**News and Views**

**GBS/CIDP FOUNDATION OF CANADA**
SERVING PATIENTS WITH SUPPORT, EDUCATION, RESEARCH, ADVOCACY

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**Still Available**

**Turtlewear Giving Campaign and GBS/CIDP masks**

With your generous donation of $100, the foundation is offering a gift of a Turtlewear hoodie + $70 donation receipt.

Visit gbscidp.ca for more details.

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**September 25th @ 10am**

**GBS/CIDP Virtual Walk and Roll for research and patient services**

This fall consider building a team, or registering as an individual, in your community to Walk and Roll for 50/50 research and continued support of patient programs.

Visit gbscidp.ca.

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**September 10-11 2021**

**National Virtual Conference**

Registration is open!

See inside for how to register for this excellent 2-day event and get the $20 early bird price to attend.

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**PATIENT JOURNEY AND VACCINATION VIDEOS SUBTITLED IN FRENCH**

[Watch Now!](#)
A Message From The Executive Director, Donna Hartlen

Hope restored?

I think most people have endured life-altering changes to everyday life in the last 16 months. As a vulnerable patient community, many of us continue to have worries and concerns about how to resume some normalcy in a safe way, as we see some light in the long Covid-19 tunnel with the Covid-19 vaccine campaign, with the majority of Canadians being vaccinated. It's normal. We're all feeling the same angst. If you are feeling overwhelmed or a deep sense of sadness, consider reaching out to your GP for help or join our support meetings to reduce the effect of the isolation many of us continue to experience.

We started 2021 knowing the anxiety that comes hand in hand with vaccination with our population and we know each of you struggled, or struggle, with the personal decision between yourselves and your healthcare providers whether or not to get Covid-19 vaccinated. In the first quarter of 2021, registrations and inquiries quadrupled. The foundation continues to work closely with our Medical Advisory Board and will update any recommendations surrounding vaccination. The Covid-19 vaccination statement is still available on the website. At this point, we have not heard any patient reports of recurrences of GBS post COVID-19 vaccination. That being said, we don’t have visibility to each GBS case reported unless contacted directly by the patient that has gotten GBS. The foundation has requested more information on the statistics from provincial health units reported to Health Canada and we have not received an answer yet.

As many of the provinces ease restrictions during the pandemic, many of us will be keeping our masks on for now as recommended by the Medical Advisory Board. As new information becomes available to us that directly impacts the well being of the GBS, CIDP, and the MMN community, we’ll make it available online through the website and social media.

Here is a link for the available statistics by Health Canada:
https://health-infobase.canada.ca/covid-19/vaccine-safety/

Now let’s move on to some very positive news in the newsletter!

Don’t miss out on the National Virtual Conference this September 11-12! We have some great sessions by experts in the field that shouldn’t be missed. If you aren’t technology comfortable, reach out to a family member or friend to register so that you can attend. We have a special guest interview that is really exciting!

In this edition you'll find information on an upcoming Virtual Walk and Roll September 25th in support of research and patient services (we plan to announce a research grant opportunity the end of 2021), a patient journey, medical articles, online support group meetings, and awareness and advocacy updates. Enjoy!

Wishing you a safe and enjoyable rest of summer and I hope one day soon we will meet in person once again!

My very best, Donna

Thank you to the following sponsors for your continued support

GBS/CIDP Foundation of Canada
My Journey through CIDP

PETE MORRO

Early in 2016 I noticed numbness in the soles of my feet. Someone suggested “cool laser” treatments. After 15 appointments with no results, I gave it up. I was kayaking, riding my bike along trails, and playing with a band. I was 81 years old.

My wife and I celebrated our 25th anniversary August 8, 2017, so we booked a Danube river cruise. Disembarking from the aircraft in Frankfurt there was, as usual, a crowd pushing for the exit. I failed to notice the six-inch drop from the aircraft to the ramp. With no feeling in the soles of my feet, I must have put my foot half-way off the step and fell on the ramp. Attempting to get up, before I got trampled, I had severe pain in my right foot.

There was nothing to do but carry on to the bus and on to the boat. I limped around until a lady loaned me a cane. This helped, but we missed out on the walking tours in Vienna, Budapest and other places.

When we got home I saw my doctor, who had trained as a neurologist in Ireland, but was now a GP. He told me I had broken my metatarsal bone. He attended to it and made an appointment for me with Dr. K, an experienced neurosurgeon. This was Sept 26, 2017. I was using a cane.

