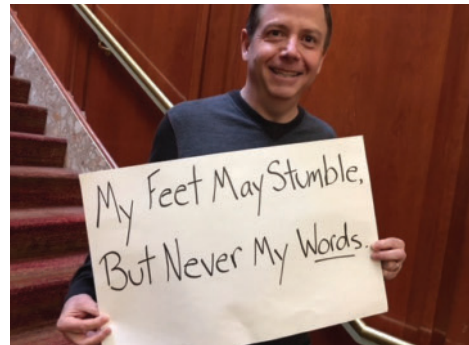
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Heroes on The Hill!

On May 22, as part of our continued advocacy efforts, the GBS|CIDP Foundation International hosted a Hill Day in Washington DC. A group of fifteen representatives, including patients, staff and lobbyists from the community, were all in attendance. The primary focus of the day was to encourage support from members of congress for the Medicare IVIG Access Enhancement Act. We'd like to also express our gratitude to all who have participated in our 2018 advocacy efforts!

Stay tuned for progress updates at gbs-cipd.org.



Virtual Patient Education: Understanding CIDP for Patients and Caregivers

July 11, 2018 12:00-1:00 PM

Ask Top Experts Your Questions, in Real Time

On Wednesday, July 11 at 12pm ET, please join us for a live video education program that will enable you to interact with some of the country's best CIDP specialists. We'll be discussing treatment options and sources of support for managing issues and complications associated with CIDP – beyond the presentation from the panel, the program will include real-time poll questions and live Q&A. Save a seat at: <https://bit.ly/2FVVQ5I>.

Can't join us on live day? Don't worry – the program will be available on demand afterwards.

To receive the recording, head to: <https://bit.ly/2FW1J2I>.



Disclaimer Information Questions presented in The Communicator are intended for general educational purposes only and should not be construed as advising on diagnosis or treatment of Guillain-Barré syndrome or any other medical condition.

Privacy Policy In response to many queries: Intrusive practices are not used by GBS|CIDP Foundation International. The organization does NOT sell its mailing list nor does it make available telephone numbers! The liaisons are listed in the chapter directory with their permission. We are proud that none of our members has ever been solicited or sent materials other than those concerning GBS, CIDP, and related syndromes such as MMN. We respect your privacy.

Dear Friends,

From the many expressions of gratitude we receive by phone, mail or email, this one really encapsulates why we are so passionate and motivated to do what we do, every day. It's amazing how far a gesture of caring and kindness can reach. I wanted to share it with you, as I know many of you will find inspiration in this message as well.

"Not sure if you remember but I do very vividly. You talked me through the most traumatic time of my life. My then 5 year old little girl diagnosed with Miller Fisher and on life support for what seemed like an eternity (month and 1/2) released from the hospital equivalent to an infant couldn't hardly sit up by herself much less walk. We spoke several times throughout the crisis - you will never know what a life saver you were. You made unbearable days bearable! As Alexis graduates high school this year a happy healthy bright eyed beautiful young lady as you many times assured me would happen it just seemed right that I say THANK YOU for being there during our darkest hours. Now we are seeing brighter happier days hopefully you are too."

-Jeanne Maddeaux and family

This is what we call our "psychic wages" - the feeling we get from helping our many patients, year after year. We are so grateful that we can help. It is truly a privilege to be a part of this amazing circle of caring and healing. Thank You!

Happy summer!

Lisa Butler

Executive Director



It's amazing how far a gesture of caring and kindness can reach.

Our Research Dollars at Work! 2018 Research Grant Finalists Announced

Research is critical to serving the cause and the community. The GBS|CIDP Foundation International believes in supporting research by funding grants for projects that contribute to the knowledge and advancement of treatment of GBS|CIDP and variants of the condition. We are pleased to announce our 2018 Research Grant Awardees are as follows:

Elisabetta Babetto, PhD

SUNY Buffalo

Study: Targeting Wallerian-like degeneration in GBS mouse models

Luana Benedetti, MD, PhD / Lucilla Nobbio, PhD

University of Genova, Italy

Study: Sphingomyelin as a biomarker in GBS/CIDP patients

Luis Querol MD PhD

Hospital de la Santa Creu i Sant Pau, Barcelona, Spain

Study: Disease-specific biomarkers in inflammatory neuropathies

Paolo Ripellino, MD

Neurocenter of Southern Switzerland, Lugano

Study: International GBS Outcome Study (IGOS) in Switzerland: a deeper look into HEV induced GBS

Dr Laura Zambreanu, MD MRCP

National Hospital for Neurology and Neurosurgery, London

Study: OPTIC protocol for induction treatment of CIDP

Congratulations to all and thank you for your continued commitment to research in the area of GBS|CIDP and variants of the condition.



