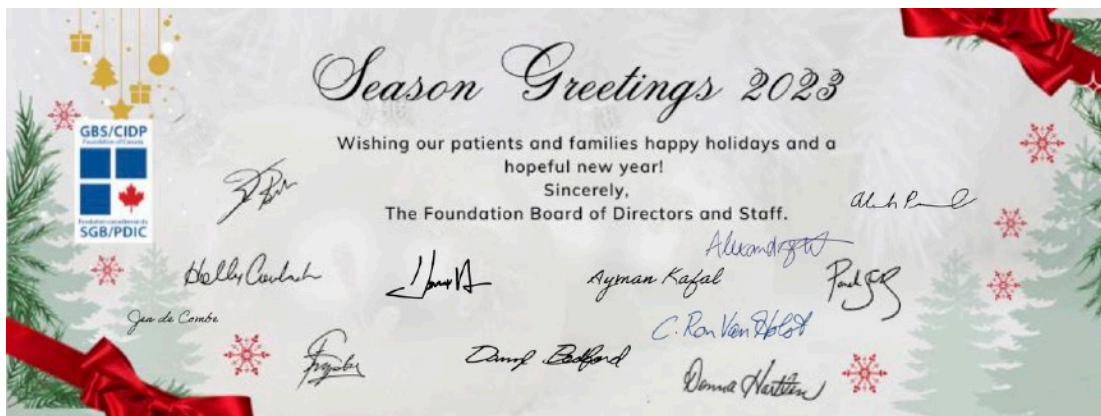


# News and Views

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 a successful 20th year for the foundation. Our founders 20 years ago made patients and families the centre of all decisions, and we continue to keep the needs of our patients and families in focus. May no patient feel alone! This year, the Board of Directors actively engaged in strategic planning and identified unmet needs of our community. Patients and their families remain the priority of future planning, and we look forward to sharing the strategic plan with you in an upcoming newsletter. A special thank you to our committed volunteers, board, and medical board, without YOU, this foundation isn’t possible.

To our wonderful community, happy holidays, and we’ll be by your side in 2024. *Sincerely, Donna Hartlen, Executive Director*

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Celebrating 20 years of service to patients and families

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Intensive Care Units: What to Expect  
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Be Determined  
*Lynn Steeves*

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## Celebrating 20 Years of Service to Our Patients and Families of the GBS, CIDP, MMN, and Variant Community

November 2023 was our official 20th birthday! We're thrilled to celebrate two decades of serving the GBS, CIDP, MMN, and variant community!

It's been an incredible journey from our Founder, Susan Keast, and the first Board of Directors laying the foundation for the Guillain-Barre Syndrome Foundation of Canada. Today, we proudly stand as the GBS/CIDP Foundation of Canada! Here's to the past, present, and future of supporting patients with GBS, CIDP, MMN, and rare variants. Let's keep making a difference together!



Darryl Bedford, President, and Holly Gerlach, Vice President, cut the cake at the Montreal National Conference in May 2023.



**“I am newly diagnosed with CIDP and had the opportunity to go to the 2023 20th anniversary of the foundation in Montreal. I am so happy that the foundation exists, it is such a support system for people dealing with these autoimmune diseases . Thank you so much”. - Wendy**

**“Happy 20th Anniversary to the GBS/CIDP Foundation of Canada. You have been there when I needed hope, information, support and friendship. You have been like a warm blanket of community surrounding me. I look forward to being involved with the Foundation for another 20 years”! - Cheryl**




**“When I was diagnosed with MMN in 1988, I felt very alone. There was no one I could talk to who understood what I was experiencing. Finding the GBS/CIDP Foundation 20 years ago helped me cope with my disease. Finally, someone knew what MMN was and also knew of treatments available to mitigate symptoms. I am very grateful for the GBS/CIDP Foundation in Canada. Congratulations on 20 years of caring support for those of us who have these rare diseases”. - Phyllis**

# Awareness Month 2023: Proclamations

**Awareness month is May. The Foundation continues to raise awareness in our local communities through provincial and municipal proclamations.**

Many thanks to the volunteers that took the time to submit proclamation requests. Each year this campaign grows, and 2023 was no exception!

If you are interested in learning more about how to get GBS-CIDP Awareness month proclaimed in an unrepresented city, send an email to [info@gbscidp.ca](mailto:info@gbscidp.ca).