My first MRI was November 12 in Hamilton on what Dr. K called the lower gut. I was back in D. K’s office December 27 as nothing was determined. My next appointment was January 3. By now I was using a walker. D. K asked me if I could go into the US. I said yes and he told me about the Seton clinic in Amherst, NY. My second MRI was the next day on the middle gut and cost $760 US. I saw Dr. K again January 11. This time I fell flat on my face in front of the doctor, his receptionist, my wife and the other patients — a bit embarrassing. Dr. K commented, ”Next time I see you, be in a wheelchair.” From then on I used a wheelchair.

We were living in a brick bungalow in the north end of St. Catharines, with a big covered deck, breezeway leading to the garage, a 150-foot backyard, trees, shrubs, flower, etc. We had planned to stay there forever. Of course it wasn’t suitable for a wheelchair. We found a single story townhouse with wide doors. I was unable to climb the two steps from the garage to check the place out. Luckily the realtor and my wife got me in. We obtained a lift for the garage and a stair chair to go downstairs and had the tub removed and an accessible shower installed.

I had an emergency MRI on January 13 in St. Catharines on the upper gut and was back in Dr. Ks office three days later. Next it was St. Catharines hospital January 29 for a CT scan and back to Dr. K on Feb 2. Okay, enough is enough. I took it upon myself to phone the Seton clinic for an MRI on the brain, on February 6. Back to Dr. K three days later, but all they found was a narrowing of an artery in the brain — the least of my problems. Next was an appointment for a spinal tap on February 26 with Dr. K. As soon as he looked at the fluid he mentioned that my problem looked like CIDP. On March 7 he made the firm diagnosis. Wow, what a trip!

I was set up with IVIG in the St. Catharines hospital starting April 11. Each visit took about four and a half hours. I got a lot of reading done but never met another CIDP patient. Apparently privacy is a big deal even though I told the nurses to give them my name. CIDP is a lonely journey.

So, IVIG from April 11, 2018, every three weeks until June 13, 2019. Then Dr. K took me off the treatments saying, “That’s as good as you’re going to get.”

→ next page
**My Journey through CIDP - Cont’d**

So, now I’m in remission. When Dr. K retired he asked Dr. B to look after me. I went to the clinic in Hamilton twice, for strength tests, electric current, etc. My last contact was summer 2020. Dr. B wished me well and removed me from his patient list.

The only problem I have is with my left knee. It got crunched when I fell between the bed and the wall, too small a space for me. I stretched ligaments in my knee and wear a brace now. So, here I am, 86 years old and in remission. I feel very fortunate as very few achieve this.

I’m a woodcarver. I did songbirds for a few years, but carve aircraft now (33 years in the RCAF). I play my harmonicas in a band. Well, until Covid is done with us, I stay home or go shopping with my wife – wearing our masks.

I realize I am extremely fortunate in so many ways. I wish there were a secret I could share, but it appears to be simply luck.

My thanks go out to Dr. Matt Greenway, my GP. who had the wisdom to send me to a neurologist, Dr. Ed Klimek who didn’t quit until I was walking, and Dr. Steven Baker, who put the finishing touches on my CIDP journey.

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**Alexander Grant, Quebec**

Designated to the GBS/CIDP Foundation of Canada

Board of Directors

Alexandre Grant was diagnosed with GBS in 2017. He joined the GBS/CIDP Foundation of Canada in 2020 as a Quebec Liaison and later joined the Board of Directors in 2021.

Alex is committed to ensuring that every person and family affected by GBS, CIDP, or MMN in Canada is well supported and receives the best care while navigating a diagnosis and treatment. Notably, he aims to help expand the Foundation’s outreach within the francophone community.

Alex is a first year master's student in Microbiology and Immunology at McGill University, where he studies ways to improve the immune system’s response against pulmonary infections, including influenza, tuberculosis, and SARS-CoV-2. In his free time, Alex enjoys outdoor sports like hiking and sailing.

