

GBS/CIDP Foundation of Canada

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

News & Views

Issue: 14

Spring/Summer

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A Message from Donna Hartlen, Executive Director



Spring has finally arrived! It has been one of the toughest winters Canadians have experienced and those of us that have residuals or CIDP, we can now take time to relax, get vitamin D, and be able to get around outside without the worry of slipping and sliding on snow and ice.

As anticipated, 2014 is turning out to be a very busy year and it has been exciting so far. Thanks to the dedication of board members, doctors on our Medical Advisory Board, and volunteers, we have had a successful first part of the year.

Congratulations to Sherry Nejedly, Vice President, Director, and BC Liaison, for her efforts in having a successful regional conference in Richmond, BC on May 3. I would like to Dr. Kristine Chapman and Dr. Gillian Gibson for their efforts informing their patients of the conference. It is through their support that we had many new patients attend and be able to see their doctors present.

It was a busy and informative day! The first segment of the day was the presentation on GBS. Dr. Kristine Chapman was disappointed when a scheduling conflict arose and she could not present. With thanks to Dr. Chapman, she immediately found Dr. Michelle Mezei to give her presentation and she did a wonderful job and was also able to stay and attend the 'Ask the Expert' segment to help answer patient questions. Dr. Mezei also brought along Dr. Gaadeer Almomem, a neurology student from the university, in hopes that our upcoming young doctors get a better understanding of the patient community. Dr. Mezei, it was fantastic to meet you and many thanks for taking the time to support the foundation and its patients.

Dr. Gillian Gibson gave us an informative presentation on CIDP. Patients gained a better understanding of the dynamics of the disorder and the treatment options that doctors have available to control its progression. It was wonderful to see Dr. Gibson connect with her patients at every opportunity. Her dedication to her patients was obvious by the crowd that would surround her waiting for their chance to connect. The foundation and patients appreciate her continued dedication and thank her for supporting the conference.

Attendees then were able to get a glimpse into the research happening by brilliant international doctors surrounding GBS. Through research funding, the GBS/CIDP Foundation of Canada is excited to support the International GBS Outcome Study (IGOS). Dr. Tom Feasby, who is the coordinator of Canadian clinics involved in the study, gave an

A Message from Donna Hartlen, Executive Director (continued)

excellent presentation. It is the hope through the collection of blood and spinal cord fluid of early onset GBS patients, and the treatments that patients received, that markers be found that indicate how a patient is treated for GBS that will bring a better recovery outcome for the patient. The study aims to have 1000 patients entered into the research around the world and we are well on the way to meeting that goal as the world now has over 500 patients entered into IGOS with Canada having 12 participants as of May 3. Thank you Dr. Feasby for enlightening us on this very important GBS research. Your willingness to answer questions, great sense of humour, and stories from years of experience in GBS, gave us a very engaging presentation.

We were delighted to have Tracy Ross, a physiotherapist from G.F Strong, do a presentation on physiotherapy during the recovery of GBS and ongoing struggles with strength and mobility for those with CIDP. Attendees left the conference with a better understanding of the importance of continued exercise with each of the disorders and felt comfortable enough, with each other and Tracy, to even get on stage to show others the differences in AFOs. Thank you Tracy for your continued dedication and support.

The day ended with a touching story of a Mother with a child diagnosed with GBS. Christine Rego and son Van gave attendees a personal description of the fears surrounding the diagnosis of a child. Van has had a wonderful recovery from GBS and described residual tingles in his toes like "bugs in his feet". Thank you Christine and Van for sharing your experience with GBS.

Thank you to attendees that took the time to fill out the evaluation form as feedback allows us to make improvements to upcoming conferences such as the National Conference May 2015. Our hope is that the conference has armed our patients and caregivers with

information to support recovery and that you were able to make connections of support with other patients and caregivers. Many thanks to all doctors, presenters, directors, and liaisons for supporting Sherry's hard work in bringing such an important and successful conference to the region. I also cannot forget our sponsors, Grifols Canada and CSL Canada, thank you for your continued support and attending the western conference to connect with our patient group. We would not be able to provide such events without you.

