# **News and Views**

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



It's back!

Turtlewear Giving Campaign

Hoodies, car decals, and masks are available for an unreceipted donation.

For more details:

http://www.gbscidp.ca/turtlewe ar/

Covid-19 Vaccination Guidance for GBS, CIDP, and MMN patients – updated Nov 11, 2021

See page 3

September 9-10, 2022 National Montreal Conference, Sheraton Montreal Airport Hotel

Save the date! More details on agenda and registration coming soon!

Thank you to all the presenters at the GBS/CIDP National Virtual Conference



Dr. Carolina Barnett-Tapia Dr. Vera Bril

Candine Blackbeard **Christopher Cross** Dr. Pierre Bourque Sylvia De Melo

Dr. Alexis Gagnon Dr. Hans Katzberg Juan Lopez

Dr. Rami Massie Laura Wang

We look forward to seeing everyone in-person in Montreal 2022!

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# Executive Director Donna Hartlen

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# A Message From The Executive Director, Donna Hartlen

The year 2021 is coming to a close. I am very proud of the work the Foundation has accomplished. Of course keeping each of you the focus of our efforts, our patients and families.

Here are some of the highlights from the year:

- We started strong with the Rare Disease Day campaign. A few of our Canadian patient journey videos selected and posted on the Rare Disease Day website
- For awareness, we had 11 community proclamations, 2 provincial proclamations (BC and Alberta), and we were added to Health Canada's calendar for May's GBS/CIDP/MMN awareness month. If you are interested in applying for your community to have May 2022 as GBS/CIDP/MMN awareness month, reach out to Kim, kbrooks@gbscidp.ca by early January for direction.
- New condition symptoms cards created, used at medical conferences, and posted to the website. French versions on the way!
- The Foundation is expected to provide 35 support meetings this year and will have supported an estimated 300 patients and their families.
- We walked and rolled virtually for programs and research in September. Thank you to all
  that participated. Get your walking shoes on for 2022! It's looking like we can move
  forward with local walks. Do you want to chair a Walk and Roll in your local community?
  Contact Nancy Edwards, nedwards@gbscidp.ca.
- A big effort went into the success of the GBS/CIDP National Virtual Conference. It was
  great to see so many of our patients and caregivers attend the virtual educational event.
  We look forward to seeing you in Montreal in Sept 2022.

"I think this was the most informative conference I've ever attended. Maybe it's that it connected the dots for me on so many things."

"Keep up the good work educating us out here in the community"

- We attended 3 medical conferences building awareness in emergency departments and with rural and family physicians. Ran Ads in the medical community. We hope to announce some exciting news on our efforts to educate emergency physicians in the next newsletter.
- We more than doubled our patient registrations this year and took 4 times the amount of patient phone calls.
- Provided Covid-19 vaccination guidance. Latest update inside!
- We continue to advocate with federal and provincial jurisdictions.
- Day-to-day activities like our social media presence, website updates, newsletters, etc...

Foundation programs would not happen without the support of sponsors and our generous donors. The Foundation cannot thank each of you enough for supporting us, and each other, in hope of a better patient journey. Our journey doesn't end at diagnosis, it lasts a lifetime! As well, we depend on our volunteers. Thanks everyone for your continued passion to give back.

Wishing 2022 will bring each of you a year of hope and wellness.

Yours, Donna

Thank you to our sponsors of the 'News and Views'









Guillain-Barré Syndrome/Chronic Inflammatory
Demyelinating Polyneuropathy/Multifocal Motor Neuropathy

#### Support • Education • Research • Advocacy

#### Updated: Nov 11, 2021: COVID-19 Vaccination within the GBS, CIDP, and Variant Community

The Foundation continues to advise you to have a conversation with your treating specialist or your healthcare provider about the benefits vs. risks of vaccination based on your individual health status. Visit our website www.gbscidp.ca for links to more resources for COVID-19 vaccination information.

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The Canadian Medical Advisory Board of GBS/CIDP Foundation of Canada has just released the following updated COVID-19 vaccination guidelines for Canadian patients with GBS, CIDP, and MMN.

