GBS/CIDP Foundation of Canada

Guillain-Barré Syndrome / Chronic Inflammatory Demyelinating Polyneuropathy

Support, Education, and Research

News & Views

Issue: 13 *Fall/Winter 2013*

A Personal Message from Susan Keast, Past Executive Director

This is an exciting News & Views. We, as a Foundation, are moving forward and hopefully we can make your lives better. Our aim is about our Mission, it is always "patient first" and to support all our patients and families. To educate – hospitals, the medical community as well as the general public. Research – there is much going on in this area, and you can read more about this in our Newsletter.

In moving forward, we have a new Executive Director, Donna Hartlen, who will be introducing herself in this Newsletter. She is wonderful and each of you is so lucky to have her. She is also a patient of GBS and now CIDP and so no one has a more in depth feeling and compassion for our patients, and no one wants to see more fairness for each in our medical community, than Donna. I know you will all give her the help and support that you have shown to me over the years as we all move forward in keeping this Foundation strong and there for each of you for the many years ahead.

I will be around for a while until all areas of the Foundation are carefully in place. While my time has come to move on, I will always be available for any kind of help that is needed to make this Foundation, under Donna's care, the best that it can be for each of you. Each of you has been an important part of this GBS/CIDP Family. I pass all this on to Donna with great confidence, not only as a GBS/CIDP Family member, but also as your link to a great future.

A Message from Donna Hartlen, Executive Director

Let me introduce myself as a wife, mother of two school-age girls, a patient of both GBS and CIDP, and new Executive Director.

Having been diagnosed with GBS and hospitalized after my H1N1 immunization in December of 2009, my world was turned upside down and inside out. It was a nightmare for my family and me. It was through our desperate call for help, that the Foundation contacted our family. I remember the calls like it was yesterday. "You mean I am not alone?" "There are others?" The telephone support received by foundation liaisons and hospital visits by Susan Keast and Jim Strongolos, were positive and encouraging. It was through these support avenues that our fears were lessened and we allowed ourselves to hope that our world would be given back to us, but slowly.

A Message from Donna Hartlen, Executive Director (continued)

After fifteen months of recovering from GBS, and deciding it was time to get back to my career in consulting, I relapsed twice after catching two flus in 2011, the second relapse much worse. It was through a desperate call once again to the foundation that I was told, "get to your doctor it could be CIDP". So off to my Neurologist I went, carried to the car and into my Neurologist's office, I was diagnosed with CIDP. Through every step of recovery with my GBS and CIDP journey, the foundation was there for me, and now it is time for me to give back to that same foundation. Through my caring Neurologist, working together, we have found the right treatment recipe that has given me a quality of life that I am lucky to have once again, and the energy to dedicate to our foundation family of patients, caregivers, and the medical community.

2014 is shaping up to a busy year and I am excited to get working on our bright future with an active board of directors, doctors that are appointed on our Medical Advisory Board, and volunteers. It is through the dedication of all mentioned that we can be there for our patients and continue to grow.

Sherry Nejedly, Vice President, Director, and BC Liaison, has been working hard on the western conference to be held in Vancouver, May 3, 2014. The conference will bring patients and speakers from the medical community together to bring information and support to all attending. Please start getting your questions together as this is the time to get answers and to connect with other doctors. This is also your chance to meet other patients and to support each other. Invitations will be sent out to our western patients and caregivers early in the year, and available online to print for patients wanting to attend from across Canada. We look forward to seeing you there and meeting new members.

A project team will be meeting in Montreal in the New Year to begin planning for a stronger GBS-CIDP community of volunteers and presence within the province of Quebec so that new and past patients of GBS, CIDP, and variants have a larger base of liaisons to call upon. Therefore, if you are resident of Quebec and want to support other patients and build awareness in the province, please contact the foundation.

The foundation will be utilizing social media in the New Year to keep members up-to-date with news happening in the GBS-CIDP community outside of our bi-annual newsletter. Please join our new Facebook page 'GBS/CIDP Foundation of Canada'. Our hope is that we can further support our patients through this trending resource.