A team met in Montreal March of 2014 to plan the building of awareness in Quebec. The foundation now has volunteer liaisons in the region that are there in support of patients. Thank you Muscular Dystrophy Quebec for the distribution of our literature to enquiring patients and the willingness to share information about our foundation. Through joint efforts over the coming year we hope the foundation will gain more visibility within Quebec.

Our liaisons continue to be an integral part of supporting our patient community. This winter saw an increased amount of new patients, GBS, CIDP, and variants, in the BC and Saskatchewan regions. Thank you to our western liaisons for taking on the extra effort of supporting these new patients and all other liaisons willing to donate their time in supporting patients across the country. Liaisons are the first point of contact for patients. Therefore, we continue to look for more volunteers to support all Canadians, coast to coast, and our northern regions. If you would like to volunteer for the foundation and become a liaison or support the foundation in other ways, please contact Gail Kammer, President and Regional Director, via email at gail.kammer@gbscidpcanada.org to help with any questions or more information about volunteering.

For more information on upcoming support group meetings and events, please visit gbs-cidp.org/canada.

Wishing everyone continued health and wellness for the rest of 2014.

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

On-label vs. Off-label Use of a Prescription Drug

By Dr. Steven Roblin, Ph.D. Grifols Canada



In Canada, the responsibility for health care is spread across different groups. The approval of drugs is regulated by Health Canada, the delivery of medical care is primarily paid for by the provincial and territorial Ministries of Health, while guidance of medical practice is the responsibility of a number of physician boards and associations (including the Canadian Medical Association).

Before a drug can be sold in Canada it must be approved to treat at least one specific illness. To become approved, the manufacturer of the drug must demonstrate to Health Canada that there is sufficient scientific evidence showing the drug is safe and effective for the proposed use in a specific type of patient. This is generally done through a series of robust clinical studies. Once a prescription drug is approved for sale by Health Canada it can be sold by the manufacturer to any licensed pharmacist or physician for distribution to patients, but may only be marketed to treat the *specific* illness, in the *specific* population of patients, and at the *specific* dose for which it was approved (i.e. “on-label use” – use as described in the product *labeling* approved by Health Canada).

However, as noted above, the practice of medicine is not regulated by Health Canada. As such, once a drug is available on the market any individual physician is free to prescribe that drug for any other use, in any patient and at any dose, where they feel the potential medical benefits outweigh the potential harm to their patient. If that use is outside of what is described in the labeling approved by Health Canada, this is called “off-label” use.

So, why would a doctor use a drug off-label? When a new drug is first marketed, the majority of physicians will likely only use the drug as approved by Health Canada (on-label), since there is generally no other data to suggest using it in any other manner. However, over time, top specialists, experts and researchers may begin to understand more about how a particular drug works in their patients, and they will also gain experience and confidence in predicting the specific types of patients who will respond best to the new drug. Based on this knowledge, physicians may decide to try using the drug in new ways. This may involve using it to treat different illnesses, different types of patients, or at different doses than those originally approved by Health Canada.

If the drug appears to work under these new conditions, physicians will frequently share these experiences with their colleagues at conferences or through the publication of academic papers. As you can imagine, this leads to other physicians trying the drug in their patients and so on and so forth. Eventually, this kind of use can become common-place. In some cases, these new uses or conditions of use can even become recommended in published treatment guidelines to become what is known as the “standard of care”. All this can happen without the drug ever becoming formally approved for that new use by Health Canada. This kind of situation often arises with rare diseases where large studies may not be feasible, and/or in serious illnesses with few treatment options, where doctors will often try any drug with a chance of working, whether or not it is approved for the condition.

On-label vs. Off-label Use of a Prescription Drug (continued)

Sometimes, once sufficient evidence is available, a drug manufacturer may submit the data to Health Canada to try and have the new illness, patient population, or dose added to the approved product labeling so that the “off-label” use becomes approved (i.e. “on-label”). It is only at this point that the manufacturer may begin to promote the new use for their drug to pharmacists and physicians.

