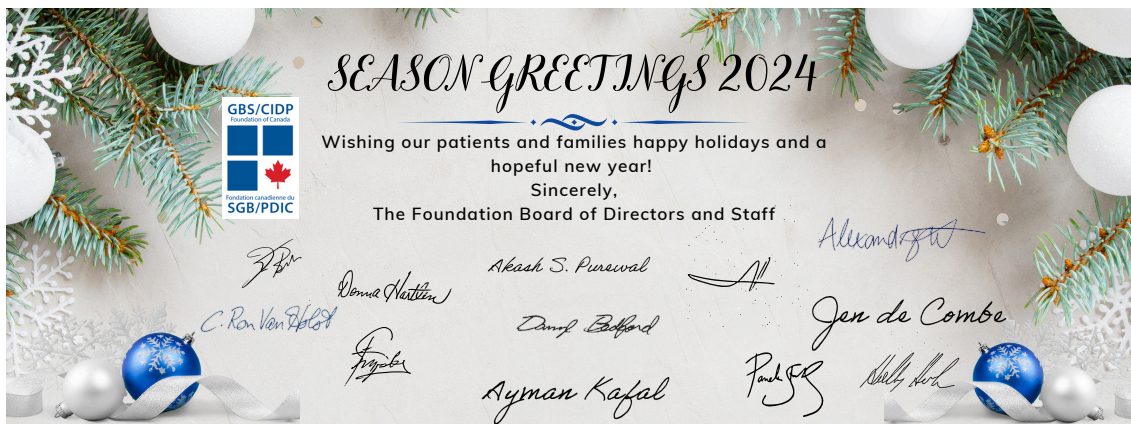


News and Views

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



Lights, Cameras, and Major Action!

Donna Hartlen, Executive Director

I am blown away as we put together this year's end-of-year newsletter. It never ceases to amaze me what this little train can and does accomplish! Today, I find myself wondering if we are even a little train. Oh, I know we are considered a small foundation in the grand scheme of things, but I am beyond proud of this community's strength, resilience and desire to fight for those who need us. We are small, but this year, once again, mighty! This annum, we blew some statistics out of the water. We had the most patients register in one year. We had the most attendees sign up for an event we've ever seen. We held the most Walk and Rolls in one year. We had the most successful awareness campaign to date. We were forward-facing to the largest number of healthcare professionals in a year. The list goes on.... Our volunteers, board, medical board, staff, and generous donors are instrumental in everything we do. These fantastic accomplishments take a village, and we thank YOU! Enjoy the holidays. With gratitude,

Donna Hartlen

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Honorary Board

- Larry Brenneman (Deceased)
- Tom Feasby, MD
- Angelika Hahn, MD
- Susan Keast, *Founder*
- Serge Payer
- Kenneth Shonk, MD

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Donna Hartlen

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★ **2024** ★
AWARENESS

**New - Light It Up
for GBS and CIDP**



**8 WALK AND ROLLS +
2 VIRTUAL WALKS**

Calgary - Coquitlam - Edmonton - London
Montreal - Regina - Toronto - York Region



**GBS-CIDP (MAY)
AWARENESS MONTH**

Proclamations: 2 provinces, 42 cities,
and Health Canada
Light it Up Campaign: 23 landmark
illuminations



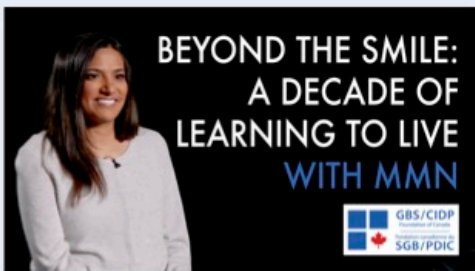
**NEW IN 2024: MMN (FEBRUARY)
AWARENESS MONTH**

We actively participated in MMN
Awareness Month by leading a social
media campaign and promoting new MMN
patient videos



**WE ARE GRATEFUL TO ALL LIAISONS
AND COMMUNITY MEMBERS WHO
SUBMITTED PROCLAMATIONS, TOOK
PART IN ILLUMINATIONS, AND
PARTICIPATED IN AWARENESS MONTH
AND RARE DISEASE DAY SOCIAL MEDIA
CAMPAIGNS.**

**EACH ACTION MAKES A DIFFERENCE IN
THE LIVES OF FUTURE PATIENTS!**



**New Patient
Videos**

The Foundation
released 7 new
ultra-rare patient
stories for Rare
Disease Day





★ 2024 ★

Education

CIDP Patient Night
An educational event collaboration with the University of Calgary that also included a chance for patients to participate in CIDP research.



