

# GBS/CIDP Foundation of Canada

Guillain-Barré Syndrome / Chronic Inflammatory Demyelinating Polyneuropathy  
*Support, Education, and Research*

## News & Views

Issue: 16

Spring/Summer

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### *A Message from Donna Hartlen, Executive Director*

So long brutal Canadian winter, 'Hello' sunshine! Spring and summer can change how we as patients get around in our communities, and it opens up a whole new world of accessibility. It doesn't last long, so enjoy these warm summer days.

We are half way through 2015 and it has already been an exciting year!

On May 1st, 2015, our committed volunteers traveled to Mississauga for our Liaison Training Day. I want to thank all those that attended. Everyone put on their thinking caps and I look forward to successfully implementing some of your great ideas. Always putting patients and families first, it was a very successful day! If you are interested in volunteering for the foundation, contact Gail Kammer, [gail.kammer@gbscidpcanada.org](mailto:gail.kammer@gbscidpcanada.org) for more information.

The National Conference was held in Mississauga, Ontario on May the 2<sup>nd</sup>. With the support of volunteers and presenters it was a successful and informative Day!

Dr. Kurt Kimpinski, of London Health Sciences Centre, provided a relaxed and informative workshop for GBS. Patients were presented with more detail surrounding the disorder mechanisms, treatment, and recovery. When Dr. Thomas Feasby was unable to attend due to a short illness, Dr. Kimpinski stepped in to give attendees a presentation on the International GBS Outcome Study. London Health Sciences has entered several GBS patients into the international study. The study aims to have 1000 patient sample collections of blood and spinal cord fluid and treatment information, that markers be found that indicate how a patient is treated for GBS that will bring a better recovery outcome. Since the conference it was announced that the study has reached its worldwide total of 1000 patients, but the study remains open until the fall for more patient entries. Thank-you Dr. Kimpinski for doing both presentations and your sense of humour when we had some minor technical difficulties. We appreciate your continued dedication to our patient community and the foundation.

Dr. Vera Bril and Dr. Ari Breiner, of Toronto University Health Network, presented on CIDP. Patients gained a better understanding of the dynamics of the disorder and treatment options that doctors have available to control its progression. Patients also learned of current trials surrounding the disorder, such as subcutaneous immunoglobulin, known as the PATH study. Both doctors are obviously dedicated to the disorder and we appreciate Dr. Bril's passionate speech on how patients can advocate for IVIG treatment availability in our CIDP community and the foundation appreciates her ongoing efforts to protect the well being of patients.

## *A Message from Donna Hartlen, Executive Director (continued)*

The foundation was excited to offer an MMN workshop for the first time by Dr. Hans Katzberg. Attendees learned about the disorder's presentation, treatment, and progression. Dr. Katzberg also reviewed the results of the subcutaneous immunoglobulin trial in MMN and the overall positive results for participating MMN patients. Subcutaneous IG is self-administered by the patient, at home, into fatty tissue below the skin. We were pleased to be able to provide this new workshop and we will continue to let the MMN community know that the foundation supports those affected by the disorder. Thank-you Dr. Katzberg for supporting the conference and also presenting MMN to our volunteers.

Dr. Bril and Dr. Jerry Green, board certified anesthesiologist with 20 years of clinical experience and Assistant Professor at the University of Texas Southwestern Medical Center in Dallas, gave the presentation 'Anesthesia in Inflammatory disorders GBS, CIDP, and MMN'. This presentation was well received at the International Symposium and we thank Dr. Bril and Dr. Green for offering this workshop at our National Conference. Dr. Green, also a CIDP patient, teamed up with Dr. Bril, to alleviate concerns for patients that would potentially have to have surgery in the future. Thank-you Dr. Bril and a special 'Thank-you' to Dr. Green for traveling to Canada.

Dr. Katzberg and Dr. Breiner also gave an overview of treatments across all three disorders. All presenting doctors took part in the 'Ask the Expert' segment of the day. Always a favourite, we thank each of you for candidly answering our questions. I want to highlight attendee comments of their appreciation of each doctor to present in simple layman terms. The foundation truly appreciates each doctor volunteering their personal time to share their expertise and educate our patients and families. Thank-you!