*****Announcement*****

Dr. Vera Bril and Dr. Hans Katzberg of The Prosserman Family Neuromuscular Clinic, at the University Health Network, Toronto General Hospital EMG Lab, welcome Dr. Ari Breiner to their team as Assistant Professor of Medicine (Neurology) effective July 1, 2014.

Dr. Ari Breiner completed his medical studies at McGill University in 2005. He was inspired to pursue a career in Neurology based on an encounter with a patient suffering from CIDP during his clerkship rotations. He did his Neurology residency at McGill University and the University of Toronto. Following residency and certification by the Royal College of Physicians of Canada, Dr. Breiner pursued fellowships in electromyography and Neuromuscular Medicine at Columbia University in New York, and at the University of Toronto. He is nearing completion of a Master's degree in Clinical Epidemiology, also at the University of Toronto. He is particularly interested in caring for patients with neuromuscular disorders, especially polyneuropathy. His research interests include outcome measures and diagnostic criteria in CIDP, as well as imaging of the peripheral nervous system in polyneuropathy.



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



Teaming Up to Fight a Rare Disorder – GBS/CIDP

By Amanda Tadgell



“Life is too short,” says my father now living with GBS and CIDP. Formerly an avid fisherman and hunter, my father’s life has slowed down significantly since being diagnosed this past winter. Despite his poor health, he still maintains his roles as a loving husband, father and grandfather; he is the strongest man I know.

This whole experience has been a roller coaster of emotions that came out of nowhere. My family spent part of last Christmas in the Muskokas in Northern Ontario where my dad was snowmobiling in –30 degree weather and everything was fine – he only complained of cold feet. Two months later, he and my mother started venturing in and out of the hospital trying to figure out what was wrong with him.

He could barely walk or talk and looked 10 years older. It was then when we became aware of GBS and CIDP, and the lifelong battle that he would now endure.

I am his little girl. He was always the one taking care of me and now it is my time to do what I can for him. As part of my Business Marketing program at Fanshawe College, we were given the opportunity to run our own event. My group members, Alexandra Willsher, Jocelyn Gates and Michelle Blumentrath, all shared my passion for helping my family through this new wrinkle in our lives. We all wanted to raise awareness of this rare disorder and raise money for the GBS/CIDP Foundation of Canada. We held a paintball tournament in London, Ontario at Flagswipe Paintball called “Teaming Up To Fight a Rare Disorder– GBS/CIDP”. We had teams come out to help support the cause by playing rounds of paintball. Many others attended the event to watch and bid on the silent auction items – it was a lot of fun. With the support of our friends, family and Flagswipe Paintball we were able to raise \$2053.15 for the foundation.



It astonishes me how many people are completely unaware of this rare disorder. For many friends and family members, it was confusing describing to them what was actually happening to my dad. The foundation was very helpful and resourceful. Along with sending information booklets for the guests of our event, the foundation and its committee members have also been there for my mother. They have provided her with the support that no one else could give her during this tough and confusing time. I cannot thank the foundation enough for being so supportive, which is why I want to help raise money for this cause for the rest of my life.

Teaming Up to Fight a Rare Disorder – GBS/CIDP (continued)

We are thankful for all the support from family, friends and the foundation as my dad continues to get through this difficult time in his life. He has his good days and his bad days, but his strength and positivity will get him back in the boat, into the marsh and there to see his granddaughter's first steps.

Ottawa Celebrates It's 10th Annual AccessAbility Day

By Linda Paul, Ottawa Liaison

On December 3, 2013, Ottawa celebrated its 10th Annual AccessAbility Day, in conjunction with National Housing Day and the UN International Day of Persons with Disabilities. As a member of the Accessibility Advisory Committee for City Council, I was a part of the planning committee for this event.

AccessAbility Day was emceed by Jody Mitic. He was the runner up of Amazing Race Canada. Jody Mitic is a veteran of the mission in Afghanistan, has renovated his own house to make it accessible, and is now designing and building a new accessible home for his family.

