News and Views

Serving patients and families affected by GBS, CIDP, MMN and variants

Learn. Connect. Get Inspired.

Donna Hartlen, Executive Director

Winter and Spring 2026 were in full swing, and so were our efforts to raise awareness. Across the country, participants joined volunteer-led community Walk and Rolls and supported awareness efforts during MMN and GBS-CIDP Awareness months, helping shine a spotlight on GBS, CIDP, and MMN. We extend our heartfelt thanks to the volunteer teams and participants who make all awareness efforts possible. We hope to see you at one of the local walks this fall.

The Foundation is busy planning this year's Calgary National Conference - an event created for you! We've heard your feedback and are working to secure the sessions you've asked for, while expanding the conference to include a second day. In addition to providing valuable educational content to support your overall wellness, we've added some fun to the program. We look forward to seeing you in Calgary, to learn, connect, and get inspired!

In April, we celebrated our volunteers during National Volunteer Appreciation Week. This Foundation has a heartbeat only because of our many community volunteers, medical advisors, and volunteer board. We can't thank you enough! Our thanks to all of our donors who allow us to continue our important work, and to our patients and families, thank you for being part of the Foundation family. With sincerity,

Donna Hartlen

Reg# 887327906RR0001

Recovery from GBS AMSAN/AMAN

Chris Sutherland

Three and a half years ago I was diagnosed with Guillain-Barré Syndrome (GBS). I was 41 years old and had been in great physical health. They told me it might take a couple months, but I would make a full recovery. I heard many stories from hospital staff and even some friends about people they knew who recovered fully from GBS. As the months went by it started to become apparent that I had a rare variant of GBS that didn't just destroy the coating on my peripheral nerves, it destroyed the nerves completely. Fortunately, nerves grow back, but they work their way slowly from the spine out. I've been told that if a muscle does not have a signal from a nerve for longer than 12 to 18 months, it won't come back at all. It turns into a race to see if the nerves grow back and meet up with the muscles before the muscles throw in the towel. I have the AMSAN (acute motor sensory axonal neuropathy) variant, and by most accounts, I will not make a full recovery. However, I am trying my best to make do with what I have.

Believe it or not, my life is actually incredible! I have an amazing wife, family, and friends. I might not be able to play all the sports I used to, but I'm lucky enough to have lots of hobbies I can look forward to. These include board games, socializing, going to the gym, walking, recumbent cycling, camping, travelling—and this list is always increasing. I know that not everyone has the same support system as I do, but I would imagine most people can find something to look forward to.

After spending nearly a year and a half in the hospital, I was really able to focus on "perspective." Yes, I did see a lot of people who made full recoveries from all sorts of conditions, but instead of being jealous to see people walk or even feed themselves, there were always patients in way worse shape, both mentally and physically, than I was. I chose to focus on what I could do, not what I could not do (although, sometimes that was easier said than done). On an early day pass, when I couldn't even lift an arm, I remember being strapped into the Handy Dart to

Believe it or not, my life is actually incredible!

go to an off-site appointment. At a stoplight, I looked out to see some drug-addicted men stumbling around. I remember thinking how lucky I was to not have to live their lives. I also remember how lucky I was to even be able to see; as in physically "look" at something and appreciate the beauty of trees, mountains, buildings—our world. Some people don't have that ability, so who am I to complain.

Recovery from GBS AMSAN/AMAN

Chris Sutherland

I've worked hard to get where I am, and I will continue to push myself to strengthen the muscles I do have. After six months in the hospital, my shoulders and hips regained movement. At that point I was on the rehab floor, so I took all the possible classes and spent as much time as I physically could strengthening and trying to move those muscles. As the months went by, more nerves awoke and I kept pushing them. Once I could use the Nu-Step (modified exercise bike, where they had to strap in my hands and feet), I stayed out there for as long as I could, with sweat pouring off my face. When I left the hospital, I spent a year going to an adaptive gym three times a week for two to three-hour sessions each time. I also went to outpatient therapy twice a week and swimming at a public rec centre once a week. I'm really bad at swimming, but I'm still doing this, and still improving. A year ago I went back to work at my previous job as a compliance auditor with the province of B.C. I am lucky enough to have an office job that accommodated my physical disabilities (adaptive mouse, adaptive keyboard, voice control software). Once at work full-time, I stopped doing outpatient therapy and going to the adaptive gym. Amazingly, I can now use most regular gyms, which I go to two or three times a week. My work is 1.25 kilometres from my house. I used to push myself there in my wheelchair, but now I walk to work.