#### COVID-19 Vaccination Guidelines For Patients with GBS, CIDP, and MMN - Nov 11, 2021

- 1. We recommend vaccination for all GBS, CIDP, and MMN patients as soon as possible as per their provincial authorities.
- 2. If a patient has developed their disease within 6 weeks after receiving a COVID-19 vaccination, the patient should make an informed consent after discussing the risks versus benefits with their healthcare professional about receiving a second dose of authorized COVID-19 vaccine that is of a different type, preferably mRNA, as per the National Advisory Committee on Immunization (NACI) guidance.
- We recommend an authorized mRNA Covid-19 vaccine (Pfizer or Moderna) as per the National Advisory Committee on Immunization (NACI) recommendations.
- 4. We do not recommend a specific timing of the vaccine with plasmapheresis treatments or with IVIG/SCIG infusions. It can be done at any time during their cycle.
- For vaccines requiring 2 doses, we recommend receiving the second dose within 28 days of the first one, if possible as per each provincial authority.
- 6.We recommend booster shots as per the National Advisory Committee on Immunization (NACI) recommendations

While data specific to the safety and efficacy of the currently available vaccines in people with autoimmune disease and who take immunosuppressant therapies is not currently available, we agree that the benefits of COVID-19 immunization outweigh any theoretical risks of immunization.

As the immune response to COVID-19 immunization is unknown for those taking immunosuppressant or immunomodulating therapy, patients with neuroimmunological disease who receive the COVID-19 vaccine should continue to closely follow public health recommendations including social distancing, regular hand washing/disinfection and avoiding public transport.

## National Advisory Committee on Immunization - COVID-19 Vaccine Use in Special Populations

https://www.canada.ca/en/public-health/services/immunization/national-advisory-committee-on-immunization-naci/recommendations-use-covid-19-vaccines.html#special

Canadian charity registration number: 887327906RR0001

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# My year through COVID from GBS to a marathon

## BY BRANDON WILLIAMS

Rewind to October 17, 2020. Life was great. I was 24, in great shape, happy, making great progress in my schooling. I had just entered the hockey officiating season and had been spending great time with a person I love.

October 27, 2020. After a visit at the dentist I began feeling unwell. I had a fever, body aches, and a headache, along with numbness in my lips. I assumed it was from the dental procedure. For the next three days the numbness and tingling continued, while the other symptoms disappeared.

Unconcerned, I fought through the numbness and thought it would clear up on its own. After officiating a hockey game the numbness and tingling became worse, and I began to feel it in my feet. This led me to set up an online doctor's visit through my university as COVID-19 had made in-person visits almost impossible. After explaining the symptoms to the doctor, he thought the most likely cause of my sickness was COVID-19, and I should get tested before proceeding further. My strength was diminishing at an alarming rate, and the trip to get to the testing clinic felt nearly impossible. While driving it took all my strength and extreme focus to turn the wheel. I'm sure I looked like a novice driver at best. After getting tested, I returned home and entered my mandatory quarantine. As I waited for the results, my symptoms grew worse. I had extreme loss of strength, numbness and tingling in my lips, hands, and feet.

November 4, 2020. I could barely muster the strength to walk to the bathroom.

November 5, 2020. I was extremely concerned as I woke up with about 90 per cent of my motor functions diminished. For all intents and purposes, I was paralyzed. As I was no longer in a state to take care of myself I called 911 and ordered an ambulance. I was admitted to the emergency department at the Royal Inland Hospital of Kamloops and questioned, poked, and prodded all night long. By mid-evening I was no longer able to speak coherently. A couple of hours later I was diagnosed with GBS.



I was paralyzed from head to toe, unable to communicate, and unable to close my eyes. I grew worse. It wasn't long before I was placed on a ventilator and moved into the ICU. Unbeknownst to me, I was fighting for my life.

My time in the hospital—what I can remember—was filled with anxiety, depression, anger, and helplessness. Not being able to move and communicate left me isolated in my own mind. My health was at the mercy of others. I remember the constant flashing lights, alarms, and call bells of the hospital machinery, leaving me afraid to sleep. I also remember at the beginning waking up each morning in a true state of panic before I remembered why I could not move. Because of COVID, only one parent could be with me, for only two hours a day. They came from Vancouver and lived in a Kamloops hotel during my entire hospital stay. Even though the nurses were around, I remember spending my nights alone, staring into the halls of the busy ICU, often making sure my nurse was close by because it made me feel a bit more at ease. These nurses became my everything, but a handful also became my biggest fear. → next page

# My year through COVID from GBS to a marathon - cont'd

Over two months in the ICU I became familiar with most of my nurses. I had my favourites, and others I was truly afraid of. I remember the ones who would talk to me and go the extra mile, even though I could not communicate back. I also remember the ones who would ignore my cries for help, remove my call bell, scold me in the middle of the night for not sleeping or ringing my call bell too much, and the ones who simply ignored me. This, however, did not break me but only motivated me to get better.