We are excited to announce that the GBS/CIDP Foundation of Canada has committed research funds to the World Study for IGOS under Dr. Tom Feasby from Calgary, AB who is undertaking this research in Canada. We look forward to the results of this study and how it will impact the treatment of GBS. You can read more about the study in the article written by Dr. Feasby.

Our liaisons are an integral part of the team supporting our patient community. I thank each of them for volunteering their time, as they are the foundation. Please read their reports on some of their activities that support patients throughout the year. The foundation grows stronger with each volunteer. Liaisons are the first point of contact for patients. Therefore, we need to be available to all Canadian patients and their families, from coast to coast, and our northern communities. If you would like to become a liaison, please contact Gail Kammer, Regional Director, to help with any questions or information. (Continued next page)

Thank you CSL Behring Canada Inc.
for making this newsletter possible with
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A Message from Donna Hartlen, Executive Director (continued)

With Susan Keast's leadership, she, past and present Board Members, have been part of the inception and growth of the Foundation and made it strong. The Board and myself, now take those reins to continue her vision of a patient first organization through education, awareness, and research. Susan has had an impact on many of our patient's lives through her dedication, compassion, and willingness to stay on a phone for hours at a time. Susan will continue to have an influence Internationally for our Canadian GBS-CIDP Community, as she will remain on the GBS-CIDP Foundation International Board of Directors. We also thank Walter Keast for volunteering thousands of hours to the foundation supporting Susan. It is now time for Susan to spend quality time with her children and grandchildren. I want to thank her on behalf of the foundation for the many years of passionate service and personally for her, patience, sharing of knowledge, and friendship. We wish you well.

As the year comes to the end, we wish you all a wonderful holiday season and all the best and wellness in 2014.

Announcement

GBS/CIDP Foundation of Canada has partnered with CanadaHelps to facilitate donating electronically online. We realize that today online financial transactions are convenient and popular, and so we wish to provide that option to our donors. Of course, we will continue to accept donations by cheque through the mail.

- CanadaHelps is a registered charity (charitable number 896568417RR0001) with a mission to provide accessible and affordable online technology to both donors and charities in Canada.
- CanadaHelps assesses a 3.9% fee from each donation made through CanadaHelps.org. This 3.9% fee includes the costs of processing the transaction itself including credit card fees, banking fees, reconciliation, disbursement and receipting costs.
- CanadaHelps recognizes that privacy and security are important issues for both donors and charities and is committed to ensuring a safe online experience. You can review the measures that CanadaHelps takes to protect your security and privacy by going to their website at www.CanadaHelps.org and reading their policies.
- Because CanadaHelps processes your donation before sending the funds to our organization, your credit card will be charged by CanadaHelps.

To access the facility, go online to www.gbs-cidp.org/canada and you will see the following "Donate Now" button. By clicking on the button you will be taken to the www.CanadHelps.org website to make your donation