In addition to strengthening my muscles, I spent time researching, learning, and practising how to do tasks that I used to do before. Although my hands don't work as they used to, I have figured out how to manipulate my fingers to tie my shoes, cook food, and be mostly self-sufficient in the bathroom—although flossing my teeth and clipping my toenails require my wife's help. This month my wife went on a 10-day trip without me. We missed each other, but it was incredibly rewarding to get back to a place where I can be self-sufficient for 10 days in a row.

I know that everyone has different limits. And for some people, pushing those limits may do more harm than good. However, I do suggest at least questioning your limits. For me, I question three areas of improvement:
1. Attitude - Focus on what you can do and what makes you happy.
2. Physical strength - Get your exercise in where you can.
3. Adaptation - Research, learn, and practise the everyday tasks.
You might surprise yourself with what you can do.

If you're curious to learn more about me and/or see some of my progress, I have a few videos posted on YouTube: https://www.youtube.com/@GBSguy

Want to submit your patient or caregiver story? Get the guidelines

Connecting with Rural Physicians

Over many years, the Foundation prioritizes medical conference as a means of presenting the work we do for patients in these forward-facing events in an effort to connect with healthcare professionals.

Getting a timely diagnosis for our rare conditions is already a challenge and it can be even more difficult in rural and remote areas, where medical teams may encounter only one or two patients over the course of their careers.

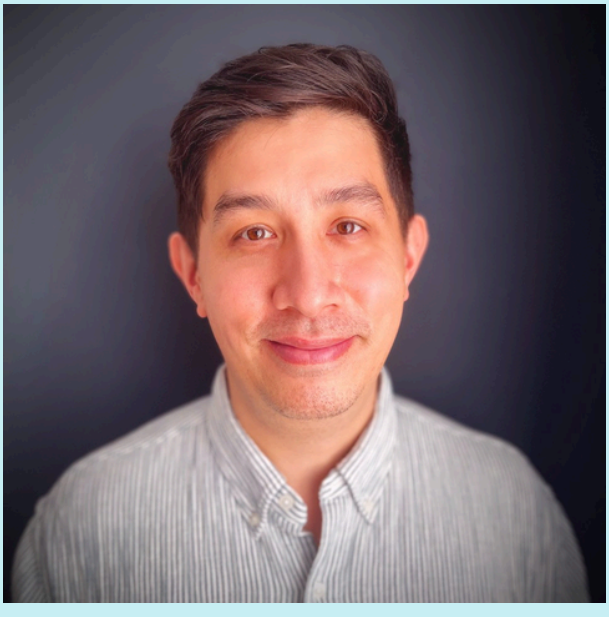
That's why the Foundation participates in the Rural and Remote Medical Conference each year. It was a pleasure to collaborate with several patient organisations through Network of Rare Blood Disorder Organizations (NRBDO) to bring awareness to many rare diseases with rural physicians. Every patient, no matter where they live, should have access to timely diagnosis, care, and treatment.

Board of Directors: Jamie Imada

The board welcomes Jamie to the team

Originally from Toronto, Jamie has worked as a veterinarian across Ontario. After five years of practicing general medicine, he returned to study population medicine at the Ontario Veterinary College. His doctoral thesis utilized a holistic approach to disease control. Jamie currently works as a veterinary epidemiologist with the Canadian Food Inspection Agency in Guelph where his work is focused on animal disease surveillance.

The foundation was instrumental in supporting his family when his dad was diagnosed with GBS and hopes that he can leverage his experience with qualitative and quantitative research methods to help advance the foundation's research efforts.



Calgary National Conference

Learn. Connect. Get Inspired

**People don't leave the National Conference with just information.
They leave with answers, new connections, practical tools, and hope.**

This September in Calgary, patients, caregivers, healthcare professionals, and advocates from across Canada will come together to learn, connect, and support one another.
We hope you join us!

