

News and Views

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

Celebrating 20 Years!

We are celebrating 20 years of service to the GBS, CIDP, MMN and variant community. Two decades ago, our Founder, Susan Keast, and the first Board of Directors, were working tirelessly to have the Guillain-Barre Syndrome Foundation of Canada become a registered Canadian charitable organization. All these years later, Demetrios (Jim) Strongolos continues to reside on the Foundation Board of Directors as one of the inaugural members. Through their example of dedication to patients and their families, we have never lost sight of what is important to those that we serve. Since the Foundation's inception, we evolved into the GBS/CIDP Foundation of Canada and more recently we are working toward building a better support network for MMN and rare variants and working on a 3-year strategic plan. Please join us in Montreal, QC for this year's Montreal National Conference, where we will finally come together once again as a community seeking knowledge, shared experiences, and friendship, in a year of celebration of 20 years of service to our community. See you there! *Sincerely, Donna Hartlen*



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Walter Keast Award
2022
Nancy Galaski

2

Montreal National
Conference
May 5-6
(Live Translation)

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A Cautionary Tale
Daniel Gunn

Walter Keast Award 2022: Nancy Galaski

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

Nancy has passionately committed much of her personal time to raise awareness and supported our patients and families during 2022.

We are so proud of you Nancy,
Congratulations!

Walter Keast Award 2022

NANCY GALASKI

Nancy has passionately committed much of her personal time to raise awareness, advocate, and fundraise for our patients and their families.

Nancy has volunteered her time in 2022 to:

- Proclamation Training
- 8 Proclamation Requests
- 6 Successful Proclamations
- Rare Disease Day
- Volunteer Appreciation
- Toronto Walk and Roll
- Chaired York Region Walk and Roll



Thank you to our supporters of 'News and Views'

CSL Behring

GRIFOLS



Life Support: Holly Frances

Vice President, GBS/CIDP Foundation of Canada

Writing about one's truth is an act of pure bravery. All of us with the Foundation are proud of Holly's latest book release, *Life Support*. As patients and caregivers, we connect to her journey, but beyond the patient connection, is the human connection. Holly spares no details of her ICU and recovery journey, and health care professionals should consider this a real-world must-read.

Holly will have a booking signing at the Montreal Conference and inspire us through a keynote session.



To Order: <https://a.co/d/5PI9iJV>

Weeks after giving birth, Holly Frances went from being a healthy 26-year-old new mom to paralyzed and on life support—in less than 72 hours. Diagnosed with a rare autoimmune disorder called Guillain-Barre Syndrome, Holly was trapped in her own body, unable to move, speak, or hold her newborn daughter.

Life Support tells the story of how Holly struggled to overcome the despair, hopelessness and pain of recovery, to regain her health and get back to being a mother to her daughter.

Both a memoir and a resource guide, this is the true story of how Holly found purpose in the 126 days spent in hospital. A journey of strength, determination and hope, Holly's story reminds us that life doesn't always go as planned, sometimes, in the most dire and challenging ways, it turns out better.

This book is the go-to resource for those living with GBS and other autoimmune illnesses in need of hope, encouragement, and helpful tips; and for caregivers, friends, and medical professionals looking for insight on how to care and support someone dealing with the challenges of these devastating illnesses.

Holly's recovery videos on YouTube have inspired many with her fighting spirit and have over 20 million views from around the world. With the addition of new chapters and years passed, Life Support replaces Holly's first book, Happily Ever After: My Journey with Guillain-Barre Syndrome and How I Got My Life Back.

A Cautionary Tale

Daniel Gunn

Until my spinal cord injury I was active and in good physical shape for a man of 65. My hope is people will take notice of what went wrong and take the necessary precautions to prevent a similar incident.

September 2003 – Spinal decompression and fusion L3-S1 done by Dr. A in Hospital 1. Back pain and mobility improved.