December 10, 2020. I was moved from the ICU to a medical ward and began rehabilitation. This was excruciating and tested my mental and physical toughness. I relearned every motor function, just as if I were a toddler. My motivation to get better, however, was unwavering. I was the talk of the hospital as no one ever caught me taking a break from some sort of exercise. I was consumed with increasing my range of motion by stretching, building strength, and honing my motor skills. I coloured, wrote, typed or played catch. I dedicated all the time available to every task my doctors, physiotherapists and occupational therapists gave me.

My motivation to get better was sparked by my unrelenting support from my family and my drive to reunite with my girlfriend, who could not visit me. My rehab process in the hospital was a strict regimen. It kept me focused and my mind busy which allowed me not enough time to worry or feel sorry for myself.

January 13, 2021. I was released from hospital and allowed to continue rehab at home. Doctors encouraged me endlessly and cheered me on as they explained I was within the top two per cent of recovery, given the high severity and complications of my illness. This instilled a fire in my belly and motivated me more to get back to doing the things I love. Even though I was a day out of the hospital and still suffering, I would plan my days with rehab, workouts, and anywhere from two to four hours of my masters research work.



September 30, 2021, I ran my first-ever marathon to prove to myself and others that things do get better. I wanted to help uplift the community surrounding this rare syndrome and help instill passion that overcoming adversity only makes you stronger.

Today. I am back to normal and life is great.

This experience solidified my passion for what is most important in my life, what keeps me fueled with doing what I love. During this time, I received so much support from my friends, family, and university colleagues. I will only hope to repay them in whatever way I can. This experience changed my outlook on life and made me not take for granted the people around me that I

love, the hobbies I have and the abilities of my body. It has allowed me to love more deeply and have more compassion. It drives me to be a better person.

When you think you're ready to give up, keep on fighting because the human body is truly amazing.

Brandon Williams is studying for an MSc in environmental sciences at Thompson River University in Kamloops, BC. So far, he's avoided the dentist.

The Foundation would like to congratulate Brandon on the success of his marathon. Thank you Brandon and your supporters for raising awareness and \$1645 for research. Way to go team!



# Plasma Update: GBS/CIDP Foundation of Canada newsletter

#### Plasma donation at Canadian Blood Services

Providing vital support for patients

It's our job at Canadian Blood Services to ensure the safety and security of blood and blood products, including plasma, for patients in Canada, today and into the future. That is why we opened our first donor centre fully devoted to the collection of what is called "source plasma" last year in Sudbury, Ont.

# What is plasma?

Plasma is the straw-coloured, protein-rich liquid (<a href="https://www.blood.ca/plasma">https://www.blood.ca/plasma</a>) in blood that helps other blood components circulate throughout the body. While some donated plasma is transfused directly to patients, most is required as the source material for a variety of treatments (<a href="https://www.blood.ca/en/plasma/donating-plasma/how-your-plasma-donation-helps">https://www.blood.ca/en/plasma/donating-plasma/how-your-plasma-donation-helps</a>) manufactured products for patients with rare, life-threatening, chronic and genetic conditions, such as Guillain-Barré Syndrome. The health of patients with Guillain-Barré Syndrome can improve dramatically with immunoglobulin, a medication derived from plasma. Each dose may contain the antibodies of thousands of plasma donors.



Plasma recipient and donor Jeff Brown and registered nurse Carol Ann Crozier were part of the Sudbury plasma donor centre's first anniversary celebration on Aug. 25, 2021. For Jeff, enjoying life as a husband and father is possible thanks to immunoglobulin, a medication derived from the plasma of thousands of Canadians. Several years ago, Jeff developed Guillain-Barré Syndrome, and was paralyzed from the neck down. But he recovered, and this past year he also became a plasma donor himself. On Aug. 25, Jeff was able to make his own fourth plasma donation at the pioneering facility.

# How does plasma donation work?

Canadian Blood Services extracts plasma from donations of whole blood, but at our dedicated plasma donor centres as well as at several other sites across Canada we separate plasma from other blood components during the donation process itself.

In that donation process, the donor's blood flows through a machine at their bedside. Their plasma is collected

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## Plasma Update: GBS/CIDP Foundation of Canada newsletter – cont'd

in a bottle or bag, and the red blood cells and platelets are returned to them. As a result, donors can donate plasma more frequently than whole blood. And by doing so, plasma donors play a vital role in securing a domestic supply of plasma for patients in Canada.