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Subcutaneous Immunoglobulin: A Newly Approved Treatment Option for CIDP

David Saperstein, MD

Co-Director GBS|CIDP Center of Excellence; Phoenix Neurological Associates, Phoenix, AZ;
Member of the GBS|CIDP Global Medical Advisory Board (GMAB)



Intravenous immunoglobulin (IVIg) is one of the main therapies used to treat CIDP. This therapy can be very effective but there are drawbacks. Some people experience headaches related to the intravenous infusions. Some people have difficulty with IV access. Also, the need for IV infusions lasting several hours one or more days every month can prove burdensome with respect to work or travel. In recent years there has been growing interest in infusing immunoglobulin through the skin in a process called subcutaneous administration (subcutaneous immunoglobulin, or SClg). SClg is commonly used in patients with immunodeficiency. SClg is administered by patients themselves at home. Infusions are generally given



in the fat under the skin in the stomach or thighs. Over the last few years there have been small studies of SClg in patients with CIDP. It has become a popular strategy for treating CIDP in Europe and has been used in some patients in the United States. Several brands of IVIg can be given subcutaneously, but there are a couple of products made specifically for subcutaneous administration. These are 20% in concentration, in contrast to most IVIg products which are 10%. The more concentrated 20% products allow infusions to be completed in just a couple of hours one or two days each week. Unlike IVIg which is usually given in a big dose several weeks apart, SClg must be administered every week).

The FDA recently approved a 20% formulation of SClg called Hizentra for maintenance treatment of CIDP. This is based on the results of a large international study of Hizentra called the

PATH study (for polyneuropathy and treatment with Hizentra). One hundred and seventy-two patients from North America, Europe, and Asia were studied. These were all patients who were receiving regular maintenance treatment with IVIg. To be eligible to participate in the PATH study, patients had to demonstrate that they needed regular treatment with IVIg. This required them to come off of IVIg and display objective worsening within 12 weeks. Of 245 patients taken off of IVIg, all but 28 worsened within 12 weeks. Ultimately, 172 patients were enrolled. 57 received low dose SClg (0.2 grams per kilogram per week), 58 received high dose SClg (0.4 grams per kilogram per week) and 57 received placebo (albumin protein solution). The patients were watched closely over the next 6 months. The main outcome was to see how many patients in each group worsened. Since each patient in the study had already shown that they worsened when coming off of regular IVIg treatments it was assumed that most of the patients in the placebo group would worsen. Interestingly, only 63% did. It is not clear why more did not. Nevertheless, many more patients in the placebo group relapsed over 6 months compared to patients who got SClg (39% in the low dose group and 33% in the high dose group). Both dose groups did significantly better than placebo, but there was no significant difference between the low and high dose groups. Not surprisingly, the patients receiving SClg had more skin irritation than patients getting placebo

(19% in the low dose group, 29% in the high dose group and 7% in the placebo group). However, much fewer patients experienced reactions to Hizentra than they did to IVIg.

Approximately 90% of subjects rated the SClg injection process as being easy to learn. About 53% of patients receiving SClg preferred this treatment to IVIg, citing increased independence and less side effects.

Anyone with CIDP currently receiving IVIg could potentially be switched to SClg. Of course, if the IVIg is working fine there is no reason to change anything. SClg is a particularly appealing option for patients who get side-effects such as headaches or nausea from IVIg, who have trouble with IV access, or who prefer to have control of their treatment. Another advantage of SClg is that it can be stored at room temperature, so people can easily take it with them if they are travelling.

Safety and Efficacy of Eculizumab in Guillain-Barré Syndrome: A Multicentre, Double-blind, Randomised Phase 2 Trial

RESEARCH FROM JAPAN!