The day opened with a declaration by the Mayor, Jim Watson. This was followed by a panel discussion by various experts in the field of accessible housing. After a networking lunch, participants had a choice of four



workshops; Community Consultation on City of Ottawa Accessibility Design Standards; Accessibility for Ontarians with Disabilities (AODA) Integrated Accessibility Design Standards; Information Session on Falls Prevention and the Ontario Renovates Program; and Canada Mortgage and Housing Corporation (CMHC) Resources for Accessible Housing by Design and FlexHousing Concept.

Fourteen resource tables were set up in the lobby. These tables had information on city services, various organizations, and upcoming events. The MS Society kindly shared their table with me, and I was able to provide information on GBS and CIDP. I provided information on a Disabled Exercise and Weight Room Program in the city to a GBS patient whom I had invited to the event, provided the

Overview and Caregivers brochures to someone with a recently diagnosed GBS family member, and provided information on physiotherapy and our Foundation to a physiotherapist with a CIDP client.

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 at donna.hartlen@gbscidpcanada.org or by calling 1(647) 560-6842

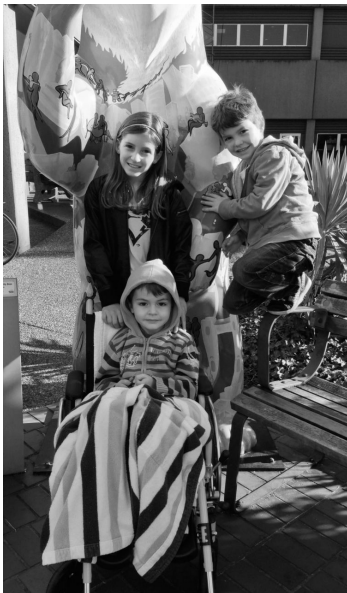
A Mother's story of a Child with GBS

By Christine Rego

On October 7th, 2013 my 4-year old son Van could not stand on his feet because they hurt so much. After being sick with a cold for almost three weeks I figured he was just physically and emotionally drained.

The second day he didn't want to stand and I decided to take him to Children's Hospital in Vancouver. After running a battery of tests and coming up with no answers as to what was wrong, the ER doctor called in neurology. Within an hour we had a possible diagnosis of Guillian-Barre Syndrome, something I had never heard of.

The doctors told me that they wouldn't know for sure if he had GBS for about another 17 hours and that it had to settle into his body more. The next day they gave our little guy a lumbar puncture and MRI. The test results were back in two hours and showed that he did in fact have too much protein in his spinal fluid. That evening the nurses started his first of two IVIG treatments.



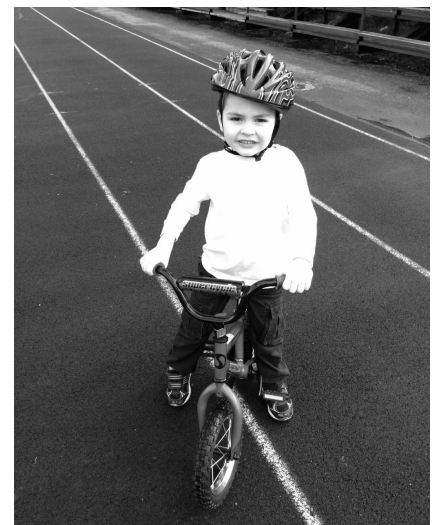
A day after his two treatments he was able to stand for about 5 seconds at the side of his bed. The following day he took a couple steps with the tiniest walker you've ever seen. Every day he took a few more steps with the help of the awesome physiotherapists. We were very lucky that he was diagnosed so early into his illness. His legs were paralyzed but the rest of his body was only slightly affected. Constipation was an issue and doctors closely monitored his respiratory system by having him blow into a chamber a couple of times a day.

While in the hospital our son flew into fits of rage that we had never seen in his behaviour before. The psychologist told us to let him express his anger and frustration. We made up a song that REALLY helped – "I'm getting stronger, stronger, every day...I'm getting stronger, stronger, every day". I explained to my sad, confused little boy that right now his legs were very weak and tired but not broken. I told him that he needed to work on his muscles every day to make them stronger.

