GBS|CIDP FOUNDATION INTERNATIONAL

The Communicator

PROVIDING STRENGTH THROUGH SUPPORT

GBS|CIDP Foundation International

Working for a future when no one with Guillain-Barré syndrome (GBS,) Chronic Inflammatory Demyelinating Polyneuropathy (CIDP,) and related syndromes such as Multifocal Motor Neuropathy (MMN) suffers alone and that everyone has access to the right diagnosis and the right treatment, right away.

IN THIS ISSUE

BETWEEN *fire&favor*

By Violet Amukonyi

SURVIVING GUILLAIN-BARRÉ SYNDROME

I am from Kenya. My symptoms began on July 10th, 2022. I started experiencing strange weakness and tingling sensations in my body. Over the next few days, these symptoms worsened rapidly. After a frustrating and confusing period of uncertainty, I was finally diagnosed with Guillain-Barré Syndrome (GBS) on July 15th. What followed was an urgent transfer to the High Dependency Unit (HDU) where I received IVIG treatment for five days.

The shock of the diagnosis and the speed at which my body deteriorated was overwhelming. I was completely dependent on others, even for the simplest tasks. I spent one month admitted at The Mater Hospital, undergoing specialized care. After that, I began a six-month period of intensive physiotherapy and occupational therapy to help me recover mobility and function.

The journey was filled with physical pain, emotional distress, and mental exhaustion. I had to relearn everything—from sitting up to

"The shock of the diagnosis and the speed at which my body deteriorated was overwhelming."

Violet

continued on page 3 ▶

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

Dear Friends,

Although this year has been challenging for so many, the world over, I am proud and honored that the Foundation truly is a place of unity, inclusivity and support for ALL in need.

In these pages you will learn about our global champions from regions of Africa, New Zealand, Germany, Spain, South America and Nepal. You will learn about a new Physical Therapy series that was specifically designed for global access to strength and balance, and a coffee chat series to inspire and support our young adults, who are facing the challenge of neurological disorders, in the midst of the often most demanding stage of life. And you will be supported by our staff in finding mental health resources, and the best ways to stay connected to our community,

I am continually awed by our global community's willingness to engage with our mission with open arms, no matter where in the world they reside, or what they themselves may be facing; to always treat others with respect - to be kindred, to hold a space of unconditional support, and to make this foundation a home for all.

I am forever inspired and eternally grateful.

Sincerely,

Lisa

Lisa Butler, *President and CEO*

GBS|CIDP Foundation International

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

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

Nonprofit 501 (c)(3)

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

Privacy Policy: In response to many queries: Intrusive practices are not used by GBS|CIDP Foundation International. The organization does NOT sell its mailing list nor does it make available telephone numbers. Liaisons are listed in the contacts & resource 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.

Violet continued

Violet visiting with a GBS patient in Kenya. "The visit was a moment to give hope — reminding both the patient and caregivers that recovery is possible, progress may be slow but it is real, and they are not alone on this journey."

walking. But through it all, I found strength in my faith, my family, friends, my church, and the incredible healthcare professionals who stood by me.

During this period, I learned to appreciate the power of community. My support system became my lifeline. Their visits, prayers, words of encouragement, and constant check-ins reminded me that I was not alone. Each day brought small victories—moving a finger, sitting unaided, taking a few steps—and we celebrated them all.

GBS changed my life completely. It forced me to pause, to re-evaluate, and to trust God more deeply. It taught me resilience, patience, and gratitude. Healing was not instant, but every bit of progress was a miracle I didn't take for granted.

Today, I am still on a recovery journey. There is still some numbness in my feet, and my energy levels fluctuate, but I am walking, I am independent, and I am hopeful. GBS may have interrupted my life, but it didn't stop my story. I have come through fire. It was truly uplifting to witness the impact of encouragement and shared understanding. These moments matter so much to patients and families walking the GBS journey. Violet became a Foundation volunteer officially in 2026. She's actively supporting her local community through events and outreach.

GBS may have interrupted my life, but it didn't stop my story. I have come through fire.

Violet

No One Rides Alone

CLIVE PHILLIPS' TOUR de MMN

In 1993, Clive Phillips stood at the bottom of the Col du Télégraphe, a mountain pass in the French Alps, watching the world's top cyclists tackle the climb during the Tour de France. Some 30 years and a Multifocal Motor Neuropathy (MMN) diagnosis later, Clive found himself back in the same spot. This time, he was the one who was cycling.