February 2008 — Decompression and a “mass” removed by Dr. A. This was the cause of my original right foot drop.

December 2009 – I was working out regularly at a gym and going to physiotherapy with no improvement in general leg strength. Physiotherapist advised me to see Dr. A.

January 31, 2010 – MRI of spine done at Hospital 2. Surgery booked for May 11.

February 16, 2010 – At pre-op appointment Dr. A told my wife and me that the disease had moved up my back to L2-L3. The operation should alleviate some pain and improve walking.

May 11, 2010 – Decompression and extend fusion to L2 and replace all screws and wires as needed to the bottom of previous fusion done.

June 16, 2010 — Post surgery appointment with Dr. A who said everything appeared to be healing okay.

July 3, 2010 — My legs had not felt right since the surgery. My right foot drop got worse and the leg was more numb. I had about 10 per



cent use of my right foot, which went down to about one per cent that day.

July 7, 2010 – Physiotherapist had no answer for the sudden foot drop.

July 21, 2010 – Saw Dr. A, who also had no answer. He said I should exercise the foot several times a day, which I was already doing. Something was wrong.

August 9, 2010 – MRI.

August 27, 2010 – Dr. A saw nothing on the MRI that would indicate a problem. He said he would keep the MRI and look at it on the big screen at the hospital.

September 23, 2010 – Doppler ordered by Dr. A to check blood circulation in the legs. Checked out okay.

October 1, 2010 – Saw Dr. B, neurologist at Hospital 3. He said my problem was “common —> Next page

A Cautionary Tale

Continued

peroneal nerve compression at the fibular neck” and told me to stop crossing my legs, don’t squat and don’t kneel. Come back and see him in 12 weeks.

October 19, 2010 – Physical with Dr. C. Ordered arterial doppler for October 29. Checked out okay, again.

October 27, 2010 – Appointment with Dr. A who said he saw nothing wrong on the MRI from August 9 on the big screen. I wondered why Dr. A would not look for a problem further up my back as he had said previously that the disease was moving up my back.

November 8, 2010 – Told Dr. C I was concerned about the loss of use of my legs. He ordered an MRI of my head. It showed a slight brain shrinkage but otherwise all okay.

November 12, 2010 – There was a shock feeling down my left leg and it momentarily gave out under me. Scared me. I was losing control of my body from the waist down.

November 22, 2010 – Getting desperate. Went to emergency at Hospital 1. Waited six hours to be told there was nothing they could do to help me.

Same day, I went to emergency at Hospital 3 and waited another six hours. The emerge doctor said he thought something was being missed and ordered an MRI from the neck down. He didn’t know how long it would take to get the MRI. As my legs were deteriorating rapidly, I knew I didn’t have much time.

November 23, 2010 – Appointment with Dr. C.

I told him I was getting desperate. He said he would consider other specialists.

November 26, 2010 – Went to Hospital 4’s emergency. Everyone I had talked to said, “If the symptoms get worse, to go to the hospital.” I saw their neurological department and after much poking and probing, they advised me to keep my appointment with Dr. B on December 2 because he would have other tests for comparison.

December 2, 2010 – Saw Dr. B at Hospital 3. To Dr. B’s surprise, I arrived in a wheelchair. After doing several tests — electric shocks, pricking and poking — he concluded that I likely had chronic inflammatory demyelinating polyneuropathy (CIDP). He told me to go to emergency and stay there until I was admitted. During the next few days I had a spinal puncture that showed a high end of normal protein. I also had an MRI looking for evidence of CIDP but there was none.

December 13, 2010 – Transferred to Hospital 5 for appointment with Dr. D, who did several more tests and agreed I had CIDP and should start on a treatment called IVIG. This diagnosis of CIDP caused everyone to stop looking for anything else. I was transferred back to Hospital 3 and got IVIG as prescribed.

December 17, 2010—Discharged from Hospital 3 and continued IVIG as an outpatient.