Where can people donate plasma? https://www.blood.ca/en/plasma/where-donate-plasma

## Demand for medications made from plasma is rising

Demand for products made from plasma is surging in Canada and around the world. That is why we are dedicated to collecting lifesaving plasma for patients. In its first year, the Sudbury plasma donor centre saw strong collection results that were not slowed down by the COVID-19 pandemic. We welcomed almost 2,500 donors in Sudbury in the first year and collections surpassed 12,000 units and 9,000 litres of plasma.

Celebrating a year of plasma donation in Sudbury https://www.blood.ca/en/stories/celebrating-year-plasma-donation-sudbury

Plasma security and sustainability: learn more https://www.blood.ca/en/plasma/donating-plasma/plasma-security-and-sustainability

Since opening the Sudbury plasma donor centre, we have already opened two others in Lethbridge, Alta., and Kelowna, B.C. More will follow in the Ontario cities of Ottawa and Brampton in 2022.

Are you or someone you know interested in plasma donation? Plasma donors can help meet the growing needs of patients by booking appointments at any of our many sites across the country. Learn more about where to donate plasma, or book now by using the GiveBlood app, calling 1 888 2 DONATE, or at <a href="https://myaccount.blood.ca">https://myaccount.blood.ca</a>

Are you a plasma recipient and would like to share your story? We want to hear from you! Contact us at communications@blood.ca and we will be in touch to learn more about your story.

Read stories of how donated plasma has touched the lives and families of thousands of patients at <a href="https://www.blood.ca/en/stories/all-stories?story-category=4008">https://www.blood.ca/en/stories/all-stories?story-category=4008</a>.

If you have questions, please contact info@gbscidp.ca.

# Walter Keast Award 2021 Cheryl Dean, BC Liaison

The Walter Keast award is given to an individual for exemplary service to the GBS, CIDP, and MMN community.

Cheryl has passionately committed much of her personal time to raise awareness and supported our patients and families during 2021.

She has volunteered her time in 2021 to:

- Apply for 14 BC community proclamations and the province of BC
- · Presented her GBS story to her city council
- Support patients and families on countless phone calls
- Chaired quarterly online support meetings
- Participation in Foundation events

We are so proud of you, Cheryl Congratulations!





GBS/CIDP face masks are available for a un-receipted donation of \$15.00 each.

New! (GBS/CIDP Foundation of Canada) vinyl car decals are available for an un-receipted donation of \$20 each.

Please note we have a limited supply. All shipping costs are included. If you would like to order from outside of Canada, please email <a href="mailto:info@gbscidp.ca">info@gbscidp.ca</a> for shipping costs.

To receive your Turtlewear go to www.gbscidp.ca/turtlewear.



Note: In compliance with Canada Revenue guidelines, no tax receipts will be issued with hoodies, masks, or car decal donations.



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

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http://www.gbscidp.ca/turtlewear/

# GBS at 8: One Child's Resilience

#### BY OSKAR GLOWACKI AND TARA SYLVESTRE

The first changes we noticed in Oskar that summer were that he started to slow down, and he got clumsy. We'd spent a weekend camping with friends, and for the first time he was not louder, faster, stronger, and crazier than the kids around him. I remember thinking, as I watched him fishing calmly on the back of another kid's kayak, that maybe he was finally mellowing a bit. Oskar, eight years old, had always been an extremely energetic child.

"My feet were fuzzy and I was really tired. At sailing camp the boom hit me in the head and half of my tooth broke off."



Monday morning, we left the campsite to go home. We got in the car and Oskar looked at me and said, "My feet feel fuzzy."

I didn't think too much of it, but over the next few days he became increasingly lethargic. It was not only too much to bike up the hill to summer camp, but he was also too tired to bike down the hill on the way home. We assumed he was experiencing a growth spurt; his discomfort must be growing pains. He was unmotivated to do anything. He was uninterested in eating.

We spoke to our medical friends. I took him to the local clinic. He had blood tests, but the results would take a while due to where we lived. He had no reflexes, but we were told this was common in children. Mostly we justified things and settled in to wait for results.

But quietly, alone and together, Darek and I started to get worried, and scared. Oskar would cry out in the night and pant, and his heart would race. Later, Darek told me, as he watched Oskar struggle to balance while brushing his teeth, that he went to our bedroom and cried. Whatever was going on, it looked like something from which Oskar wasn't going to recover.