A research group led by Professor Satoshi Kuwabara of the Department of Neurology, Chiba University Hospital, conducted a clinical trial to study effects of a drug called eculizumab in patients with severe Guillain-Barré syndrome. The trial's results suggested the possible efficacy of eculizumab in treating the syndrome for the first time in the world.

The clinical trial examined the effects of eculizumab administration in addition to conventional immunoglobulin therapy in patients with severe Guillain-Barré syndrome.

A total of 61% of patients treated with eculizumab regained the ability to walk without aids (45% in the placebo group) 4 weeks after the initiation of eculizumab treatment*, and 72% (18% in the placebo group) recovered to be able to run at 24 weeks. Anaphylaxis and cerebral abscess were noted as severe adverse events that could not be excluded from having a causal relationship with eculizumab, but all such patients recovered. These findings were published in the international medical journal, *The Lancet Neurology*, on April 20, 2018.

Comment from Prof. Satoshi Kuwabara:

This trial's results have drawn attention from specialists all over the world as a novel and potentially efficacious treatment for Guillain-Barré syndrome, which has been elusive for the past 20 years. We will make further efforts to realize the practical application of eculizumab.



ATTENTION Medical Researchers!

GBS Deemed Eligible for Research Studies through Department of Defense Peer Review

April, 2018 - The Peer Reviewed Medical Research Program (PRMRP), established in fiscal year 1999 (FY99), 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. Program oversight is provided by a programmatic panel with joint military service and interagency representation. Congress appropriated \$330 million for the FY18 program to solicit research proposals in 52 topic areas. **Guillain-Barré Syndrome** was again listed as a condition eligible for study.

Researchers, now is the time to begin applications for available grants. All applications submitted to the PRMRP must address at least one of the FY18 PRMRP Congressionally directed topic areas.

For more detailed information regarding applications and possible awards go to gbs-cidp.org/PRMRP.

Results from Nationwide CIDP “Treatment” Survey

In 2017, 475 CIDP patients participated in a nationwide “CIDP Patient Experience and Treatment” survey. The results demonstrate that both CIDP, and commonly prescribed CIDP treatments, are associated with burdens that impact school, work, and home activities. Data collected was reported as follows:

Data from an online survey of 475 individuals, aged 18 years or older, recruited by the GBS|CIDP Foundation and self-reported to have CIDP, was used to assess disease and treatment burden. Data were analyzed overall and patients were categorized into “likely CIDP” (n=187), “somewhat likely CIDP” (n=170), and “unlikely CIDP” (n=118) based upon their responses within the questionnaire. Of those with “likely CIDP”, the most bothersome symptoms at the time of starting treatment were loss of balance/coordination, weakness in hips/legs, and pain and numbness in hands and feet. Among all respondents,

24% moved to a new home and 40% made adaptive home changes after they were given a CIDP diagnosis. Moreover, 47% stopped working after the diagnosis, 20% missed school/work within the past month, and 14% made changes to their work environment (eg. reducing hours). The two most common treatments were intravenous immunoglobulin (IVIG) [63% currently using] and corticosteroids (19%). Corticosteroids were discontinued in 68% of users, among these 37% discontinued due to tolerability issues. A full day or more from school/work was missed with each infusion session in 27% of IVIG-treated patients and venous access difficulty was reported by 8%. A subgroup analyses (n=32) showed that benefits of SCIG administration and avoiding difficulties with IVIG infusion were the most common reasons for SCIG preference (81% and 38% respectively).

Further analysis by stratification group will be presented.

AUTHORS & AFFILIATIONS

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Congress Eliminates the Hard Cap on Outpatient Physical Therapy Services under **MEDICARE** Part B

Philip Goglas II, Legislative Director

Health and Medicine Counsel of Washington

The “Balanced Budget Act of 1997” imposed a \$1,500 cap on outpatient therapy services. Section 4541 (c) and (d) of the act increased the financial limitation to no more than \$1500 of the incurred expenses in a calendar year, and applied it to outpatient therapy services furnished in skilled nursing facilities, physician’s offices, home health agencies (Part B), skilled nursing facilities (Part B), in addition to physical therapist private practice offices. The effective date of this \$1,500 cap was January 1, 1999.