CONDITION VIDEO (VARIANTS)

We are in the final editing stage of our next condition video, which explores our rare variant conditions.



EDUCATIONAL INSERVICES

Connected with over 18 allied health providers and 33 student nurses.



2-DAY NATIONAL VIRTUAL CONFERENCE

331 Registered attendees
8 Relevant sessions
12 Speakers



262
Registered



39
Registered



30
Registered

In a cyber world, we are able to expand our reach and make education accessible to patients near and far.



EDUCATIONAL INSERVICES

BC Liaison Cheryl Dean told her GBS story and provided an interactive CIDP Patient Journey experience to over 50 allied health providers and nurses this year!

Research Grant Announcement

Introduction

The GBS/CIDP Foundation of Canada is pleased to announce the upcoming \$10,000 Canadian research grant for studies that aim to improve the diagnosis, treatment, and/or rehabilitation of Canadian patients affected by Guillain-Barre syndrome (GBS), chronic inflammatory demyelinating polyneuropathy (CIDP), multifocal motor neuropathy (MMN), and their variants.

Overview

The GBS/CIDP Foundation of Canada is a registered Canadian charity founded in 2003. Our foundation continues its long history of connecting patients and their families with caring and dedicated volunteers who have been affected by GBS, CIDP, and variants, such as MMN. It is our hope that no patient or family will have to go through any of these disorders alone. Along with this patient-to-patient support, the Foundation has proudly established a National Medical Advisory Board of Neurologists trained in the diagnosis and treatment of our disorders. We are committed to building relationships with experts in rehabilitation and support disciplines who understand the challenges facing our patients during and after recovery. Our latest goal is to create a council of professionals that will help guide and educate patients on best practices in their disciplines. We support Canadian research that will improve the diagnosis, treatment, and rehabilitation of patients affected by GBS, CIDP, and variants. Our ultimate goal is to help pave the way to a cure.

Research Areas

Patient-oriented research in any scientific or humanities discipline will be considered. The successful candidate will be expected to work in collaboration with the GBS/CIDP Foundation of Canada membership, Board of Directors, and Medical Advisory Board. The Foundation will assist with participant recruitment of its members.

Expected deliverables

- Initiate, analyze, and complete a patient-oriented research project with GBS/CIDP Foundation of Canada membership, which includes both anglophone and francophone patients.
- Accepted conference presentation (travel and registration fees may be eligible for reimbursement by the Foundation).
- Peer reviewed research paper

Funds available

The total amount available for this funding opportunity is \$10,000 for one year. Payment will be dispersed in quarterly instalments based on milestones. Additional funds may be available for translation services.

Timeline

Launch: Dec 1, 2024

Application deadline: Jan 31, 2025

Successful applicants notified: Mar 14, 2025

Funding start date: May 1, 2025

Quarterly milestones review

Final report/presentation to the Board: May 12, 2026

Research Grant Announcement

Continued

The application package must include:

- Current investigator CV
- Names and contact information for 2 references that can speak to the candidate's research skills and experience (one must be a current or past direct supervisor)
- Two-page research project proposal including proposed methods, timelines, and literature.
- Proposals should explain how the proposed study meets the GBS/CIDP Foundation of Canada mandates and goals.

Contact information

Email: research@gbscidp.ca

MEDICAL ADVISORY BOARD DESIGNATION: DR. KATHERINE BEADON, VANCOUVER, BC

Please join us in welcoming Dr. Katherine Beadon to the Foundation's National Medical Advisory Board.