The Tour de MMN was supported by argenx.

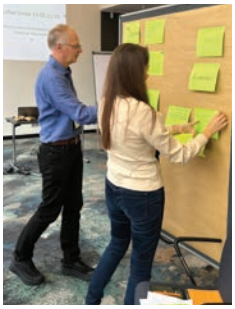
READ MORE ▶ ABOUT CLIVE'S ADVENTURE HERE:

Above, full Tour de MMN Team, with Ben Watson (British Para-cyclist and GBS patient) and Ilaria Brugnoli (Italian para-triathlete, and MG patient)

"It's about finding your Tour de France. Something that's meaningful to you."

CLIVE PHILLIPS, MMN PATIENT

PRINCIPLES OF Care



PRINCIPLES OF CARE FOR CIDP WORKSHOPS 2025

Summary and Next Steps

In October and November 2025, the Principles of Care (PoC) for CIDP project brought together patient advocates and healthcare professionals from across Europe through two in-person workshops designed to strengthen the evidence base for improving CIDP care.

This international initiative by GBS|CIDP Foundation International and the European Patient Organisation for Dysimmune and Inflammatory Neuropathies (EPODIN), supported by Patvocates, is developing a patient-centered framework to help improve care standards, support advocacy, and inform health policy discussions.

The workshops in Berlin and Barcelona brought together representatives from more than 14 European countries to examine challenges and potential solutions from both clinical and health system perspectives. Participation across both workshops was strong and provides a solid foundation for the next phase of work, including follow-up interviews and synthesis across community experience and clinical practice. The Foundation would like to thank all participants and collaborators for their time, expertise, and commitment to improving CIDP care. We gratefully acknowledge the support of our sponsors: argenx, Grifols, Johnson & Johnson, Sanofi, and Takeda. The project will now move into the next steps, including a post-partnership forum meeting with sponsors, continued collaboration, follow-up individual interviews, a third workshop bringing patient advocates and healthcare professionals together, and further development of the Principles of Care for CIDP into a manuscript.

CHAMPIONS FOR change

YOUNGADULT SERIES

JOCELYN DELGADO

Navigating young adulthood with GBS or CIDP comes with unique challenges—from relationships and career transitions to managing energy, symptoms, and daily routines. In January, the Foundation launched a new six-week coffee chat series designed by and for young adults (ages 18–35) looking for practical tools, honest conversation, and community. Led by Jocelyn, Occupational Therapy student and CIDP patient, each session covered topics that matter most, including communication and boundaries, social participation, school and work navigation, adaptive technology, online safety, and energy-efficient meal planning. This interactive series offered evidence-informed strategies to build confidence, strengthen routines, and support a more balanced life.

Join our YA Facebook for our calendar of events!

ASK THE HEALTH NAVIGATOR

MORGAN DUHE, GBS|CIDP Health Navigator

SUPPORTING EMOTIONAL WELLBEING THROUGH THE GBS, CIDP & MMN JOURNEY

The diagnosis and treatment process for GBS, CIDP, MMN and related conditions can feel incredibly overwhelming for patients and care partners. Many people describe feeling depressed, anxious, or simply exhausted by the challenges. You are not alone in this journey, and it's important to remember that emotional wellbeing is an important aspect of overall health. In honor of Mental Health Awareness Month, we're highlighting resources that can help support your mental health and overall wellbeing. Whether you're looking for practical tools, a listening ear, or simply reassurance that others have walked this path too, there is support available.

What resources does the Foundation offer?

The Foundation offers connections with volunteer liaisons who provide peer-to-peer support. Most of the liaisons are current patients, or family members of patients who have their own experiences with these conditions. To connect with a volunteer near you, visit: ***https://www.gbs-cidp.org/support/resources/connect-with-a-volunteer/*** or contact the Foundation by phone to request to be connected with a volunteer liaison. We also offer a wide range of fun and educational events designed to help people connect, learn, and feel supported. Our Coffee Chats are casual, virtual meetups that offer a relaxed space to check in with the community, share experiences, and simply say hello. Our Speaker Series is an ongoing webinar program featuring knowledgeable experts from across the Foundation's community. Each Speaker Series session is presented live and recorded, with all episodes available to watch on-demand through our website. There are many additional opportunities for connection in the form of Chapter Meetings, Walk-and-Roll events, and other activities. To explore the full calendar of upcoming Foundation events, please visit: ***https://www.gbs-cidp.org/events-calendar/***

Where do I start looking for mental health services?

