

News and Views

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



Happy Holidays

With the commitment of our volunteers, Board of Directors, Medical Advisory Board, staff, and generous donors, we've seen another successful year of growth for the Foundation. We promise to keep the needs of our patients and families as our guiding compass. Due to increased initiatives this year, we are behind on newsletters. Watch for the next News and Views in late January and we'll be back on track for spring. Have a wonderful holiday season and we'll be your side in 2023. *Sincerely, Donna Hartlen, Executive Director*

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Take Charge!
Managing Your
Condition and
National Conference

Board of Directors welcome Akash Purewal

Edmonton, AB

Akash is dedicated to improving treatment, outcomes, and family support for those with GBS/CIDP. Although he never faced GBS himself, Akash's father had a serious case of GBS in 2014. For several months and years, Akash's life and his family's world changed drastically. Akash was one of his father's primary caregivers, providing physical and emotional support, while also trying to maintain his own personal and professional goals. It took several years, but Akash's father re-learned how to walk, and slowly improved enough to live more independently. Although this was a different experience, it initiated Akash's passion for helping GBS/CIDP patients and their families. While going through the whole process, it became clear that the existing system was not built for GBS/CIDP patients. Akash hopes to help physicians better understand and treat GBS, provide patients with the resources they need to recover and thrive, and help families deal with these unique situations.



Akash has a degree in Commerce and a degree in Law, both obtained from the University of Alberta. He has experience as an entrepreneur, working at a large multi-national company, and most recently he started his career in law. Akash hopes to use his experience and education to help GBS/CIDP patients and families across Canada.

Thank you to our supporters of 'News and Views'

CSL Behring

GRIFOLS



New Video Content Available

In 2022 the Foundation added 5 condition videos and 5 French patient journey videos to our YouTube channel and website.

We thank Dr. Bril, Dr. Katzberg, and Dre. Matte for their participation in the production of the GBS, CIDP, and MMN videos. The Foundation is planning more filming in May 2023 in an effort to expand the video catalogue.

An amazing video. Thanks for sharing.

In June of 2022, 5 francophone patients volunteered to share their patient journeys with us. All 5 videos are now available to watch online. We thank each of them for their courage and candour. Bravo!

For anyone interested in sharing their journeys, reach out to Donna, dhartlen@gbscidp.ca to inquire.

YouTube Channel



LAST CHANCE TO ORDER TURTLEWEAR ONLINE

The Foundation is removing online ordering of our Turtlewear hoodies. If you've been wanting to order and ship a hoodie for yourself or a loved one, this is the last chance! Starting Jan 1, 2023, Turtlewear will only be available at some in-person events.

To order: <https://www.gbscidp.ca/turtlewear/>



Our Journey of Hope: ICU Nurse to Caregiver

Shannon Brayley, RN

I was working a night shift in the ICU (Intensive Care Unit) when I got a message from my husband, He wasn't feeling well and needed me to come home. I left work early, got the kids ready and off to school and had my mother-in-law take him to the hospital. He was admitted and I went to see him the following day. Little did I know, the next 24hrs would change our whole world as we knew it.

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My husband went into septic shock and was admitted into the ICU. There he would spend 18 days on a ventilator and on continuous dialysis as his kidneys had failed. He became profoundly weak and stopped moving everything except his head and shoulders. He could feel touch but wasn't able to move. The nurses and doctors also recognized this and an EMG (Electromyography) test was done. I remember looking at his ICU nurse and saying to her, "He presents like GBS!?" (Guillain Barré Syndrome) She looked at me and said, "but he doesn't have any demyelination on his EMG, it can't be". The medical team made the diagnosis of Critical Illness Polyneuropathy. Ten days later my husband was moved from the ICU to the stepdown surgical unit.



Once there the left side of his face became paralyzed and numb. My first thought, Stroke. This brought in Neurologists, who then brought in a Neuromuscular Neurologist who then made the diagnosis of GBS, and so our GBS journey began.

Being an ICU nurse, the diagnosis of GBS was familiar to me. I had taken care of GBS patients in the ICU before. I knew what was coming and that the road to recovery was going to be long. My husband received 7 treatments of plasmapheresis. He was unable to receive IVIG (Intravenous Immunoglobulin medication) due to his kidney failure. There was something about my husband's symptoms of GBS that didn't seem to be typical. —> next page

Our Journey of Hope: ICU Nurse to Caregiver

Continued

This prompted me to start researching deeper into GBS. I had no idea that GBS had variants. AMAN (Acute Motor Axonal Neuropathy) was the variant my husband had and as I read more my heart sank. I knew his road to recovery wasn't going to be easy, it may not be complete and it was going to be a lot longer than I had anticipated.



