GBS|CIDP
Foundation International

GLOBAL UPDATE

GBS|CIDP FOUNDATION INTERNATIONAL VOICES AROUND THE WORLD SUMMER**2026**

Advocacy Without Borders

MAUREEN NEVILLE, Chief Programs and Marketing Officer

In recent years, alongside my wonderful colleague, Nancy Di Salvo, I have had the privilege of helping to synthesize our global efforts, partnerships, and resources, and contribute to the growth of our global support network.

We have facilitated international committees, regional patient meetings, and volunteer workshops, and have been honored to collaborate with our international allied partners and volunteers. Through the years, we have witnessed the growth and impact of our global community and profound effect of our unsung leaders as they strive to ensure that no one walks alone.

From working toward integrating support and awareness of these rare conditions into global health systems, to answering the emerging need to translate our resources, our global volunteers bring education to their local regions and offer kinship to those in need. Their efforts are as remarkable as they are endless. *It never ceases to amaze me how a small dedicated and heart-centered tribe, can have the most enormous and resounding impact on patients, legislators, and the healthcare community at large, in even the most isolated and out-of-reach regions of the world.* **Today, I am thrilled to present this very first edition of the GBS|CIDP Global Update, a bi-annual publication that will provide a cross-border view of this tremendous work to support individuals all over the world.**

The stories in the following pages will take you on a journey into the very heart of our global tribe, our growing family and partners in support, and introduce you to the immense power of compassion, and the global impact of human kindness.

> "Together, we continue to raise awareness, foster international collaboration, and ensure that no patient feels alone on their journey."
>
> Nancy Di Salvo
> *Director of International Affairs*

CONNECT TODAY

Join thousands who've found support through the Foundation. Visit our website to explore what's available for you.

3 New Global Fund

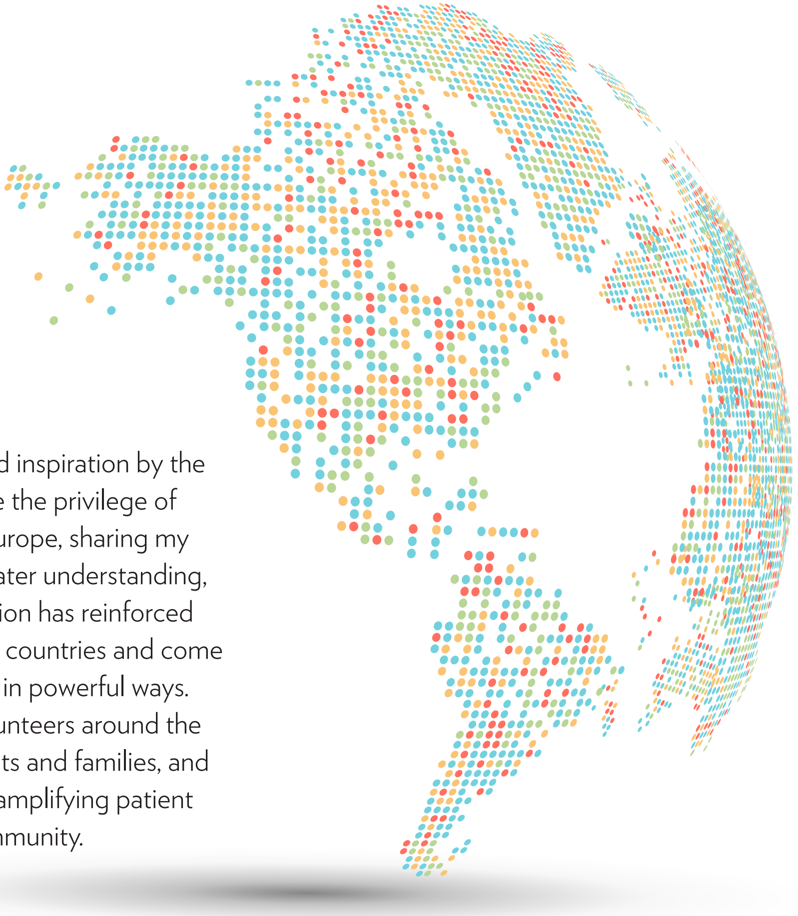
4 Awareness, Support, and Education Worldwide