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

A Special Report

by Vera Bril, MD

This is an exciting time for patients with CIDP. There are a lot of research projects in the works and these have the potential to change how we treat patients with CIDP. The staple treatment of IVIG continues to work for many patients who need it. However, it means losing a day about every 3 or 4 weeks at either an infusion center or in a hospital to get this treatment. The PATH study which is sponsored by CSL investigates whether patients can administer immunoglobulin themselves via the subcutaneous route, i.e. SCIG, rather than having to receive the immunoglobulin intravenously. The first part of the PATH study aims to ensure that everyone who is receiving IVIG still needs that type of treatment. Patients are given a treatment "holiday" and monitored closely to see if they get worse as determined by worsening of the INCAT score. This score was used in the ICE trial that showed that IVIG is better than placebo in helping treat patients with CIDP. This has been changed recently, so that a worsening of grip strength is sufficient to demonstrate IVIG responsiveness. If the person on the IVIG "holiday" does get worse, then they are given the CSL IVIG product, Privigen, and are restabilized immediately. After the study participant is stable and has recovered to baseline, he/she is then randomized to either SCIG, or placebo SC (50:50 chance of getting either active treatment or an inactive treatment). If the participant worsens while in this part of the study, he/she is withdrawn and given IVIG again immediately. For those patients in this study, access to open label treatment with SCIG has now been made available. This means that the patients will be given subcutaneous immunoglobulin for an interval of time to assess the safety of this treatment in more patients. There will be no placebo or inactive treatment in this part of the study. As with most research studies, this study demands that patients return for assessment frequently, and much more frequently than is usually the case in regular treatment of patients with CIDP. The frequent visits that are necessary prevent many people from considering participation in this study. The other cause of concern is the treatment "holiday". Still, it is necessary to be sure that someone needs this kind of therapy before continuing with it indefinitely. Therefore, even in regular practice, the IVIG treatments can be stopped for a while or the treatments are spread out and given at longer intervals, or the dose is reduced to see if a patient with CIDP is still dependent on IVIG. We are really grateful to those patients who have agreed to participate in this study and encourage anyone with CIDP who is on regular IVIG to consider being evaluated and to consider participating in this research trial. If interested, please call Ed Ng, research co-ordinator, at 416-340-3898.

Another study that we have been part of is one that assesses CIDP from the point of view of how patients are doing in their daily lives. These are called "patient related outcomes" and we have participated both in North American and European studies using this type of assessment. The aim is to see how changes in measures of function [nerve conduction testing and clinical examination] relate to patient activities. The work from these studies should be published soon and will be of interest to physicians and caregivers of people with CIDP as well as to patients who suffer with this chronic disorder.

An interesting development is the study that is testing the use of fingolimod in patients with CIDP. This medication is helpful in patients who have MS, and is now being tested in patients with CIDP. In CIDP, the immune system attacks the peripheral nerves of patients producing weakness, numbness, unsteadiness and the other symptoms that patient experiences. In MS, the immune system attacks the myelin of nerves in the brain and the spinal cord producing similar symptoms. In both disorders, the immune system attacks myelin, peripheral nerve myelin in CIDP and central nerve myelin in MS. Fingolimod acts against the abnormal immune attack and the question is whether it will be effective in CIDP as it is in MS. So we encourage people to get in touch with our research co-ordinator, Ed Ng at 416-340-3898, if they have any interest in the fingolimod study. With these developments, we hope that new treatments are effective in controlling this difficult disease. There are many other new immune treatments that are on the horizon, but are still

A Special Report (continued)

to be tested in patients with CIDP. It may be that these treatments could be used occasionally in single patients, but they are expensive, difficult to obtain, and may have harmful side effects. That is why it is so necessary to prove that they work in patients with CIDP, generally, before they are recommended as a treatment for CIDP. However the future outlook is very hopeful.

The other line of treatment that we always have to recall is nerve regenerative treatment. That is still a dream and effective treatments are not yet available.

Congratulations to Vera Bril, MD

Dr. Bril, a neurologist practising in Toronto, Ontario, and on the Medical Advisory Board with the GBS/CIDP Foundation of Canada, has been appointed with a seat on the GBS/CIDP Foundation International Medical Advisory Board. World patients will benefit from Dr. Bril's ongoing dedication to the GBS-CIDP community.

A Generous Donation by Array

Golf Tournament Summer 2013 – with Darryll Blencowe, Liaison, Ontario

The foundation would like to thank Darryll Blencowe and his company Array for supporting Darryll, a liaison for Southern Ontario, and the foundation with efforts to raise money for Cancer Research and the GBS/CIDP Foundation of Canada during their company golf tournament this past summer. Their efforts through various raffles, putting contests, and a very generous donation from Array themselves, which was a delightful surprise to Darryll, raised $900 for GBS-CIDP and $900 for Cancer Research.

The Foundation appreciates the generosity of Array and all that attended, it is through efforts like this that the foundation remains strong and is able to continue supporting patients and caregivers.

