

IMPACTREPORT

ROOTED IN VISION, BRANCHING INTO THE FUTURE.





Dear Friends,

We have truly entered the wide-lens era of the Foundation, where our focus has broadened to every corner of the world.

Our worldwide global network of patients, volunteers, and medical experts has grown far beyond our wildest imagination. People who are experiencing or working with these conditions, are not only finding us, but we have created a pathway where they are able to find each other. And you, our loyal supporters, have been right by our side every step of the way.

With your support we have bridged more underserved communities than ever before. Our worldwide community outreach has provided patients and caregivers who are struggling for health care access and emotional support, with the medical and social support they so need and deserve. Notably this year we've been able to create an international "scientific think tank" and tap into the minds of leading scientists and physicians studying and researching GBS, CIDP, MMN for a better tomorrow.

We've also built our full time team to include social services, international program management, and expert strategic planning. All the ingredients necessary for us to continue our mission of finding those who are walking alone, showing them the way, and welcoming them in to our global family. The impact we have been able to make has been tremendous, sustaining, and remarkable, and we could not have done any of it without you!

As we celebrate our 45th year as a Foundation, let's also renew our commitment to each other- to listen, to uplift, to advocate, and to keep pushing forward. Let's celebrate how far we've come and envision what's next. When patients, families, researchers, and advocates come together, there is no limit to what we can achieve!

With much appreciation,

Gratefully,



Lisa Butler
President and CEO



corevalues

Patient Inclusivity

We believe in patient inclusivity. Therefore, we will empower and prioritize the voice of the patient community in all Foundation decisions and activities.

Inclusivity and Health Equity

We acknowledge the harmful impact of disparities on the communities we serve. By building the core values of inclusivity and health equity into our operations we will seek to dismantle inequalities and intentionally make space for positive outcomes to flourish.

Empowerment

We will empower the patient community by providing opportunities, support and education to advocate for themselves at every step of their journey.

Innovation

We will endeavor to be agile and adaptive by consistently seeking continuous improvement and opportunities that deliver maximum value to our stakeholders.

Trust

We see ourselves as a place of trust and integrity. Therefore, we will be open, honest, and transparent in our partnerships and actions. We will vet and verify our information with leading experts for relevance, value, and accuracy.

Compassion

We understand that the patient community faces life-changing events. For those affected, we build an understanding community of people ready to listen and respond in a timely manner. We create connections that serve as a lifeline of support throughout their journey.

“

Jeff Allen
GMAB Co-Chair



“At the GBS|CIDP Foundation International, we are committed to advancing the understanding, diagnosis, and treatment of CIDP through a multi-faceted approach. We are actively working to improve clinical outcome measures for CIDP, helping ensure more accurate diagnosis and better tracking of disease progression and treatment response. As a testimony of these efforts, a collection of leaders representing both the patient community and global CIDP experts convened in the spring of 2025 to agree upon formal definitions for key terms that can be used to make treatment decisions and follow clinical changes in patients with CIDP. We expect that these definitions will standardize the way patients, clinicians, clinical trialists and regulators talk about CIDP, and ultimately lead to better patient outcomes. The fields of GBS, CIDP, and MMN are in the midst of unprecedented clinical trial activity. These trials hold promise for more effective and safer treatment options for affected patients. The Foundation, has supported the dynamic clinical trial landscape by promoting innovation, guiding clinical trial design, providing an informational platform for prospective investigators and patients, and advocating for patient safety. We remain deeply engaged with our patient and clinician community through educational webinars, interactive Foundation meetings, and advocacy initiatives that amplify patient voices, provide clinicians with disease state awareness education, and update experts on cutting-edge therapies. Additionally, the Foundation continues to invest in clinicians and scientists that push the boundaries of science to unlock new knowledge about these disease states.”

leadershipteam

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“Over the past two years, the Foundation has experienced accelerated growth toward our vision, expanding services to reach rural, marginalized, and international patient communities. We’ve strengthened global partnerships, launched new chapters, supported advanced research, and expanded our GMAB and COEs worldwide. Our outreach continues to grow through patient events, volunteer networks, and an enhanced IT infrastructure that supports these efforts. All of this growth is united by one purpose: improving the quality of life for our patient community.”