September 19 - 20
Calgary Westin Airport Hotel
Calgary, AB

> The human connection piece is always the best.
>
> Caregiver, AB
> 2023 Montreal National Conference

> Exceeded expectations, very informative.
>
> GBS Patient, ON
> 2023 Montreal National Conference

REGISTER

Thank you to our sponsors

GRIFOLS

CSL Behring argenx Takeda

Kenneth & Jillian KOCH

GBS/CIDP Foundation of Canada
National Conference CALGARY

Calgary National Conference

Learn. Connect. Get Inspired

NATIONAL CONFERENCE SESSIONS

We have prepared an amazing line up of speakers, with more to be announced soon! Draft of program available HERE

DR HANS KATZBERG

Ask the Experts and a session on latest treatments and research

DR CHRIS WHITE

Ask the Experts and a session on diagnostic pathways

DR KATHERINE BEADON

Ask the Experts and a session on condition management

DR GORD JEWETT

Ask the Experts and a session on condition management

DR ANDREA LOEWEN

Session on sleep with chronic conditions.

CLIVE PHILLIPS AND PAMELA STOIKOPOULOS

Keynote conversation and Clive Phillips's documentary *No One Rides Alone*

CANDINE BLACKBEARD

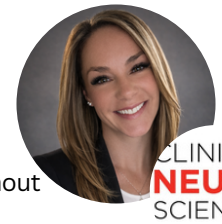
Session on sexual health for women with chronic conditions

BEN JESPERSEN

Session on sexual health for men with chronic conditions

ANDREW SCHMIDT

Pro tips on exercises to improve strength and mobility. Available as a resources person throughout the conference.



CRYSTAL ALLEN AND KATE KAIN

Sessions on Immunoglobulin:

- Subcutaneous Ig
- Side effect management with IVIG

MS HOPE

MATHEW EMBRY

Session on dietary strategies in neuroimmune conditions

More to be announced....

OTHER AMAZING FEATURES:

- **Mix and Mingle** on Saturday night
- **Disability Alliance Canada** will be hosting a Disability Tax Credit clinic throughout the conference
- Screening of the **No One Rides Alone film**
- Regular **wellness breaks**
- **Calgary Walk and Roll**

Calgary National Conference

Registered? Are you ready?

The Calgary National Conference is just around the corner!
Once you've registered, here's a quick checklist to help you get ready:

□ **Reserve your hotel room.** Don't miss out on the special conference rate available through our room block. Book your room **HERE.**

□ **Register for the Calgary Walk & Roll.** The Walk & Roll will take place during the conference and is one of the highlights of the weekend. Don't miss this opportunity to connect with others in the community while supporting patients and families affected by GBS, CIDP, MMN, and variants. Register **HERE.**

□ **Follow the Foundation's Facebook/ Instagram pages**. Stay up to date with conference news, connect with fellow attendees before the conference, and ask questions. Join **HERE.**

□ **Review the agenda.** Take a look at the conference schedule and identify the sessions you don't want to miss. Draft agenda **HERE.**

□ **Make a list of your questions.** Whether you're newly diagnosed or have been living with one of these conditions for years, this is a rare opportunity to learn directly from experts and connect with others who understand what you're going through.

□ **Introduce yourself to someone new.** One of the most valuable parts of the conference is the opportunity to connect with others who truly understand the challenges of living with these conditions. Don't be shy! We're a friendly group!

□ **Pack for relaxation and exploration**. Bring your bathing suit, workout gear, and comfortable outdoor clothing. The Westin Calgary Airport offers a pool, spa, fitness centre, and easy access to nearby trails.

□ **Consider donating an item to the Silent Auction**. We're collecting items to help raise funds for Foundation programs and services. Gift baskets, artwork, gift certificates, and new items are all welcome. Email us at info@gbscidp.ca.

□ **Know a potential sponsor?** We're looking for small and medium-sized businesses that want to make a difference for the GBS, CIDP, MMN, and variant community. Share our sponsorship package with businesses in your network. Sponsorship package **HERE.**

Fall 2026 Walk and Rolls

Join. Connect. Raise Awareness.

We can't wait to see you at our fall Walk and Rolls!

Calgary Walk and Roll - September 19th

Calgary Westin Airport Hotel

This year's Calgary Walk and Roll is extra special!

We are hosting it during our Calgary National Conference! It is going to be an amazing event bringing together a large number of patients, caregivers and friends.

If you are attending the conference, don't forget to **REGISTER** for the walk!

OTHER WALKS THIS FALL

Montreal Walk and Roll - October 17

Halifax Region Walk and Roll - October 24

Thank you to our sponsors!

PLATINUM argenx

GOLD GRIFOLS

Gifts for fundraisers

Raise over $250 and you also get a Turtlewear cap!

Hero Box

for those who raise over $100

Spring 2026 Walk and Rolls

Join. Connect. Raise Awareness.