Grifols Patient Open House

September 2013, Raleigh, North Carolina
by Donna Hartlen – Executive Director and Liaison, Eastern Ontario

Grifols Inc. is an approved distributor of IVIG (Intravenous Immunoglobulin) within Canada for the treatment of CIDP. As a CIDP patient involved in patient education and awareness, I was given the opportunity to attend the Grifols Patient Open House, held in North Carolina. There were patients there from across North America representing GBS-CIDP, Alpha-1, and Primary Immunodeficiency to learn more about plasma-derived products. The patient connections made during my stay are invaluable. I was enlightened by the experience and trust in the safety of my Gamunex treatment every 4 weeks.

All patients attending the Open House were given a tour of the Raleigh donor centre. There are 150 plasma donor centres for Grifols across the United States. During this tour we learned about their screening procedures for all donors. Donors require valid ID, a local permanent address, and during registration are checked to see if their name resides on a National Deferral Registry to check for eligibility. This registry is based on previously obtained blood tests. Each donor has a complete health interview, medical examination (for first time donors and annually after that), and blood samples are checked for the health of the blood and plasma prior to donation. If there are any red flags during this process the patient is immediately put on deferral and added to the registry and may not donate for a period of 8 months. A plasma donation takes approximately 1 ½ hours, sometimes longer, and the donor is compensated for their time. Samples from each plasma donation tested and the plasma is quarantined for 60 days prior to being sent to the production facility and tested for transmissible diseases such as HEP-C, HEP-B, HIV, to name a few. If the tests detect these viruses the donation is destroyed and the donor is permanently added to the National Deferral Registry. Each plasma donation is documented and can be traced through to the final lot of medicine that is received by a patient.

I had the pleasure of talking with donors and explained the impact of their donation and extended a thank-you from my husband, children, and myself. I found this to be an emotional experience that I will not soon forget.

All patients had a tour of a plasma derived products' production facility. We were quick to learn about the importance of a sterile environment. After changing into one uniform, and then covering the first with the second, for that period of time, I certainly was not worried about catching a virus.

We had a complete tour of all aspects of the final processes to complete production, purification and isolation of therapeutic proteins, inactivation of potential pathnogens and viruses, and filling and packaging. It takes 7 to 9 months from time of plasma donation to the end of production to be able to administer the medicine. At the end of the tour, I was chosen to speak to a large group of Grifols employees. This gave me the opportunity to spread awareness about GBS-CIDP and convey that our families need their loved ones to be healthy and Gamunex for some CIDP patients is important in reaching that goal.

I would like to thank all presenters, tour guides, and Canadian representatives for their openness to answer any question and overall care during my stay.

*****Announcement – Facebook page coming January 1, 2014*****
Please join our new Facebook Page for GBS-CIDP news throughout the year!
Please search within for 'GBS/CIDP Foundation of Canada'

GBS/CIDP CONFERENCE

Saturday May 3rd, 2014

at

EXECUTIVE AIRPORT PLAZA HOTEL
and CONFERENCE CENTRE

7311 Westminster Hwy
Richmond, British Columbia

presented by

GBS/CIDP Foundation of Canada

serving patients with GBS, CIDP, and variants
through support, education, and research

Newfoundland Support Group Meetings

by Ivan Sheppard – Director, Liaison, St. John's, Newfoundland ivan.sheppard@gbscidpcanada.org

Support groups bring together people facing similar issues, whether that's illness, relationship problems or major life changes. Members of support groups often share experiences and advice. It can be helpful just getting to talk with other people who are in the same boat.

While not everyone wants or needs support beyond that offered by family and friends, you may find it helpful to turn to others outside your immediate circle. A support group can help you cope better and feel less isolated as you make connections with others facing similar challenges. A support group shouldn't replace your standard medical care, but it can be a valuable resource to help you cope.

My name is Ivan Sheppard and I am a proud director of the GBS/CIDP Foundation of Canada and I would like to get a support group started in the St. John's, Newfoundland area for people, family and friends who have been affected from GBS or CIDP. All individuals interested in taking part or helping out please contact myself at ivan.sheppard@gbscidpcanada.org.