On Saturday morning Darek left for work for two weeks in the mountains, out of cell phone range. I took the kids to my parents' house on the Shuswap. We waited for test results. We went to the lake. My daughter Olive, four, swam and played in the water while Oskar sat on the beach looking sad and tired.

"Everything seemed dark. I remember crossing the road in front of the beach and getting really scared because a car was coming".

When we left the beach one day, Olive ran ahead with my girlfriend Hannah and her children. Oskar and I made our way slowly up from the beach and across the road. A car came up quickly on us, and I reacted by saying, "Oskar, run!" It was in that moment that I realized he couldn't. Even with the threat of danger and the adrenaline of the situation, he couldn't run across the road.

#### GBS at 8: One Child's Resilience - cont'd

The car wasn't that close, it wasn't going fast. But we were not ok. When we reached the car park, I started to sob and told Hannah what happened. She grabbed me hard, hid my face from Oskar and whispered, "Don't show him you're scared."



That afternoon she watched Olive as I drove Oskar to Kamloops emergency. It was August long weekend, and emergency was very busy, but I felt relieved to finally have him somewhere we could get help. We waited. Oskar had more blood tests. They thought he might have Lyme's disease; he must have a tick on him somewhere. We saw a doctor. Oskar couldn't get on the table without help and he couldn't balance standing up on his own. He was still exhausted. I told the doctor that this was bizarre behaviour for my son, an extremely active and bright child. Then the doctor told me his thoughts: The good news was that Oskar's blood tests showed nothing was wrong, except for the test for Lyme's disease, which would take longer as it needed to go to Vancouver. The bad news was that he, the doctor, couldn't help me. They sent us home.

I had no idea what to do, other than to take Oskar out for a special lunch to try to convince him to eat. Hannah was horrified to hear that we'd been sent home. I felt awful that I'd left the hospital, that I hadn't been more horrified or adamant to get help. I was unsure and so frightened.

That night was awful. Oskar was in terrible pain all night and hardly slept. I had to carry him up and down stairs. My daughter had already been experiencing night terrors for over a year; I was exhausted, totally impatient, and unravelling. The next day we went to visit Hannah. Oskar could barely sit up and was hardly eating. He slept most of the day. Hannah, not a medical professional but a meticulous researcher, was wondering if he in fact had GBS. She was from Vancouver and told me that if it was her child, she would take him straight to Children's Hospital. I called 811 and told the nurse our story and asked her what she thought of my plan to drive him to BC Children's Hospital. She said that, given his condition, we should never have been sent home. She told me to get some sleep then wake up early and drive to Vancouver.

My mom came home from her retirement camping trip, and the next morning the four of us drove to Vancouver. I propped Oskar up in the backseat because he couldn't hold himself up. As we drove through Merritt, he told me his lips felt funny. All I could think was that whatever was happening was getting close to his brain. I kept breathing and driving. In Hope, when we stopped for gas, I noticed he had no expression left on his face. I propped him up again and we made plans for Hannah's mom to pick up my mom and Olive from the hospital. It was all I could do to go straight to the hospital.

At BC Children's hospital it was another long wait. While trading stories with other parents, I noticed that one side of Oskar's face had fallen as though he was having a stroke. I told a nurse, and we were ushered in to see a neurologist immediately. Shortly after, the doctor gave us a nearly certain diagnosis of GBS. She wanted to test his spinal fluid to be sure of the treatment. Finally we had help and direction.

When we first arrived at the hospital, I had called the Alpine Club of Canada's office to pass a message to Darek by satellite phone. When I went outside and turned on my phone → next page

#### GBS at 8: One Child's Resilience - cont'd

that evening, it immediately started to ring. Darek was desperate to know what was happening. These moments were the only regrets I have of our family crisis. Darek wanted to get on a helicopter and fly out immediately to be with us. As the wife of a mountain guide, I'd been used to parenting on my own for long stretches, and I insisted we were ok, we were in the right place, and it was just a matter of treatment and time. But I should have supported him and insisted he come, and he should have come. We both learned valuable lessons and the dynamic of our family structure shifted after this incident in a powerful and positive way.

# "I looked at the medicine going into me, and I just loved that stuff."

That first night, Oskar did not take well to the intravenous immune globulin (IVIG), and we ended up stopping mid-treatment. For the next two days, however, he received it well and began to improve.