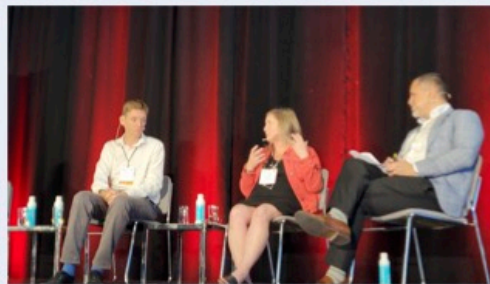
I am an Assistant Clinical Professor at the University of British Columbia in Vancouver, Canada and a co-director of the St. Paul's Immunotherapy in Neurology (SPIN) Clinic. I completed neurology residency and neurophysiology training at Vancouver General Hospital and a fellowship in inflammatory and hereditary neuropathies at the Centre for Rare Neuromuscular Disorders at the Salpetriere in Paris, France. My research is focused on autoimmune neuromuscular disorders. My current research and clinical work involves implementation and tracking of objective measures with a focus on Value-Based Healthcare, working to improve equitable access to alternative forms of treatment such as subcutaneous immunoglobulins and novel immunomodulatory agents and looking at balance and novel markers of inflammation in CIDP. In addition to my clinical practice, I sit on the provincial neurology IVIg utilization panel. This work involves creation of guidelines for appropriate use of immunomodulatory therapy, monitoring use over time and liaising with ordering physicians to provide support and education to optimize care.



Prior to my medical career, I completed a master's in biomedical engineering. When I'm not working, you can find me playing in the mountains or on the ocean with my kids skiing, biking or paddling.



2024 MEDICAL CONFERENCES



6 MEDICAL CONFERENCES

In 2024, we were forward facing to over 2500 Healthcare Providers.



250+ COMMUNICATION CARDS

Communication cards, designed to help ICU patients express their needs, were distributed to over 250 nurses and doctors!



3X INVITED TO SPEAK

Our Executive Director, Donna Hartlen, was invited to share her expertise at three events this year, including one in Washington.



THANK YOU

WE ARE INCREDIBLY GRATEFUL TO OUR LIAISONS WHO WERE PRESENT AT THE MEDICAL CONFERENCES, NOT ONLY RAISING AWARENESS BUT ALSO ENSURING THAT THE PATIENT VOICE REMAINS FRONT AND CENTER WHEN DISCUSSING OUR CONDITIONS WITH MEDICAL PROFESSIONALS.



Each conference we attend raises awareness of our conditions and equips healthcare professionals with the knowledge to better support our patients.



KEEPING THE PATIENT
VOICE
FRONT AND CENTER

www.gbscidp.ca



★ 2024 ★

Advocacy

PLASMA PROTEIN THERAPEUTICS ASSOCIATION

GBS/CIDP Foundation of Canada was invited to participate on a Canadian advocacy panel at this year's PPTA forum in Washington, DC.. Also representing GBS, CIDP, and MMN patients were the GBS | CIDP Foundation International and Corbin Wittington, who shared his CIDP patient journey.



MS AND NEUROIMMUNE SUMMIT 2.0 - DR. TERRY WAHLS

Donna Hartlen, Exec. Dir., spoke to an anticipated attendance of 75K+ about her patient story and the work of the foundation.



TREATMENT ACCESS

We are an active stakeholder with Canadian Blood Services and Hema-Quebec



PAID PLASMA DONATION

In 2024, we advocated for municipal support of paid-plasma centres in Hamilton, Toronto, and Whitby

MEMBER ORGANIZATION



Network Rare Blood Disorders Organization



Neurological Health Charities Canada

DEDICATED SUPPORT LIAISONS CONNECT WITH LOCAL PATIENTS AND CAREGIVERS TO PROVIDE SELF-ADVOCACY GUIDANCE BASED ON THEIR OWN LIVED EXPERIENCES.