My husband spent 8 months in an acute care hospital. I was at his side morning to night 4 days a week. My mother-in-law was there for the other 3 days while I was home looking after our two young boys. The hospital was a comfortable place for me, after all, I had been a nurse for 16 years. I knew how to care for my husband. Feeding, repositioning, bathing, transferring, inspecting skin for any redness

on pressure points. I knew how to do passive range of motion and helped with his daily physiotherapy. I took my husband outside for long walks in his wheelchair in the summer months, which did wonders for his mind. Our young boys would come down on weekends when the weather was nice for outside visits (due to covid). We reached out to the GBS/CIDP Foundation of Canada for support. Our liaison got us in contact with people who had been where we were. The support from the foundation got us through some pretty dark days.

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My husband was transferred to a neuro-rehab facility where he would spend an additional 4 months. During this time, we started getting our house ready for his return home. Doors were widened, a ramp installed and a bedroom was made on the main floor. An adjustable bed, bed rails and transferred boards were ordered. We practised car transfers at the rehab facility until we were comfortable and confident. My nursing experience and knowledge was the key factor in being able to bring my husband home. He needed total care for all activities of daily living. After spending 380 days in the hospital.
—> next page

Our Journey of Hope: ICU Nurse to Caregiver

Continued

my husband was finally coming home. My life was about to shift from full time nurse to full time caregiver.

Being a 24/7 caregiver isn't an easy job. Being a mom, wife, running a house and a 24/7 caregiver is physically exhausting, mentally draining and to put it into two words Completely Overwhelming. I reached out to psychiatry for help to support my mental health. I had to be well in order to take care of everyone else around me. I would highly encourage GBS patients and their caregivers to reach out and get the support they need for their mental health. It's a huge factor that needs to be addressed.

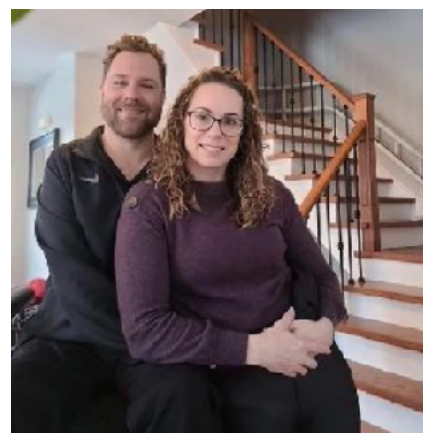
My husband's recovery from AMAN is a journey, a slow and steady one. He has now been home for just over a year. There have been ups and downs. Roller-coasters of emotions that seem to come in waves and cycles. Moments of joy, laughter, frustration and tears. My husband and I are a team and we are dedicated to his recovery. To be able to watch him achieve milestones, no matter how small they are, is rewarding and gives us the encouragement we need to keep going. We have a support system of family, friends, medical professionals and new friends we have met along the way. We live life one day at a time trying not to think too far ahead but living in the now. We face challenges as they come and learn from past experiences.

Not ever in my wildest dreams did I think my life would take this turn, but it did, and I'm here, and it could have been so much worse. Each day I get up and I am thankful that I am able to take care of my family. I am thankful for the support systems around me. I am



thankful for the nursing experience and knowledge that I have. The future is unknown and it can be daunting but I am confident my husband, family and I will overcome whatever comes our way. We will navigate this new way of life together.

I have joined the GBS/CIDP Foundation of Canada as a liaison in hopes that I will be able to support others in their GBS journey and share my experiences as both a caregiver and a nurse. To all the people living and effected by GBS and their families I say this to you, keep your chin up, surround yourself with support systems, put one foot in front of the other and keep going!








WALK AND ROLLS 2022
TOTAL \$23,730.00

TORONTO MAY 14/2022
\$5054.00 Raised!

CALGARY MAY 15/2022
\$9741.00 Raised!

SASKATOON MAY 15/2022
\$385.00 Raised!

YORK REGION SEPT 24/2022
\$8550.00 Raised!

Interested in chairing or participating in a Walk and Roll? Go to www.gbscidp.ca under Act Now.
Email info@gbscidp.ca or call
647-560-6842



Advocacy in 2022: Efforts to Improve the Patient Journey

Thank you to everyone that
participated in advocating for our
patients and families in 2022

Donna Hartlen

I read a recent article in the Canadian news that revealed the results of a recent Canadian survey. More Canadians are concerned about our health system than the bleak economic climate that we are all facing. As patients and caregivers, we've been feeling these pressures for some time. The foundation hears over and over about the long lines in emergency rooms, difficulties in getting timely followup appointments, months, if not years, to get a referral to a specialist, and being the lucky one if you have been able to secure a primary care doctor. These pressures on the health system ultimately lead to longer wait times in getting a diagnosis. In 2022 we required more effort in advocacy than any previous year.