Nova Scotia Support Group Meeting – October 27, 2013

by Deb Bernasky – Director, Liaison, Nova Scotia, deb.bernasky@gbscidpcanada.org

The third bi-annual support group meeting for the Nova Scotia area was held Oct. 27th. Even with the poor weather, 4 patients and their families were able meet to share support. The next meeting will be held in the late spring, watch for details or contact Deborah at deb.bernasky@gbscidpcanada.org.

Edmonton Support Group Meeting – October 2013

GBS-CIDP patients and their families met in Edmonton the third weekend in October for another successful support group meeting. Holly continues to spread awareness in the Edmonton area and has started planning for the second annual awareness picnic in May of 2014. Patients and their families will now have the opportunity to attend quarterly meetings throughout 2014. For more information on attending and location please contact Holly Gerlach, your Edmonton Liaison, holly.gerlach@hotmail.com.

Meeting dates for the upcoming Edmonton 2014 year:

Saturday, February 8th
Saturday, May 10th (this will be our annual picnic)
Saturday, September 13th
Saturday, November 8th

All the meetings are scheduled for 1-3pm

The International Guillain-Barré Syndrome Outcome Study (IGOS)

By Tom Feasby, MD, Professor of Neurology and Past Dean, Faculty of Medicine, University of Calgary

The IGOS Study is a major international collaborative study that will better delineate the natural history of Guillain-Barré Syndrome (GBS). It also aims to develop markers, both clinical and biochemical (biomarkers) that will help doctors to more accurately predict the outcome from GBS early in the course of the illness and to prescribe customized appropriate treatment more effectively. For instance, IVIG may work well for some patients and not for others and this study may help us predict who those responders are and to develop other more effective treatments.

The study is being run by the world leaders in the field of GBS, led by a group in Rotterdam under the direction of Dr. Bart Jakobs. The study aims to include 1000 patients, each followed for two years. The patients will receive all the usual care but their data will be carefully collected. This data will include the history of the illness, such as preceding infections, symptoms etc. and the clinical condition, including strength, sensation and reflexes. Data will be recorded at weekly intervals initially and then less frequently up to two years. We will also collect serum and spinal fluid and the results of the nerve conduction studies and other tests. Later, special research studies will be done on the serum and spinal fluid to look for predictive biomarkers.

Over twenty countries are involved in the IGOS study. It's likely to be the biggest GBS study in the world. I am the coordinator for Canada. We currently have five centres enrolled in the study and are aiming for ten. We have enrolled our first three patients and are hoping for one hundred. With an annual incidence of 1-2 cases/100,000 people, we think this is possible, but it will require a lot of effort.

Usually, studies of this sort are supported by research foundations of various kinds or pharmaceutical companies. However, for IGOS, that is not the case, because it is not a clinical trial where a new treatment is being tested. Most of the costs are simply being absorbed by the investigators in each of our centres. This is why the support of the GBS/CIDP Foundation is so important. This will allow us to cover some of the costs of the various tubes we need for serum and spinal fluid storage, for data forms, for storage and shipping and for nursing assistance.