Recently, Congress passed a fix for the therapy cap by permanently extending the current exceptions process, eliminating the need to address this issue from year to year. Among the provisions included in the new policy:

- Claims that go above \$2,010 (adjusted annually) still will require the use of the KX modifier for attestation that services are medically necessary.
- The threshold for targeted medical review will be lowered from the current \$3,700 to \$3,000 through 2027; however, CMS will not receive any increased funding to pursue

expanded medical review, and the overall number of targeted medical reviews is not expected to increase.

- Claims that go above \$3,000 will not automatically be subject to targeted medical review. Instead, only a percentage of providers who meet certain criteria will be targeted, such as those who have had a high claims denial percentage or have aberrant billing patterns compared with their peers.

Congress chose to offset the cost of the permanent fix (estimated at \$6.47 billion) with a last minute addition of a payment differential for services provided by physical therapist assistants (PTAs) and certified occupational therapy assistants (COTAs) compared with payment for the same services provided by physical therapists (PTs) and occupational therapists (OTs), respectively.

The payment differential states that PTAs and OTAs will be paid at 85% of the Medicare physician fee schedule beginning in 2022.

Learn more from our experts at the Health & Medicine Counsel at the 2018 Symposium, November 1-3!

2018 SYMPOSIUM UPDATE!

NOVEMBER 1-3, 2018 • San Diego, CA

Just months away! Symposium 2018 will feature a wide array of presentations and workshops led by world renowned medical professionals, and will offer a unique opportunity for those affected by GBS, CIDP, and variants, to meet with other patients and families from around the world.

We are delighted to share that the following presenters from our esteemed GBS|CIDP Medical Advisory Board have been confirmed:

Dr. David Cornblath, Dr. Kenneth Gorson, Dr. Bart Jacobs, Dr. Richard Lewis, Dr. Jeffrey Allen, Dr. Jon Katz, Dr. David Saperstein, Dr. Diana Castro, Dr. Carol Lee Koski and Dr. Joel Steinberg.



Breakout sessions will include:

Pain Management, Research Updates, Insurance & Advocacy, New Therapies, Life After GBS, Managing Fatigue, Vaccinations, PT/OT and Exercising on Your Own, All about Infusion Process, Managing Stress, What if My Treatment isn't Working?, Managing Residuals...and more!

The Symposium will be held at the beautiful Hilton San Diego Resort & Spa, located on scenic Mission Bay. The San Diego resort is situated on an 18-acre park with lush gardens and rolling lawns, just steps from the beach. Hilton San Diego Resort & Spa is an ideal destination for exploration!

Hilton San Diego Resort & Spa

1775 East Mission Bay Drive
San Diego, California 92109
Telephone: +1 619-276-4010



For special group rate, when reserving please mention:

Group Name: GBS | CIDP Foundation Symposium 2018.

Group Code: GBS108

REGISTER for SYMPOSIUM TODAY!

Register for the Symposium at <https://www.gbs-cidp.org/symposium/symposium-registration/>
or call the GBS|CIDP Foundation International at 610-667-0131.

Registration rate will increase August 15th- Don't miss out on early bird discounts!
Please Note: All Event Registration Cancellations will be subject to a \$25 processing fee.
Hotel Cancellations are up to the hotel's discretion.



All About Home Infusion – What to Expect!

Meet Infusion Nurse, Amy Clarke

Amy Clarke is a registered nurse and has been in the specialty and home infusion space since 1994. Ms. Clarke has a passion for immune globulin therapy having done over 2000 intravenous and subcutaneous infusions to date. Working with home infusion pharmacy in the 1990's it became quickly evident that IVIG was often not well understood by nursing staff, pharmacies, payers, and in many instances the physicians themselves.

Amy has provided multiple presentations on IVIG and SCIG administration specifics, including CE presentations for the National Home Infusion Association (NHIA); Infusion Nursing Society (INS) and the Immunoglobulin National Society (IgNS). Amy is currently Director of Nursing Clinical Program Services for Diplomat Pharmacy's Specialty Infusion Group and is the IgNS president emeritus for the 2016-2018 term. Please join us in welcoming Amy to the Symposium team of presenters!



symposium zen den

Meet Zen Den Facilitator, Pam Butler

How do you cope with the stress of living with a rare neurological condition? This year we are excited to announce the inclusion of a new feature – the 2018 Symposium Zen Den! What is a Zen Den you might ask? Throughout the weekend the Zen Den will provide a place to unplug, relax and enjoy discovering the best practices for stress management. Sessions will include “stress less” presentations, mindful morning yoga, guided meditation, chakra balancing and more. A few stops at the Zen Den and you are guaranteed to leave the symposium with a brand-new plan for calming your emotions and feeling your everyday best.