6 Global Team on the Move

7 New Voices in the Community

A Letter from the Director of International Affairs

NANCY DI SALVO

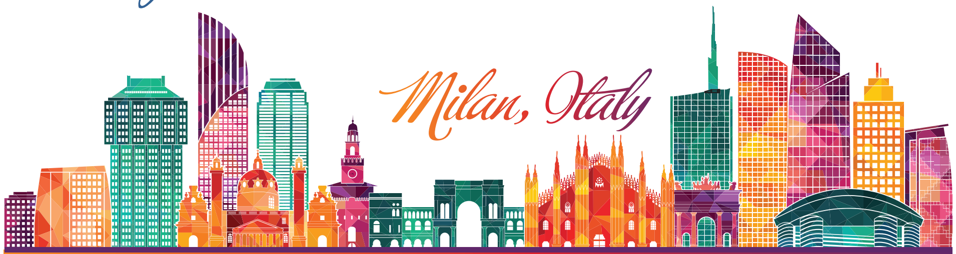


Gratitude, Connection, and a Global Community

As I reflect on the first half of 2026, I am filled with gratitude and inspiration by the strength of our international community. This year has given me the privilege of representing the patient voice at meetings and events across Europe, sharing my personal journey with GBS and CIDP, while advocating for greater understanding, access to care, and patient-centered treatment. Each conversation has reinforced something I have always believed: while we may live in different countries and come from different backgrounds, our shared experiences connect us in powerful ways. I have been especially encouraged by the dedication of our volunteers around the world, whose efforts are helping raise awareness, support patients and families, and build meaningful connections across borders. Together, we are amplifying patient voices and creating a stronger, more compassionate global community.

Thank you for being part of this journey.

Nancy



EUROPEAN REGIONAL CONFERENCE

GBS|CIDP FOUNDATION INTERNATIONAL // ADVANCING CARE ACROSS EUROPE

Join us in Milan for a Day of GBS, CIDP, & MMN Community Building!

Saturday, October 10, 2026 • 9:00 AM (CET)

Don't miss this opportunity to connect with other patients, families, caregivers, and healthcare professionals at our first-ever European Conference in Milan, Italy this October. Click here to learn more and register today!

REGISTER NOW!

Scan this QR code to see the full agenda and register today.

GBS/CIDP
Foundation of Canada

National Conference
CALGARY

LOOKING TO CONNECT WITH YOUR COMMUNITY IN CANADA?

Consider attending their National Conference on September 19 & 20, 2026, at the National Conference Calgary in Alberta, Canada.

Learn more and register here.

NEW GLOBAL FUND

Global Program Fund Supports Patient Outreach in Denmark

IN 2026, THE FIRST GBS|CIDP FOUNDATION GLOBAL PROGRAM FUND (GPF) WAS LAUNCHED.

These funds are available, through an application process and approval, to international volunteers and allied partners, in all regions of the world. They are designated to assist in education, support, and awareness of GBS, CIDP, MMN and variant conditions. Our first GPF grant recipient from Denmark utilized the funds to create two regional education meetings in his homeland of Denmark.