**Proclamations  
2023  
43 Cities  
2 Provinces  
Health Canada**

*Celebrating our 20 year Anniversary*



**Thank you to our supporters of 'News and Views'**



## Be Determined

Lynn Steeves

*Lynn lives in Lacombe, Alberta with her husband Gene. They love to unplug and enjoy the outdoors—hiking, biking, trail riding and fishing. They have passed this desire to their children and grandchildren and are thrilled to have them tag along on adventures.*

It's been 9 years of managing the residual effects of GBS. Being totally paralyzed and placed on life support certainly left a few challenges that will remain a part of my life. These years of compensation, injuries, and aging have taught me that my rehabilitation is somewhat fluid. It changes because I am changing.

For example—I had badly injured my right foot by carelessly jumping out of the truck box. It already has a substantial amount of nerve damage (not a medical term, but the neurologist said “it is messed up”) from GBS. After trying physiotherapy and three steroid injections my next best option was surgery. Six months post-surgery I was still very limited because of pain, and I became frustrated and disappointed. I had been diligent with the necessary exercises, but my recovery had plateaued. Plus, I gained weight from not being active enough and emotionally eating. I was in a rut.

A close friend told me about a certified sports therapist who may be able to help me. I remembered my own advice to others: keep an open mind, if something, or someone, doesn't work then try something, or someone, else. I encourage others to keep trying, to not give up. In my dad's words “if you won't do it, who will?” A great reminder to take responsibility myself.



**Lynn carefully traverses one of the Havasu River crossings in the Grand Canyon.**

My appointments with Carly have been extremely successful. She focuses on specific areas to target the affected nerves, while also considering how my entire body is compensating. These sessions can feel like workouts at times as she aggressively targets the nerves. However, it has been highly effective in improving my strength and flexibility. Carly expects me to continue doing the exercises at home to maintain and enhance my progress. This is the same goal I had when I started my recovery from GBS, but now, years later, I am achieving it through a different approach. This past year she has helped me to trust my body again and push myself in new ways.

—> next page

## Be Determined

### Continued

#### **I am changing, therefore my treatments change**

Along with accepting the effects of GBS, now I am aging too. It's ok, I am grateful to be growing older. I have ways to manage. Probably the most important, and most difficult, coping skill I have is to take time to rest. I function really well for three busy days in a row, but this is my maximum. I used to say I need a down day, but that sounds negative. Now I refer to it as a recharge day. If I push too hard for too long, it takes me too long to bounce back. I am sure everyone can relate—when we are tired, we are at a higher risk of injury. Our bodies hurt more, issues seem to multiply, even our sleep is affected. Prevention is important.

I try hard to manage a healthy diet. Added weight is very hard on joints and ultimately effects balance. I am reminded of this every time I carry a backpack. My feet get sore faster, and I must pay closer attention to stability. I attended a nutritional webinar where a neurologist shared evidence that certain foods play a role in increased inflammation and should be limited or avoided while other foods are necessary to improve certain functions and maintain health. This information aligns with what nutritionists say as well. It's definitely advice to consider.

I greatly value the expertise and advice of my doctors. For example, COVID, and the heated debates surrounding vaccinations was especially hard for me to navigate because my GBS was caused by the flu vaccine. My neurologist was as concerned as I was. He even arranged a private meeting for me to discuss

with the Alberta Health Communicable Disease Control specialists. I was encouraged that they wanted to speak to me, they typically only have medical discussions with other specialists. They gave me accurate and heartfelt information to consider, of which I am so thankful.

#### **I have a bucket of things to do**

I also continue to trust friends and family. They are considerate and understanding of my limitations. They may roll their eyes a little when I say, "I have an idea", but they always support and encourage me. I could not accomplish my goals and dreams without them. I have an actual bucket of things I want to do and places I want to go, not just a bucket list!

Recently I did another one of these items in the bucket—hike to Havasu Falls in the Grand Canyon again. I had to accept a couple modifications this time. The orthopedic surgeon didn't want me to pack a heavy backpack, so we had a mule haul our gear. We still hiked the gruelling 10 miles to the canyon floor with daypacks containing our water and snacks. I was also diligent about stopping to check my toes and feet for blisters or red areas. Poor sensation in my toes and feet increases the risk of these concerns becoming very problematic.

