News and Views

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

2020

Season's Greetings

Wishing our patients and families happy holidays and a hopeful new year!

Sincerely,
The Foundation Board of Directors
& Staff

C. Ron Van Holst
Donna Hartlen
Howard Hess
Marilyn Rose
David Bedford

Fall 2020

Turtlewear Holiday Giving campaign and GBS/CIDP masks now available

With your generous donation of $100 this season of giving, the foundation is offering a gift of a Turtlewear hoodie + $70 donation receipt. See Inside!

Fall 2020

Now available! Recorded Ask the Expert sessions

Some of the Ask the Expert sessions this fall were recorded after questions were submitted. There are more sessions being uploaded in December. Visit **gbscidp.ca.**

September 10-11 2021

Montreal National Conference rescheduled

Due to the current COVID-19 pandemic and our concern for patient safety, the foundation has postponed the 2020 Montreal Conference until fall of 2021. Save the date!

ON TOP OF THE WORLD

GBS/CIDP FOUNDATION OF CANADA REACHES K2 BASE CAMP!

Friends of our Alberta director, Dean Lower, wore their Walk and Roll T-shirts and helped Dean climb a mountain and built awareness for GBS, CIDP, and variants. K2 is second to Mt. Everest for height in the world. Congrats on this achievement and thank you Andrew & Brad for helping us reach for the sky!

A Message From The Executive Director, *Donna Hartlen*

A year of positive change!

I know you must be thinking has Donna gone mad? Positivity as our country faces another wave of COVID-19?

We started 2020 with a planned program year that the foundation was excited to provide. We all know how the decade started and then quickly shifted. I recently went through the exercise of creating ‘A Year In Review’ presentation. It was an emotional experience as I highlighted foundation initiatives that have evolved since the spring lockdown that translated into a year of successful adaptation that has lead to permanent changes to our programs. It was a lot of hard work! The foundation team of staff and volunteers dedicated themselves to be all-in and continued to be patient focused, took on steep learning curves, and always focused on how we could continue to support patient and caregiver lives that have been profoundly affected by our conditions.

Some of the notable accomplishments thus far:

- Our patient journey videos have had 15K+ engagements on YouTube
- Provided 30+ peer-to-peer support group meetings and supported more that 350+ participants in just 7 months
- Provided an online educational program through ‘Ask the Expert’ sessions
- Reached 1K+ Facebook likes and rising daily with some international followers.
- Created partnerships with Canadian Association Emergency Physicians and the Association of Electromyography Technologists of Canada, and continue to build relationships with other medical associations
- Virtual Walk and Roll
- Turtlewear
- Expanded the Medical Advisory Board
- Added liaisons across regions
- Expanded content in both English and French
- Continued to grow awareness, and more on the horizon

We still have many uncertainties, but we will continue to be here for patients and loved ones in the coming months and years. It is with appreciative thanks to our sponsors, medical board, Board of Directors, liaisons, private donors, and staff for your support during 2020. You helped us go virtual, educate, advocate, and support our patients.

Thank you for your consideration in supporting the foundation through the Holiday Giving Campaign during these uncertain economic times.

I wish you safety, happy holidays, and a bright and hopeful 2021! Sincerely, Donna

Thank you to the following sponsors for your continued support

Platinum Sponsor	Platinum Sponsor	Platinum Sponsor	Bronze Sponsor
GRIFOLS	CSL Behring	Takeda	octapharma

My Experience with COVID-19 and Rituximab

ROGER WALLS

I'd like to share with you my experience of going through COVID-19 while being on the immunotherapy drug rituximab.

First, let me give you some background.

I'm a 53-year-old guy, relatively healthy and very active. In the summer of 2015 I was diagnosed with the autoimmune disorder Anti-MAG (myelin associated glycoprotein) Peripheral Neuropathy, a variant of CIDP. I also have a condition called MGUS (monoclonal gammopathy of undetermined significance), as do all people with Anti-MAG. I spent two and a half years getting IVIG treatment every four weeks. The IVIG became ineffective towards the end of 2017, at which time my neurologist and hematologist switched me to a combined chemotherapy and immunotherapy treatment of bendamustine and rituximab, also known as R-Benda. This lasted for six months, ending in May 2018. The R-Benda treatment put my condition into remission. Then I was kept on a maintenance dose of rituximab for two years, getting a subcutaneous injection every three months. My last injection was in June.