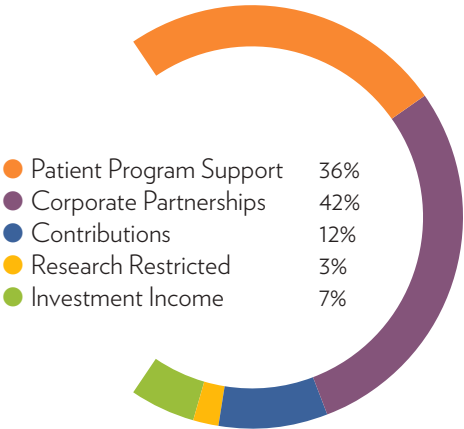
Corbin Whittington, *President, Board of Directors*

*Member is deceased

financials

REVENUE

\$4,740,541



EXPENSES

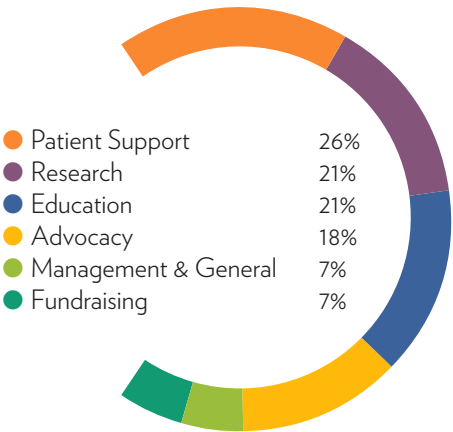
\$4,551,791

\$250,000

2024 FINANCIAL ASSISTANCE PROGRAM EXPENSE

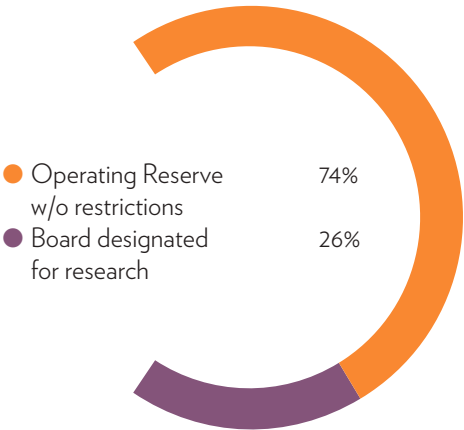
\$150,000

2025 FINANCIAL ASSISTANCE PROGRAM EXPENSE



CAPITAL AND RESERVES

\$15,145,672



REFERENCE → Audited financial report dated 12/31/2024

Celebrating 45 Years of the Foundation



A MESSAGE FROM OUR FOUNDER

When I started the organization, I envisioned a support group of GBS patients who would share experiences and support each other. Little by little it grew—and over the past 40+ years did it grow!

I am writing this message to express how awestruck I am when I witness not only the enormity of the Foundation, but the services we provide, the research we underwrite, the patient support available, financial and emotional among so much more.

I started with 1/2 person to help, she worked two half days. I could rarely pay her salary. Now we have 21 people working in a real office. They are all busy and have carried out our mission of support, education, research and advocacy. I am so pleased to know the reason my husband and I started the group was to help patients. We wanted no GBS'er to travel this journey alone. Of course, now we embrace the variants of GBS including rarer than-rare disorders, such as CIDP, MMN, ASAM etc.

How did we even get here? In looking back over the 40+ years, I experienced the caring, passion and believing in us from thousands of people—patients, caregivers and industry. Without all of you we could not have grown to where we are today.

So, in the tumultuous world we live in today, I feel blessed that something so positive, real, and meaningful to so many people exists. As part of our “family,” I feel fortunate to have helped the dream come true.

Sending love to all,

Estelle Benson
Founder

1980

OUR FOUNDER

Estelle meets Ralph Neas, known to many as a civil rights leader and president of the National Coalition on Healthcare, who donates \$2,000 to Estelle which he raised to start a Foundation. Ralph recognizes Estelle's potential and passes his dream to her!

1981

FIRST MEETING

The first support meeting, attended by eight people, was held at Estelle's house in Philadelphia.



The Leadership Collaborative

GBS|CIDP FOUNDATION INTERNATIONAL



PARTICIPANTS

Participants included members of the Foundation Team and global experts. The Steering Committee included Dr. Jeff Allen, Dr. Claudia Sommer, Dr. Filip Eftimov, and Dr. Luis Querol.

KEY EXPERTS TO ADDRESS EMERGING CHALLENGES THAT DISRUPT THE TREATMENT, CARE, OR INNOVATION IN GBS, CIDP, AND MMN.