The day didn't end there! Santo Garcia, Occupational Therapist by trade and President, Foundation International, gave us a kick-start in the afternoon with

his 'Chairobics'. It was amazing to see persons with different levels of mobility get our heart rates up, while completely seated. The room was energized and it was truly an experience that attendees will fondly remember. Thank-you for your practical advise as a CIDP patient, traveling to the conference and getting to know the Canadian patient community, and motivating us to feel the beat and get active!

Wilma Koopman and Dr. CathyLee Benbowe held patient and caregiver workshops for emotional issues. We thank each of you for giving us advise on how to cope with the challenges of each of the disorders and letting us know its OK to ask for help. Attendees have asked for more time in the future for this workshop. In the meantime, the foundation will continue to provide support group meetings so that patients and families continue to connect with others affected by our disorders. Watch for posted upcoming meetings on the website and Facebook.

Thank-you to Christine and Van Rego for telling 6-year old Van's GBS Story. Van was our youngest and most brave presenter, and when asked how he's doing today, he simply said 'Better'.

Thank-you volunteers, presenters, and our sponsors, Grifols, Octapharma, CSL Behring, and Baxalta, for without your support, we could not provide our patient community with such a great educational event.

The second half of the year is exciting! The foundation will have a second conference in Calgary, Alberta on Saturday, Sep 19, 2015. This event will have workshops for GBS, CIDP, and MMN. Also presentations on 'Lung Health', 'The role of Physiatry', and 'Available Treatments'. More workshops to be confirmed. Invitations will be sent out the beginning of July and more details are available within the newsletter.

It's an exciting time and a lot of activity within our disorder community. Enjoy the newsletter articles on exciting research, treatment trials, patient stories, and resources. Have a wonderful Summer and see you in Calgary! Donna

*Thank you CSL Behring Canada Inc. for making this newsletter possible with an unrestricted educational grant*

## Canadian Investigators Awarded Research Grants from GBS | CIDP Foundation International



We would like to congratulate investigators Drs. Ari Breiner, Vera Bril, Hans Katzberg, and Ali Naraghi – all from University Health Network in Toronto – on being awarded a GBS|CIDP Foundation International pilot grant to fund a research study in CIDP!! **Their study will focus on the role of MRI imaging to improve the diagnosis and follow-up of CIDP patients, and in tracking response to therapy.**

At present, there is no marker in the blood, urine, spinal fluid, or nerve that can identify CIDP with certainty. Nerve conduction studies, which are the current gold standard, capture up to 60–70% of CIDP cases, however they are painful, miss 30–40% of disease, and do not track improvements with therapy. Immune treatments are costly and have potential side effects; and therefore the development of biomarkers is critical. The upcoming research project will use emerging MRI technology to



compare the appearance of peripheral nerves (in the arms and legs), in patients with CIDP and in healthy controls. Hopefully, MRI could be used in the future to allow for more accurate diagnosis without the discomfort of nerve conduction studies. They will also explore whether MRI can help physicians to make better decisions about treatment – when to start, how much to give, or when to stop treatment. The investigators are hopeful that the research will have a real impact in improving the quality of life of patients with CIDP.

**For anyone newly diagnosed with CIDP, who has not yet started treatment, and is interested in participating in this study, please contact Dr. Ari Breiner (principal investigator) or Eduardo Ng (research co-ordinator) at 416.340.4184.**



We'd also like to congratulate Dr. Kenneth K.S. Ng, who is the principal Investigator, on being awarded a GBS|CIDP Foundation International grant for his research entitled '**Molecular Structural Basis of Autoantibody Recognition in Guillain-Barré Syndrome**'.

Antibodies that bind sugars of glycolipids cause an axonal form of GBS. This project will visualize the antibody interaction with specific carbohydrates on the glycolipid and reveal for the first time how specific carbohydrates are recognized in a three dimensional manner. Highly sensitive and specialized techniques using synchrotron x-ray radiation and mass spectrometry will be used to study crystals of purified antibodies bound to carbohydrate antigens. The techniques are usually the province of physical chemistry and not medicine, but the study is expected to provide fundamental information that may have multiple applications for improving the diagnosis and treatment of GBS and other autoimmune diseases in the future. The detailed three-dimensional information revealed in this study may lead to the development of novel reagents for detecting and possibly blocking the action of anti-ganglioside antibodies central to the development of GBS and related diseases.