Van hated being in the hospital but I explained to him that we needed the doctors and nurses right now to help him get better and that mommy couldn't do it on her own. I drew a picture on the whiteboard in his room of what his body had done to itself...he got it! The last night he spent in the hospital was fun, his big brother came for a sleepover and we got a pass to go to the Lego Store. In total, our brave little guy was in the hospital for 10 days. We went for wheelchair walks a few times a day and had lots of visitors pop by for short visits.

When we got home we had amazing support given to us by Reach Child and Youth Development Society in Delta, B.C. Twice a week for 4 months Van was visited at home or at the local pool by an incredible physiotherapist. A couple of visits by a wonderful occupational therapist were made to his preschool to.

It has been almost 6 months since Van's ordeal started and he's doing great, almost 100%. In February he had a huge milestone, he learned to ride his bike on two wheels! As his mother I can tell he's still a little weak but "getting stronger every day".



Western Conference 2014

Richmond, BC

Thank you to all of the doctors, presenters, liaisons, and attendees for helping make our regional conference a success. Thank you to the sponsors Grifols Canada and CSL Behring Canada, as we would not be able to plan regional conferences without your support.

Although we all know what our onset is like, I do hope we all learned something new that helps with our future. Also I hope you met new friends that you can keep in touch with and help to support each other. I am looking forward to hearing from you all in the future.

Sherry Nejedly, Vice President, Director, BC Liaison



Dr. Gillian Gibson



Ask the Expert Panel: Tracy Ross, Dr. Gillian Gibson, Dr. Tom Feasby, and Dr. Gaadeer Almomem



Sherry Nejedly and Donna Hartlen

Western Conference 2014

Richmond, BC



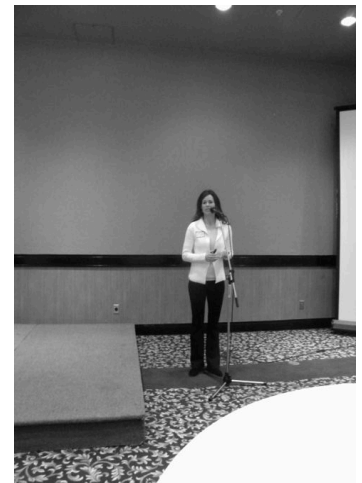
Sherry Nejedly



Christine Rego and son Van



Dr. Gaadeer Almomem and Dr. Michelle Mezei



Tracy Ross



Friday Night Meet and Greet



Sherry Nejedly and Donna Hartlen



**I AM SAVING
LIVES EVEN
IF I CAN'T
DONATE.**

**BECAUSE I AM
DONATING FOR
HIM.**

BE AN ALLY. DONATE BLOOD. SAVE A LIFE.

**ALLY BLOOD DONOR CLINIC
67 College St., Toronto
Friday June 27, 2014
11:00 a.m. to 5:00 p.m.**

Many people who are not able to donate seek meaningful ways to be involved with Canada's blood system. If you or your loved one is not able to donate, there is an option. With support from members of the LGBTTQ community and patient groups, Canadian Blood Services is holding an Ally Blood Donor Clinic where you can ask someone to donate on your behalf.



**Book your appointment:
www.blood.ca
1-888-236-6283**



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1 888 2 DONATE

BE AN ALLY. DONATE BLOOD. SAVE A LIFE.

BASIC REQUIREMENTS FOR BLOOD DONATION

IDENTIFICATION Identification with full name and signature, or full name and photograph required.

AGE Between 17th and 71st birthday (regular donor), or between 17th and 61st birthday (first-time donor). To continue donating after their 71st birthday (regular donor) or after 61st birthday (first-time donor) donors should contact Canadian Blood Services prior to donation for further eligibility information.

WEIGHT At least 50 kg (110 lbs). Between 17th and 23rd birthday (first-time donor), visit www.blood.ca or call for additional criteria.