It was an amazing and exciting four days of camping in this beautiful and remote area of the Grand Canyon where the Havasu Creek meets the Colorado River. The hardest and most rewarding day was descending and ascending Mooney Falls, a 210-foot precarious climb to the base of the falls using worn

—> next page

## Be Determined

### Continued

ladders, chains and footholds in the cliff face. Quite a challenge for someone with residual nerve damage in both feet. Gene, my husband, climbed down ahead of me and placed my feet in the holes and on small ledges, definitely an exercise in my trust and faith in him. On day four we started the difficult hike back to the canyon rim. It had rained a bit the night before, so the gorgeous turquoise waters had become murky and the Havasu Creek was rising. The trail goes through the Havasupai Indian village where the Supai Tribe that manages this part of the canyon live. We noticed several people congregating near the helicopter pad. Something was up. A ranger stopped us and said the bridge ahead of us was washed out and the bridge behind was washed out. The only way out was a helicopter! The rain “on top” caused a dam to break upstream, creating a flash flood in this part of the canyon. Hikers ahead and behind us were sent to higher ground.

**I am determined to continue to search for ways to help me navigate the expected and unexpected changes and challenges associated with post-GBS and aging**



**Lynn’s husband Gene makes sure to place Lynn’s feet safely as they descend 210 feet to Mooney Falls.**

We were stuck between them and probably in the best location because of the proximity to the Havasu Creek. By the time we were evacuated out, the waters were very high, thick and muddy. As far as I know everyone made it out safely. Quite an end to this adventure.

I am determined to continue to search for ways to help me navigate the expected and unexpected changes and challenges associated with post-GBS and aging. I will keep in mind the fluidity of it all, re-evaluate and make changes as circumstances change, so I can function well and continue to live a life full of adventure!

## MEET JEN DE COMBE: BILINGUAL PROGRAM MANAGER AND VOLUNTEER COORDINATOR

*Please join us in welcoming Jen de Combe to the Foundation team !*



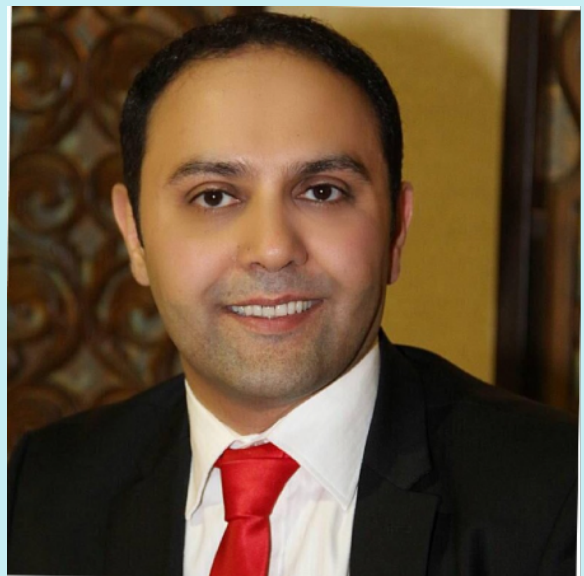
Jen de Combe is a committed leader with over 20 years experience working in the field of leadership development, community organization, volunteer engagement and grant program management. Along with her work in community development, Jen has also served on the board of directors for the Centre de santé et services sociaux Sud-Ouest-Verdun in Montreal.

She has a Master's degree from McGill University and is currently studying grief counselling with Couleur Plume, a grief doula association in France. Jen enjoys cooking big family dinners, painting and exploring new places. She lives in Gaillac with her husband and three children, but still considers Montreal her hometown.

## NEW BOARD MEMBER: DR. AYMAN KAFAL

Dr. Ayman Kafal is the current Vice President at ARS Pharmaceutical. He's been in the pharmaceutical industry for over 17 years, working for various companies in rare diseases, including Neurology, Allergy and Immunology. His work focuses primarily on Medical Affairs, drug safety, and Pharmacovigilance. He is an adjunct university professor of Drug safety and Pharmacology and a member of the Clinical Research Advisory committee at Rutgers University in New Jersey.

With a solid background in medical research, he hopes to contribute his knowledge and expertise to strengthen the research component of the foundation. Ayman's goal in joining the foundation is to help shape and establish the GBS/CIDP Foundation as a key contributor to the advancement of science and research in neuropathies.