On March 16, I started feeling like I was getting the flu. For five days I experienced quite profound fatigue and body aches. I didn't ever spike a fever, so I didn't think that I had COVID. At the time, I didn't qualify for testing, according to the Alberta Health Services online assessment. The flu-like symptoms then turned into symptoms more typical of a nasty cold. Lots of coughing and nasal discharge. Also, for the first three weeks I felt "dizzy in the head" from time to time. On March 31, Health Services agreed to test me and three days later I found out I was positive for COVID. It took a total of five weeks for my symptoms to go away, and on April 20 I was told I could come out of isolation.

Going through COVID wasn't much fun, but the good news is that I never felt like I needed medical assistance. My chest would feel tight at times, but I never felt remotely close to the point of not being able to breathe.

When I got the news I was positive, I called my hematologist to ask his opinion of what I could expect as I went through the illness. He said that being on rituximab wouldn't increase the chances of me getting COVID, nor would it influence my immune system's ability to mount the initial fight against the virus. This initial immune response is carried out by our T cells, which aren't affected by rituximab. He said the rituximab would reduce, but not eliminate, the ability of my B cells to produce antibodies against the virus.

The antibodies are responsible for two things. One is to help our body get rid of the virus after the T cells have done the bouncer's job of mounting the big fight. The other is to help protect us if we are exposed to the same virus again.

So, because I was on rituximab, he said I should expect my symptoms to linger a little longer than normal and I might be more susceptible to getting the virus again. My level of protection would be less than that of a normal person, whose antibodies would protect them from reinfection for a time.

→ **Next page**

My Experience with COVID-19 and Rituximab - Cont'd

Keep in mind that most of what my hematologist tells me goes straight over my head, but this is my best rendition of what he told me. He also said he's sure my level of fitness had a positive impact on my ability to beat the virus.

Two weeks after I had recovered from COVID, I developed bacterial pneumonia. I'd never had pneumonia before, but I believe that my 23-year-old son exposed me to it (darned kids). The doctors who treated me said they didn't know for sure if I was more susceptible to getting pneumonia because I had recently been through COVID. They said it's possible my lungs had been impacted by COVID and hadn't totally healed, and that's why I wasn't able to fight the pneumonia without antibiotics. Another contributing factor might have been that, soon after recovering from COVID, I went back to exercising vigorously, which probably wasn't a very good idea. I should have taken it slowly and let my body fully recover.

The best news is that now, not only is my condition in remission, I am taking no prescription medications.

Our journeys are all different, but from my particular experience, I think these are the important take-aways:

1. You are no more susceptible to contracting COVID-19 if you are receiving rituximab
2. It's totally possible to successfully beat COVID-19 if you are on rituximab
3. It's important to take it easy following recovery from the virus so that your body can heal properly.

I hope that you are all able to stay healthy and happy during this pandemic.

Sandrine Larue, MD
Quebec

Designated to the GBS/CIDP Foundation of Canada Medical Advisory Board

Dr. Sandrine Larue has been working as a neurologist at the Department of Neurology at Hôpital Charles-Lemoyne since 2008. After completing studies in psychology at Université de Montréal and a residency in neurology at Université Laval, Dr. Larue completed a subspecialization in neuromuscular diseases at the Institut de Myologie (Hôpital Pitié-Salpêtrière, Paris). Since then, she has been in charge of the Neuromuscular Clinic at the Neuro Rive-Sud Clinic. She is also a clinical teaching professor at the Université de Sherbrooke Faculty of Medicine.

Currently, the main focus of Dr. Larue's clinic work is on the diagnosis and follow-up of patients with genetic and acquired neuromuscular diseases (Neuro Rive Sud Clinic, HCLM and CHUM). She heads up a number of clinical research projects in neuromuscular diseases (neuropathies, ALS) and is also co-investigator, with her research colleagues, of multiple clinical research projects in general neurology (multiple sclerosis, dementia).

My MMN Story

KATE VAN DER MEER

I started my MMN journey about 5 years ago, before I even knew what MMN was. I was almost 25 years old with 2 young boys and one more on the way, working full-time and then some. I didn't have time to slow down, but life had other plans.

At first it was just an odd feeling in 2 fingers. As the months went by, I noticed I was losing strength in my hands, my writing was getting sloppy and eventually I could no longer fully extend the fingers of my right hand. I showed this to my family doctor one day and he said "That's weird." I would hear this a lot over the coming years. I was referred to a specialist for an EMG, which led to many more tests. After over 3 years of head scratching, "Let's see how you are in a few months," and no clear answers, I was referred to my current neurologist. Fourteen months later, I was diagnosed with MMN and began IVIG treatment every 3 weeks.