FREQUENCY OF DONATION Minimum interval between blood donations is 56 days.

HEALTH In general good health and feeling well. You should have had something to eat and adequate sleep. You must also meet hemoglobin (iron) requirements (test done at clinic).

SCREENING At the time of donation, you will be asked a number of questions to determine your eligibility.

MALE DONORS In the last five years, if you have had sex with a man, even once, please ask someone to donate on your behalf.

If You Have...	You must wait before donating...
Had dental treatment (extractions, fillings, cleaning, restoration)	For cleaning or filling: until the day after treatment For extraction, root canal or dental surgery: 72 hours provided there is full recovery
A cold, flu or sore throat	Full recovery
Had ear or body piercing or tattooing	6 months

DONATING BLOOD – A SAFE PROCEDURE

Donating blood does not put you at risk of disease. All needles are sterile, used only once and discarded. The usual blood collection – a “unit” – is about half a litre, or one pint. Your body soon replaces all the blood you donate.

The above eligibility requirements were accurate at the time of printing. Eligibility requirements are subject to change. For complete eligibility requirements, please contact Canadian Blood Services by calling 1 888 2 DONATE (1-888-236-6283).



Canadian Blood Services
it's in you to give

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A Story of 6 Sisters

By Betty

Six Catholic girls born into a family of 9, raised in Nova Scotia. All but two of the girls remained in the Maritimes. Mary Catherine, aka Kay: adventurous and independent, ventured off to Toronto to embrace city life. There, she lived in a high-rise apartment, worked for banks and investment firms, traveled by subway, and enjoyed the diversity and opportunity living in a large city could offer. Our sister Kay made annual visits to NS for weddings, funerals, graduations, baby showers, or summer visits. Seldom did we venture to Toronto.

September 16, 2014 all that changed.

A mysterious, sudden and serious case of GBS had turned her world upside down and ours too. A call from her good friend Edna, who had provided care in the previous days, informed us she had been admitted to Toronto East General Hospital. Needing family consent for treatment, our oldest sister Ann flew to be with her. Little did we know how scary the months ahead would prove to be. Daily communications with all family members was crucial, and we promised to keep it off social media sites, using email instead.

With Ann at her side, Kay's condition continued to worsen. Within days she was placed in the ICU, trached, ventilated and helpless. Collectively we read articles on GBS, cried and prayed for God to help her through this. As the days turned into weeks without any improvement it was obvious Kay would need one of us there continuously. It was as much for us as it was for her. We soon developed a plan for a rotation of 'sister visits'. Some of us, still working, had to secure time off. Others were able to go for longer periods.

During the most critical stage we overlapped visits. Kim arrived from Alberta, later Betty then Dorothy from Nova Scotia.

Kay remained totally paralyzed and ventilated in ICU for 3 long months. We anxiously watched and talked to staff while they cared for her. Our eyes were glued to the monitors as her blood pressure and heart rate fluctuated for months. Numerous infections and a heart attack complicated any progress. The TEGH staff did their very best to keep Kay alive and comfortable, for which we are grateful. They too, had to endure 5 different sisters, with various personalities, viewing and questioning every procedure, sometimes even disagreeing on the plan of care. Some staff, neurology, respiratory and physio, who had GBS experience, were wonderful in caring for her and us. Others required constant reminders of her needs.

Coping with Kay's illness was difficult. But being so far from our home and adapting to the city life she had embraced for years was yet another challenge. We were ill prepared to travel unfamiliar locations using public transit, often in the dark. The extreme winter weather added more difficulty. Coming home to her empty apartment exhausted and emotionally drained often involved crying with each other via Skype.

Our saviors were Kay's good friends and neighbors. They provided drives, meals, advice, and much needed comfort in a big unfamiliar city. These were folks we heard stories of for more than 20 years, but had never met. Suddenly we became deeply connected in our effort to see Kay through this. One friend in particular, Wendy secured our contact with the GBS Foundation.