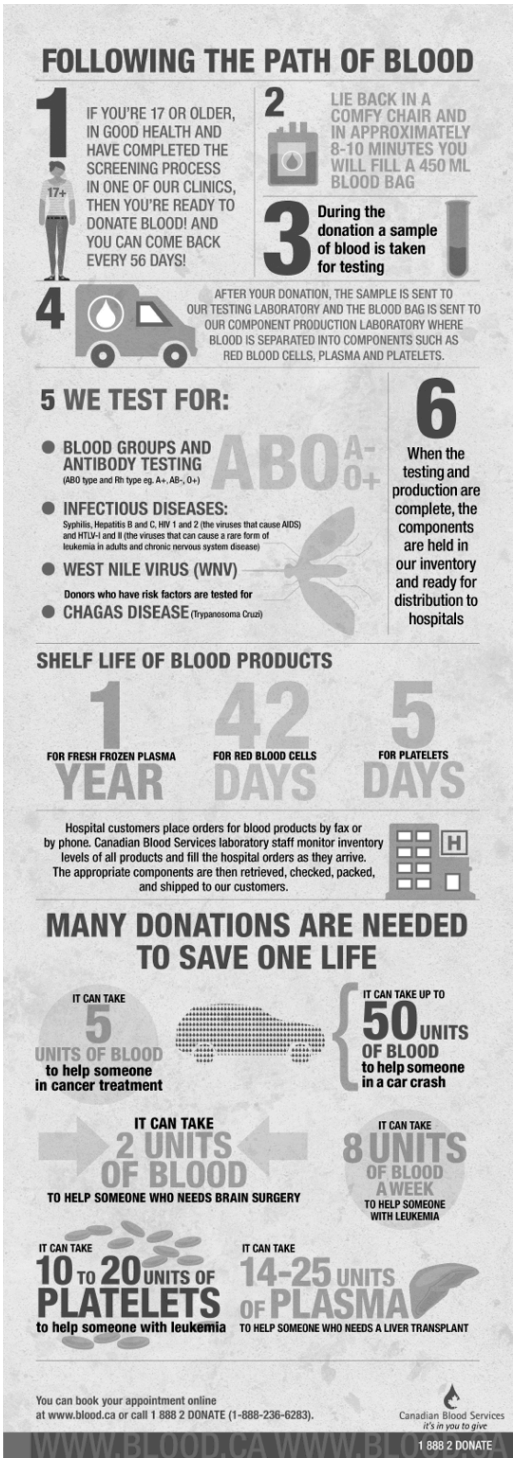
We hope to make a major contribution to the IGOS Study from Canada. This will ultimately provide us with new insights into Guillain-Barré Syndrome, a still challenging and mysterious disease.

Announcement – Address Change
3100 Garden Street
PO Box 80060 Rossland Garden
Whitby, ON L1R 0H1
(647) 560-6842

Collaborating To Save Lives

How Patients Can Help Other Patients and Empower Themselves at the Same Time

Canadian Blood Services – CBS, by Tami Clark



Recently, we've been hearing more about "collaborative health care" where health-care providers work together with patients, their families, caregivers and communities to provide high-quality care.

But what if instead of patients working only with health-care providers, they worked with other patients? Or families with families and groups with groups? Health-care collaboration could suddenly take on a whole new meaning—on a one-to-one level.

Simply put, people can be advocates for each other. Because you understand what other patients are going through, you can bring a knowing voice to their cause.

Every minute of every day blood, plasma, platelets, stem cells, organs and tissues are needed to save or improve lives. You understand this need on a first-hand basis and you can use this knowledge to encourage, educate and inspire friends, family and members of your community to get involved. There are many ways to support the blood system; from making a blood donation to registering on OneMatch Stem Cell and Marrow Network, signing your organ donor card or volunteering.

In the end, not only can advocacy be empowering, it can also be lifesaving.

In many ways, Canadian Blood Services has evolved alongside patients on this journey of collaborative work to improve patient care and the health and well being of Canadians. We too are excited at what can be accomplished if the boundaries of "health-care collaboration" are pushed.

What does this dedication to collaboration mean for you? It means that Canadian Blood Services is committed to quality, including being a leader in the health-care system in which you play an integral role. This quality journey, like that of our partners, is grounded in a patient-centric view of health care in order to address growing demand, anticipate future needs and consistently meet or exceed expectations.

But while Canadian Blood Services moves forward on its strategic journey, health-care collaboration must continue at all levels for all patients to benefit. From you to your friends, family, hospitals and patient groups, we all must work together and reach out to one another in support.

Become a health-care collaboration advocate. Encourage friends and family to give blood, or register to be a potential stem cell donor, or organ and tissue donor.

For more information please visit our website at www.blood.ca or call our toll-free line at 1 888 2 DONATE.