IVIG made me feel exhausted and sometimes gave me headaches and other side effects. I was supposed to switch to SCIG after 2 months because I lived so far from the hospital but due to an immunoglobulin shortage, I had to wait an extra 4-5 months. This meant more travel, more side effects and more time away from my kids than necessary. My hubby worked afternoons so I was essentially a single mom after 2 p.m. I would come home from treatment, get my youngest from his Nana, snuggle up to watch cartoons and rest as much as I could until my older boys came home from school.

As the saying goes, "You never know how strong you are until being strong is the only choice you have." Trying to raise kids when you have a chronic illness is tough. Aside from the daily struggle to keep up with meals, laundry, cleaning and trying to still have enough energy to play, MMN takes an emotional toll as well. I did not respond well to treatment and continue to slowly progress. I have had to adapt my parenting over the years because of this progression and it has brought me a lot of guilt.

I was healthy when I chose to bring my children into the world. I had high expectations for the mother I planned to be. For the first 6 or 7 years I was able to be that mom, but eventually I had to let that go. That has been the hardest part about living with MMN for me; not only does it affect my body, it affects my kids.

At times I've felt like life is all downhill from here. If you're reading this as a patient, I want you to know that it's okay to feel that way sometimes. You don't have to put on a brave face every day to make others feel comfortable. It's okay – and sometimes necessary to grieve the life you had before diagnosis. I also want you to know that it *isn't* all downhill from here, it's just different.

I may not be able to chase my boys around the yard like I used to, but we can snuggle up for family movie night. I may not be able to make Pinterest-perfect birthday cakes for them, but we can have deep conversations about life. I walk slower and my body gets tired easier, but I listen longer, I cheer louder, and I hug them tighter. For everything I feel my children have lost to MMN, they have gained in appreciation, compassion, nurturing, resilience, and I take comfort in knowing it will make them better men.

GBS/CIDP Foundation of Canada

Introducing Turtlewear – Our Holiday Giving Campaign…

We’re so excited to share our Turtlewear across Canada and we hope that you’ll wear your Turtlewear with pride.

With a donation of $100. or more, you will receive a GBS/CIDP Foundation of Canada Turtlewear hoodie or sweatshirt – plus a tax receipt for $70.00

For full details please go to www.gbscidp.ca/turtlewear

You can choose 2 hoodies or sweatshirts for a donation of $180. For more information on gift and donation levels please go to our site: www.gbscidp.ca/turtlewear These high quality hoodies and sweatshirts make the perfect Holiday gift!

GBS/CIDP face masks are great quality, 2-ply, with opening for a filter, adjustable straps, washable and available for an un-receipted donation of $15.00 each. No tax receipt will be issued for masks.

To receive your Turtlewear go to www.gbscidp.ca/turtlewear Please note we have limited numbers. You’ll receive your Turtlewear by mail along with a tax receipt for $70. per hoodie or sweatshirt. All shipping is included.

Etransfer your Donation for Turtlewear to: donations@gbscidp.ca to complete your order.
Security password should be: Turtle

Thank you for your generous support of the GBS/CIDP Foundation of Canada and our work in serving patients and families!

GBS/CIDP Foundation of Canada www.gbscidp.ca email: info@gbscidp.ca Phone: 647-560-6842
Serving Patients through Support, Education, Research and Advocacy
Registered Charity: 887327906RR0001

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

In collaboration with
CSL Behring
Biotherapies for Life®

LIVE EDUCATIONAL WEBINAR

Join us for a live educational webinar for people living with CIDP.

This webinar features a presentation by a trained nurse for people living with CIDP, their families, and caregivers.

View from the convenience and comfort of your own home.

TUESDAY / January 12, 2021

7:00 PM – 8:00 PM ET

*This program will be held in **English** and is intended for Canadian residents.*

WEDNESDAY / January 13, 2021

7:00 PM – 8:00 PM ET

*This program will be held in **French** and is intended for Canadian residents.*

REGISTER NOW!

cidpeducation.ca

Nurse Speaker

Sylvia de Melo, BScN, CNN(c)
Neuro Day Centre and Neuromuscular Program
Montreal Neurological Institute-Hospital
McGill University Health Centre

Register online at cidpeducation.ca

CIDP: A New Treatment Era?

DR. VERA BRIL

This is an exciting time for patients with autoimmune disorders of the neuromuscular system, such as those with chronic inflammatory demyelinating polyneuropathy or CIDP since new treatments are being developed for the first time in many years.

We know that patients who have CIDP get better with treatments that change the immune system; either suppress activity, such as prednisone, or adjust it like plasma exchange (PLEX) or intravenous immunoglobulin (IVIG) and subcutaneous immunoglobulin (SCIG). The immune modulators (PLEX, IVIG, SCIG) work for short periods of time and all have “burdens” or potential side-effects associated with treatments. Access to PLEX is very limited as this is administered in hospital units and subject to hospital global budget issues. Access to IVIG/SCIG can also be at risk in times of shortage, such as may happen now due to the COVID pandemic and consequent reduction in plasma collections. Also, both PLEX and immunoglobulins have broad action on the immune system that may not be necessary to treat CIDP.