Without seeing any improvement in Kay for months, we challenged the staff to consider another IVIG

A Story of 6 Sisters (continued)

treatment. Shortly after the second treatment we saw what we considered a miracle. Kay had very slight movement in both arms. Everyone in ICU celebrated the good news.

Throughout November and December Kay continued to show signs of healing. She gained more upper body movement and some ability to breathe. Kay had a visit from two women from the GBS Foundation who offered support and encouragement. The best Christmas gift we received was a video sent by Eunice of Kay's visit to the hospital lobby to see the Christmas tree. There she was sitting up in the wheelchair with the trachea tube closed off! It was only then we began to believe the GBS was finally leaving her body. Eunice spent 5 weeks with Kay over the holiday season, away from her husband, coping with terrible weather and a bad cold. We are grateful for her commitment.

Early in the New Year Kay transferred to the respiratory unit to be weaned from the ventilator and various other apparatus attached to her body. Betty had the pleasure of being with her while the catheter, pic line, trach, and feeding tubes were removed, all in one week! She was thrilled to be eating real food and having her voice again. Soon afterward Kay asked to visit the ICU to thank the staff that took such good care of her. Although it was an emotional visit, the staff was overjoyed to see the new Kay.

Plans then began to secure a suitable rehabilitation facility, hopefully one with other GBS folks. Leaving TEGH was both exciting and frightening for all of us. We were familiar with the staff, location, and they knew our sister Kay so well. But starting over someplace else meant her physical rehabilitation could begin. We all wanted that badly. Word of the move came to us on a week when none of us were with her. She transferred to Baycrest Hospital with the support of a devoted neighbor and friend Terry. Only after Ann arrived did we realize it was primarily a geriatric centre with little or no GBS experience. A quick call to Donna Hartlen of the GBS Foundation, assured us that Kay was in good hands. After some initial bumps, it has turned out to be a perfect location with good physio/occupation therapies. While there Kay has resumed more control of decisions and choices in her own care and rehabilitation planning. We are relieved and happy for her. Kay now owns an iPad Air; a family Valentine Day gift. With this tool she skypes us daily, emails friends, reads the paper, listens to radio, watches movies, reads books, etc. Having time on her hands has allowed her to maximize its use to stay connected with the world beyond Baycrest.

Kay is an inspiration to us in her determination to regain mobility, starting with the most basic things as using a fork or pulling on her shirt. At times it is overwhelming and she needs to let the tears run. Being with her then is important not because we can say anything to help, but just to hold her hand to get through that moment.

*****Going Green*****

We would like to do our part for the environment and reduce paper usage. Let us know if you want to receive future newsletters and other information by email. Please send you e-mail address to donna.hartlen@gbscidpcanada.org for updating.

A Story of 6 Sisters (continued)

We sisters are on our third rotation of 'sister visits' and appreciate everything that's been done for Kay; from us and the medical system. We will continue to support her as much as needed until she regains her former life. As a family we are now closer than ever. Our one and only living brother Bob in Florida, has been in constant communication, providing a sounding board and gentle advice. Each of us has brought their own perspective and attributes to the situation; all of these helpful at different times. We did truly rely on each other's strengths and are forever grateful for having each other.

In reflecting on what we've been through we have some advice for caregivers in similar situations:

- Establish Power of Attorney for medical and financial needs. Frequent communication was needed with Kay's physicians, employer, bank, insurance company, etc. All required proper documentation along with photo identification before allowing us to act on her behalf.
- Please talk to and reassure your family member. Let them know you are there even when they appear unaware. Our Kay has few clear memories of her early weeks in ICU, but she remembers us speaking to her and letting her know we were taking care of her.
- Appreciate the fact you won't always agree with medical staff decisions. Don't be afraid to question it, but accept that some decisions are made for the right reason even if you don't fully understand.
- Let the little things go. Not all staff performed procedures the same way. Nurses had different dispositions, as did we. In the end every one of them aided Kay's recovery in some way.
- Accept the support offered by friends and neighbours. It is important for them to do something constructive to show their love and concern for us and for Kay.
- Be an advocate for your family member, but do it elsewhere. Assume they can hear every conversation you have in the room. If you are questioning procedures, step out of the room and/or ask to speak to the nurse manager. Our best results came from putting our concerns in writing and having the right email addresses.
- Remember the recovery of your family member is not only physical, but also emotional and spiritual. It takes endurance unlike anything before in their life. Some days you have to share that load to help them get through to the next day. Prayer may not be a part of your daily life, but it will bring comfort.