This year's Collaborative focused on defining terminology frequently used across clinical care, research, and regulatory frameworks for CIDP. The process began by hearing from patients. In an initial meeting, patients shared their insights and interpretations of terminology commonly used in CIDP. This initial workshop was critical to the

process and influenced the direction of definitions and expanded what terms would be defined. A paper was then developed to reflect these perspectives, ensuring that the patient voice would guide expert discussions. Subsequently, key opinion leaders from the global healthcare professional community met to align and clarify those terms. Doctors from the US, Germany, Netherlands, United Kingdom, Spain, Argentina, and Japan were present. Together, they reached consensus on seven critical terms, which were presented at the most recent Peripheral Nerve Society annual meeting in Scotland. A white paper will follow to further share these findings, but the defined terms in their current form are listed on the next page. Thanks to this collaboration, the global patient community benefits from a unified effort to improve communication, care, and outcomes. We're incredibly grateful for the leadership and dedication shown by all who participated in the patient meeting and physician workshop, helping pave the way for lasting impact in our community.

1985

FIRST RESEARCH

First "Research" sponsorship (\$5,000) by Foundation is for an oximeter for ICU patients at Johns Hopkins University Medical Center.

1989

FIRST SYMPOSIUM

First Symposium is held in Philadelphia bringing together our rare disease community!

Read about our 2025 Symposium on Page 14

Definitions for Physicians and Healthcare Professionals Treating CIDP

The definitions below are simplified to help patients explain their current CIDP status to their loved ones, friends, and neighbors. These simplified definitions do not replace the important official definitions used by healthcare professionals. Instead, they supplement and provide an easier way to talk about CIDP to non-healthcare professionals.

TERMS DEFINED

IN-EDA

Inflammatory Neuropathy-Evidence of Disease Activity

This means that it is likely that your immune system is actively injuring your nerves.

- You feel that your neuropathy is worse, and there is a measurable negative change in strength, function, or both.
- You and your doctors should also make sure there isn't another reason for the change.

IN-NEDA

Inflammatory Neuropathy- No Evidence of Disease Activity

This means that it is likely that your immune system is not active and not causing new injuries to your nerves. There are two levels:

IN-NEDA 1

You do not feel your neuropathy symptoms worsening and for at least 6 months, you either:

- Haven't gotten worse in your daily function as measured by your doctor, OR
- Haven't gotten worse in your strength as measured by your doctor.

IN-NEDA 2

You do not feel your neuropathy symptoms worsening and for at least 6 months, you:

- Haven't gotten worse in your daily function as measured by your doctor, AND
- Haven't gotten worse in your strength as measured by your doctor.

MINIMAL RESPONSE

You feel a bit better with small test improvements.

PARTIAL RESPONSE

You feel better with bigger test improvements.

OPTIMAL RESPONSE

Improved as much as possible (some residuals may persist) ; no disease signs for 6 months.

RELAPSE

Symptoms return, and tests show you're getting worse.

REFRACTORY

Treatment doesn't help or must be stopped.

REMISSION

No disease signs for 12+ months without treatment.

RESIDUALS

Ongoing symptoms even without active disease.



BART JACOBS & RICH LEWIS

Global Medical Advisory Board

At the 2025 Peripheral Nerve Society symposium in Edinburgh, Dr. Bart Jacobs (left) and Dr. Rich Lewis (right), members of our Global Medical Advisory Board, were awarded the Alan J Gebhart Prize, the most prestigious prize for research in peripheral neuropathies.



1990

FIRST EMPLOYEE

The Foundation hired its first employee.

Meet our new staff on page 18

1992

FIRST INTERNATIONAL CHAPTER

First International Chapter is established in England by Glennys Saunders

Now the Foundation has 45 international allied partners



TOUR DE MMN

On May 30th, MMN patient Clive Philips, embarked on an extraordinary challenge alongside fellow military veterans. Inspired by the 1955 Tour De France, the team rode 3200km (nearly 2000 miles) to increase awareness of MMN, connect with the international rare disease community, and raise money to fund critical research.

Stronger Together

Thanks to the passion and generosity of our community, grassroots fundraisers like Tour de MMN fully funded the Foundation’s first-ever MMN Research Grant, a \$50,000 award supporting groundbreaking work led by Dr. Simon Rinaldi (University of Oxford) and Dr. Nicolas Dubuisson (UCLouvain/ Cliniques Universitaires Saint-Luc). Their study, “Anti-GM1 neuropathies, from antibodies to phenotype,” is advancing much-needed progress in diagnostics and treatments for MMN.