More focused immune treatments are now being studied for potential use in CIDP. These include 2 main categories of agent: those that work earlier in the cycle to drop antibody levels, called FcR inhibitors, and those that work at the end of the cycle to prevent membrane damage, called terminal complement inhibitors.

FcR inhibitors act within cells to reduce the normal recycling of immunoglobulins. They interfere with immunoglobulins being returned to the circulation and promote destruction in a part of the cell called lysosomes. As a result, total immunoglobulin levels fall to about the same levels as seen after PLEX. They work quickly, within 2 weeks, in most patients although some take longer to respond. Both subcutaneous and intravenous FcR inhibitors are being developed. The side-effects so far have not been severe and include things like headaches although not at the same level as in those who get headaches after IVIG. Studies in CIDP are being done now on rozanolixizumab (subcutaneous) and efgartigimod (intravenous), 2 new FcR inhibitors.

Terminal complement inhibitors work at the end of the immune cascade and block the splitting of complement and formation of the “membrane attack complex” or MAC which then damages the nerve membrane. Eculizumab has been developed for patients with myasthenia gravis (MG), an autoimmune disorder that blocks nerve communication with muscle, and has been approved for use in MG. It is now being studied in CIDP and may be useful in that disorder. Other complement inhibitors are also being investigated for efficacy in CIDP.

These novel immune therapies are more focused than the ones we have now. These new agents work quickly within weeks as opposed to some immune therapies where the effect can take 6-12 months to be seen. There may also be fewer side-effects in the long-term with these new treatments and that would be welcome to those who require chronic treatment of any type. So, in summary, it is a very exciting time for patients with immune disorders affecting their neuromuscular system, as new treatments may well help and be less burdensome than what is now available.

For more information on additional studies, please call Ed at 416-340-3898.

A Clinical Study of Rozanolixizumab in Patients with Chronic Inflammatory Demyelinating Polyradiculoneuropathy (CIDP)

My CIDP CHOICE Clinical Study

Clinical research studies are scientific evaluations in people, led by researchers and physicians. They can help advance the understanding of a disease and are the most important way for researchers to find out if potential new treatments are safe and effective. Studies like these are needed to be able to make new treatments available to patients.

The international My CIDP CHOICE study is currently enrolling CIDP patients to help us understand how effective and safe a new investigational drug, called rozanolixizumab, is for the treatment of CIDP. Rozanolixizumab is a non-blood product and aims at lowering the levels of immunoglobulins (IgG - a type of blood protein) in the body, including IgG linked to CIDP.

At the beginning of the My CIDP CHOICE study, the study participant's Ig treatment will be replaced by the study treatment (either rozanolixizumab or placebo). It will be given as a subcutaneous (under the skin) infusion. Study participants will have an equal chance of being assigned to rozanolixizumab or placebo. A placebo looks exactly like the investigational drug, but it contains no medicinally active ingredients. In case the study treatment does not work for the study participant, Ig treatment will immediately be prescribed again (without waiting for the end of the study) by your study doctor.

About the Study

The study is looking to enroll a total of approximately 34 participants at approximately 24 study sites globally. The My CIDP CHOICE study will last for about 28 weeks (up to a maximum of 40 weeks) for every participant. Some study visits may be conducted at home. Participants for whom the study treatment works well may be able to enroll in a 6-month follow-up study where everyone receives rozanolixizumab (no placebo), provided they meet the entry criteria.

Patients interested in joining the My CIDP CHOICE study must:

- Be 18 years of age or older
- Have a definite or probable diagnosis of CIDP
- Have prior experience of discontinuing/reducing their immunoglobulin treatment
- Have been receiving immunoglobulin treatment with a stable dose for at least 4 months

You can find more information on clinicaltrials.gov if you search for the identifier NCT03861481 or CIDP01 in the "Other terms" field.

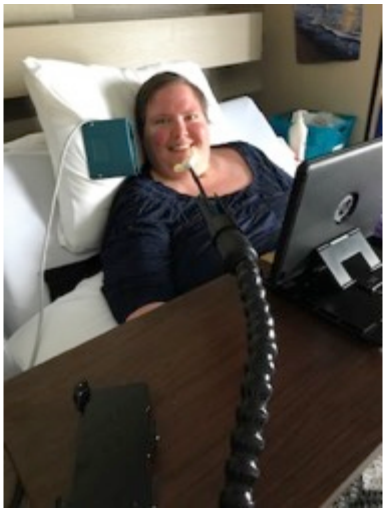
If you are interested in participating, you can contact the clinic of Dr. Vera Bril (neurologist at Toronto General Hospital) by calling her study coordinator (Eduardo Ng) at 416-340-3898.