NETWORK RARE BLOOD DISORDERS ORGANIZATION



NRBDO 20TH ANNIVERSARY



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Oh, Back to Work

Brittany McCabe

Hi! I'm Britt—a 35-year-old, new(ish) mom living with CIDP. In just 12 days, I'll be heading back to work after two years off. It's yet another chapter in this constantly-evolving journey since my diagnosis. I wanted to share my experience of returning to work in the hopes it might help others navigating a similar path. But before diving into the 'going back' part, I think it's important to reflect on the past two years—why I stepped away from work and the recovery journey that's brought me to this point.

Let's start here: on November 9, 2022, at 34 weeks pregnant, I started noticing my first symptoms—symptoms that would lead to my Guillain-Barré Syndrome diagnosis just 10 days later, on November 19. By then, I was 36 weeks pregnant. On the same day as my diagnosis, I ended up delivering a happy, healthy baby boy via emergency C-section. He's been growing and thriving ever since, and for that, I'll always be endlessly grateful.



I was taken straight to the ICU, where I spent the next month, followed by another month in a neurology ward and then three months in a rehabilitation hospital. When I finally left rehab,

I was still in a wheelchair, and we had to install a stairlift at home. Safe to say, this was *not* the maternity leave I had imagined! At that point, work wasn't even on my radar—I was focused on



learning how to be a mom and taking care of my baby while navigating life with a significant disability. And let's not forget the mental and physical challenges that came with everything I was going through!

To throw another curve ball into this saga, I was diagnosed with CIDP in August 2023 after experiencing a relapse that brought on double vision. I finally started walking again in the fall of 2023, but as my 'year of maternity leave' was coming to an end, I still wasn't ready to start up work again. My doctors recommended I take another year or two off to focus on my health.

So, how did this affect my family financially? Honestly, it was a serious hit. Anyone who's had to take significant time off work due to illness can probably relate. It wasn't just me off work for the first 14 months—I was lucky to have my husband as my primary caregiver, but that meant he was also off work, taking care of both me and our son.

As my maternity leave was coming to an end in September 2023, I started reaching out to my
 → **next page**

Oh, Back to Work

Continued

insurance provider through work. I'm lucky to have long-term disability coverage, which meant I could get some income while I was still recovering. That 'something' was 60% of my salary. As a millennial with a new baby and an expensive mortgage, it was still a financial hit, but hey, it was something. And honestly, I'm really grateful to have that coverage.

I also looked into the [Disability Tax Credit](#) and disability benefits through the Canadian government. If you're in a similar situation, these might be options for you too. I found this page really helpful for figuring out my options: [Disability Benefits](#)

As we rolled into January 2024, my husband went back to work, and my son started daycare. My only job during that time was to keep getting better. That meant intense physio, learning to walk without mobility aids, speech therapy, psychotherapy, acupuncture for my still-severe facial paralysis, and even learning to drive again. And then, finally, taking care of my son on my own (yay!), which I was able to do by April 2024.

Okay, I think you're all caught up. So here we are in November 2024, and like I mentioned, I'm going back to work in 12 days.

You might be asking, what do I even do for work? I'm an Account Executive in the tech space. For anyone not super familiar, I work in sales, trying to grow the business by bringing in new customers and closing deals. I'm in the start-up world, which definitely has its own grind, but with my athletic background and competitive nature, I love it and thrive in that environment.

That said, maybe it's more accurate to say, 'I *used* to thrive in this environment' or 'I was really good at this.' Before I knew anything about GBS and before

becoming a mom, this was a space I was good at. I feel like I should be honest about the fact that I'm a little nervous and unsure now. Will I be able to keep up? Will my fatigue get the best of me? My priorities have completely shifted. My health and being the best mom to my son are my top priorities now.

My health and being the best mom to my son are my top priorities now.

The good news is, I have an 8-week phased return-to-work plan. I'll be starting slow with reduced hours and days, gradually ramping back up to full-time by the end of those 8 weeks. My employer has supported me since the onset of GBS—through my time off and now as we talk about my return—so I have no reason to believe that will change. I feel set up to succeed, and honestly, the only way to know how things will go is to start.