This milestone was made possible entirely through grassroots fundraising and donors like you. Every mile biked, every dollar given, and every message shared brought us here. Together, we’re proving that when our community unites, real change happens.



“This experience transformed my perspective on cycling and disability. When you set your sights on a goal, nothing can stand in your way—not disease, not MMN, not MG, not CIDP. Nothing can stop the human heart and mind from achieving something extraordinary.”

Nancy DiSalvo, *Director of International Affairs*

1997

THE COMMUNICATOR

The homegrown Foundation newsletter becomes an official quarterly publication. The first “Communicator” Newsletter is published.

2012

FIRST COE

Our Centers of Excellence (COEs) help patients from around the world find a trusted hospital with knowledge in these rare conditions. New COEs include Huashan Hospital in China and Yale School of Medicine in Connecticut.



PATIENT- FOCUSED DRUG DEVELOPMENT

Patient-Focused Drug Development (PFDD) is a systematic approach to help ensure that patients' experiences, perspectives, needs, and priorities are captured and meaningfully incorporated into drug development and evaluation.

In 2024, the Foundation hosted two key PFDD events to elevate the voices of our community.

MAY

Externally-Led PFDD Meeting on the patient needs and treatment priorities for Anti-Mag, GBS, and MMN.

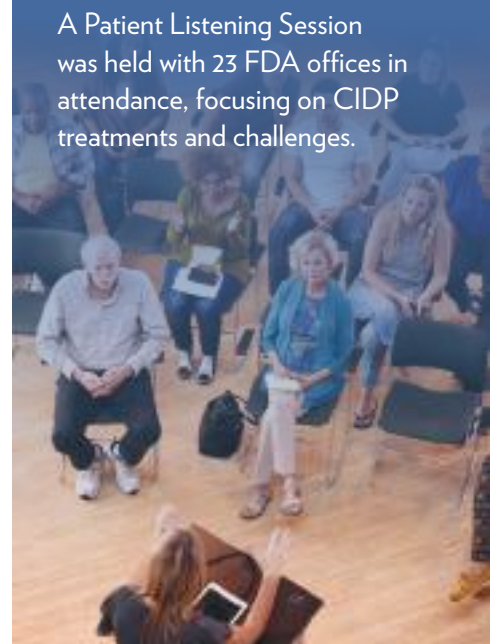
JUNE

A Patient Listening Session was held with 23 FDA offices in attendance, focusing on CIDP treatments and challenges.

BENSON FELLOW

The Benson Fellowship is a prestigious three-year award providing up to \$150,000 for research on peripheral nerves, granted to only one scientist every three years.

The newest Benson Fellow is Claire Bergstrom Johnson, a Clarendon Scholar completing her DPhil in Clinical Neurosciences at University of Oxford. Inspired by her twin sister's severe CIDP diagnosis, Claire's doctoral research uncovered unmutated autoreactive B cells and IgM autoantibodies against neurofascin in inflammatory neuropathies, challenging existing beliefs and opening new avenues for diagnosis and treatment. Through the Benson Fellowship, she will extend her work in the Rinaldi Lab at Oxford, focusing on mechanisms of B-cell tolerance failure, developing antigen-specific tools for monitoring disease, and generating monoclonal antibodies to improve diagnostics. Her long-term goals include launching a research program on immune pathways in inflammatory neuropathies, collaborating with industry for patient-focused therapies, advocating for awareness, and mentoring women in neuroimmunology. The Fellowship will support these ambitions, advance science, and benefit patients and families affected by these disorders.



FIRST HILL DAY

A Hill Day is when a group of volunteers travel to Washington D.C. to share their story with lawmakers.

Read about our 2025 Hill Day on page 13.

2012



FIRST WALK & ROLL

The first Walk & Roll was held in Philadelphia.

See how our program has grown on page 14

2012

EUROPEAN VOLUNTEER WORKSHOP

In Amsterdam, the GBS|CIDP Foundation International welcomed 26 dedicated volunteers from 11 countries for our European Volunteer Workshop — a powerful reflection of how we are growing together as a global community. With support from staff members Maureen, Nancy, Pam, and Richard, the workshop sparked meaningful dialogue, fresh ideas, and hands-on collaboration. United by a shared commitment to raising awareness for GBS, CIDP, MMN, and related conditions, our international volunteers strengthened connections and inspired one another to drive change in their communities.