December 22, 2010 — Still tried to work out at home but got weaker day by day. Incontinence was becoming a problem, as was sex.

—> next page

A Cautionary Tale

Continued

December 30, 2010 – Emailed Dr. D saying I was still getting weaker and asked if there was any alternative or experimental therapy that could help arrest my condition. Dr. D replied that it usually takes longer to take effect and I may need another treatment. Said Dr. E would call me in the new year.

January 2, 2011 – Legs below knees were very numb. Could not control my feet and was afraid of falling.

January 4, 2011 – Dr. E called. He checked my chart and agreed with the CIDP diagnosis. Some people get relief from IVIG in a few days and some take four weeks or longer. We should finish the IVIG treatments and then reassess. I should go to physio to keep as strong as possible.

January 11, 2011 – Appointment with Dr D. Examined by Dr. F. Decided to continue on IVIG and also take steroids. Dr. F ordered an MRI of the thoracic spine because it was the only area where I had not had an MRI and constipation and incontinence are rare in CIDP. I was astounded that there was a whole other area of my spine that no one had ever looked at.

January 16, 2011 – I could hardly move my left foot.

February 13, 2011 – Numb penis and rectum big concern. Can no longer tell when a bowel movement is starting or finished.

All this time a synovial cyst was growing by my spinal cord causing more damage each day.

February 24, 2011 –Emailed Dr. D. Explained that after several weeks of IVIG, my condition



was getting worse. I asked if the numbness below the waist (bowels and penis) were common to CIDP and just not talked about because of embarrassment or was something else wrong with me. No reply.

February 25, 2011 – Got a phone call from Dr. C that Dr. B thinks he and a radiologist from Hospital 3 see something on the MRI. Dr. C will fax the information and a referral to Dr. A. I called Dr. A's office requesting an appointment as soon as possible.

February 28, 2011 — I got info from Dr. C to take to Dr. A. Went back to Hospital 1. At 11:30 a.m. I was examined and waited for a specialist. At 6:30 p.m. the hospital sent my MRI by cab to Dr. G at Hospital 6. At 1:00 a.m. I learned the following from the ER doctor at Hospital 1 from Dr. H at Hospital 6: I should get an operation as soon as possible. The operation would not restore the problems with the bladder, bowel and legs, but would stop further progression. I did not, could not believe it. I had a difficult time accepting I was f*****d for life.

March 1, 2011 – Dr. I from Dr. G's office said it was best to go to Dr. A, my previous back surgeon. —> Next page

A Cautionary Tale

Continued

Dr. A's office said he was unavailable but agreed I should have an operation.

March 2, 2011- Got changed to being Dr. H's patient (who had seen the MRI). His office called and said to go to Hospital 6 emerge at 8:00 a.m. the next day. They would probably admit me and operate the following day.

March 3, 2011 – Arrived at Hospital 6 at 7:30 a.m. Checked over several times by different doctors. I gave them my previous history after which one of the nurses said “You're with us now, we will look after you.” Waited all day. Operation was around 10:00 p.m. I was back in my room around 2:00 a.m.

March 8, 2011 – Neurology team came and did an assessment and then came back with some students and did another. Their opinion was that it could be a combination of CIDP and a synovial cyst (SCI). They said the operation should help the spinal cord issue and I should keep on the meds for CIDP. I would be on intermittent catheterization for the rest of my life. Sex would never be the same and my bowels would remain unpredictable..

March 15, 2011 – Admitted to a rehab facility. Everyone there was great. I learned about wheelchairs and walkers and worked out the best medications for me.

May 7, 2011 – My first day home from rehab to stay. It was nice to be home, but scary. No nurse to call on.

July 26, 2011 – Saw Dr. J and everything was as good as could be expected. Had an appointment with Dr. K at rehab regarding my

bone density test two weeks prior. I was doing OK. Saw Dr. H at Hospital 6 with an x-ray. There was loose hardware at the operation site but it hadn't moved. Check it every three to six months. It did sometimes cause a sharp pain in my upper left middle back but so much else was wrong, loose hardware seemed trivial.