Our Zen Den will be facilitated by Pam Butler, a familiar face to the GBS|CIDP community. Pam is a certified meditation and yoga instructor, and a Transformational Bliss Coach who provides workshops, classes, and instruction to individuals, groups, and businesses throughout the South Florida community, and the author of *Return to Life: Finding Your Way Back to Balance and Bliss in A Stressed-Out World*.

More details to come in the upcoming months!



April, 2018 American Academy of Neurology Annual Meeting

Executive Director
Lisa Butler, along with
members of the GBS|CIDP
Medical Advisory Board

gathered at the CSL Behring display booth at this year's American Academy of Neurology Annual Meeting.

Pictured above (left to right) Dr. Jeff Allen, Dr. Rich Lewis, Dr. David Saperstein, Lisa Butler, Dr. Diana Castro, Dr. Robert Lisak, Dr. Gil Wolfe.



May, 2018 Immunotherapy for Neurologic Disorders Conference

Kelly Mccoy and Lori Baseige
from the GBS|CIDP staff
attended the Immunotherapy
for Neurologic Disorders on

May 18 in Philadelphia, along with GBS|CIDP GMAB member, Dr. Gil I. Wolfe, MD FAAN, Irvin and Rosemary Smith Chair Department of Neurology from University at Buffalo Jacobs School of Medicine and Biomedical Sciences/SUNY Biomedical Sciences/SUNY. Dr. Wolfe spoke at the conference on the topic: “Myasthenia Gravis.”

WALK & ROLL

Walk & Roll for GBS|CIDP is a great way to raise awareness, show your support, make friends and build a local network. Have you heard the 2018 Walk & Roll news? We are walking for research! *Thus far (as we write this newsletter) we have raised \$70,000 toward our goal of \$150,000!*

Funds raised through our walk program will specifically help to support our research initiatives including:

- Diagnosis** Developing methods to more rapidly diagnose GBS, CIDP and its variants, such as MMN.
- Treatments** Developing more effective treatments to limit the disease progression, prevent complications and reduce long-term adversities.
- Genetics** Identifying mechanisms involved in the pathogenesis of family disorders.

2018 Walk & Roll Schedule:

Philadelphia • 6/3/2018
 San Francisco • 6/9/2018
 New Jersey • 6/10/2018
 Seattle, WA • 8/25/2018

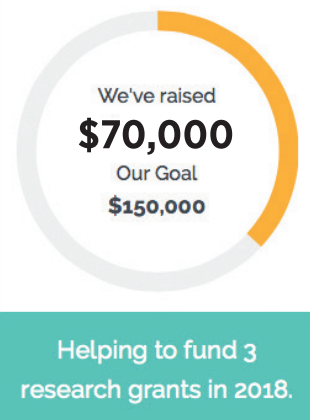
Myrtle Beach • 9/8/2018
 Portland, Oregon • 9/9/2018
 Staten Island, NY • 9/15/2018
 Pittsburgh, PA • 9/15/2018

Columbus, OH • 9/23/2018
 Indianapolis, IL • 9/29/2018
 Symposium • 11/1/2018
 Partial listing (more dates to come).

Walk & Roll for GBS-CIDP

Volunteer for Walk & Roll

WALK & ROLL FOR RESEARCH



Find a walk near you, or it's not too late to plan one of your own!

Contact Walk & Roll Manager

Jessica McManus

jessica.mcmanus@gsb-cidp.org

Stay up to date with our minute by minute fundraising count at www.gbs-cidpwalk.org

Clovis Walk & Roll Breaks Record!



The GBS|CIDP Foundation International is delighted to share this important Walk & Roll update! On March 10 at Dry Creek Park in Clovis, California, GBS volunteer and Clovis Walk Chairman, Robert Vasquez hosted an exciting Walk & Roll fundraising event with a record-breaking 300 walkers in attendance! Thus far the event has raised over \$9,000 (and counting) to support GBS|CIDP research.