Things were still difficult, but there were improvements. My mom and Olive and Hannah and her kids visited us. We watched movies, Oskar and Olive snuggled in the hospital bed, and Oskar slept a lot. One sunny afternoon we took him outside in his wheelchair. He asked me to lift him out of his chair and put him on the grass. He desperately wanted to try standing and walking, but he immediately fell over. Instead, he pulled himself around on his tummy to look at the bugs. It was beautiful and awful all at the same time, but Oskar was laughing, even enjoying himself. Within a couple of days, he was pushing himself to walk. Before we left Children's he'd managed 11 steps to the bathroom.

We then transferred to Sunny Hill for rehab. We spent a week there and Oskar improved dramatically. He was incredibly driven to use his body again. He'd insist on walking to the washroom down the hall instead of using his wheelchair, stumbling and flailing but determined to get there on his own. One day I overheard a nurse giving him trouble for making skid marks in the hallway with his wheelchair. Always a big personality, Oskar often got in 'trouble' from adults. This was the first time I was ecstatic to hear him getting heck. There was a hint of that spirit we hadn't seen in a while. Through physical therapy he went from the wheelchair to a walker and, somehow, we went home without any physical aids.



It was still a long road. We had a hiking trip booked to Lake O'Hara for my dad's 70th birthday. We decided to go anyway, knowing we could just camp and enjoy the lake. We hiked more than expected, but Oskar was still skinny and unsteady and tired easily.

"I'd get so mad because I couldn't run fast, and my legs would collapse."

When he played with the other children at the campsite he was no longer the fastest, and his legs would give out from under him when he was running and he'd fall down. He was still Oskar, a social

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## GBS at 8: One Child's Resilience - cont'd

being who wanted to be in the middle of everything. But it was tough for him, and he'd get very frustrated and disappointed in himself and his body.

"I was scared to go back to school."

Frustration was the main theme for the next six months. School started not long after we got home from the hospitals, and he was still taking Gabapentin. He was in a lot of pain despite the medication, but the longer he took it the more it worried us. Not only is it a strong drug, but we noticed it eat away at his personality. We were relieved when he was finally able to manage without it. School was difficult and he was especially worried about getting roughed up by the other boys and not being able to hold his own. He loved soccer but we had to keep him off the field until he could risk getting hurt. We were told that January, five months after he was diagnosed, he could try playing again.

"When we went to the last appointment with the doctor, she said I was all better, but I didn't feel all better, and I was still really skinny and weak."

Although he continued to improve, even a year later the nerves in his feet were still affected. Now, five years after diagnosis, Oskar is a healthy and athletic 13-year-old. He competes in trampoline gymnastics, plays volleyball and generally loves activity, but any in-tune practitioner notices that his nervous system is easily stressed. He has his 'team' that supports him and pays attention: his gymnastics coach, his physio and massage therapists, and his parents.

Will we remember this a pivotal crisis in our family history? Absolutely. Will Oskar hold on to this experience with stressful memories and anxiety? Not so much.

"What I really regret is when you took me to the Lego store, and you said I could pick out anything I wanted, and I just picked out that little set. There was that huge Ghostbusters set I could have got. What was I thinking? But I really would have liked to talk to another kid who'd also had GBS. I would have liked that a lot, just to talk, and maybe I wouldn't have been so scared sometimes."



Tara Sylvestre and her son Oskar Glowacki live in Revelstoke, BC, where Oskar is in Grade 9. They are both available to talk with kids who have GBS and with their parents.

A library of 'News and Views' patient and caregiver stories are now available on the website!

Articles: <a href="https://www.gbscidp.ca/patient-stories/">https://www.gbscidp.ca/patient-stories/</a> Videos: <a href="https://www.gbscidp.ca/patient-videos/">https://www.gbscidp.ca/patient-videos/</a>

December 2021 News and Views



# Supporting our Patients

# Support is Just a Click Away!

Have you thought about joining one of our peer-topeer online support group meetings? It's as easy as clicking a link in an email.



For more details, https://www.gbscidp.ca/new-events/





# National Caregivers Meeting - Dec 4th

Join Patti Kent and Nancy Edwards for topic: Caregivers of GBS/CIDP/MMN: Self-care Through Mindfulness and Meditation. RSVP nedwards@gbscidp.ca

National SCIG Meeting - Nov 27th Join Kim Brooks and guest speaker Evelyn Sarpong, RN & Research Coordinator at TGH. Topic: CIDP/MMN: Subcutaneous (SCIG) Your Questions and Concerns. Are you transitioning between SCIG products? Considering the move from IV to subcutaneous IG? RSVP kbrooks@gbscidp.ca