CONFERENCE IN MEXICO CITY

Chief Strategy Officer Richard Sperry and Board member Valentina Treviño attended the 2025 SOLANE conference in Mexico City, connecting with nearly 400 physicians and researchers across Latin America. The Foundation is now planning its first in-person patient event in Mexico City for 2026.

THE BIG GET TOGETHER IN LONDON

The Foundation and GAIN (Guillain-Barré & Associated Inflammatory Neuropathies) partnered at the Big Get Together in London to support patients across the UK. Over 70 community members gathered to deepen their understanding of their conditions and build meaningful connections.



PRAVINCHETTY
Volunteer

An email from our Allied Partner, Tony Pearson, of the New Zealand GBS Support group, detailed global connections between a patient from New Zealand who was traveling South Africa, and diagnosed with GBS. Tony reached out to Nancy, and she connected him with Pravin of our South Africa Allied Partner group, and other members of the South African group; one of these volunteers went to visit the patient at the hospital and then gave feedback to the parents who live in Auckland New Zealand. Global teamwork at its finest!



2014

BENSON FELLOWSHIP

The Benson Fellowship launched to fund Peripheral Neuropathy Fellowships in honor of Robert Benson, a survivor of Guillain-Barré Syndrome, and his wife Estelle Benson.

2017

FIRST REGIONAL CONFERENCE

First Regional Conference held in Fort Lauderdale



This year marked 13 years of Hill Days in Washington, D.C., bringing together over 20 patients and advocates from across the United States.

THEIR MISSION

To support the Medicare IVIG Access Enhancement Act, which would expand Medicare Part B coverage for in-home IVIG treatments for those with CIDP and MMN. Advocates met with lawmakers, sharing personal stories that highlighted the urgent need for accessible, home-based care. If passed, this bill would help ensure timely treatment without the barriers that often disrupt care for people in the US who use Medicare.

GBS PATIENT REGISTRY



This Rare Disease Day, the GBS|CIDP Foundation International released a new report mapping the Guillain-Barré Syndrome (GBS) patient journey—from symptom onset to recovery.

The GBS|CIDP Foundation International Patient Registry is a unique opportunity for patients and primary care partners to help advance research while knowing their privacy is fully protected. By sharing your experiences through confidential, de-identified questionnaires, you contribute critical information that gives healthcare professionals and researchers a deeper understanding of life with GBS, CIDP, MMN, and related conditions.

Hosted in partnership with the National Organization for Rare Disorders (NORD), this collective, anonymous data helps power research, supports the development of better treatments, and guides resources that meet the real needs of patients.

2019

FIRST GBS/CIDP PATIENT REGISTRY

Launched the GBS|CIDP Patient Registry, 700 + patients currently enrolled

LEARN MORE

<https://gbs-cidp.iamrare.org/>



2020

FIRST VIRTUAL PROGRAMS

In response to the isolation of the COVID-19 pandemic, the Foundation creates its first virtual programming to connect our community.

Symposium 2025

The Denver Symposium brought together more than **500 patients, care partners, physicians, and industry leaders** for three days of education, connection, and community. This landmark event offered opportunities to learn from experts, share experiences, and strengthen the bonds that make our Foundation family so powerful. We are grateful to everyone who joined us in Denver and helped make this symposium a true celebration of knowledge, hope, and support.



“

Walking out of those sessions, Marcia and I both felt something we don't always feel when it comes to GBS and CIDP: hope. Not vague, distant hope, but grounded, tangible hope. Hope that treatments are evolving. Hope that patients and caregivers are finally being heard. Hope that the future doesn't have to look like the past. And that hope is worth holding onto.”

Chris Willard, *Patient & Symposium Attendee*

COMMUNITYDAYS

The GBS|CIDP Foundation International's new Community Days are free, all-inclusive events designed to bring vital support, education, and connection directly to patients, care partners, and healthcare providers — especially in underserved and rural communities. These one-day gatherings offer a unique chance to meet with knowledgeable medical experts, connect with fellow patients, and access valuable resources close to home. Community Days are created to empower individuals living with GBS, CIDP, MMN, and related conditions with the information and support they deserve, helping ensure that no one feels isolated on their healthcare journey. This year, the Foundation hosted three community days in Ohio, Alabama, and Michigan.