## 2023 Walk and Rolls

Mother Nature was kind enough to give us great weather this walk season! We are grateful and want to thank our 2023 Walk and Roll Chairs, those that came out and walked or rolled, or donated to a participant or team. We are now planning our walk schedule for 2024. Stay tuned!

Chairs: Montreal and Toronto: Nancy Edwards | London: Darryl Bedford | York Region: Nancy and Justin Galaski | Calgary: Shai Virani and Kim Brooks



GBS/CIDP  Fondation canadienne de  
Foundation of Canada  SGB/PDIC

**WALK AND**  
**ROLL**  
**MARCHE**  
ET ROULE

**WALK AND ROLLS 2023**  
**TOTAL: \$38,484.59**

<b>MONTREAL MAY 5TH</b>	<b>\$11,872.59 Raised</b>
<b>TORONTO MAY 13TH</b>	<b>\$4,225.00 Raised</b>
<b>LONDON JUNE 17TH</b>	<b>\$3,961.00 Raised</b>
<b>YORK REGION SEPT 16TH</b>	<b>\$15,341.00 Raised</b>
<b>CALGARY SEPT 16TH</b>	<b>\$3,085.00 Raised</b>

Interested in chairing or participating in a Walk or Roll? Go to [www.gbscidp.ca](http://www.gbscidp.ca) under Act Now. Email [info@gbscidp.ca](mailto:info@gbscidp.ca) or call 647-560-6842



## Intensive Care Unit: What to Expect

Shannon Brayley, RN

Hearing a doctor say to you or a loved one that they will be admitted into the Intensive Care Unit (ICU) can be very frightening and overwhelming. This article aims to inform you about what to expect from an ICU environment and hopefully answer some questions you may have.

First, let's discuss why you or your loved one might need to be admitted to the ICU.

GBS can, but not always, affect your ability to breathe properly. Being admitted into the ICU means that you or your loved one requires closer monitoring which will be provided to you by the ICU nurses, respiratory therapists (RT) and intensivists (physicians). The nurse-to-patient ratio in the ICU ranges from 1:1 – 1:2. ICU nurses and respiratory therapists (RT) will closely monitor your GBS symptoms. If your breathing becomes difficult, the ICU nurses, respiratory therapists and intensivist are there to intervene and support you. Many healthcare team members work within the ICU environment. A physiotherapist will help you with range of motion exercises and mobilization. A dietitian will ensure you're getting adequate nutrition, and a social worker will support you and your family.

Now, let's talk about what an ICU room looks like.

Every ICU room has a special bed that provides extra skin protection to help prevent bedsores.

You will see a cardiac monitor, which looks like a flat-screen TV. The cardiac monitor will continuously monitor your heart rate, heart rhythm, respiratory rate, blood pressure and oxygen level. You will see an intravenous (IV) pole and a few IV pumps. These IV pumps are used to provide you with IV hydration or IV medication should you need it. You may also see a mechanical ventilator. This machine will assist and support your breathing should it be needed.

Finally, what can you expect from the ICU environment?

ICUs are very busy and can be loud. There are many machines like the cardiac monitor, IV pumps, and the mechanical ventilator that have pre-set alarms. These alarms go off from time to time. Although it can be hard, try not to get too anxious when these alarms sound. The ICU nurses will manage the alarms. The ICU nurses will help you turn and reposition, assist you with bathing and feeding, and, if needed, administer medications. Respiratory therapists will assess your breathing and manage the mechanical ventilator if required. The intensivist will check on you daily and as needed.

A communication tool was created to be used in the ICU by families and healthcare professionals to assist patients who may not be able to communicate verbally. —> **next page**

## Intensive Care Unit: What to Expect

Continued

Mechanical Ventilator



Cardiac Monitor



ICU Bed



IV Pumps



Please find this communication tool under resources on the [website](#). You will also find a sign that can be printed off and given to the ICU nurse to be placed above the head of the bed as a visual reminder to the healthcare team that you or your loved one has GBS, and even though they may not be able to move or communicate they are mentally aware of everything around them.

Helpful tips: Depending on how long your ICU stay will be, ask your ICU nurses what personal items can be brought in from home.

For example, your pillow or blanket. A toothbrush, toothpaste, hairbrush, shampoo, soap and/or an electric razor. Items to help pass the time, such as your phone, tablets, pictures, a small radio, and a clock, may be helpful.