#### Alberta Support Meeting Nov 25, 2021 National SCIG Meeting + Speaker Evelyn Sarpong, RN Nov 27, 2021 Caregivers Support Meeting Dec 4, 2021 **British Columbia Support Meeting** Dec 5, 2021 Saskatchewan and Manitoba Support Meeting Dec 12, 2021 Jan 22, 2022 Quebec French Support Meeting Quebec English Support Meeting Jan 29, 2022 **Toronto Support Meeting** TBA Atlantic Canada Support Meeting **TBA Ontario Support Meeting TBA**

# \*Important Last Call! This is the last mailing by post of the 'News and Views'

The 'News and Views' newsletter will go paperless in 2022, doing our part for our great Canadian Forests. Reducing expensive mailing costs, providing a better digital experience, and connecting with you more frequently for timely information. Stay Connected! Update your contact information NOW

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

# Introduction to Mindfulness

CANDINE BLACKBEARD, BSCN, RN, CCRN

Mindfulness is being present at the moment, becoming aware of your thoughts and feelings as they are happening, and allowing space for those thoughts and feelings to occur in a state of non-judgmental acceptance.

Mindfulness is born from Eastern traditions, primarily Hinduism and Buddhism. Hinduism goes back more than 4000 years and has roots in Vedic tradition. It is the third largest religion in the world and has more than 900 million followers. Buddhism is about 2500 years old. These teachings laid the groundwork for how mindfulness is practised today. Western culture has only recently adopted mindfulness. The increasing rise in mindfulness in the West is further fueled by the rise in yoga, which brings awareness to one's breath and body.

#### Mindfulness can:

- Regulate your emotions. You can have more control over your negative thoughts (Moore, 2020). Negative thoughts contribute to depression, anxiety and stress. The more upset you get, the worse it is for your body, particularly when dealing with an autoimmune disease. You can have control over your emotional reaction, which will, in turn, directly affect your physical wellbeing.
- Lessen the experience of pain by as much as 57 per cent (Zeidan, et al., 2011). Suffering and pain are part of being physical beings, but our experience of pain can be influenced by how we think and feel about pain. Mindfulness gives us tools to better manage our pain.
- Support eating nutritious food that impacts our mental and physical well-being. Eating disorders are widely prevalent. Overeating, binge eating and non-nutritive consumption are common. By eating mindfully, we can nourish our bodies and enjoy our food thoroughly.
- Sleep better. Sleep is integral to our body healing and gives our brain a chance to process events into memory and learning. We need sleep to function. Pain, stress, worry, and so many other factors can contribute to poor sleep.
- Encourage empathy towards others and greater self-compassion (DeSteno, 2015). Wouldn't it be nice if you were able to be nicer to yourself? We are often our own worst critic. Being kinder to yourself will also improve your relationships with others. Self-care is not selfish. You cannot help others if you do not first help yourself.

#### **Proof**

- The scientific community is exploding with studies that consistently back up the benefits of practising mindfulness. In the West, notions tend to be dismissed unless there is science to back up the theory. There was no scientific data, 2500 years ago, to back up the benefits of practising mindfulness.
- Practising mindfulness regularly has been shown to have positive health benefits on the mind, body and even on the cells of the body (Harvard Health Publishing (n.d.). → next page

For more articles on Mindfulness by Candine Blackbeard, visit: https://www.gbscidp.ca/medical-articles/

# Introduction to Mindfulness - cont'd

Today the world has many challenges with Covid-19 and life's stressors. Living with an autoimmune disease puts extra physical, emotional, cellular and mental stress on your body. There are now studies that support a mind-body connection phenomenon whereby what we think and feel affect our physical experiences right down to how our neurons are firing

(Weinberg, 2020).

 Does your heart start racing when you feel nervous or stressed? This stress response is attributed to the stress hormone cortisol. Cortisol has particularly negative effects on the immune system, which is already under duress for persons with GBS/CIDP/MMN and variants. Cortisol and other stress hormones have been shown to worsen the symptoms of autoimmune diseases and lengthen the duration of exacerbated symptoms. Mindfulness practice can lower cortisol levels and help alleviate suffering faster.

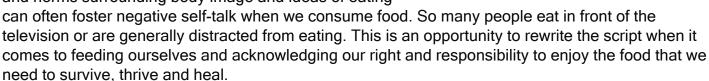
To reap the benefits of mindfulness, you do not have to sit for hours on a cushion meditating.
 Rather, you can bring the practice into your daily life in small doses doing the things you already do.