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**Hizentra Announcement: 20ml (4g) Syringe now available**

Canadian Blood Services and Hema-Quebec announced in early spring that Hizentra will now be available in a 20ml (4g) syringe and will be phasing out the 20ml (4g) vial size. The 50ml (10g) vial size will remain available. If you have any questions you should reach out to your healthcare provider or infusion nurse. To see the official announcements:


Advocacy Update: VACCINE INJURY SUPPORT PROGRAM
Donna Hartlen, Executive Director

On December 8, 2020, Justin Trudeau announced the creation of the Vaccine Injury Support Program for all Canadians. The Foundation sent a letter to Health Canada requesting more information on the implementation plans and offering our assistance and understanding of the devastating effects that adverse events due to vaccination can have on an individual.

The foundation is engaged with Public Health as a stakeholder. Here are some of the concerns voiced directly to them:

1. Length of time it takes to be approved by the program if you were a GBS injury. Due to the length of recovery, GBS patients may have to wait months or more than a year for an application to be accepted.
2. The language of ‘Serious and Permanent’. Helping Public Health understand the onset, recovery, and residual effects of our conditions.
3. The start date of the program. Quebec has had a program implemented for 32 years, leaving the rest of Canada without a program and especially leaving out the fall 2020 flu campaign that was pushed by the provinces in 2020 to help combat the COVID-19 pandemic.

If you had an adverse event by any vaccine, make sure it was reported to Public Health. If you make the decision to apply for the program, make sure that the physician that is signing off on your application is an expert in treating the condition. For GBS, a neuromuscular physician would be suggested. Once your application is in the system, it remains until the review process is complete. If your application was denied, you may appeal the decision with more supporting evidence of a permanent injury and the review process will begin again.

We will continue to communicate your concerns and give advice to Public Health Canada as the program rolls out and to the appropriate governments. Many voices can be more impactful, consider writing to your MP with your concerns related to this program.

Pamela Stoikopoulos, Ontario
Designated to the GBS/CIDP Foundation of Canada Board of Directors

After a 7-year epic journey that included assessment by three neurologists, Pam Stoikopoulos was diagnosed with MMN in 2017. She feels fortunate that IVIG treatment almost immediately improved her hand and leg function, bringing it to a “new normal.” She is currently trying out subcutaneous treatment so she can work and travel (post-pandemic) without interruption.

In those early days of diagnosis Pam turned to social media groups for support, insights and ideas and realized quickly how important these connections were to staying informed and positive. In 2018 she attended the GBS/CIDP Foundation of Canada’s national conference in Toronto and was blown away by the comprehensive sessions, range of topics and connections she made with people who “got” what she had been through.

Professionally Pam has over 15 years of experience working in communications as both a consultant and as Sr. Manager of Communications for VHA Home HealthCare (VHA)—a large, Ontario-based not-for-profit. Wanting to be more directly involved in shaping change in the health care space, she set her sights on health innovation. She earned a Master’s of Management, Innovation and Entrepreneurship from Queen's University in 2019 and is now the Head of Innovation Engagement at VHA.

Pam is excited to apply both her personal and professional experience to her board role to help more GBS/CIDP/MMN patients—so no one ever has to go it alone—and to advocate on their behalf for greater awareness, better support and sustainable treatment options.

Pam lives in Toronto with her husband Junya, three boys aged 8, 12 and 14 and two cats. Though she’s had to give up ice skating, she was excited to discover that she can use a kick scooter to keep pace with her family on long walks!
Join Us
September 11-12th, 2021

Featured Speakers / Conférenciers:

Dr. Carolina Barnett-Tapia
Candine Blackbeard, RN
Dr. Pierre Bourque
Dr. Vera Bril
Dr. Alexis Gagnon

Dr. Hans Katzberg
Juan Lopez, OT
Dr. Rami Massie
Sylvia de Melo, RN
Laura Wang, RPh, ACPR

Register Today!
Inscrivez-vous dès aujourd’hui!
https://pheedloop.com/gbscidp/site/home
Get the Early Bird price of $20 until Aug 25th!
To register and for more details: https://pheedloop.com/gbscidp/site/home

**Confirmed Presentation / Présentations confirmées**

**Welcome Day 1 / Journée d’accueil (jour 1)**

- A North American Survey of CIDP treatments and patient satisfaction
  Un sondage sur les traitements en PDIC et sur la satisfaction des patients en Amérique du Nord
  
  Carolina Barnett-Tapia  
  MD, FRCPC

- Current treatment in GBS, CIDP, and MMN
  Traitement dans SGB, PDIC et MMN
  
  Rami Massie  
  MD, FRCPC

- Quels sont les méthodes diagnostiques du SGB, de la PIDC et de la NMM
  What are the diagnostic methods for GBS, CIDP, and MMN
  