The foundation continues to engage as a stakeholder with Canadian Blood Services, representing our conditions that have indication for immunoglobulin (Health Canada approved use in GBS, CIDP, and MMN). Our executive team, along with members of our Medical Advisory Board, play a key role with CBS in tabling concerns. It is through engagement with CBS that we can advocate for continued access to treatment through participation in consultation meetings, plasma member meetings, and represent patient perspectives during the immunoglobulin procurement process. In September of this year

CBS announced their [Blueprint for the greater security of immunoglobulins for patients in Canada](#). The plan was born from voiced stakeholder concerns that Canada is becoming increasingly vulnerable to world demand of immunoglobulins and Canadian self-sufficiency is currently inadequate to meet growing patient need. To learn more about whole blood and plasma, how they are used, and where to donate, visit blood.ca.

On December 1st, the foundation presented at the CBS open board meeting. On top of voicing our support for their new strategic plan to improve the security of supply of immunoglobulins, we called on CBS to help us advocate with the provinces and territories to reimburse, and make available, Rituximab for our complex and hard to treat CIDP patients that meet specific criteria. Along with the presentation, a letter was submitted to the CBS Board of Directors and endorsed by 13 Canadian neuromuscular specialists. Access to Rituximab not only benefits a specific subset of our CIDP patients, it will reduce usage of IVIG where a more appropriate alternative treatment is available for some of our CIDP patients. The foundation will move to phase 2 of this advocacy initiative with a campaign targeting each provincial and territorial jurisdiction in early 2023 that continue to deny access.

Similar engagement that happens with Canadian Blood Services needs to happen within the province of Quebec. To truly advocate with blood operators that are responsible for immunoglobulin, we must build a strong relationship between the foundation and Hema-Quebec. The foundation has put forward an application to have Alexandre Grant, director from Quebec, represent our patient perspective on HQ —> **next page**

Advocacy in 2022: Efforts to Improve the Patient Journey

Continued

stakeholder committees. We are pleased that the application tabled for review now awaits a decision by the HQ Board of Directors of Alex's acceptance.

Advocacy doesn't stop with treatment access. Advocacy initiatives for our patients and families must work toward a better health system that supports our patients through diagnosis, treatment, recovery, and beyond. This year we provided input for the Quebec provincial rare disease plan. We advocated through awareness of our conditions with medical professionals through medical conference booths, participation on discussion panels, and sponsored a Canadian Association of Emergency Physicians webinar on neuromuscular disorders presenting to the emergency department. We became a member representing peripheral nerve conditions with Neurological Health Charities Canada, a coalition of patient organizations that advocate to advance a framework for a national neurological health strategy. Last but not least. Each day we do what we can to advise our



Remember that Patient you saw with Weakness ...?
Current Approaches to Neuromuscular Emergencies in the ED

WEDNESDAY, MAY 11, 2022 - 7 PM ET | 4PM PT



Jeff Perry
MD, MSc, CCFP-EM
Moderator



Hans Katzberg
MD, MSc, FRCPC, FAAN
Speaker



Miguel Cortel-LeBlanc
MD, MHA, FRCPC
Speaker

REGISTRATION IS COMPLIMENTARY

Learning Objectives:
At the end of this webinar, participants will be able to:

1. Recognize the key clinical features of neuromuscular conditions presenting to the emergency department, including Guillain-Barre Syndrome and myasthenia gravis
2. Review an approach to the investigation of patients presenting to the ER with rapidly progressive weakness or acute neuropathy
3. Discuss the emergency management of patients with neuromuscular conditions
4. Differentiate acute neuromuscular presentations from functional disorders

This event is an Accredited Group Learning Activity (Section 5) as defined by the Maintenance of Certification program of The Royal College of Physicians and Surgeons of Canada and approved by Canadian Association of Emergency Physicians. You may claim a maximum of 1 hour (credits are automatically calculated).

This 1 credit per hour Group Learning program has been certified by the College of Family Physicians of Canada for up to 1 Mainpro+ credit.

patients and caregivers that are experiencing difficulties navigating our health system.

We are focused on the needs of our patients. We hear you. We prioritize advocacy based on the experiences of our GBS, CIDP, and MMN patients and caregivers within the Canadian health system and as the pressures mount, we will continue to fight on.

THANK YOU FOR SUPPORTING THE FOUNDATION
DURING THIS SEASON OF GIVING!