04 September 2020

Dealing with Grief and Loss in my GBS Journey

LAURA RUTHERFORD
Authorized to re-publish - Blog Post September 30, 2020

Grief and loss. Two human emotional reactions we deal with in our lives. Traditionally, we relate grief and loss to losing a loved one in our lives. Or when someone faces a challenge or trauma, there is a loss and/or grief. On Sun Sept 27, 2020 I attended a webinar on dealing with grief and loss, hosted by the GBS/CIDP Organization of Canada. Initially, it was difficult to link my grief and loss as many of the examples given were related to a death of a person. Luckily halfway through I was able to try taking the tools given and adapt them to a “thing”, which would be GBS in my case.



These traumas can be small or large but impacts your life none the same. Plus each time our reaction to these traumas can be different as one’s coping skills vary. They speak of the 5 stages of grief - Denial, Anger, Bargaining, Depression and Acceptance. It is these stages of grieving I learned about when I went to counseling in November 2009. My counselor shared with me, I had not fully grieved for my sister who had passed away 18 years by this time. I was shocked to hear this. What I have come to realize, I dealt with my grief in two ways. I went through the process superficially to the point to be able to continue moving on with my life without my sister. What I had done was bury and not dealt with my emotional attachments to the grief - my anger of why did she have to die; sadness because I no longer have a sister; and guilt of why didn’t I see the signs of a person having suicidal thoughts. Sometimes I still have those feelings but I know now how to process these thoughts so I don’t dwell on them long. I just simply acknowledge those feelings, but then go on about my day.

Through counseling, I found grieving is associated to any type of traumas one may face. Many I didn’t know would fall under the umbrella of Grief & Loss. Unbeknownst to me, I found out I needed to work through the feelings of being bullied because of my size (being obese) since I started kindergarten (age 5) all way to adulthood where I was bullied by my managers in the workplace. The traumas I faced at the age of 16 when my mom was diagnosed with Stage 3 breast cancer and 10 months last my sister Kathryn was diagnosed with osteogenic sarcoma of her humerus. We had to face as a family similarly when their cancer returned and metastasis to their spines, making it stage 4 in their cancers. Happily both went into remission. Even though I was 26 years old when it happened, there is grief and loss as a child of divorce. In the beginning, I felt caught in the middle between my parents while still processing my loss of Kathryn’s death. It was difficult to sort out my thoughts and feelings for sure. Having it become overwhelming as I was feeling “where do I start”, with so many different traumas at once. What I do know though - each of these traumas I had faced in past, have shaped my personality as well as developed the coping skills to help me face the biggest trauma - being diagnosed with Guillian-Barre Syndrome (GBS). People who have GBS/CIDP (and other GBS variants) face a major trauma (the disease) but then we have to process with the continuous different levels of grief and loss that comes with having this disease.

I am assuming people who suffer from chronic illnesses or from other autoimmune diseases go

→ **Next Page**

Dealing with Grief and Loss in my GBS Journey - Cont'd

through the same process of having to deal with setbacks throughout their life. Therefore, facing repeatedly the grief and loss with each of those setbacks. The ultimate goal would be to know which coping skills to use; so does not get stuck in a rut and vicious cycle which could lead to depression and feeling surrounded by only negativity. I know that have been so fortunate to have an awesome support of family, friends and even the staff at the facility I am living in - AgeCare-Skypointe have been encouraging too. With my GBS variant, outcome is said to have a slow and poor recovery, but my support team reminds me where I was and where I am today; they send me encouraging messages to help lift my spirits and their shoulders are ready to just let me vent and have good cry when everything gets to be too much and overwhelming. Plus they have continued to pray for healing and to keep my faith to carry on.

I thought I would share and provide an idea of some of my traumas I have had to face these last 4 years, and I will continue to face for the rest of my life, if I do not recover more.

1. Feeling the loss and grieving of the life I once had (ie. being able-bodied)

2. The loss of my mobility (my paralysis improvements has been small). Only going from total paralysis (head to toe, eyebrows weren't even moving) to remaining a quadriplegic but the paralysis is from shoulders down. This improvement took 4 years to achieve.