  Alexis Gagnon  
  MD, FRCPC

- Stress and Mindfulness
  Stress et pleine conscience
  
  Candine Blackbeard  
  RN

- Developing Treatments in Inflammatory Neuropathies
  Développer des traitements dans les neuropathies inflammatoires
  
  Vera Bril  
  MD, FRCPC

*Live translation will be provided in French and English | Traduction en temps réel en français et en anglais*

**Welcome Day 2 / Journée d’accueil (jour 2)**

- SCIG : Transition de la thérapie d’IgIV aux perfusions sous-cutanées d’Ig à domicile
  
  Sylvia de Melo  
  RN

- SCIG: Transition from IVlg Therapy to Subcutaneous Ig Home Infusions
  
  Pierre Bourque  
  MD, FRCPC

- Bone Marrow stem cell transplantation for treatment resistant CIDP
  Greffe de cellules souches de moelle osseuse pour CIDP résistant au traitement
  
  Juan Lopez  
  OT

- A journey of Self-Discovery: An OT’s Perspective
  Un voyage de découverte de soi : la perspective d’un ergothérapeute

- Steroid use in Pediatric patients and potential complications
  Le rôle des stéroïdes dans le traitement des maladies neuro-inflammatoires ainsi que la gestion de leurs effets secondaires
  
  Laura Wang  
  RPh, ACPR

- Fire and Ice: Symptom Management in Immune Neuropathies
  Feu et glace : gestion des symptômes dans les neuropathies immunitaires
  
  Hans Katzberg  
  MD, FRCPC
**The dreadful headache, IVIG and infusion rates**

**DR. CAROLINA BARNETT-TAPIA**
ASSISTANT PROFESSOR OF NEUROLOGY, DEPARTMENT OF MEDICINE, UNIVERSITY OF TORONTO
PROSSERMAN FAMILY NEUROMUSCULAR CLINIC, UNIVERSITY HEALTH NETWORK

Intravenous immunoglobulin (IVIG) remains the first line treatment option for people with CIDP. While the rate of severe adverse events is low, up to 3 in 10 people experience headache, chills, fever and rash, that while not dangerous can be quite severe, and sometimes disabling. Most of these adverse events occur during the infusion, and we have known for several years that many of these are related to the infusion rate (i.e. how fast the infusion is given).

So what is the "optimal" infusion rate? Well, it depends. Some people have a high tolerance of IVIG and never develop these symptoms and can have fast infusions. Some people develop symptoms even with slow rates. So the optimal rate is the one that works best for an individual. Some people simply cannot tolerate IVIG regardless of the infusion rate and, fortunately, other options, such as subcutaneous Ig are now available.

How do we calculate rates? Well, to make thing trickier, infusion rates are calculated based on weight; remember that the dosing of IVIG is by weight so the rates take this into consideration. Different formulations have different manufacturer's indications regarding rates, but most have a maximum rate, usually around 0.08 mL/Kg/min. Using this rate, as an example, a person who weighs 70 Kg could receive a maximum rate of 5.6 mL per minute, which is approximately 336 mL per hour. This maximum rate comes from older studies and older formulations which may have had more potential for adverse reactions.

We recently conducted a study to test whether this maximum rate number could be safely exceeded. We enrolled 25 patients with known CIDP attending our clinic. They could be new to IVIG or be on chronic treatment. We planned 13 IVIG (10%) infusions, starting with a low infusion rate on day one, increasing only if tolerated, with a maximum of 0.08 mL/Kg/min. After several infusions, we slowly increased the maximum rate according to tolerance to 0.1, 0.12 and finally to a maximum study rate of 0.14 mL/Kg/min. Using the same example as above—a person who weighs 70K, this would be a maximum rate of 9.8 mL/min or 588 mL per hour.

What did we find? Well, 19 (76%) of the patients were able to safely increase the rate to our maximum study rate. Of these 19 individuals, 2 had some adverse events at the highest rate, and needed to go to a lower rate, but on subsequent infusions, they were able to tolerate the higher rate. Overall, the patients who were able to receive the highest infusion rate were able to reduce their total infusion time by 23%.