Kenneth K.S. Ng received his B.Sc. and M.Sc. in Biochemistry from the University of Calgary in 1990 and 1992, respectively, and his Ph.D. in Structural Biology under the supervision of Professor William I. Weis at Stanford University in 1998. He then completed postdoctoral work with Professor Michael N.G. James in the Department of Biochemistry at the University of Alberta (1998-2002). In 2002, he became an Assistant Professor in the Department of Biological Sciences at The University of Calgary and in 2007, he was promoted to the position of Associate Professor with tenure. Group research interests are focused in the area of structural biology, particularly with the use of X-ray crystallography to understand the mechanisms of recognition and catalysis in proteins and enzymes from pathogenic bacteria and viruses. The group is particularly interested in understanding the structural basis of protein-carbohydrate interactions in *Clostridium difficile* toxins and the enzymes and antibodies involved with mycobacterial cell wall biosynthesis and immune recognition. In addition, the group has also been investigating the mechanisms of catalysis and inhibition in the polymerases and proteinase essential for replication in RNA viruses for many years. Additional interests include the structure-based design of novel reagents for biotechnology using streptavidin, and studies of regulatory and biosynthetic enzymes in plants. Most recently, his research group has begun investigating antibodies that recognize cell-surface carbohydrates involved with the development of cancer and autoimmune diseases. Recognitions include Establishment Grant, Scholar and Senior Scholar awards from the Alberta Heritage Foundation for Medical Research, a CIHR New Investigator Award and an Award of Excellence in Research from the University of Calgary Faculty of Science. In 2011, he and four colleagues were co-recipients of the Brockhouse Canada Prize for Interdisciplinary Research in Science and Engineering from NSERC.

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# National Conference 2015

## Mississauga, ON

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*Thank-you doctors, presenters, liaisons, and attendees for helping make our National Conference a success.*

*Many thanks to our National Conference sponsors:*

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Mr. and Mrs. David Sleeth, and Santo Garcia



Ask the Expert Panel From Left: Wilma Koopman, Santo Garcia, Dr. Kurt Kimpinski, Dr. Ari Breiner, Dr. Hans Katzberg, Dr. Jerry Green, and Dr. Vera Bril



Hillary, Jane Field, Dr. Angelika Hahn

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# *National Conference 2015*

## *Mississauga, ON*

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Friday Evening 'Meet and Greet'



Christine and Van Rego  
tell Van's GBS Story



Liaison Training Day



Holly Gerlach and Marilyn Rose  
tell their GBS Story during 'Meet and Greet'



Liaison Training Day



Dr. Hans Katzberg – MMN



Troy Boettinger, Barbara Sherman, Susan  
Keast, Donna Hartlen, Dr. Angelika Hahn

## FORCIDP Trial

Submitted by Dr. Angela Genge

FORCIDP is the name of a clinical trial using an oral medication to treat chronic inflammatory demyelinating polyneuropathy (CIDPN). The medication is currently available for use in certain patients with multiple sclerosis, a disease caused by inflammation in the brain and spinal cord. This trial is set up to determine if the new medication, fingolimod, also known as Gilenya® is effective for the treatment of CIDPN. The study is open to patients with the diagnosis of CIDPN who are currently on treatment with either IVIG or steroids such as prednisone or solumedrol. Patients can enter the study if they are on one or both treatments. When a patient enters the study they are followed very closely. If the patient gets worse their regular treatment can be restarted immediately. Patients in 15 countries are participating and there are neurologists participating in the trial in Montreal, Kingston, and Calgary. To find out more contact ***clinicaltrials.gov*** or ask your neurologist about the FORCIDP study.