September 28, 2011 – Saw Dr. J. I could move my right toes a bit.

I asked both Dr. H and Dr. J if all my recent physical problems could have been caused by an SCI. They both said yes.

Life now — I'll lie in bed in the morning, not because I want to be there, but my legs feel as good as it gets. Warm. No pain. No spasms. So I let them be for a while and tell them “just get me through one more day.”

I was told that my doctors were the best. It seems that even the best have their bad days.

When is CIDP not CIDP? When it is a synovial cyst growing on your spinal cord, getting worse by the day while you are being given drugs to knock out your immune system to control a disease that you don't have.

I was told that my doctors were the best. It seems that even the best have their bad days.

Not much has changed over the last while. I don't seem stronger or weaker. Life has been difficult but I'm adapting as best I can.

LUNCH AND LEARNS

BC Liaison Cheryl Dean, is seen below sharing her GBS journey, experience and knowledge with her Physiotherapist, Occupational Therapist and Rehabilitation Assistant colleagues during a lunch and learn in-service at Langley Memorial Hospital.

Many of her colleagues expressed that they now have an increased knowledge about these rare illnesses and how to deal more effectively with their patients to help them receive their best outcomes. Another popular take-home was the crazy hair pens which were loved by all.

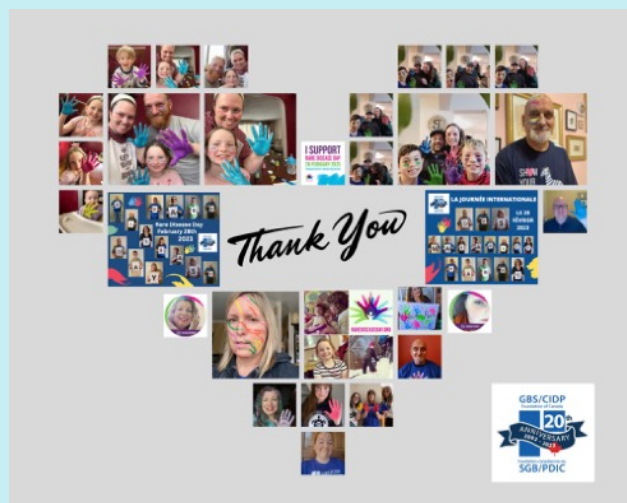


FEBRUARY AWARENESS INITIATIVES

Thank you to everyone that participated in the annual worldwide movement to raise awareness during Rare Disease Day 2023!

The Foundation also had the pleasure to do a virtual introduction and provide information to members of the Association of Electromyography Technologists of Canada.

Did you know depending upon what type of EMG testing you are having to check the health of your nerves, you can listen to music or play a game on a handheld device to distract yourself? Ask your technologist next time you have an appointment.





Conférence 2023 de MONTREAL

Conference 2023



Date:
May 5-6 / 5 et 6 mai 2023

Location / Emplacement :
Sheraton Montreal Airport Hotel
Hôtel Sheraton, Aéroport de Montréal

Celebrating our 20th Anniversary!
Célébration de notre 20e anniversaire!

Live translation provided in English and French / Traduction en temps réel en français et en anglais

May 5 Mai	Walk and Roll / Marche et roule 18:00 h Mix and Mingle / Soirée sociale 19:00 h
May 6 Mai	Education Day / Journée éducative 7:30 h - 17:00 h
May 5-6 / 5 et 6 Mai	Patient Experience Exhibit Exposition sur l'expérience du patient

- Learn more about condition management, self-care, security of IG supply, latest research, and more. / Venez en apprendre davantage sur la gestion de nos maladies, comment prendre soin de soi, l'approvisionnement en IG, les avancées en recherche et bien plus encore.
- A full agenda with speakers and topics will be shared on our website. / Un ordre du jour complet comprenant des conférenciers et des sujets sera affiché sur notre site Web.