The Story of Nice Relations with Others

by Phillippe Valdenaire, France

From tetraplegic to another way of apprehending the future, it is the lifeline that I have chosen.

I published a book September 2013 " S'il Vous Plait" – English "Please ... Thank-you" with the subtitle "Numbed by an Illness, that made me aware"

After a long period of combat still lasting today against an illness of chronic autoimmune, I describe a "beautiful experience" with awareness and mockery. The syndrome Guillain – Barre which transformed into acute chronic Polyradiculoneuritis and kept me nine months in the hospital, four months of tetraplegia, ten months in a wheel chair and seventeen months of kinetotherapy.

This is the journey I want to write about, encouraged by my daughter, to help those who went through the same ordeal, without transferring my worries to others. If there is a benefit that I can gather, it is to witness the "to be human is a marvel." I discovered my hand is an irreplaceable fantastic tool that can bring the divine relief to scratch our nose.

During months five and six my hands didn't function. Even still today I have paresthesia of the extremities, I take pleasure every day using them to take my shower by myself. Tetraplegia is something that marks us, and I certify that we only realize our happiness when we loose it, then get it back when we are able to use our limbs again. I didn't only lose the use of my hands. The illness slowly progressed since 2011, which brought me to the state of tetraplegia.

Being of a positive nature, I have always tried to communicate and keep in contact with others. Being with other patients I have discovered other different people than I am used to being with. With the caregivers, becoming an actor in the process of healing, and the improvement of care possible.

With my family and friends who have been indispensable in my progress I stay optimistic even with the severity of this illness and I profit each day with morning energy, to do short term projects and be much more open with others. I wish my experience can help those near and far, touched by illness, for family and care-givers.

My book is 185 pages. The preface was done by my neurologist, Nancy and an aide who followed me for seven months designed the cover. My book was written in collaboration with Etienne Duchene from The Memory Editing Company.

You can visit my website at www.philippevaldenaire.fr where you can find the actual golden book and contacts to purchase the book or ask questions.

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 your e-mail address to donna.hartlen@gbscidpcanada.org for updating.

My Experience abroad with Guillain-Barré Syndrome

by Carol Spiteri, Mississauga, Ontario

Each year since my Dad died my Mom would visit us in Canada spending a couple of weeks, my husband, our two daughters, and myself, in Mississauga, Ontario. This year my Mom did not feel up to traveling, so I decided to visit my Mom and family in the United Kingdom for a couple of weeks, (June 21st – July 6th).

Five days into my visit I caught some form of stomach virus. A few days after this (3 July) I experienced pins and needles in my right thumb, then my left. Later that day, I had the same sensation in both my big toes. By the evening, the pins and needles had spread to both my hands and feet, and my lips were feeling tingly. I did not mention this to my Mom, as I did not want to worry her, but I told her partner what I was experiencing. I reassured him that I was sure I would feel better after a good nights sleep.

I woke 1:00 AM in the morning; the pins and needles sensation was still present. On trying to get out of bed, my feet and legs felt weak and I could not walk properly. I had to support myself using walls, furniture and doorways to make it to the washroom and back into bed. I lay awake until 5:00 AM, and then I phoned my brother. I left a message explaining I was not well and asked him to come over. I then phoned my Mom's partner who I had spoken to the night before, he said he would get in touch with my brother, and would come over too. Upon seeing that I was unable to walk unaided my brother phoned for emergency assistance, shortly after which a paramedic arrived, and I was transported to the Acute Assessment Unit at Bedford General Hospital. My brother accompanied me, while my Mom's partner stayed with her for support at home.

As I was being examined by several doctors, the pins and needles sensation was spreading to my arms and legs, my speech was becoming slurred, and I was experiencing double vision. A doctor told me I had Guillain-Barré Syndrome, (diagnosis Bickerstaff's Brainstem encephalitis, GBS variant) that GBS was rare, and usually triggered by an infection. He explained that my immune system had attacked all the nerves in my body and that GBS patients could take months or years to recover. I had never heard of GBS, I was in shock and I was scared. I could not believe this was happening, I was scared. I could not believe this was happening, how was I going to fly home to Canada in two days, to my husband and daughters (age 17 and 19) I wasn't!