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*The Foundation would like to thank all those who have made donations. We could not manage without you. Tax-deductible receipts will be given for all gifts of \$10.00 or more.*

*For online donations please visit*



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***GBS/CIDP Foundation of Canada is pleased to communicate the availability of the Octapharma Canada Inc. developed 'My IVIG Infusion Diary', a Free Mobile App, which is available for patients receiving Intravenous Immunoglobulin (IVIG) Therapy***

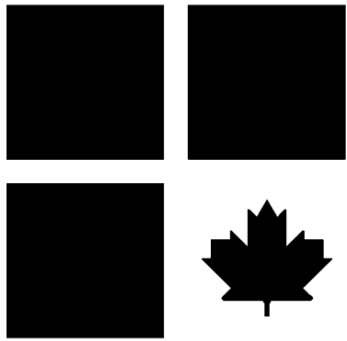


Patients with chronic health conditions that require regular IVIG infusions, that have embraced modern technologies such as smartphones and other handheld devices, are now able to keep track of their IVIG infusions within the Octapharma Canada Inc. developed 'My IVIG Infusion Diary' App available on iOS and Android phones/tablets.

The App experience includes the following capabilities:

- Record infusions and status of general health pre and post infusion
- Create contacts
- View maps for contacts with street info
- Record episodes and medicine consumption
- Generate pdf format reports about their infusions (Android and iOS)
- Share their data with caregivers and clinicians by email

To download and install the My IVIG Infusion Diary app to your device, simply search for its name in the Apple iTunes Store: [itunes.apple.com/ca/app](https://itunes.apple.com/ca/app) or on Google play for Android devices ([play.google.com/store/apps](https://play.google.com/store/apps))



# GBS/CIDP

## Foundation of Canada

*Serving patients with support, education, and research*

# Calgary Conference

Sep 19, 2015 (8-5pm)

**Place:** Courtyard Calgary Airport by Marriott, 2500 48th Avenue NE,  
Calgary, Alberta T3J 4V8

<b>Confirmed Workshops:</b>	GBS	– Dr. Thomas Feasby
	CIDP	– TBA
	MMN	– Dr. Chris White
	Available Treatments:	– Dr. Chris White
	IGOS Research	– Dr. Tom Feasby
	Ask the Expert	– Attending Presenters
	Lung Health	– Dr. Alex Chee
	The role of a Physiatry	– Dr. Stephanie Plamonden
	More workshops to be confirmed...	

**Registration:** More detail on the day's agenda and registration will become available on [www.gbs-cidp.org/Canada](http://www.gbs-cidp.org/Canada) in July and invitations will be sent out to patients that are on our mailing list. For more information or to be placed on our mailing list, please call (647) 560-6842 or email [info@gbscidpcanada.org](mailto:info@gbscidpcanada.org)

**Cost:** Registered \$45



## My Childhood GBS Story

By Natalie Pallisco, Youth Liaison, Southwestern Ontario

**Tuesday May 18, 2010** When I woke up that sunny morning, I recall feeling as if my legs were very heavy – it was like I had sandbags attached to my calves and every step I took required a lot more energy than usual. When I arrived at school, we started the day with a French test. My cursive was pretty messy and I found it difficult to hold my pencil. I knew that my muscles were still tired from running at the Grade 4 cross-country meet the previous Friday, so I thought nothing more of it. That night, when I went home, I told my grandmother that I was having trouble walking up the flight of stairs in our house, and when I attempted to play songs on the piano, my fingers were unable to push down hard enough for the keys to produce sound. Grandma called my mom at work to tell her what I was experiencing, and Mom said that if my symptoms continued, she would take me to the clinic the following morning.

When Mom woke me up the next morning she asked me how my arms and legs felt. “They feel sort of numb and really heavy” I responded. When I got out of my bed to get dressed, I crashed to the floor, my legs unable to support the weight of my body. Mom helped me get dressed and drove me to one of the hospitals in Windsor, Hotel-Dieu Grace Hospital (now called Windsor Regional Hospital – Ouellette Campus). This was not the hospital that was meant for children, but Mom made the choice to take me there because it had a neurology department, and she hoped that they would be able to diagnose me properly before sending me to the Metropolitan Campus at Windsor Regional Hospital. Her choice was right. Upon arrival at the ER, I was admitted and was seen by a nurse and a doctor. They ordered blood work as well as a CT scan. Then the doctor returned and, after hearing my story, asked me to do a couple of simple actions, such as wiggling my toes and clapping my hands. He informed Mom that, although he was not certain, he believed that I had Guillain-Barré Syndrome and he was basing his diagnosis on the movement of my limbs, as well as knowledge he had previously acquired from working at a hospital in London, Ontario. With that, I was transferred to the Metropolitan Campus, where nurses and a pediatric neurologist were waiting for me.