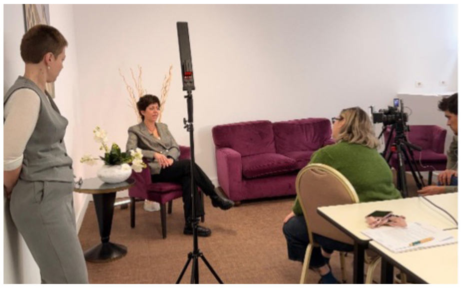
The first meeting occurred on Wednesday, March 25, 2026, hosted by the GBS-CIDP Patient Association Denmark at the DBU Hotel & Conference Center in Tilst, and focused on the latest developments within CIDP and MMN. The program featured specialized presentations from Dr. Lars Kjøbstad Markvardsen, who provided a deep dive into the diagnosis, treatment, and monitoring of both CIDP and MMN. Furthermore, Dr. Lennart Kjær Madsen shared vital insights into managing neuropathic pain—a topic of great importance to many living with these conditions.

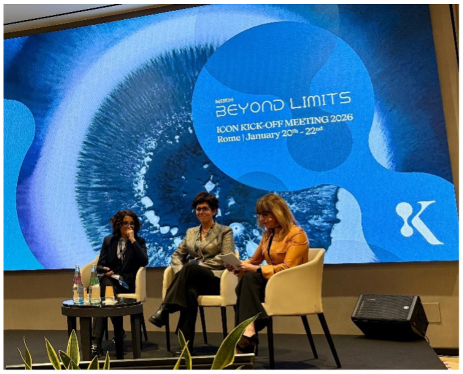
The 22 participants, consisting of patients and their loved ones, engaged actively in a concluding Q&A session, ensuring that everyone left with practical answers to their specific questions.

Beyond the clinical updates, the evening provided a valuable space for networking and the opportunity to share personal experiences to find mutual support in a relaxed atmosphere.

Congratulations to our allied partners in Denmark for a job well done!

AWARENESS, SUPPORT, AND EDUCATION WORLDWIDE





ROME ↑

Rare but Real

In January, Nancy Di Salvo represented the patient voice in Rome, Italy, at the Kedrion "Rare but Real Experience" during the Plenary 2026 ICON Kick-Off Meeting. She shared her personal journey with GBS and CIDP, while emphasizing the importance of access, understanding, and patient-centered care.

KENYA ↓

Africa & US Experts Partner for Educational Webinar in Kenya

This May, our global community stepped up to raise awareness and education in all regions of the world! An educational webinar on autoimmune polyneuropathies was produced by University of Alabama at Birmingham's Department of Medicine, in partnership with GBS Foundation Kenya, Oak Tree Centre, and St. Luke's Orthopaedic & Trauma Hospital. The webinar featured Dr. Mathew Koech as Moderator, and Eroboghene E. Ubogu, MD, as Speaker. Video is now available on demand here.

OAK TREE CENTRE FOR KIDNEY AND CHRONIC DISEASES

GBS FOUNDATION KENYA

ST. LUKE'S ORTHOPAEDIC AND TRAUMA HOSPITAL
Exceptional Commitment to Quality Healthcare

AUTOIMMUNE POLYNEUROPATHIES

RECOGNITION, DIAGNOSIS & TREATMENT.

Monday,
May 25, 2026

from 4.00 PM
to 6:00 PM

A CPD ACCREDITED WEBINAR

SPEAKER:
Eroboghene E. Ubogu, M.D.
Professor of Neurology and Neurobiology
Director, Division of Neuromuscular Disease
Department of Neurology
The University of Alabama at Birmingham, USA.

MODERATOR:
Dr. Mathew Koech
Grand Rounds Coordinator,
MUSOM

☎ 0724727277 www.oaktreecentre.com info@oaktreecentre.co.ke

GIBRALTAR ↑

Gibraltar Brings Focus to MMN

February marked MMN Awareness Month, highlighted by an inspiring community Zumba fundraising and awareness event in Gibraltar, organized by our dedicated volunteer John Navarro. The event brought patients, families, and supporters together to raise visibility for Multifocal Motor Neuropathy (MMN) in positive and energetic ways.