2021

COFFEE CHATS EXPAND

After COVID-19 limited the number of in person events we expanded our virtual support and education.

2023

FIRST FULL TIME INTERNATIONAL STAFF MEMBER

Nancy Di Salvo joined our staff as the International Affairs Director expanding our global programming.



MONTHLY COFFEE CHATS

Since 2020, 1,000+ community members have connected virtually through our virtual programs. We've also added new "chat themes," to better serve our diverse community. Take a look below at our recent additions and our wide range of topics!

NEW GROUPS

- ✓ VETERAN'S
- ✓ MEN'S
- ✓ WOMEN'S
- ✓ CARE PARTNERS
- ✓ PARENTS
- ✓ LGBTQ+
- ✓ SENIOR



"This was my first Coffee Chat for seniors, but it definitely won't be my last! It was terrific to both share and hear stories about living with rare conditions like GBS, CIDP, and MMN. I was impressed that the meeting host was none other than foundation founder Estelle Benson!

Coffee Chat Attendee



SPEAKERSERIES

MUST-WATCH EPISODES IN OUR SPEAKER SERIES

Speaker Series webinars feature experts from the Foundation community sharing their insights on a variety of topics. This educational series includes monthly live webinars that focus on a single subject. Foundation staff guide the conversation by posing insightful questions gathered directly from our community. Each episode is recorded and made available to the public. We've seen consistent growth in registrants since the start of the series.

598

Your Immune System and Vaccinations Registrants

Treatment Options for GBS, CIDP, MMN, and Variants Registrants

583

Fatigue Registrants

513

Variants of GBS Registrants

484

449

Aging and GBS Registrants



SHANESUMLIN

Men's Coffee Chat Host



"The men's coffee chat came as a surprise area of need in our community. Over the past few years, I realized I didn't deal with the trauma of my diagnosis, and I needed a group of people who understood. I found out other men needed to talk about their journey as well. To be honest, I have been so excited about these calls, and they have been very well received and attended so far. You just never know what someone else is going through."

2024

EUROPEAN VOLUNTEER TRAINING

We welcomed 26 volunteers from 11 countries.

2025

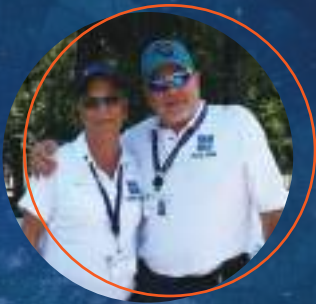
FIRST LEADERSHIP COLLABORATIVE

We brought together patients and leading medical experts to define key CIDP terms in plain, accessible language.



In 2024, the Foundation hosted its first **Walk & Roll** events in Birmingham, AL, and Louisville, KY, uniting patients, families, and friends for days filled with hope, connection, and support. Participants walked and rolled together to raise awareness and critical funds for our mission.

In 2025, the program continued to grow with new events in **Cincinnati, OH, and Spencer, IA**, the return of the **Clovis Walk & Roll** with over 200 participants, and our first **Walk on Duke's campus**, engaging future healthcare providers. These events highlight the strength of our community and the power of coming together.



MERRILYNMACURAK
RICKFORNEY
Conway/Myrtle Beach Chairs
and Volunteer W&R

“The main reason we started the Walk & Roll in Conway/Myrtle Beach was to bring patients and the community together. Our ‘aha’ moment was when we stepped back during the Walk and saw everyone enjoying the moment, some laughing, some crying, all sharing stories and connecting with others who’ve been through similar challenges who they can finally relate to.”