There were many questions that were rushing through my mind as I learned of my diagnosis. The main question was: “*What is GBS to begin with?*” I did not know what had caused the sickness and I was very confused as to how a healthy and physically active child could contract such a rare syndrome. However, I was able to cope with the confusion by talking to healthcare providers, reading medical books and searching online for more information. Another group of questions that continued to worry me was: “*What now? Where do we go from here? How will this affect my family and our day-to-day lives?*” Luckily, social workers and child life specialists worked with us to answer all of those questions in a calm and compassionate manner. Finally, the worst feeling that I had at the initial stage of diagnosis was: “*Why me?*” It took me roughly a week to get over the initial stage of self-pity where I was constantly wondering what I could have done to possibly deserve such a frightening diagnosis. But, with the help of family, friends and my medical team (physiotherapists, occupation therapists, social workers, child life specialists, pediatric neurologists, family physicians, nurses and resident students), I was able to see the positive side of everything that was happening to me.

Once we arrived at the Metropolitan Campus, Mom told everyone the story of what had happened, as well as what the doctor from the emergency room had said. Then a group of doctors came into the room to talk to Mom. They said that they agreed with the ER doctor, but the only way to be sure that I had Guillain-Barré Syndrome was to perform a lumbar puncture (commonly known as a spinal tap). They prepared me for the procedure and I had it done within a couple of hours.

The procedure ended at dusk and I was taken back to my hospital room. My back was numb and I was very delusional, to the point where I slept for long periods of time and had only a vague idea of what was going on. I also received intravenous immunoglobulin (IVIg) through my arm, which was a very foreign feeling for me. Throughout the night (and over the next couple of weeks), I was woken up every hour by a respirologist so that I could blow into a tube as a form of “exercise” for my lungs



## *My Childhood GBS Story (continued)*

to ensure that the GBS was not spreading to the vital organs. That night was the first of many that I spent in the hospital, waking my mom, dad or grandparent – who slept on the chair next to bed – so that they could move my body into a comfortable position...only to have them change my position a half an hour later.

In addition to the lumbar puncture and the CT scan, I was subject to other tests for statistical purposes and to confirm my diagnosis. I had breathing tests done periodically to make sure that my lung capacity was not changing due to the GBS spreading to the lungs. Two MRI scans were done to see if anything besides the GBS was affecting my spinal cord or brain. I found the MRIs very scary because of the loud, unexpected sounds. Also, the MRIs were long and I became very agitated and a little claustrophobic since the machine does not allow much space around the patient. Lastly, I had two nerve conduction studies done – one two weeks into my stay and another one done six weeks into my stay at the hospital. The nerve conduction studies allowed the doctors to see how I was progressing and to confirm my diagnosis of Guillain-Barré Syndrome.

Over the course of the six weeks that I spent at Windsor Regional Hospital – Metropolitan Campus, I received daily occupational and physical therapy. During physical therapy, we would focus on maintaining my flexibility so that I would not become stiff from lack of movement, as well as exercises to increase the circulation. The physiotherapist also had me wear compression stockings to prevent the development of blood clots in my legs. In addition, occupational therapy helped me focus on my fine-motor skills. I would practice writing (although it was illegible for at least 2 months), using utensils and doing puzzles so that I could rehabilitate the muscles in my fingers responsible for doing simple tasks that seemed so hard with GBS.

When I was not receiving therapy or having tests done, I spent a lot of time sleeping. Even the simplest of things, such as doing a 25-piece puzzle, would drain me and I would have to take a nap. This, in turn, caused for many sleepless nights where I would toss and turn because

I had already been asleep for a large part of the day. When I was not sleeping, I would attempt to colour, draw and make crafts; all activities that were very frustrating to complete because of the long hours that were required. In regards to my education, my fourth grade teacher was most helpful with keeping me up to date with the schoolwork that I was missing. I was e-mailed the worksheets that my parents and friends helped me complete before I would e-mail them back to my teacher. Julia, my twin sister, although in a different class, always brought home notes and books that would assist me with my homework. Lastly, I never felt very lonely because, at night and during the weekend, friends and family members would come visit me and we would talk about anything and everything – the FIFA World Cup 2010 being the usual topic of discussion, since I love sports. All of these activities would make the time at the hospital fly by.