HUNGARY ↓

Supports and Educates Local Community

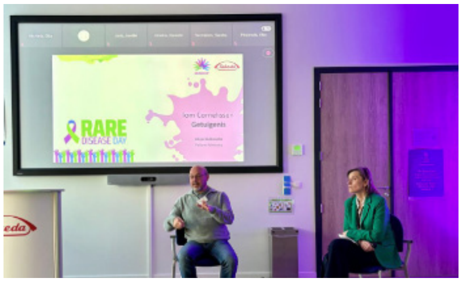
Our local volunteers and allied partners in Budapest, Hungary came together for Rare Disease Day 2026 to raise awareness of GBS, CIDP, and MMN through support group activities, education, and community building!

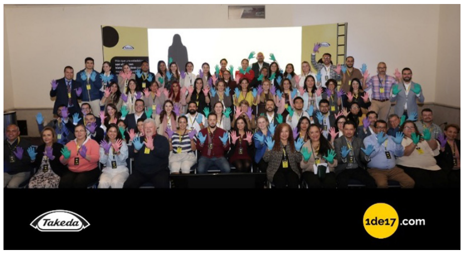
BELGIUM AND MEXICO →

Rare Disease Day Awareness

For Rare Disease Day 2026, Belgium volunteer, Tom Cornelissen, participated in a TAKEDA event in Belgium, helping amplify the voices of rare disease patients and advocating for greater recognition and support for the GBS, CIDP, and MMN community. Additionally, Sandra Bermudez, Program Manager for Latin America, had the opportunity to participate in Takeda Mexico's "1 in 17" Rare Disease Day initiative, an event focused on raising awareness, fostering collaboration, and giving visibility to people living with rare diseases. The initiative is called "1 in 17" because approximately 1 in 17 people live with a rare disease.

The platform, 1de17.com, currently features information and educational resources on eight rare diseases. In the next phase of the initiative, GBS will be highlighted, helping to expand awareness and education for our community.



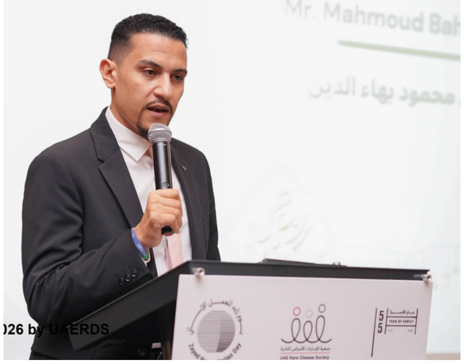


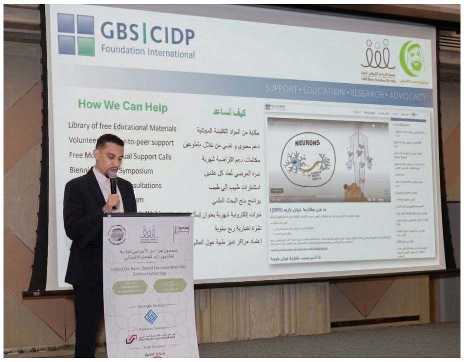
AWARENESS, SUPPORT, AND EDUCATION WORLDWIDE

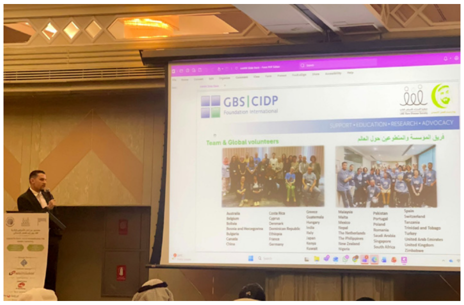
DUBAI ↓

Rare Disease Day Awareness

In March, Dubai volunteer, Mahmoud Bahaaeldin, participated in UAE's Rare Disease Society, Zayed Humanitarian Day Event, an educational gathering for rare disease. The event included a number of rare disease patients, caregivers, families, and other representatives from sponsors and participating institutions. Mahmoud was given the opportunity to briefly introduce the Foundation, share his personal journey, highlight the guidance he received, and outline how the Foundation will continue to support the patient community. Congratulations on a job well done, Mahmoud!