Proud siblings of Kay,
Ann, Eunice, Dorothy, Betty, Bob, Kim

*****Announcement – Facebook Page delayed til July 2014****

We do apologize for the delay in the creation of the Facebook page. This project will resume shortly and we hope you will join the page for news and support throughout the year. Please watch the website for the launch of the 'GBS/CIDP Foundation of Canada' page coming this July.

Edmonton Support Group Meetings

Patients and their families will continue to have the opportunity to attend the quarterly support group meetings throughout 2014. For more information on attending and location, please contact Holly Gerlach, your Edmonton Liaison, holly.gerlach@hotmail.com. All meetings are scheduled for 1–3pm.

Meeting dates for the upcoming Edmonton 2014 year: Sat, September 13th and Sat, November 8th

Nova Scotia Support Group Meeting – May 2014

The fourth bi-annual support group meeting for Nova Scotia area was held in May 2014. This meeting had a great turnout of 19 patients and family members that were able to meet and give support to each other. The next meeting is to be held the weekend of August 16–17 this year. Donna Hartlen will be in town for this meeting and looks forward to meeting patients in the area. Watch for details on location under 'Events' on the website or contact deb.bernasky@gbscidpcanada.org.

Quebec Support Group Meetings

It is always comforting to know that others are going through the same physical and emotional challenges that come with each of our disorders. Support group meetings are a wonderful way for patients and caregivers to support each other. Quebec now has dedicated liaison volunteers that have had their own personal experiences with the disorders and are available to support new and past patients of GBS and CIDP in the province. Our volunteers are listed below and would love to hear from you if you are interested in attending a support group meeting.

GBS

Beryl Bergeron
alain0848@hotmail.com

CIDP

Charles LeClerc
leclercc@gmail.com

CIDP

Peter Levick
Peter.levick@videotron.ca

Upcoming Support Group Meetings – Fall 2014

A support group meeting is an important avenue to gain information and to make connections with other patients that suffer with the same illness. There are several liaisons that would like to plan support group meetings in other areas of the country in the fall timeline. If you are an interested patient or caregiver and would like to attend a meeting within your province/area, please communicate your interest to your area liaison below.

Saskatchewan

Gail Kammer
gail.kammer@gbscidpcanada.org

Manitoba

Denis Dupuis
denis.dupuis@gbacidpcanada.org

Toronto, ON

Donna Hartlen
donna.hartlen@gbscidpcanada.org

Calgary, AB

Alex Chee
alex.chee@gbscidpcanada.org

Support Charles Leclerc, Quebec Liaison - Zombie Walk October 25, 2014

Many people have heard of 'The Zombie Walk' in the media at some time. This annual walk allows teams to raise money for their charities and is building popularity every year. Zombies participate in cities all over the world.



Charles Leclerc, a Quebec liaison that has CIDP, is hard at work putting together teams of 4 to build awareness and fundraise for the GBS/CIDP Foundation of Canada in the next Zombie Walk. There are three locations in Quebec holding the walk. He also plans to build a social media site that will explain how to get involved and to pledge for his team. Once this is up and running, we will be posting the link on gbs-cidp.org/Canada. In the meantime, if you would like to learn more about how to get involved with the walk in Quebec, please email Charles via leclercc@gmail.com. If you would like to get a team together in your city to fundraise for the foundation and would like to discuss more details, please contact Donna Hartlen via donna.hartlen@gbscidpcanada.org or call the foundation at 1(647) 560-6842.

Montreal Zombie walk

<http://montrealzombiewalk.com/fr/>

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 conditions.