There is growing recognition that obtaining access to mental health services can be challenging; especially when confronted by mental health symptoms. In response, many health insurance companies have developed services to support their members in connecting with requested mental health services. Although it may not seem like an obvious choice; the customer service department of the entity that provides coverage for your medical services can be a good place to begin connecting with mental health treatment. It's worth noting that in the US, Medicare has expanded its mental health coverage over the years and now includes many types of mental and behavioral health services.

Are there any resources specifically for patients with rare diseases?

Rareminds is the first specialist, non profit, rare disease counseling and psychotherapy service in the United Kingdom. They work to provide affordable, timely access to highly specialized counseling for the rare disease community, and campaign for recognition of the importance of specialist mental health support by informing policy, practice and promoting standards of excellence. For more information, please visit: ***https://www.rareminds.org/***

Doctor Al Freedman is a psychologist and consultant in the United States who has personal experience with rare disease. In addition to providing Keynote Presentations and Trainings, Dr. Freedman has a private practice called Freedman Counseling Associates. For more information, please visit: ***https://www.rarecounseling.com/***

WALK Calendar

Walk season is here! You can now register to join our community as we come together to support one another, show that no one is alone in their journey, and help raise funds to advance critical research related to GBS, CIDP, and MMN.

MARCH 21, 2026
Clovis, CA

APRIL 26, 2026
Denver, CO

MAY 9, 2026
New York, NY

JUNE 6, 2026
Philadelphia, PA

JUNE 14, 2026
Bernards Twp., NJ

JUNE 27, 2026
Houston, TX

JULY 11, 2026
Chicago, IL

JULY 26, 2026
Twin Cities, MN

AUGUST 1, 2026
Des Moines, IA

AUGUST 22, 2026
Portland, OR

SEPTEMBER 5, 2026
Kansas City, MO

SEPTEMBER 19, 2026
Pittsburgh, PA

SEPTEMBER 19, 2026
Detroit, MI

OCTOBER 3, 2026
Mobile, AL

OCTOBER 4, 2026
Washington, DC

OCTOBER 10, 2026
Los Angeles, CA

OCTOBER 17, 2026
Atlanta, GA

OCTOBER 17, 2026
Phoenix, AZ

OCTOBER 24, 2026
Columbus, OH

TBD – Seattle, WA

TBD – Cincinnati, OH

TBD – Durham, NC

TBD – San Francisco, CA

TBD – Birmingham, AL

> "BEING SURROUNDED BY OTHERS WHO UNDERSTAND EVERY STEP IS A VICTORY AND WE'RE ALL HELPING EACH OTHER MOVE FORWARD IS POWERFUL. THE WALK AND ROLL IS A CELEBRATION OF PROGRESS, CONNECTION, AND FRIENDSHIP.
>
> *Catherine Sheridan* GBS

GBS | CIDP Foundation International

WALK AND ROLL

REGISTER TODAY →

HILL DAY Q&A

JACOB FULLER, ADVOCACY MANAGER

1

What is Hill Day, and why is it important for our conditions?

Each year, the GBS|CIDP Foundation International hosts its annual Hill Day, convening patients and advocates in Washington, D.C. to meet with lawmakers, and share their stories. The goal is to advance the Foundation's legislative agenda and raise awareness of our conditions in Congress. While all of our outreach elevates patient voices Hill Day provides the greatest opportunity for legislators and their staff to engage directly with our patient community and is an invaluable tool in advocating for our community.

2

I'm interested – how do I sign up to get involved?

Individuals interested in attending Hill Day should contact Jacob at Jacob.Fuller@gbs-cidp.org. We are always looking for new advocacy volunteers to join us on the Hill. If selected to participant, the Foundation will cover travel related expenses. If Hill Day isn't an option for this year, there are so many other ways to get involved with advocacy, like writing letters or holding visits in your district. We can help you find the right activity for your interests!

3

What should I expect? What is Hill Day like?