LATIN AMERICA ↗

LATIN AMERICA Programs…on the GO!

Since the addition of the Foundation's new Latin American Program Manager, Sandra Bermudez, the GBS, CIDP, & MMN community has gained momentum and visibility and participation in important conversations. Our volunteers in this region are dedicated to creating safe spaces and initiatives that provide support, education, and connection for patients, families, and caregivers. The main goal remains to strengthen its voice to build a more united and supported community across the region.

Through online Coffee Chats hoted by LATAM volunteers, topics such as "Healing Through Community," were explored to highlight the importance of connection during the recovery journey. Each month, a Chapter Meeting named **"Conectemos LATAM"** offers a space for patients, families, and caregivers to connect and bond, while fostering the celebration of progress, victories, and encouragement to keep moving forward in the healing journey. Don't know about our Coffee Chats? Click here to learn more.

In addition, a monthly virtual Speaker Series named **"Habla con el Experto"** was launched, with the goal of addressing these conditions in a more holistic and comprehensive way. Some topics were designed to address emotional and mental health, such as "I'm Not My Illness; I'm My Purpose," an invitation to discover purpose beyond a diagnosis. This session was led by Psychologist, Logotherapist, and grief counselor, Paola Gamboa. A session on vaccines featuring Dr. Eli Skromne, a Neurologist from Hospital Angeles Lomas (the first Center of Excellence certified by the Foundation in Mexico) was also offered. Don't know about our Speaker Series? See a list of upcoming events here.

During Awareness Month, a yoga class was held with postures intentionally focused on bringing calm and regulation to the nervous system. At the end of the session, information and awareness about GBS and CIDP were shared, creating a meaningful space that combined wellness, connection, and education for the community.

> "There is still much work to do in Latin America, but there is also something incredibly powerful growing: a united community filled with optimism and a deep commitment to continue supporting one another. Together, we are creating an environment where patients, families, and caregivers feel seen, heard, and empowered. We believe healing happens through connecting with our community – not in isolation."
>
> **Sandra Bermudez,** *Program Manager, LATAM*

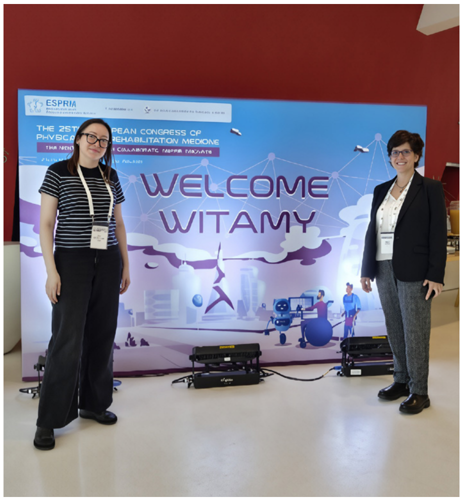
GLOBAL TEAM ON THE MOVE

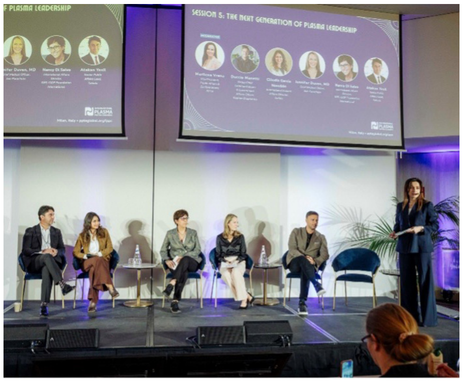
The first half of 2026 has already been an exciting and impactful year for our international community, with growing global awareness, advocacy, and volunteer engagement across multiple countries.

POLAND ↓

ESPRM

This spring, the Foundation participated in the European Congress of Physical and Rehabilitation Medicine (ESPRM) in Krakow, Poland, together with our Polish allied support group axON – Association for People with CIDP | GBS | MMN – and volunteer Daria Majchrowicz. The congress provided an important opportunity to strengthen collaboration between rehabilitation professionals, researchers, and patient organizations across Europe.