This year's Walk and Roll season got off to a great start, with four walks (Coquitlam, Toronto, London and West Vancouver) taking place across the country. Thank you to everyone who chaired, volunteered, participated, donated, and helped spread the word. **We are incredibly grateful for your support.**

At a time when many families are facing uncertainty and schedules are overloaded, opportunities to come together as a community are more important than ever. No matter the size of the event, we consistently hear from participants how meaningful it is to connect face-to-face with others who understand the challenges of living with GBS, CIDP, MMN, and variants.

Thank you for being part of our community!

We'd love to hear your ideas.

Have you participated in a fundraising event that brought people together?

Is there an activity you'd like to see the Foundation explore?

We are always looking for new ways to strengthen our community while raising funds to fulfill our mission to support patients.

Email us at info@gbscidp.ca

Community Fundraising

Helping Us, Help Others

One of the things that never ceases to inspire us is the way members of our community turn their experiences with GBS, CIDP, MMN, and variants into opportunities to help others.

This year was no exception. From wine fundraisers and hockey tournaments to a major campaign supporting research, community members across Canada found creative ways to give back. When asked what motivated them to organize a wine fundraiser in partnership with Megalomaniac Winery in support of the Foundation, ON Liaisons Rob Pividor and Brendan Bakaluk answer was simple: This is just what we do.

They believe in supporting causes that make a difference, especially when they have the opportunity to support a Canadian charity. Their efforts extended beyond fundraising. During MMN Awareness Month, they also encouraged friends and family to donate plasma, helping raise awareness about the importance of plasma-derived therapies for many patients living with our conditions.

After chairing several Walk and Rolls, ON Liaisons Justin and Nancy Galaski launched the GBS Warriors, an organization dedicated to bringing people together through the power of sport. This winter, they hosted a 3-on-3 hockey tournament that gave players a chance to prepare for the season while raising funds for the Foundation. More than just a competition, this initiative encourages character and leadership development on and off the ice!

This past year also saw an ambitious campaign: the Vision Sanâa and Richard initiative in support of research. Motivated by Richard's experience with CIDP and the challenges this and related conditions can bring, Richard and Sanâa set out to make a major contribution toward advancing research. To date, the campaign has raised an incredible $160,000.

Community Fundraising

These stories remind us that fundraising can take many forms. Do you have an idea you'd like to bring to life? We'd love to hear it. Contact us at info@gbscidp.ca to learn more about how you can get involved.

Every fundraiser starts with one person deciding they want to make the path a little easier for someone else.

Many thanks to the people who generously gave to these fundraising initiatives as well as to all of our amazing donors! We appreciate you!

Research

Three Research Grants Awarded to Canadian Investigators

The Foundation is committed to supporting our GBS, CIDP and MMN investigators in their efforts to improve the lives of those affected by GBS, CIDP, MMN, and their variants. We are pleased to announce that the following Canadian investigators who were awarded grants during the 2025 and 2026 research grant competition cycles.

Awarded in 2025
In 2025, a research grant was awarded to Dr. Yiu-Chia Chang, for the development of an ultrasound testing protocol that will help assess patients with Chronic Inflammatory Neuropathies (CIDP and MMN) and better measure their response to treatment.

Awarded in 2026
The 2026 research grant was awarded to Dr. Juan Francisco Idiáquez Ríos for a study investigating the ideal treatment window for GBS patients, with the aim of improving recovery outcomes and reducing long-term disability.

A second grant was awarded in 2026 to Luce Bourdages for a research initiative examining the information needs of patients recovering from GBS, with the goal of improving access to and understanding of condition information throughout the rehabilitation process.

thank you

We are grateful to the Fonds Sanâa et Richard and to all of our community members who donated to the Sanâa and Richard Vision Fund. Because of your generosity, research can continue to advance, bringing hope for better treatment and improved outcomes for future patients.

Walter Keast Award

for volunteerism

Each year, we recognize an exceptional volunteer with the Walter Keast Award. Walter, the husband of Foundation founder Susan, worked tirelessly alongside her as she built the Foundation from the ground up.

We are delighted to present this year's Walter Keast Award to Sylvain Bousquet, a Quebec Liaison whose dedication, leadership, and commitment have made a lasting impact on our community. Congratulations, and thank you for all that you do.

Volunteers

We'd love for you to join our volunteer team!