3. Grieve the loss of not being able to go back to work as a Coding Coordinator for the AHS-Calgary Zone Data Collection Team in the Health Records Department of Calgary's Hospitals. I have worked in the Health Records Department since I was 16 years old as a summer student in Thunder Bay, Ontario and I never looked back. Almost 30 years! Wow! Not many people can say they stayed in one field their whole career, which they still enjoyed performing.

4. Feeling a loss of my identity, my sense of purpose. Before getting sick, I felt my work identified who I was as I didn't have a family of my own. GBS took that away from me. I feel my life is in limbo. I didn't have that confidence, that anchor any more.

5. Now that I am on Long Term Disability, who am I? What identifies me to others? What could be my purpose to "society" as a quadriplegic? (*I think improving my confidence in myself will play a part in finding my identity and purpose moving forward.*)

6. Grieve the loss of my independence. Being a quadriplegic, I require total care for my daily basic needs. Needing to learn that it is okay to ask for help, your family and friends want to help you. Allow them.

7. When I was able-bodied I enjoyed travelling. Travelling to Ontario and Quebec to spent time with my family, my relatives and my friends. Of course, enjoyed travelling to different countries like England, Scotland, the Netherlands, France, Germany, Switzerland, Spain, and Italy. Plus within Canada seeing the Cabot Trail and Cape Breton in Nova Scotia - definitely a highlight for me. Now, dealing with the loss of not being able to travel anywhere in the foreseeable future, will take time to accept.

→ **Next page**

Dealing with Grief and Loss in my GBS Journey - cont’d

8. I can’t seem to be able to catch a break. Always seems I am dealing with something. It’s exasperating needing to face it on a daily basis. Dealing with constant pain. It really does bring you to the edge and you have a meltdown. Just looking since I arrived to AgeCare-Skypointe: 2018 (nephrologist, urologist); 2019 (urologist, gynaecologist, neurologist, ophthalmologist); and 2020 (urologist, gynaecologist, dermatologist). Due continuous issues with my urinary catheter, dysfunctional uterine bleeding (DUB) and atypical cells recently found in a mole on my left back shoulder; I’ll be having ongoing follow up appointments with my urologist, gynaecologist, dermatologist. Never a dull moment for me.

9. Dealing with the loss of “my normal life” occurring at diagnosis of GBS, which will be my “new normal” living as a quadriplegic. Then in 2020, Covid-19 global pandemic of a highly deadly contagious virus arrived gripping the world. At the time I type this post, in a short 7-8 months we have lost over a million people to this virus. If you have as many pre-existing conditions which increases your risk of a fatal outcome as this disease attacks more than the lungs, it’s systematic - the whole body. Once again, I am having to change to another “new normal” which includes Covid-19 as this virus is here to stay.

Having gone through counseling once before working on grief and loss, I am more aware of signs when I am heading down that “rabbit hole”; therefore able to recognize when I need to reach out to a family member, a friend or a third party (a counselor or a psychologist). As I have said in the past, if I have my 3Fs, I can basically face anything. The 3Fs - Family, Friends, Faith. Tonight, a friend posted this scripture from the book of 2 Corinthians. Another reminder that God is there to comfort us by putting people in my life to see me through my troubles. Then in turn, I am able to be there for someone else who is going through something similar. A verse showing us the importance of “*paying it forward*”. For me, this concept of paying it forward is a part of my grief and loss process towards a healing in my life.

2 Corinthians 1:4 He comforts us in all our troubles so that we can comfort others. When they are troubled we will be able to give them the same comfort that God has given us.

Online Peer-to-Peer Support Group Meetings

Online support group meetings have been a positive initiative ignited by the COVID-19 pandemic and our inability to meet in-person during these tough times. The online meetings have had 350+ attendees since they began in May. We appreciate everyone’s patience with the steep learning curve. We are getting the hang of things! These meetings will become a permanent service to our patients and their families. Keep visiting https://www.gbscidp.ca/new-events/ for updates to the schedule!

The Benefits of Modified Yoga

NANCY EDWARDS

Yoga in its many forms has been around for many years. I started doing yoga as a teen by reading a book. I've had some people tell me that they started 40 years ago from a record album. It has definitely evolved into a popular activity in North America, and rightly so. I've been a yoga instructor for just over 10 years and have taught yoga to many different kinds of groups, from toddlers to people in there 90's. I started studying Chair Yoga as a practice to help some of the seniors who I teach. We needed a safe and stable way to move through the program. In addition, I studied through University of Western and the Canadian Institute for Activity and Aging. What are the primary things that I have learned through teaching? Never stop moving and being active. Keep your brain active. When things get stressful, remember to slow down and breathe. Just focus on breathing in and out. Movement and exercise relieve pain and stiffness, releasing muscle tension and stress. Providing recreation and a sense of community support.