Please join us for this year's GBS, CIDP, and MMN Montreal National Conference. / Joignez-vous à nous pour la Conférence nationale de cette année sur le SGB, la PDIC et la NMM qui aura lieu à Montréal.

Can't travel to the Montreal Conference? For the first time, we'll be offering a virtual component accessed via Whova of 3 conference sessions, that can be viewed live or post-event for up to 3 months! The in-person sessions that have been chosen with a virtual option are identified in the agenda. This will also help the attendees that will be joining us in Montreal make session choices, or rest if needed. Anyone that purchases an Education Ticket, has virtual access included.

Vous ne pouvez pas vous rendre à la Conférence de Montréal? Pour la première fois, nous offrirons l'accès virtuel à trois sessions de conférence via l'application Whova. Ces sessions pourront être visionnées en direct ou jusqu'à 3 mois après l'événement! Les sessions qui seront accessibles virtuellement sont indiquées dans l'ordre du jour. Cela permettra aussi aux participants qui se joindront à nous à Montréal de choisir leurs sessions ou à se reposer si nécessaire. Toute personne qui achète un billet pour la Journée éducative aura accès aux sessions virtuelles.

Register Today! / Inscrivez-vous dès aujourd'hui!
www.gbscidp.ca



Conférence de Montréal Conference 2023



GBS/CIDP
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SGB/PDIC



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

Sheraton Montreal Airport Hotel May 5-6

REGISTER

Information

**HOTEL
\$155 per night**

Walk & Roll

For the best French registration experience, register using a mobile device. Download the Whova App for the ultimate in-person and virtual Montreal National Conference experience. Through the App, you'll see updates as they happen, engage with other attendees, participate in polling, and have access to post-conference recordings.

Whova App

Main Events

May 5th

Montreal Walk and Roll - 6 pm

Mix and Mingle - 7 pm

Coming to the Mix and Mingle? We could use some auction items! If you would like a letter requesting a donated item from a business, reach out to Nancy at nedwards@gbscidp.ca.

May 6th

Educational Day - 7:30 am - 5:00 pm

Patient Experience Exhibit offered during the Mix and Mingle and Educational Day

May 6th Sessions

Keynote: Holly Frances : Getting Better Slowly, By Never Giving Up

EMG in GBS, CIDP, MMN: How does it help us?

Research Updates in Immune Neuropathies

(Part 1: IGOS/GBS Part 2: CIDP/MMN)

Securing IG for Canadians

Subcutaneous Immunoglobulin

Resources for Coping and Resilience

The Role of Physiatry in Rehabilitation and Pain Management

Mindfulness

Ask the Experts

Panel Discussion: Managing Residuals

[View the agenda in Whova to stay up-to-date.](#)

Walk and Roll: 2023 Spring Schedule

Walk Schedule



Montreal Walk and Roll - May 5th, 6 pm

Sheraton Montreal Airport Hotel

[Donate or Register](#)

2nd Annual Toronto Walk and Roll - May 13th, 10 am

Taylor Creek Park

[Donate or Register](#)

1st Annual London Walk and Roll - June 17th 11 am

Springbank Gardens Park

[Donate or Register](#)

Coming Soon!

Calgary


Saskatoon

Vancouver

York Region, ON



Launching in 2023, We're improving the website!



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Resources for Emergency Physicians →




You can help us support those in need.

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

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

Get involved
[REGISTER NOW](#)

Impact a life
[MAKE A DONATION](#)

NEED SUPPORT?

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





You Are Not Alone
Saskatchewan & Manitoba Support Group Meeting

Sunday, Dec 10, 2022
1:00pm-3:00pm CST on Zoom
RSVP to: Kim Brooks
kbrooks@gbscidp.ca

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

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

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

www.gbscidp.ca 647-560-6842

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