Patients will meet in small groups and attend a training session held by the Foundation staff and our lobbying team. The next morning, patients work with their group to travel to office buildings on Capitol Hill and meet with staff in a variety of Congressional offices. These meetings give each person a chance to share their story and highlight the Foundation's work. Typically, groups will meet with 4-6 offices throughout the day, with a break for lunch.

4

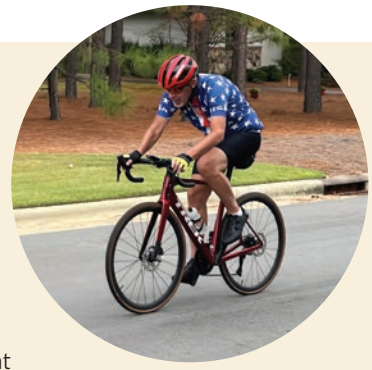
What if I need accommodations?

All Hill Day participants who require accommodations such as powered scooters or accessible hotel rooms have them provided on behalf of the Foundation. In case of offices being narrow or cluttered, meetings can be held outside of offices in hallways or other accessible areas. Capitol office buildings also have several elevators and accessible entrances. Breaks are included between meetings to account for time spent arriving.

COMMUNITY-POWERED GIVING

Hi, I'm Miles Washburn and in February 2025, after battling RSV, my body took an unexpected turn and I developed Guillain-Barré Syndrome. After seven days in the ICU, I was able to go home, but recovery hasn't been easy. Nerve pain and fatigue are constant reminders of what I've been through. After my battle with GBS, I realized patients face significant financial burdens in their recovery journey, from mobility aids, therapy, or even basic comforts. That's why I've decided to pay it forward by fundraising for the GBS Patient Assistance Fund.

As a former professional cyclist, I'm embarking on a new challenge. On August 24, 2026, I'm riding up Mount Ventoux in France (16.2 mile) climb, all uphill, to a summit of 6,263 feet. Known as the "Giant of Provence," this mountain has tested the world's strongest riders — and now it stands as a symbol of faith, resilience, and the climb toward recovery for everyone affected by GBS.



LEARN MORE ABOUT THIS FUNDRAISER ↓

FOLLOW MY JOURNEY ON FACEBOOK ↓

CYCLE & GOLF CHALLENGE

Cycle & Golf Challenge

SEPTEMBER 13-16 // BOULDER, CO

One of our amazing community members is participating in a special event that combines cycling and golf to raise funds for the GBS|CIDP Foundation International.

This fundraiser supports vital programs that provide education, research, and support for individuals and families affected by GBS, CIDP, MMN, and related conditions. Together, these efforts help strengthen and support our community. We're so grateful for community members who turn their passions into purpose.

LEARN MORE OR GET INVOLVED →

Raise a Glass!

ANDY HARRIS IS BACK AT IT!

For the third year, Andy, a GBS survivor in partnership with Mast Landing Brewing Company in Freeport, ME will hold a fundraiser for the GBS|CIDP Foundation. Each year, they brew their signature GBS IPA inspired by his story, donating a portion of the proceeded to the Foundation. This year, the event will tentatively take place on April 18.

Location

200 Lower Main Street, Suite 102
Freeport, ME 04032

GBS|CIDP

MAY AWARENESS Month

Guillain-Barré Syndrome | Chronic Inflammatory Demyelinating Polyneuropathy

DO YOU HAVE A MINUTE FOR GBS?

This year marks 110 years since GBS was first identified. To commemorate this occasion, we are asking for just one minute of your time to raise awareness world-wide.

GBS|CIDP AWARENESS MONTH IS JUST AROUND THE CORNER!

There's no time like now and no time to waste, contact us to find out how just one minute can have an impact on the future of GBS. If you are a patient, care partner, or health care professional having a lived experience with GBS, take a minute, reach out to Maureen.Neville@gbs-cidp.org, say "I have a minute" in the subject line, and find out more!

European Conference in Milan, Italy

OCTOBER 10, 2026

Sheraton Milan San Siro

This one day regional conference will be held in Milan, Italy for our patients, families and healthcare professionals in the European Region. We will be producing this conference in partnership with our European Allied Partners as well as our Global Medical Advisory Board.

SCAN BELOW TO REGISTER TODAY!