Tim, our Logistics Manager

2025

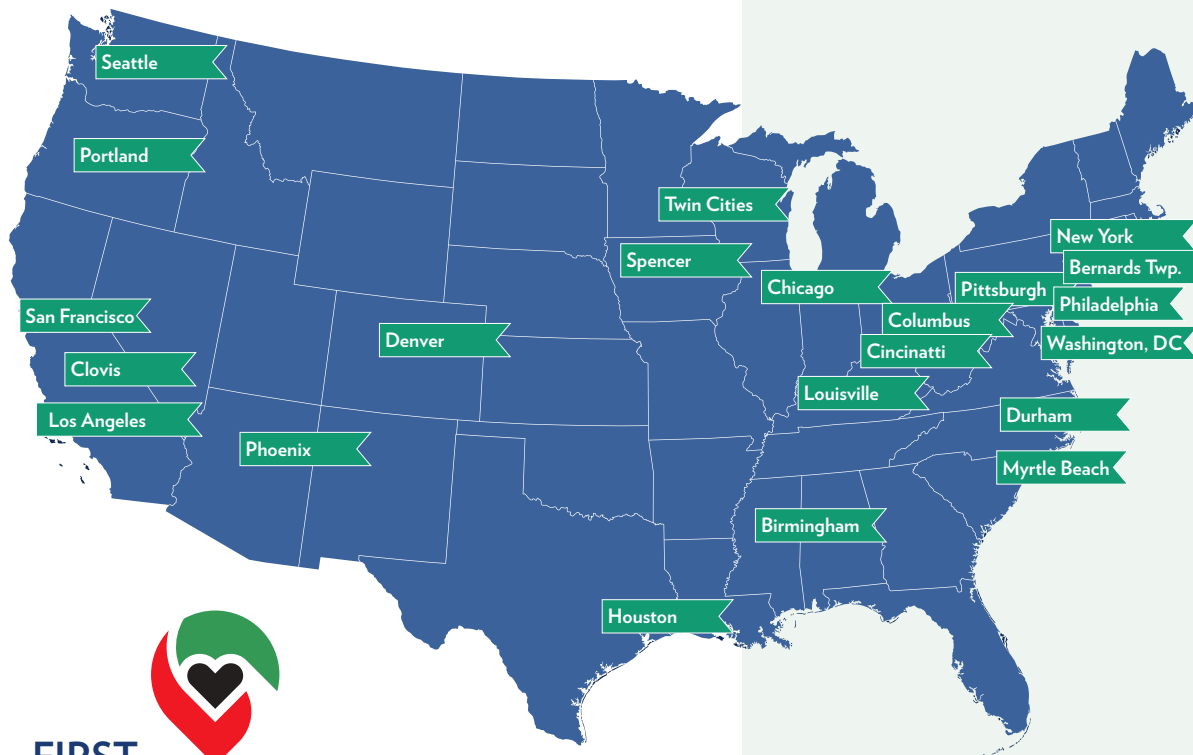
2025 COMMUNITY DAY

Our first community days were held, bringing together our Centers of Excellence and our patient communities across the country.

2025

MMN SEARCH GRANT

Our First MMN Search Grant was awarded to by Dr. Simon Rinaldi and Dr. Nicolas Dubuisson.



FIRST INTERNATIONAL WALK & ROLL

Our very first International Walk & Roll event took place in Bagheria, Sicily. Known as the cradle of the Mediterranean, this beautiful town near Palermo hosted the event on May 4 kicking off May Awareness Month 2025. Nancy was joined by our volunteer from South Africa, Pravin Chetty, and our allied organization in Germany, the Deutsche GBS|CIDP Selbsthilfe e.V. with their board member Sebastiano Sambasile.



JOIN US

Planning is already underway for 2026! If you are interested in hosting a Walk & Roll in your area or volunteering with the program, please contact ZachareyChopek @gbs-cidp.org.



“This community has given me more than information – it’s given me hope, connection, and the belief that, together, we can make a difference and create a brighter future for all of us living with GBS and CIDP.”

Annette Sylber, GBS + CIDP Patient
from the Denver Walk & Roll

2025

2025 FIRST INTERNATIONAL WALK AND ROLL

See above ↑

2025

OUR BRIGHTER FUTURE

Thanks to the generosity of donors like you, we look ahead with hope toward expanding support and education for our community, advancing critical research, and strengthening advocacy for all who are impacted.

Growing Our Staff & Support



MORGAN DUHE

Health Navigator

Morgan joined GBS|CIDP Foundation International as a Health Navigator in July of 2024. Morgan holds a master's degree in social work from the University of Buffalo. She previously worked in medical billing and in older adult protective services. Morgan provided in-person support as a Dialysis Social Worker before, during, and after the COVID-19 pandemic.



MELANIE KAMUESA

Research and Global Health Manager

Melanie joined the Foundation in March 2025 as Research and Global Health Manager. Originally from Namibia, she brings a global outlook and a strong commitment to health equity. She holds a B.S. in Health Science and is pursuing an MPH in Healthcare Management.