The ICU can seem scary at first, but once you understand why you or your loved one is there, what to expect and the daily routines, hopefully, it won't seem so overwhelming. The healthcare team is there to help and support you through your GBS journey.

**NOW AVAILABLE FOR ICUS AND PATIENTS:  
PRINTED, LAMINATED AND RINGED  
COMMUNICATION CARDS**



Conférence de Montréal Conference 2023



**GBS/CIDP**  
 Foundation of Canada • Fondation canadienne du  
**SGB/PDIC**



*20 years of Support, Education, Research and Advocacy  
 20 ans de soutien, d'éducation, de recherche et de défense des droits*

**Educational  
 Program**

**Mix and  
 Mingle +  
 Walk and  
 Roll**

Finally, after what felt like a lifetime in planning and delays, we were able to hold our National Conference in May. We trained new volunteers, filmed new patient journey videos, mixed and mingled, Walked and Rolled, educated ourselves in a multitude of sessions for patients and families, and the Board of Directors strategically planned for our future. Thank you volunteers, staff, sponsors, translators, board members, and all our presenters for making the weekend a success. It takes a large team of invested individuals to prepare and implement large events. Thanks for helping us create memories that last a lifetime! We hope to see everyone virtually in 2024, and stay tuned for a 2025 location announcement in the new year.



Mix and Mingle



Mix and Mingle



Mix and Mingle



Silent Auction

### Conférence de Montréal Conference 2023



**GBS/CIDP**  
Foundation of Canada • Fondation canadienne du  
**SGB/PDIC**



**Educational  
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*20 years of Support, Education, Research and Advocacy  
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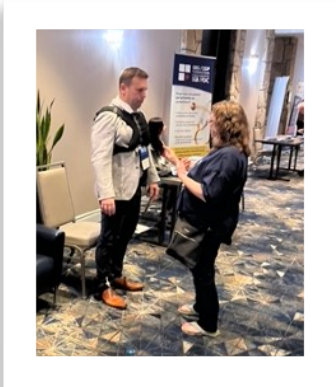
Ask the Experts Panel



Registration - Patti



Marilyn Rose sings 'I can Fly'



Patient Journey Experience



Keynote: Holly Frances



## Awareness and Fundraising Campaigns 2023

Thank you to those individuals that planned and executed their own events to raise awareness in their communities, participated in community events, and through their efforts, raised support for critical programs for our patient community. Inspiring efforts. Awesome job!



Galini's CN Tower Walk for GBS Awareness, and for her friend Tom.

Congratulations, Lynn Steeves, on the success of your inspirational 2nd long-distance swim! Lynn hopes that other GBS survivors will be inspired to reach their own recovery goals, whether large or small. Our thanks to Lynn's sponsors for their support.



Holly Frances (Vice President) and Jenny Rybie (Alberta Liaison), both GBS survivors, had inspiring NERD runs at the NERD Run.



The Palma family organized a fundraiser for Guillain-Barré syndrome in Orford, Quebec.

## Medical Professional Outreach: Awareness and Education

The foundation continues our efforts to raise awareness within the medical community and educate on the GBS, CIDP, MMN, and variant patient journey and our needs. Through our networking efforts with medical associations and having booths at medical conference, we have:

- 1: Thirty ICU packages headed out the door.**
- 2. Have educated emergency physicians**
- 3. Hope to have helped our rural patients.**
- 4. Have provided OTs and PTs some insight into how it feels to be a patient through a mini version of the Patient Journey Experience at the Bridges conference in BC.**



### Medical Conferences Attended in 2023

Rural and Remote 2023: Society of Rural Physicians Canada - Apr 20-22

CAEP 2023: Canadian Association of Emergency Physicians - May 29-31

CACCN 2023: Canadian Association of Critical Care Nurses - Sep 25-27

BC Bridges OT Conference - Oct 26th

CCCF 2023: Canadian Critical Care Forum - Nov 29-30

## NEED SUPPORT?

Our support group meeting schedule is updated regularly on our [events page](#). Keep checking for upcoming meetings in early 2024. If you require support in a non-group setting, call 647-560-6842 or email [support@gbscidp.ca](mailto:support@gbscidp.ca)

**You Are Not Alone**  
Saskatchewan & Manitoba Support Group Meeting

**Sunday, Dec 10, 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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