Roughly one month into my stay at the hospital, I was informed that I would be transferred to Holland Bloorview Kids Rehabilitation Hospital in Toronto, Ontario where I would be able to receive more specialized care, given my syndrome and age. Two weeks later, my mother and I said goodbye to our family and friends and were transferred by Patient-Transport Services to Toronto.

I began my treatment as soon as I got to the hospital. At the beginning of each week, a calendar was placed in my room, outlining the times for occupational, physical and aquatic therapy. When I was not in therapy, programs were constantly being run to keep the children and teenagers active. I participated in basketball, obstacle courses, swimming, lawn bowling, biking and tennis, with all of the activities being modified to suit my needs. There were also Activities of Daily Living (ADL) that allowed the patients to work with their disabilities to cook, bake, create jewelry, read and play video games. It was at Holland Bloorview that I saw tremendous improvement with my GBS. I was constantly pushed in my physical, occupational and aquatic therapy to do my very best and to not get discouraged.

During my stay, I received several visits from my friends and family. My dad, my oldest sister, Daniella, and Julia

## *My Childhood GBS Story (continued)*

would come up and I was allowed to leave the hospital so that we could spend family time together in Toronto. We went shopping at the Eaton Center and spent time outside in various parks. The bonding was amazing and bridged the gap between Toronto and Windsor. Seeing my family made me work even harder because it motivated me to be able to reach a point where I could be discharged from Holland Bloorview and return home.

My kryptonite throughout my time in public with either a wheelchair or a walker was the stares that I got when I was in public. I knew that I was a ten-year-old kid who didn't have any visible injuries, but they made me feel very self-conscious and different. Looking back, I understand that people were most likely just curious, but at the time, it bothered me terribly and pushed me even harder to get better.

By the end of August, I graduated from my wheelchair to using a walker. I was able to print my name without difficulties and use utensils by myself. These improvements meant that I would soon be discharged. In my last week at the hospital, I saw a Blue Jays vs. Yankees baseball game with the other teenagers at the hospital and was able to bond with them even more. Of my four months in the hospital, that baseball game was my best memory. We were all clapping and singing together, and it was at that time that I had my "epiphany", as I call it. I discovered that I was looking at the big picture in the wrong way. I spent a lot of time being frustrated about what had happened but now I would not change anything about my experience with Guillain-Barré Syndrome. I used my experience as a way to be grateful for everything that I had in my life – my family, my friends, my health and a great team of healthcare professionals who were dedicated to helping me rehabilitate. It was also at this time that I realized that I really wanted to pursue a career as a medical doctor so that I could help other people in the same predicament that I was in.

I was discharged one week after the baseball game and was able to return to Windsor in time to start Grade 5 with my classmates. Although drawing a lot of attention with my walker, I was just so happy to be able to be

with my friends. I also continued my rehabilitation as an outpatient at the John McGivney Children's Center, where I received physical and occupational therapy until late December of that year. It was at the Center that I was able to fine-tune my printing and cursive skills, as well as walking without a walker. Towards the end of November, everything was coming together well and I was able to participate more actively in Phys. Ed. I also resumed my ballet classes and swimming lessons. It required extra work to be able to keep up with the other students, but by then, I loved challenges that forced me to give 110% of my effort.

As I approach my five-year anniversary of being diagnosed with Guillain-Barré Syndrome, I realize that my life took a turn for the better, and not for the worse like I had originally thought. I still dance ballet and pointe, performing in recitals every year. I am also in the process of becoming a lifeguard, having already taken all of my first aid certifications through the Lifesaving Society. At school, I play badminton and am enjoying all of my courses, especially my math and science courses. Besides my academic pursuits, I also have begun volunteering at Hotel-Dieu Grace Healthcare, where I can help patients, just as I received help by volunteers when I was in the hospital. I have also become a volunteer with GBS/CIDP Foundation of Canada in order to socialize with and support others who have been diagnosed with GBS and CIDP. Since 2010, nothing has changed regarding my ambitions to become a doctor, although I am now considering becoming a pediatric neurologist or a pediatric neuromuscular specialist. I look forward to pursuing a career that will allow me to help children who are experiencing various types of neurological and muscular difficulties. Allowing me to help others just like those many compassionate individuals within the healthcare system that helped me when I was a child.