NEW VIDEO SERIES

BASIC MOVEMENTS FOR BALANCE & STRENGTH

We are delighted to introduce a 6-Part Balance & Strength series produced by members of the Foundation's Interdisciplinary Health Committee and patients from the community, now available on our website. These simple exercises, instructed by Physical Therapist, Maria Harris & Occupational Therapist, Kathleen Rocca of Bryn Mawr Rehabilitation, as well as Yoga Therapist, Sterling Painton, are a great way to improve balance and support confident, stable movement.

SCAN THE QR CODE FOR MORE INFORMATION.

A TRANSFORMATIONAL $1.2 MILLION GIFT BRINGS NEW HOPE TO THE MMN COMMUNITY

The GBS|CIDP Foundation International is proud to announce a landmark $1.2 million gift from anonymous donors to advance research and treatment for Multifocal Motor Neuropathy (MMN).

This first-of-its-kind donation represents one of the largest single investments dedicated specifically to MMN and marks a pivotal moment for the future of the disease. The generous commitment will provide sustained funding to support critical research initiatives, accelerate scientific discovery, and help improve treatment options for individuals living with MMN for years to come.

"This extraordinary gift is truly transformational," said Lisa. "It sends a powerful message of hope to patients and families affected by MMN and underscores the importance of continued investment in rare disease research. Because of this donor's vision and generosity, we will be able to support meaningful advancements that were previously out of reach."

Funds from this donation will be directed toward advancing MMN-specific research efforts, fostering collaboration among leading researchers and clinicians, and laying the groundwork for future breakthroughs in diagnosis and treatment. By providing long-term support, this gift ensures that progress in MMN research can continue steadily rather than in short, uncertain cycles.

As we recognize MMN Awareness Month, we celebrate not only this historic gift but also the resilience of the MMN community and the collective effort to drive progress forward.

SAVE THE DATES

GBS|CIDP SYMPOSIUM 2027 10.28-30.2027 Boston

The 2027 GBS|CIDP Patient Symposium is coming to Boston! Join us for an inspiring gathering of connection, education, and community in the heart of this historic city from October 28-31, 2027. Stay tuned for more details!

NEW STAFF

Holly Maddams

Director of Development

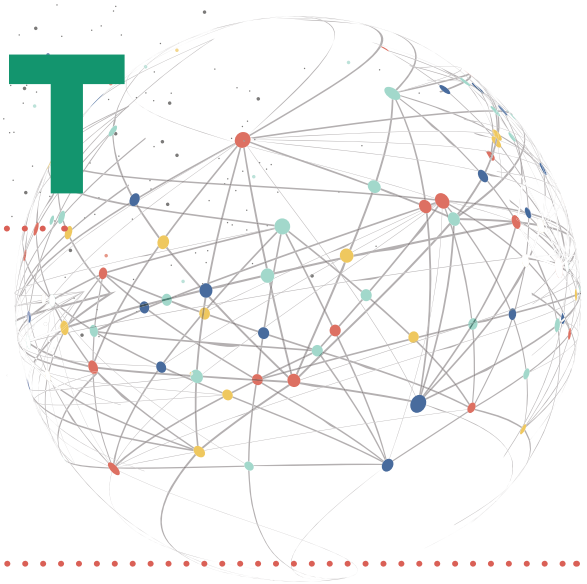
Holly joined the Foundation in December. She has more than 20 years of nonprofit leadership experience, including organizations that address chronic diseases. Most recently, she served in a leadership role with the Arthritis Foundation focused on raising awareness, building relationships with the patient community, and partnering with healthcare providers and corporate partners to secure support for critical programs, services, and research investments. Holly has a Masters in Public Administration from Widener University. Outside of work, she is a big Philly sports fan who enjoys cycling, any opportunity to be outside, and spending time with her adult sons – identical twins who have been her greatest adventure.

Sandra Bermudez

Program Manager, Latin America

Join us in welcoming Sandra Bermudez of Mexico to the Foundation team! Driven by a deep passion for helping others live fuller and more joyful lives, Sandra is a Psychologist, Health Coach, MBSR-certified practitioner, and a member of the International Association for Health Coaches. She gently guides individuals in developing emotional awareness, training the mind, finding balance between work and life, and creating meaningful goals aligned with their values. Sandra has been a volunteer since 2023 and as Program Manager – LATAM, will play a key role in implementing and managing local & virtual educational programs, growing our volunteer base in Latin America, seeking partnerships with regional healthcare entities & professionals, and leading community-building initiatives across the region.