Most of you would know me as the Foundation's event and admin person. As a yoga teacher I offer supportive classes that are modified to everyone's level of ability. I would want you to walk out of class feeling great. Then to me, the class has been a success. I teach now primarily seniors 55+. I also teach Chair Yoga for a group of Multiple Sclerosis patients in Whitby, and the GBS, CIDP, and MMN community are welcome to join us. They are individuals with varying levels of disability. Some are able to walk independently, some come with canes and scooters, and people with loss of vision and hearing. We work on stretching, releasing muscle tension. This relieves muscle pain, headaches, sore backs and necks. People sleep better after yoga class. They feel less stress, more of a sense of calm. One woman said that when she goes for a massage, her RMT can tell if she has missed a class. Others have mentioned that through the class they've built core strength, which helps with back pain.

I had in one class, asked people to focus for a moment on what they are grateful for. I believe that what you focus your mind on can help to affect your life. Do you want to make a change in your life? Start to focus on that and how you would plan to see things change, it's just a positive mindset.

One of my students said that she was so grateful for the class. I was very touched, but it made me realize what a positive impact yoga practice, including Chair Yoga, can have on our lives. I do realize that it's not possible for everyone to get out to a Chair Yoga class, and at any time, you are all welcome to join my class. Other options are searching Chair Yoga on youtube.com. Also there are videos such as Peggy Cappy's Yoga for the rest of us, which shows 3 levels of modified yoga. Standing, some modification and seated.

On the GBS/CIDP Foundation of Canada's Youtube channel there are some seated exercises, which are mostly range of motion and strengthening, but if you do it mindfully, keeping your calm focus on the movements that you are doing and being conscious of your breathing, that is yoga. I strongly encourage you all to try a class in your own community. Or borrow a DVD from your local library, or look online. You have nothing to lose for trying it, at the very least you will have 30 minutes or so to yourself for "me time". If you have young kids, they would likely love to do yoga with you. Please feel free to contact me if you have any questions, at nedwards@gbscidp.ca. Wishing you good health. Namaste.

Can a GBS, CIDP, or MMN Patient Donate Blood Through Canadian Blood Services?

DONNA HARTLEN, MEMBER: CBS NATIONAL LIAISON COMMITTEE

The question of whether a former GBS patient or CIDP and MMN patient can donate blood is usually presumed to be the answer ‘No’. That is not necessarily the case. If you are interested in donating blood, you should consider setting up an appointment by visiting www.blood.ca in order to review your current health status and the possibility that you may be able to become an eligible blood donor.

Some initial questions to ask yourselves that may help you to take the next step in reaching out to CBS:

1. Are you a recovered GBS patient, in current good health, and it’s been 6 months since your last Immunoglobulin (IVIG) treatment?
2. Are you a CIDP or MMN patient with general good health and your condition is inactive and no longer receiving Immunoglobulin (IVIG, SCIG)?

As you know, we have conditions treated by plasma protein products that require plasma or blood donation. If you or your families are able to donate, please seriously consider becoming a donor to supply the need for future and current Canadian patients that depend on blood or blood products.

Looking for GBS, CIDP, MMN, and Caregiver francophone participants to be interviewed!