# Practising mindfulness

Try some apps on your phone or mobile devices to help you explore different mindfulness meditations and podcasts. Two popular apps are Headspace and Calm. I have no affiliation with either nor recommend any app over the other. I do enjoy MyLife for meditations. The apps I am familiar with have free and paid content, and I have only accessed the free content.

However, you do not need any technology to start practising mindfulness.

One of my favorite mindfulness activities is mindfuleating. I love food. Ideally, we enjoy our food, but social pressures and norms surrounding body image and ideas of eating



Prepare a small healthy snack that you enjoy. Find a peaceful, quiet place that makes you feel good.

Sit down and get ready to eat your food. Notice how your body feels before you eat. Are you hungry? Do you feel relaxed? Take a few deep breaths.

When you are settled, open up your awareness to the texture of your food. What does it look like? Is it rough, smooth, wet, dry? Can you smell it? Does it smell spicy, sweet, aromatic, pungent? Is it warm or cold? What colour is it?



# Introduction to Mindfulness - cont'd

When your visual senses have eaten up the characteristics of your meal, touch your food if possible -- soup might be a bit challenging (after washing your hands of course!). What does it feel like? Crumbly? Solid? Heavy? Light? Grainy?



When you put it in your mouth, let it stay there for a while. Feel the texture on your tongue, notice the temperature. Can you identify all the ingredients in your mouth? Chew your food thoroughly and sink into the enjoyment of eating and nourishing your body. Understand that what you eat supports your immune function and global health.

After eating your food, sit and be aware of how your body feels different from before you ate. Are you sated? Was it enjoyable? Did you notice your attention wandering? It is okay if your mind gets distracted. Be kind with yourself and gently bring your awareness back to the present. With practice it will become easier to be more present.

I hope you enjoyed your meal.

#### ABOUT THE AUTHOR

Candine Blackbeard, BScN, RN, CCRN, is a Registered Nurse in good standing with the Ontario College of Nurses, and she is a liason for GBS/CIDP Foundation of Canada. She is trained in conventional evidence-based medicine with a specialty in critical care medicine, trauma and neurosurgery.

In addition to a Bachelor's of Science in Nursing she holds certificates in; Critical Care medicine from George Brown College, Nursing Education for the Practice Setting through the University of Toronto, and Advanced Principles and Practice of Mindfulness through McMaster University. She is in progress of a Master's of Science in Nursing at York University.

She is interested in how best to facilitate patients in achieving their optimal state of mental and physical wellness using evidence-based medicine and holistic complementary therapies. Neuroscience and wellness from a nursing perspective are the cornerstones of her professional inquiry.

Disclaimer

This article is not meant to offer medical advice but instead to introduce the practice of mindfulness meditation, which can support the journey of wellness. For any specific medical questions or concerns, please speak to your physician.

## RESOURCES AND REFERENCES

There is a great video on YouTube in which Oprah Winfrey interviews Thich Nhat Hahn on Living Mindfully. I found if highly educational and enjoyable, maybe you would like to watch it: https://youtu.be/d3Cw7r98EKY.

Congleton, C., Holzel, B., & Lazar, S. (2015.). Mindfulness Can

Literally Change Your Brain. Harvard Business Review.

 $DeSteno, D. \ (2015). \ How \ Meditation \ Builds \ Compassion. \ Retrieved \ from \ https://www.theatlantic.com/health/archive/2015/07/mindfulness-meditation-empathy-compassion/398867/$ 

Harvard Health Publishing. (n.d.). The magic of mindfulness. Retrieved from https://www.health.harvard.edu/staying-healthy/the-magic-of-mindfulness

Moore, C. (2020). What is the Negativity Bias and How Can it be Overcome? Positive Psychology. Retrieved from: https://positivepsychology.com/3-steps-negativity-bias

Weinberg, J. (2020). Mind-Body Connection: Understanding the Psycho-Emotional Roots of Disease. Retrieved from: <a href="http://statera-hs.com/articles/detail/21/mind-body-connection-understanding-the-psycho-emotional-roots-of-disease-:~:text=The beliefs you hold about,roots of health and disease.">http://statera-hs.com/articles/detail/21/mind-body-connection-understanding-the-psycho-emotional-roots-of-disease-:~:text=The beliefs you hold about,roots of health and disease.

Zeidan, F., et al. (2011). Brain Mechanisms Supporting the Modulation of Pain by Mindfulness Meditation. *Journal of Neuroscience*. DOI:

#### \*\*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.