2026 VIRTUAL SUMMIT



On May 30, our 2026 Virtual Summit will feature a wide range of educational panels and presentations, as recorded at the 2025 Denver Patient Symposium. The Virtual Summit will showcase the best practices for navigating the journey through GBS, CIDP, MMN, or variant conditions. Topics are presented by a world-renowned team of medical and wellness professionals specializing in healthcare for rare neurologic conditions. Stay tuned for more information about this event!

GBS | CIDP Foundation International
Center of Excellence 2026
Guillain-Barré Syndrome (GBS) Chronic InflammatoryDemyelinating Polyneuropathy (CIDP)

ADVANCING GBS, CIDP, AND MMN CARE ACROSS AFRICA

The Foundation is proud to announce the launch of a new Center of Excellence at Inkosi Albert Luthuli Hospital in Durban, South Africa. We are also pleased to welcome two new partners dedicated to serving and connecting with the rare disease community: GBS Foundation Kenya and GBS-CIDP South Africa. Together, these initiatives strengthen our commitment to improving diagnosis, treatment, and care for individuals affected by GBS, CIDP, and MMN across the African region.

CHAPTERS FIND LOCAL SUPPORT

We would like to welcome our newest chapter in Nepal in South Asia! If you are interested in finding one near you, please call 610-667-0131.

FREE EVENT!

COMMUNITY DAY

PHILADELPHIA , PA
PENN PRESBYTERIAN MEDICAL CENTER

SATURDAY, MAY 9, 2026

8:00 AM – 3:00 PM

Penn Presbyterian Medical Center
Heart and Vascular Pavilion, 3rd Floor
51 N. 39th Street, Philadelphia, PA 19104

YOU'RE NOT ALONE

Experience Healing through Community

These all-inclusive events offer *Healing through Community:* meaningful opportunities to connect with knowledgeable healthcare professionals, fellow patients, and trusted educational resources — all in a supportive, welcoming environment.

Whether you're newly diagnosed or further along in your journey, Community Days provide education, understanding, and community to help you feel informed, empowered, and supported.

REGISTRATION REQUIRED
Please scan the QR code to register today ▶

GBS|CIDP Foundation International
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Conshohocken, PA 19428

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SUPPORT EDUCATION RESEARCH ADVOCACY SUPPORT EDUCATION RESEARCH ADVOCACY

↘ MONTHLY EVENTS EMAIL

To streamline our email communications, we're starting a new monthly event mail for our community. If you are on your mailing list, you will now receive a monthly event email that contains the virtual and in person programs for that month from Coffee Chats to Chapter Meetings. Not subscribed? Scan the QR code to sign up today!

The event calendar also lives on the Foundation website: *https://www.gbs-cidp.org/events-calendar/*

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

DIAGNOSED WITH MMN?
Contact Volunteer Brenda Perales
brendajp62@icloud.com

MILLER FISHER VARIANT GROUP
Please call us to connect with others.

CHILDREN WITH GBS
Lisa Butler, 610-667-0131
GBS|CIDP Foundation International
Lisa.butler@gbs-cidp.org
Son, Stuart, had GBS at 5 1/2 years old

CHILDREN WITH CIDP
For children diagnosed with CIDP contact Holly Cannon whose daughter, Hailey, has CIDP, Holly.cannon@gbs-cidp.org. For more information on our youth, teen, and young adult (YTA) programming contact info@gbs-cidp.org.

INTERNATIONAL OFFICE
610-667-0131

LOOKING FOR A 20-SOMETHING CONTACT?
For more information on Youth, Teen and Young Adult (YTA) programming, contact info@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 info@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.

PREGNANT WOMEN WITH CIDP
Kelly McCoy
Director of Patient Engagement
GBS|CIDP Foundation International
Kelly.McCoy@gbs-cidp.org

ADVOCACY
If you are interested in advocacy activities on a federal, state, or local level, contact Director of Research and Advocacy Chelsey Fix, Chelsey.Fix@gbs-cidp.org.

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

gbscidp gbscidp gbscidpfoundation

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.**