Volunteer Opportunities in 2026

Host a Walk and Roll in your community
We are looking for volunteers to host Walk and Roll events in cities that are not currently on our list: places like Winnipeg, Charlottetown, Windsor, Fredericton, Ottawa, etc.

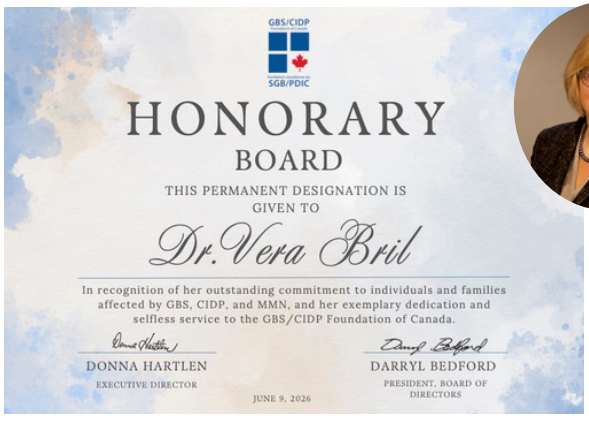
Take part in a Walk and Roll
Join us in person or virtually! What makes these events special is the people who participate. Sign up **HERE.**

Donate items for our Silent Auction
We are looking for donations of new items for the Silent Auction at our National Conference in Calgary. Gift baskets, original artwork, gift certificates, wine and spirits, and similar items are all welcome. Email us at info@gbscidp.ca to make a donation.

Help grow our social media presence
We are building a team of volunteers to help strengthen our online community. You can start by liking and following our pages and sharing our events and posts within your network. Want to go a step further? Comment on our posts and help get the conversation going. Contact Jen de Combe at jdecombe@gbscidp.ca to learn more about how you can help.

Volunteer in Atlantic Canada or the Prairies
We are putting out a special call for volunteers in the Prairies and Atlantic Canada. These areas remain underserved, and we need your help to change that!

To express your interest in volunteering, please complete the volunteer inquiry form **HERE.**



Dr. Vera Bril

Honorary Board Designation

8 October 1948 - 30 June 2026

It is with profound sadness that we announce the passing of Dr. Vera Bril.

Dr. Bril was much more than an internationally respected neurologist. She was a friend to the GBS/CIDP Foundation of Canada. As Professor of Medicine (Neurology) at the University of Toronto, she was recognized worldwide for her groundbreaking work in diabetic neuropathy, myasthenia gravis, neurofibromatosis, inflammatory neuropathies, and other neuromuscular disorders. Her research and clinical expertise helped shape the care of patients not only in Canada but across the globe, leaving a lasting legacy that will benefit generations to come.

What made Dr. Bril truly exceptional, however, was the compassion she brought to everything she did. She understood that behind every diagnosis was a person and a family searching for answers, hope, and support. She believed deeply that advances in research should lead to better care and better lives for patients.

For well over a decade, Dr. Bril was an invaluable member of the GBS/CIDP Foundation of Canada's Medical Advisory Board. She gave her time generously and without hesitation. She wrote articles, spoke at conferences and educational events, shared her expertise on advisory committees, and always made herself available to answer questions. No matter how demanding her schedule or where she was in the world, she was there when the Foundation needed her.

Those of us who had the privilege of knowing Dr. Bril will remember not only her extraordinary knowledge, but also her kindness, humility, generosity, and unwavering commitment to the GBS, CIDP, and MMN community. While her passing leaves a tremendous void, her influence will continue to be felt through the patients whose lives she changed, the clinicians she inspired, and the Foundation she so faithfully supported. We are profoundly grateful for all she gave to our community, and it is an honour to recognize her enduring contributions through her permanent Honorary Board designation. She will be missed.

LET'S TALK ABOUT CIDP

A New Children's CIDP Booklet

We are pleased to introduce the first booklet in a new series designed specifically for young people who have recently been diagnosed with CIDP and other inflammatory neuropathies.

A diagnosis of CIDP can be overwhelming at any age, but children and teens face unique challenges as they navigate school, friendships, activities, and medical treatment. Until now, there have been few resources created specifically with young patients in mind.

Developed in partnership with Julie Carlson, BC Liaison and parent of a child with CIDP, Miranda & Ameliya Pellett, ON Liaisons, and reviewed by a pediatric neuromuscular neurology team at SickKids in Toronto, this booklet provides accessible, age-appropriate information to help young people better understand their condition and feel more confident in managing it. Children's GBS Booklet in review! Get it **here.**