ITALY ↑

IPPC

In April, Nancy Di Salvo, Director of International Affairs, attended the International Plasma Protein Congress (IPPC) in Milan, Italy, where she participated in the panel discussion "The Next Generation of Plasma Leadership." Representing the patient perspective, Nancy spoke about plasma-derived medicinal products (PDMPs), emphasizing the importance of global accessibility, equity, and treatment availability for patients worldwide.

MEXICO

World Congress on Psychology and Psychotherapy, Mexico City

Also in April, our LATAM Program Manager, Sandra Bermudez, attended the World Congress on Psychology and Psychotherapy, where renowned experts, such as Enrique Rojas and Mario Alonso Puig, shared valuable insights. The conference addressed essential topics including the grieving process, the role of intuition in decision-making, emotional awareness, and the impact of emotional trauma on overall health. These topics are extremely relevant to our patient community, as they provide tools to better understand the emotional journey through diagnosis, recovery, and adaptation. Integrating these perspectives allows us to offer more compassionate, informed, and human-centered support to patients and their families.

Additionally, in May, Sandra attended a virtual conference in Mexico City, led by Gabor Maté, which focused on **Emotional Trauma and Chronic Disease**. It highlighted the deep connection between emotional experiences and physical health, encouraging a more integrative and compassionate view of healing. For our community, this perspective is particularly valuable as it supports the understanding that recovery is not only physical, but emotional as well. It reinforces the importance of creating safe spaces where patients can reconnect with and protect their identity, while processing the emotional impact of living with chronic or autoimmune conditions.

> "Overall, both experiences strengthened our ability as a Foundation to support patients from a holistic perspective–addressing not only their physical recovery, but also their emotional well-being. These insights contribute to the development of more empathetic programs, community spaces, and resources that foster resilience, connection, and a deeper sense of hope within the patient community."
>
> **Sandra Bermudez**
> *Program Manager, LATAM*

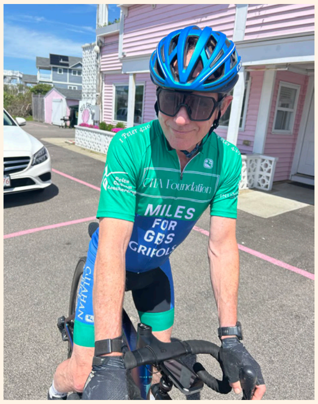
NEW VOICES IN THE COMMUNITY

New International Volunteers Expand Our Global Reach

EARLIER THIS YEAR, THE FOUNDATION WELCOMED AN INCREDIBLE GROUP OF NEW INTERNATIONAL VOLUNTEERS, INCREASING REACH ACROSS THE GROWING GLOBAL NETWORK.

With **NEW** representatives from **Australia, Denmark, Germany, Hungary, India, Italy, Kenya, Lithuania, Nepal, Pakistan, the Philippines, Poland, Portugal, Serbia, Spain, the UAE,** and **United Kingdom**, the Foundation's international outreach continues to expand and strengthen. Their dedication, compassion, and willingness to support patients and families around the world are helping to build a stronger and more connected global community every day.

To learn more about our global community and allied partners, visit: www.gbs-cidp.org/global-community/



↑ FRANCE

Miles Takes on Mount Ventoux for GBS

After being diagnosed with Guillain-Barré syndrome (GBS), athlete Miles Washburn turned his journey into a purpose—sharing his story and launching a DIY fundraiser to support this community. On August 24th, 2026, Miles will take on Mount Ventoux in France, an epic 26 km (16.2 mile) climb to the summit, all to raise awareness of GBS and funds to support the GBS Patient Assistance Fund through the Foundation. To learn more and support Miles' journey, visit: https://go.gbs-cidp.org/gbs26