What about the patients who did not reach a higher rate? One of them had to use a low rate for all the study infusions. Four patients withdrew from the study altogether, only 2 (8% of total patients) due to adverse events. Of note, the 2 patients who had adverse reactions to IVIG had it after a loading dose (2g/k) given at slow infusion rates. So we think in these specific cases it was not the infusion rate but maybe the amount of fluid or the higher total dose that was problematic.
The dreadful headache, IVIG and infusion rates - Cont’d

In our study, we analysed 264 infusions, and we only had 25 treatment-related adverse events, 7 were rash/hives (28%), and 6 (24%) were headaches. We did however pre-medicate all our patients with acetaminophen and diphenhydramine (anti-allergic), which can help prevent or reduce headache, rash and other adverse events. We also excluded people who had a history of severe reactions to IVIG.

So, what is our current practice? We always recommend to start with a low infusion rate, especially in people new to IVIG. The rate can be then increased slowly (after 30 minutes in the first infusion), according to tolerance. If symptoms develop, the infusion is slowed down or stopped, and restarted at a lower rate. Sometimes a patient is able to tolerate a higher rate in a future infusion, so if they are doing well we might re-challenge them if they want to try. The key is to do this slowly and to individualize the rate for the patient. Some patients may always need a low rate even if they don't develop headache or rash, for example people with acute kidney failure due to higher risk of blood clots (thrombosis).

Some patients develop intolerable symptoms despite good hydration and premedication. Some of these patients may find that a different IVIG formulation is better tolerated. If this does not help or is not feasible, then other treatment alternatives should be considered, such as subcutaneous infusions.

Many hospitals have infusion rate tables, which help infusion nurses to safely increase the rate according to weight, tolerance and to specific formulations. Remember to discuss with your care team if you find that your rate is too fast for you, or if you think you could safely tolerate a higher rate.

References:


May was Awareness Month!

Proclamations

It has been next to impossible to be on the ground building grassroots awareness during the pandemic, but we took the opportunity early in the year to apply for federal, provincial, and municipal proclamations. This campaign was done behind a computer! We successfully received 14 proclamations and this couldn’t have been done without the help of our volunteers. The foundation can’t thank each of you enough for your efforts and we look forward to receiving even more proclamations in 2022.

We’ll be starting the application process toward the end of the year for 2022 and if you’d like to see your city/town proclaim the month of May as GBS/CIDP Awareness Month, or a Day, reach out to us: info@gbscidp.ca.

Thank You!

Glenanne Ball
Darryl Bedford
Kim Brooks
Cheryl Dean
Nancy Edwards
Fernando Fernandez
Laura Rutherford
Duncan Taylor
Ron Van Holst

RECOGNIZING THE SYMPTOMS

The earlier we are diagnosed, the better the outcome will be!

The foundation has been working hard to educate medical professionals about our conditions and the presentation of their symptoms. We’ve created symptoms brochures, available on the website for download, and printed for distribution at medical conferences. The emergency department is often the first touch point for a patient, we have run Ads like the one below in the Canadian Association of Emergency Physicians newsletter for 13 weeks starting in March of this year.

Patients Experiencing these symptoms?
- Rapidly progressive weakness (often symmetrical and ascending)
- Loss of reflexes
- New numbness or tingling
- New back or extremity pain
- Facial weakness
- Trouble breathing
(leading to the need for intensive care) Learn more
MEDICAL CONFERENCES

The foundation will attend multiple medical conferences this year, engaging family physicians, neurologists, emergency physicians, and rural doctors. Some of the conferences will be virtual and some have decided to move forward with fall in-person events. Here is a virtual exhibitor booth that was created for the CAEP 2021 conference for emergency physicians.

Supporting Our Patients

Support is Just a Click Away!

Have you thought about joining one of our peer-to-peer online support group meetings? It’s as easy as clicking a link in an email. So far this year we have held 20 meetings and have reached 167 patients and their families.

For our francophone patients and their families, we have the Quebec French online support group meeting approximately every three months. We would like to invite everyone across Canada that speaks French to join. Please email kbrooks@gbscidp.ca to start receiving invites and information in French.

We look forward to seeing you!

Important! Mailing by post of the Newsletter will stop in 2022

‘News and Views’ is now created as a higher digital experience and does not translate well to print and the reader can potentially lose out on some content. The newsletter will no longer be printed and posted by mail in 2022. Stay connected!

If you receive the printed newsletter, update your contact information NOW at the following link:

https://www.gbscidp.ca/foundation-registration/
**Disclaimer**

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