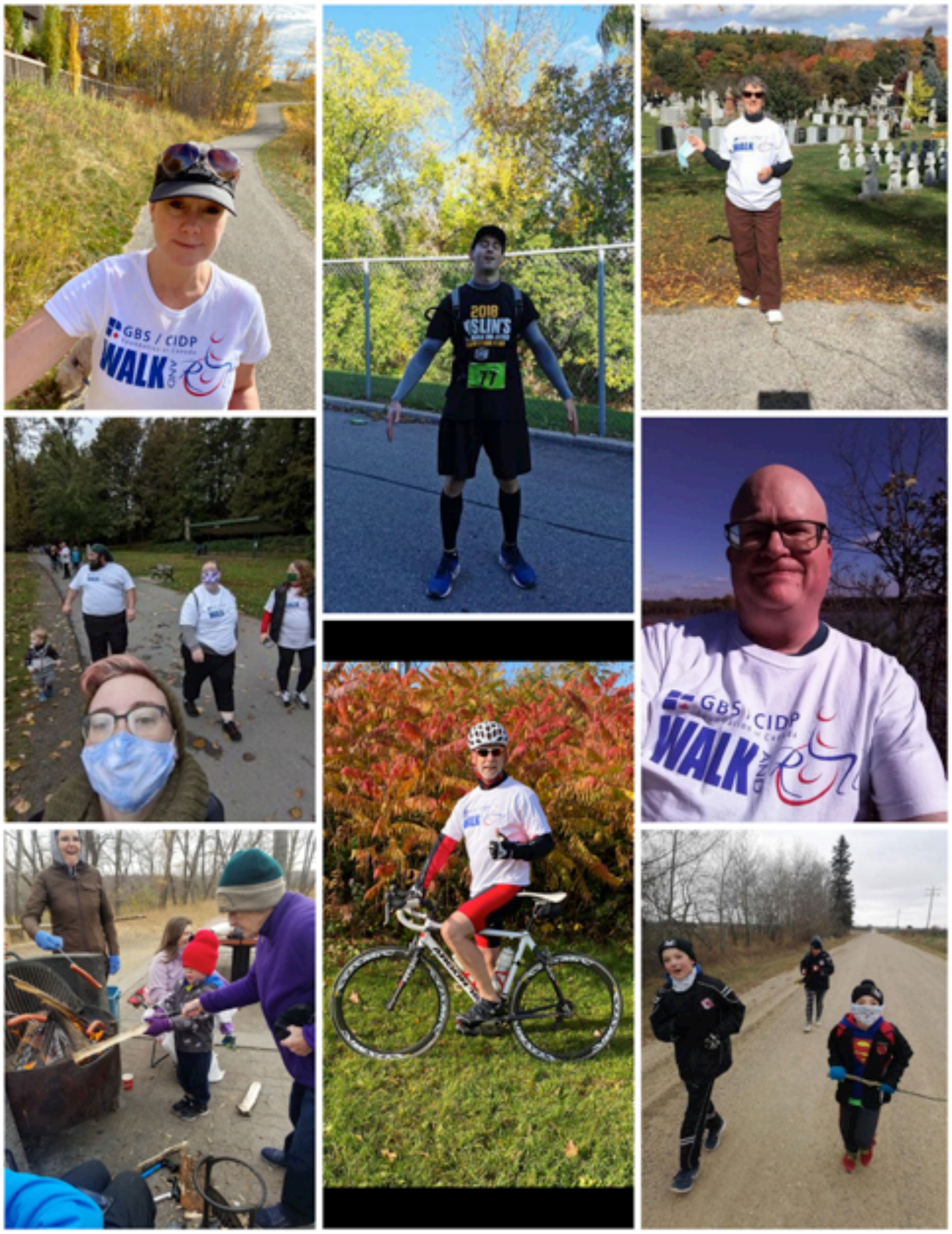
Are you a francophone patient or caregiver that has experienced the journey of GBS, CIDP, or MMN? If you are interested in participating in professional French interviews to be recorded for Youtube, please email mailto:dhartlen@gbscidp.ca

National Virtual Walk and Roll

Oct 17, 2020

The foundation would like to thank everyone that participated in the Virtual Walk and Roll in October! We also would like to thank all of the supporters of our walkers and rollers. With your support the Virtual Walk and Roll raised $15,177.00.

All of you did fantastic!



Board of Directors

Call for Applications

GBS/CIDP Foundation of Canada is a growing patient focused organization. The foundation is looking for skilled, high-energy, and committed individuals that will participate in efforts of advancing the foundation in areas of support, education, advocacy, and research in a team environment. We are currently looking for individuals that reside within British Columbia, Maritimes, Manitoba, Saskatchewan, and Quebec regions. If you have experience in marketing and social media, law, advocacy, fundraising, please highlight in your CV.

Please indicate any previous board experience and professional skills that you believe would benefit the board.

Send your CV to:

Darryl Bedford, President, dbedford@gbscidp.ca

Marilyn Rose, Vice President, mrose@gbscidp.ca

Duties and Expectations of a Board Member

- Regularly attends board meetings and important related meetings.
- Makes serious commitment to participate actively in board work.
- Volunteers for and willingly accepts assignments and completes them thoroughly and on time.
- Stays informed about foundation matters, prepares themselves well for meetings, and reviews and comments on minutes and reports.
- Gets to know other board members and builds a collegial working relationship that contributes to consensus.
- An active participant in annual evaluation and planning.
- Participates in fundraising for the organization.

On behalf of our patients and families, we thank the medical professionals that continue to care for us during COVID-19 and stay engaged in our efforts to support and advocate for patients. We realize these are extraordinary times and the pressures that our health system continues to endure and the impact it has on your clinics.

The foundation is aware that some of you are caring for patients in COVID wards, please stay safe!

Disclaimer

Information presented in the GBS/CIDP Foundation of Canada newsletter is intended for general educational purposes only, and should not be construed as advising on diagnosis or treatment of Guillain-Barré syndrome, Chronic Inflammatory Demyelinating Polyneuropathy, or any other medical condition.