CHARLOTTE STONE

Development and Marketing Associate

Charlotte started with the Foundation in August 2024 as the Development & Marketing Associate. She has a BA in Political Science from West Chester University and will bring her experience in development and project coordination to her role at the GBS|CIDP Foundation International.



RICHARD SPERRY

Chief Strategy Officer

Richard started in September 2024 in the role of Chief Strategy Officer at the GBS CIDP Foundation International. In his position, Richard is responsible for driving the execution of the Foundation's Strategic Plan and advancing the organization's mission. Richard is a patient living with MMN and was diagnosed with the condition in early 2020. He was introduced to the Foundation in 2022 and has been an active member of the Foundation community since then. Richard has over 20 years of diverse healthcare experience, most recently as CEO of AdheaRx, an innovative healthcare technology startup. Before leading AdheaRx, Richard enjoyed an 18-year career at Novo Nordisk, Inc., where he served as a member of the Executive Team after taking on roles of increasing responsibility across various commercial functions.



CHRISTIAN ZAIDAN

Systems Administrator

Christian joined the Foundation in January of 2025 as Systems Administrator. He earned a BS in Information Sciences and Technology from Penn State University in 2023, where he specialized in design and development.



JACOB FULLER

Advocacy Manager

Jacob Fuller joined the Foundation in January 2025 as the Advocacy Manager at the GBS|CIDP Foundation International. His role includes working with rare disease patient communities to advocate for federal funding for research and healthcare. Prior to his role at the Foundation, Jacob worked in both the civil rights field advocating greater protections for marginalized communities, as well as a senior political organizer.



our donors

Our donors are the roots of our mission, grounding and strengthening everything we do. Like branches reaching outward, their generosity extends support to patients and families across the globe. Each gift is a seed of hope, growing into programs, research, and resources that strengthen our community and bring us closer to a future where no one has to walk this journey alone.

President's Circle

In recognition of cumulative gifts reaching \$10,000 or more. President's Circle members demonstrate leadership in philanthropy. This group of leadership donors make financial commitments of gifts that enable the greatest impact for the Foundation. In appreciation for their gifts, President's circle members receive special recognition throughout the year.

Dave Ahrens, Aisha Javedullah
Ahrens, Mohammad Williams
and Estrellita Javedullah
Becky Alley
Carolyn Asbury
Danny and Mara Baror
William Beam
Howard and Monica Benson
Mitchell and Bonnie Benson
Estelle Benson
Donald and Sallie Bolich
Calvin Bright
Beth Brooks
Barbara Cressman
Karen L. Crombie
Chris and Trudy Cunningham
Bob Doehrmann
Marjorie Downey
Mark and Marsha Ensminger
Susan Gabay-Laughnan
Scott Grant
Jennifer Gruenberg
David and Janice Haley
Joan and David Hanisco
Debra Harvey
Ernest Hayden
David Hill
Marilyn Horan
Michael and Susan Huebschman
Margaret Hunt
Paul and Megan Kaump
Michael Kazhdan
Ryan and Phyllis Keefer
Ronald and Amy Kremnitzer
Peter Kyriacou
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To celebrate Rare Disease Day in February, he decided to host a pop-up cafe at work to raise awareness. Over 40 colleagues—CEO included—joined in, with voluntary donations and heartfelt support.

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The Legacy Circle recognizes individuals who have named the Foundation as a beneficiary in their Estate plans and have named the Foundation as a beneficiary in their will, charitable gift annuity, charitable trust, or similar vehicle. All individuals who have included the Foundation in their estate plans, and have made their intentions known are invited into membership in the Legacy Circle.

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January 1, 2024-
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GBS
Kenya

Collins organized a meaningful awareness meeting at Kapkatet Sub-County Hospital in Kapkatet Town, Kenya, helping to spread vital information about GBS. His efforts brought healthcare providers together to strengthen support and understanding.

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HAJIME UEDA

GBS
Japan

Retired IT specialist living in Tokyo and actively engaged in various volunteer efforts. His patient journey with Guillain-Barré Syndrome started in late 2014, at the age of 55. Motivated by this experience, Hajime launched a Facebook group and website in 2015 to connect patients and their families. By 2016 he organized in-person gatherings. In 2018, to further raise awareness and understanding of GBS, I led a crowdfunding campaign to distribute a manga-style GBS book to hospitals across Japan. That same year he attended his first GBS CIDP Foundation International Symposium in San Diego.

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