I still have some deficits, and I get IVIG every three weeks. For now, I plan to take those IVIG days off, but eventually, I'll be switching to SubQ treatment, which I can do from home. I've also set up accessible options on my laptop, like dictation, so I can add notes and send emails by speaking instead of typing, since my hands aren't 100% yet and fatigue sets in quickly.

I remind myself all the time that I had to learn to walk again, so I can do anything. And honestly, if this helps anyone reading this—so can you! You and I have been through too much to let nervousness about starting something again hold us back. **-> next page**

Oh, Back to Work

Continued

Maybe that’s going back to work, but maybe it’s also returning to a workout class you loved before your diagnosis, or walking on your own to meet a friend for coffee, or even sharing your story with a stranger. All things that can feel daunting, but we’ve been through too much to let those feelings stop us. That’s the mindset I’m carrying with me as I head back to work and into my old routine—and I think it’ll help me do the best I can.

With less than two weeks before I go back, things are getting real! I’ll be meeting with my new boss next week and setting up my work-from-home office. During this time of change, I’m taking it one day at a time. If you’re open to it, I’d love to keep you posted on how this next milestone and chapter in my GBS/CIDP journey unfolds. I’ll report back after a few weeks to let you know how it’s going.

In the meantime, if you need help navigating this transition from a peer who’s currently going through it, feel free to reach out to me by email at bmccabe@gbscidp.ca. Thanks for reading, and remember, we’ve got this.



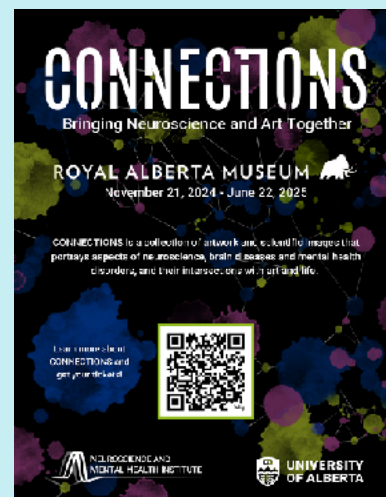
NEED SUPPORT?

Our support group meeting schedule is updated regularly on our [events page](#). Keep checking for upcoming meetings this winter.

If you require support in a non-group setting, call 647-560-6842 or email support@gbscidp.ca



Be inspired by CONNECTIONS, a collection of artwork and scientific images highlighting the intersection of neuroscience, brain diseases, mental health disorders, and art—organized by the Neuroscience and Mental Health Institute (NMHI) at the University of Alberta.





★ 2024 ★

Supporting Our Community



ONLINE SUPPORT FOR PATIENTS AND CAREGIVERS

The Foundation is proud to offer regular meetings for both patients and caregivers, ensuring that everyone in our community receives the support they need.



CONNECTING ACROSS THE COUNTRY: IN-PERSON SUPPORT MEETINGS

The Foundation was pleased to host in-person meetings in Coquitlam, Edmonton, Montreal, Regina, and Quebec City in 2024.



BUILDING A COMMUNITY OF CARE AND CONNECTION

This year, over 330 patients and caregivers took part in our support meetings, building a network of care and mutual support.



Connecting with over 330 patients and families in 2024.



5 In-person and 30 + Online Support Group Meetings

THANK YOU

A huge thank you to all the liaisons who hosted support group meetings or reached out to someone who was newly diagnosed. Your care for patients makes a world of difference!

PHONE CALLS

Over 150 calls to patients and their families, helping to ease their worries after diagnosis.



OUR COMMITMENT

★ That no patient or ★
their families will
★ have to go through ★
these conditions ★
★ alone. ★



★ **2024** ★
WALK AND ROLL

Raised
\$72,441.09



**8 WALK AND ROLLS +
2 VIRTUAL WALKS**

Calgary - Coquitlam - Edmonton
London - Montreal - Regina
Toronto - York Region



**PARTICIPANTS AND
DONORS**

222 participants and 433
individual donors



**2 NATIONAL SPONSORS
& 1 LOCAL SPONSOR**

Takeda - Gold Sponsor
Grifols - Gold Sponsor
Yubukan Karate - Bronze Sponsor



**TO ALL THAT
PARTICIPATED OR
DONATED
WE THANK YOU!**

Canadian Walk and Rolls have funds sent to 2 areas: programs and/or Canadian research. The Foundation raises funds through sponsors, private donors and philanthropic funds, but we do not receive funds from Government grants or other patient organizations. The funds we raise through Walk and Rolls are primarily used for program initiatives such as:

- SUPPORT – ONLINE AND IN-PERSON MEETINGS, PATIENT ADVOCACY, AND HOSPITAL VISITATION
- MEDICAL PROFESSIONAL EDUCATION AND OUTREACH
- PATIENT EDUCATION
- WEBSITE AND SOCIAL MEDIA
- ADVOCACY
- VOLUNTEER SUPPORT, TRAINING AND RECRUITMENT



SUPERTURTLES

We get better slowly but surely!



ASK THE EXPERTS: NATIONAL VIRTUAL CONFERENCE

Moderated by: Alexandre Grant

Dr. Katherine Beadon

Dr. Vincent Picher Martel

Dr. Jiri Vasjar

Dr. Marie Beaudin

00:03:08 Grant

So our first question is for Dr. Beadon.

00:03:11 Grant

So as, as a longtime participant in support group meetings, there seems to be an increasing amount of patients who are initially diagnosed with GBS being re-diagnosed with CIDP. So there's two kind of questions. The first are, the first question is, are neurologists seeing an increase and were they always CIDP?

00:03:36 Beadon

That's a really good question. So what we refer to is sub-acute onset of symptoms. So those people who fall into the, the time frame of symptom development in that 4-to-8-week category, we're never really sure if they're going to end up being a monophasic illness like GBS or if they're going to be a chronic illness such as CIDP and it's a bit of a pattern of practice dependence on where you are, whether you treat them for three months or just treat them once and see what happens. I think these patients have always existed and personally, in my practice, I haven't seen that there's been an increased incidence of people who initially I think are GBS and then end up having CIDP. That's something that we've sort of seen all along. One thing...Sorry, I am at home with two children. You may have just heard a giant bang in the background. One thing that we are more aware of now, though, is these, these nodal-paranodal presentations and inflammatory neuropathy and I think Dr. Katzberg spoke to, a little bit about that in this session yesterday and we know that these patients can present in a more acute fashion, but then have a chronic illness associated with that. So not that it's necessarily increased over time, but I think we're getting a bit

Ask the Experts: National Virtual Conference

Continued

And then, sorry, was there a second part as well?

00:04:57 Grant

I think, I think that that kind of answers the the question about whether there's sort of an increase that you're seeing or if, and also if patients who maybe started out with GBS, but then they turned out to be CIDP, that sort of monophasic versus chronic.

00:05:13 Beadon

Yeah, yeah. And it really is. It's sometimes difficult to predict. There are a few things that we think make us think it's more likely to become a chronic illness, but a lot of the time it is, unfortunately, a wait and see sort of approach.

00:05:27 Grant

Is there anything that you see in, let's say a GBS patient or presumed GBS patient that makes you think, maybe this patient doesn't actually have GBS, maybe it will turn out to be CIDP?

00:05:40 Beadon

Well, that's a good question. So, going in the opposite direction, I don't, I don't think so. We know that patients who end up having the more chronic version are less likely to have things like cranial nerve involvement. So weakness in the face or difficulty with swallowing or difficulty with breathing, but minor or sorry, more mild versions of Guillan-Barré can also present without those symptoms. So I would say, if there's a patient who was progressing on the slower end, because a lot of our GBS patients, they really, it's a, it's a day-by-day change in their symptoms. But if we're hearing that story that it's more of a one week to the next week that they're seeing those changes and they don't have any cranial nerve involvement, then that might me slightly more suspicious, but it is often difficult to tell at the beginning for sure.

For the complete transcription of this informative 2024 National Virtual Conference session, visit [Medical Articles](#)



The information provided in this newsletter is for educational purposes only and is not intended as a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your physician or other qualified healthcare provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read in this newsletter.

Thank you to our sponsors



GRIFOLS

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