TO DONATE

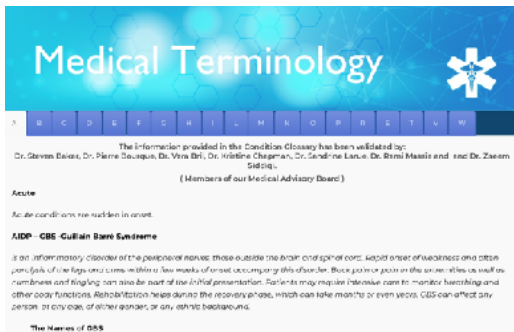


Links of Interest



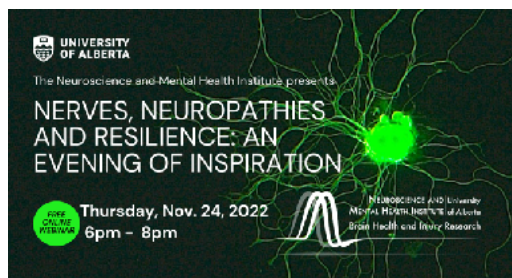
Government Benefits and Community Services

This webpage contains links to tax credits, disability benefits, and community services that may be of interest to GBS, CIDP, and MMN patients and caregivers.



Medical Glossary

After leaving your doctor appointment, did you ever ask yourself ‘what did that mean?’ The Medical Glossary contains medical terminology and their descriptions that are relevant to GBS, CIDP, and MMN and have been validated by our Medical Advisory Board.



Nerves, Neuropathies and Resilience: An Evening of Inspiration: Recording available

NMHI researchers explored nerve disorders, like Guillain-Barré Syndrome, inspirational recovery stories, new medical treatments and research advances. Holly Gerlach participated in the event as an inspirational GBS story.

AWARENESS MONTH MAY 2022 : PROCLAMATIONS

Way to go volunteers! Through your proclamation campaign efforts in the spring, YOU did an amazing job raising awareness for GBS, CIDP, and MMN. With your efforts, two provinces and 34 cities proclaimed the month of May 2022 ‘GBS/CIDP Awareness Month’. Want your city or town to support our community through proclamation? Visit ACT NOW to learn more.



Take Charge! Managing Your Condition

Previous sessions available to watch on-demand until Feb 2023. There is still time to [register](#)

My Occupational Therapy Toolbox: How Occupational Therapy Helped Me Reclaim My Life

Dietary Approaches for Stabilizing and Often Reversing Complex Chronic diseases, Including Multiple Sclerosis and Other Neuroimmune and Autoimmune Conditions

A Practical Guide to Mindfulness for GBS/CIDP/MMN and Variant Persons

Self-Management Strategies to Manage Chronic Health Conditions




Montreal National Conference May 5-6 CELEBRATING 20 YEARS: 2003-2023

The Foundation is working hard finalizing the agenda for the upcoming Montreal National Conference being held at the Sheraton Montreal Airport Hotel. We'll be opening an information page on the website in January with full details. This will include hotel block pricing, Montreal Walk and Roll, the Mix and Mingle social evening, and agenda for the Saturday May 6th educational program. We are building an educational program that will help our patients and families navigate their needs after diagnosis. There will be condition specific sessions, panel discussions, research, self-care, and of course the 1-hr 'Ask the Expert' open Q&A. A hit in Toronto in 2019, your loved ones can experience the challenges of having one of our conditions through the Patient Journey Experience. Be part of the 20-year celebration, see you in Montreal!



Launching in 2023, We're improving the website!



GBS/CIDP
Fondation du Canada
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SGB/PDIC

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Resources for Emergency Physicians →




You can help us support those in need.

Since 2003, we have provided and funded research, resources, advocacy and volunteers to the patients and families of those affected by:

- Guillain-Barré Syndrome (GBS)
- Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)
- Multifocal Motor Neuropathy (MMN)

Get involved
[REGISTER NOW](#)

Impact a life
[MAKE A DONATION](#)

NEED SUPPORT?

Our support group meeting schedule is updated regularly on our events page. Keep checking for upcoming meetings. If you require support in a non-group setting, call 647-560-6842 or email support@gbscidp.ca





You Are Not Alone
Saskatchewan & Manitoba Support Group Meeting

Sunday, Dec 18, 2022
1:00pm-3:00pm CST on Zoom
RSVP to: Kim Brooks
kbrooks@gbscidp.ca

Please join Patti and Jason Kent with other Liaisons for an online peer to peer support group meeting. A little Christmas visit.

- Coping with GBS, CIDP and MMN physically and emotionally
- Experiences and insights around treatment options
- Getting the most out of your doctor's visit
- Healing and knowledge goals
- Take Charge! Managing Your Condition - A webinar series - September 23, 2022 - January 13, 2023.

Note: This meeting is private and will not be recorded. Participants are asked to treat patient information within the group as confidential.

www.gbscidp.ca 647-560-6842

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