Go 'Green'

If you would like future newsletters digitally, send an email to [info@gbscidpcanada.org](mailto:info@gbscidpcanada.org)

## Support Group Meetings

### **Toronto, Ontario, Sunday Oct 4, 2015, 1:30–3:30pm, Northern District Library, 40 Orchard View Blvd, M4R 1B9**

A Toronto support group meeting will bring together Toronto, and area, patients and their families. Information will also be available via the [gbs-cidp.org/Canada](http://gbs-cidp.org/Canada) page and on our Facebook page 'GBS/CIDP Foundation of Canada'. Please connect with your Toronto Liaison, Jane Field, by email: [janeandhilary@gmail.com](mailto:janeandhilary@gmail.com) or call the foundation at 1-647-560-6842 to receive all future communications for this meeting. Street parking and limited library pay parking available. We hope to see you there!



The foundation with Dystrophie Musculaire Canada, will be reaching out to Ottawa/Gatineau area patients and families, and are pleased to announce the following support meetings.

### **Gatineau, Quebec Saturday Oct 17, 2015 12:30 – 4:00pm, Sheraton Four Points (34 rue Laurier, Gatineau)**

Come out and meet other patients and families that have been affected by neuromuscular disorders! This Educational Day will include the following lectures:

- Neuromuscular Disorders – Dr. François Jacques
- Finances
- Respiratory Care
- Services

**Registration is limited so register early! Contact MD by email: [Pascale.rousseau@muscle.ca](mailto:Pascale.rousseau@muscle.ca) or call: 1-800-567-2236 #3102**

*\*French presentations – translation not available*

### **Ottawa, Ontario Sunday Nov 8, 2015, Time and Location TBA**

Ottawa neuromuscular specialist, Dr. Pierre Bourque, has committed to present at this support group meeting. The GBS/CIDP Foundation of Canada and Dystrophie Musculaire Canada will review services provided to patients. We will be providing details on the location and agenda in the coming months via [gbs-cidp.org/Canada](http://gbs-cidp.org/Canada) and Facebook.

**Please let us know by email if you are interested in attending: [info@gbscidpcanada.org](mailto:info@gbscidpcanada.org) or call: 1-647-560-6842 so that you receive all future communications.**

*\* English presentation – translation not available*

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Another way to keep informed and make connections.**

### Moving?

Please do not forget to notify the foundation of any address changes you may have to ensure that you receive ongoing communications. Please contact by email [info@gbscidpcanada.org](mailto:info@gbscidpcanada.org) or by calling 1(647) 560-6842

### *Foundation Pays Tribute to Barbara Sherman as She Retires from the Board of Directors*

The foundation says 'Farewell' to long-standing Director, Barbara Sherman, at the National Conference Meet and Greet. Friend and Director, Wilma Koopman, and



Dr. Angelika Hahn, paid tribute to Barbara, for her unwavering dedication to the foundation, patients, and their families. We will miss Barb's passion for the wellness of the foundation. Barb will enjoy more time with her husband Darwin, children, grandchildren, and great-grandchild and will continue in a support role in Southwestern Ontario. We'll miss you!



### *'Welcome' New Liaisons*

The foundation would like to thank our new liaisons for their commitment to the foundation, patients, and their families. These new volunteers are listed below by region. Each volunteer would love to connect with patients in their regions. Please reach out to them or contact the foundation for us to make the connection!

#### Ontario

Judy and Ken Hopkins, Stouffville

[kjhop2it@rogers.com](mailto:kjhop2it@rogers.com)

Rohit Jaiswal, Oakville

Natalie Pallisco, Youth Liaison, Southwestern Ontario

[npallisco@outlook.com](mailto:npallisco@outlook.com)

Janine Richards, Thunder Bay

Jane Field, Toronto

[janeandhiliary@gmail.com](mailto:janeandhiliary@gmail.com)

#### Alberta

Alex Chee, Calgary

[Alex.chee@gbscidpcanada.org](mailto:Alex.chee@gbscidpcanada.org)

Kim Lange, Calgary

#### British Columbia

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### 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.