The festivities included a one-mile walk, presentations from Robert and attendees, a post walk celebration and fundraising raffle. Nearly 20 affected patients were in attendance along with GBS San Francisco Walk Chairman, and GBS Foundation Executive Board Member, Russ Walter. The Foundation would like to express sincere gratitude to Robert, his family and community, and all of the walk participants. Every step makes a difference to those living with GBS|CIDP or a variant of the condition!

Calling all Volunteers!

The GBS|CIDP Community Needs You

we need
you!

We are so proud of having 160 chapters around the world. After all – that is what we are here for, to network patients and support them through their entire journey. Our liaison volunteers are as invaluable as they are inspiring!

However, there are some parts of the United States which are underserved. If you live in Alaska, Arkansas, Kansas, Maine, Mississippi, New Hampshire, North Dakota, North Nevada, Rhode Island, South Dakota, Southern Utah, West Virginia or Wyoming, and are interested in volunteering and starting a GBS|CIDP Chapter, please contact Kelly Mccoy, kelly.mccoy@gsb-cidp.org.



CHAPTER MEETING SCHEDULE

Partial listing (more dates to come).

DATE	CHAPTER LIAISON	LOCATION	CITY, STATE	SPEAKER
3-June	GBS CIDP	Conshohocken Marriott	Conshohocken, PA	Sami Khella, MD
9-June	Bill Ansley	The Dempsey Family Education & Resource Center	Columbus, OH	Elizabeth Thirtyacre, RN
16-June	Ray Lopez	The Regina McGuinn Educational Center	Staten Island, NY	Dr. Edward Yu
16-June	Wayne Bowyer	Augusta Health	Augusta County, VA	Augusta Health
30-June	Bruce Simpson	Tulsa Brookside Library	Tulsa, OK	Dr. Tomas Martinez
14-July	Janice Dunkerton	African Inland Mission Retirement Center	Minneola, FL	Virginia Kraus

To find a meeting near you visit gsb-cidp.org/events-calendar.

Find a GBS|CIDP chapter meeting near you at <https://www.gsb-cidp.org/events-calendar/>.
Interested in planning one of your own? Contact Kelly McCoy, kelly.mccoy@gsb-cidp.org.

Estelle Benson Named 2018 NORD Honoree for Abbey S. Meyers Leadership Award

The National Organization for Rare Disorders (NORD) celebrated the 35th anniversary of the Rare Impact Awards on May 17, 2018 in Washington DC. We are proud and delighted to announce that our Founder, Estelle Benson, accepted the Abbey S. Meyers Leadership Award on behalf of GBS|CIDP Foundation International.

The Rare Impact Awards is an annual event hosted by NORD, the leading independent nonprofit organization representing the 30 million Americans with rare diseases, and brings together supporters of the organization's mission. This year celebrated NORD's 35 years as well as those who are boldly leading efforts to make a difference for people living with rare diseases.



2018 GBS|CIDP Foundation Recognizes Estelle Benson at Annual Board Meeting



GBS|CIDP Staff and Board of Directors met for their annual Board Meeting in Philadelphia on April 28. Many Foundation items were discussed including Financial Holdings, Communications Strategy, Hospital Awareness Program, Research Grant Program and planning for the upcoming 2018 Symposium Program.

A congratulatory toast was made to Estelle Benson for her recent NORD Rare Impact Abbey Meyer's Leadership Award. New Board member Josh Baer was welcomed to the team.



2018 PNS Annual Meeting • July 20-25, 2018

Once again the Foundation looks forward to participating in The Peripheral Nerve Society annual meeting this July in Baltimore, MD. A report from this meeting will appear in the 2018 fall newsletter.



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Do you live in the EU?

As of May 25, 2018 the EU General Data Protection Regulations require new consent forms for those who reside in the EU, so we can continue to send you communications from the GBS|CIDP Foundation.

If you wish to continue to receive communications from the Foundation, please re-subscribe at:

[https://www.gbs-cidp.org/
about/contact-us/](https://www.gbs-cidp.org/about/contact-us/)

Diagnosed with MMN?

Contact: Dominick Spatafora
dominck@dvsconsultants.com

Miller Fisher Variant Group

Please call us for contact with others.

Children with GBS

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

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, contact us to sign up!

International Office:
610-667-0131

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

AMAN
AMSAN
Anti-MAG
Campylobacter
GBS X2
Miller Fisher
MMN