The same day, July 4th, I was admitted to the Critical Care Unit for close observation, I had a CT brain scan and lumbar puncture which were both normal. The pins and needles sensation had spread throughout my whole body. I lay motionless unable to move, and was finding it harder to breathe. I was to receive a treatment IV immunoglobulin for five days. I was asked if I wanted to be put to sleep so I would not be in pain, I agreed, suddenly my ability to speak was gone. I was unable to breathe on my own and was put on a ventilator, I received intubation, and I was sedated and given morphine for pain.

My brother phoned my husband in Canada to let him know what had happened to me. My husband was in shock. He contacted the hospital ward and was updated on my condition. He was told I was sedated and would be undergoing treatment for a week, so I would not know if he was there or not, they also did not know how long I would be hospitalized. My husband immediately made arrangements to take time off work to come to the UK. His family, our friends and neighbors were of wonderful support, everyone rallied around bringing over meals for my husband and daughters, helping to book flight tickets, making arrangements to take care of our dog, our house, our garden, there were so many things to organize.

Back in the UK in the critical care unit I was unable to move my body and I had no voice, I could only hear and see, though I was still experiencing double vision. When responding to questions I moved my eyes up and down to answer yes, and moved my eyes sideways to answer no. I later learned when being spoken to my blood pressure sky rocketed. I was receiving treatment, ongoing in bed physiotherapy, wore elasticated socks, also I had custom made foot, leg splints on for six hours a day to prevent my feet from dropping. During this time I developed a fungal tongue and could not get my tongue inside of my mouth, as it had swollen along

My Experience abroad with Guillain-Barré Syndrome (continued)

with the rest of my body. I experienced terrible nightmares and hallucinations. which I was unable to separate from reality. To this day I can remember them and cannot bear to think of them.

I would have cried, if I could have. I just wanted to feel better, to go home, to stand, to walk, to do all the things I had once taken for granted. My thoughts were haunting, would I recover enough to be the person I once was? My husband and daughters later told me how upsetting and scary it was for them when they first saw me laying motionless, swollen, hooked up to machines, my tongue sticking out of my mouth and my eyes rolling in my head.

After five days the Immunoglobulin treatment was complete, on July 12th, under less sedation, I was able to make slight movements of my head, mouth and jaw. I could also twitch my arms and fingers. There was so little improvement it was decided by the doctors I was now to receive a Blood Plasma exchange treatment, unfortunately this treatment was not available at Bedford Hospital, I needed to be transferred to the world renowned teaching hospital, Addenbrookes which was in Cambridge, an hour from Bedford.

On July 14th I was admitted to the Neurosciences Critical Care Unit in Addenbrooke's where I received treatment for 5 days, I responded well, the doctors were pleased with my progress. I was gradually starting to get movement back in my upper body and I was improving daily. I was now able to grip and release a stress ball in my left hand, but not able to release from my right, I believe it is a known fact with GBS your more dominant side of the body takes longer to recover. I found it harder to move and exercise the right side of my body. Having my young daughters present I was even more determined to be brave, and to work harder to get better. This was not a pretty sight for them, they were so brave themselves, so supportive of me, they were overjoyed with each new movement I was able to make, always telling me how much they loved me, how brave I was, saying "keep going Mommy you can do it". I could do it, I was determined to get better, and I had so much to get better for!

By July 17th I was able to communicate by using a white board with the alphabet on it, my family members would take turns pointing to letters and I would select letters that made up words by nodding my head. Sometimes I would try and point to the letters myself, but not for long as this was so exhausting to do. I continued with ongoing in bed physiotherapy, wearing of elasticated socks, foot, and leg splints. I was still being ventilated and treated for fungal tongue.

Treatment was completed on July 19th. I was to be transferred back to Bedford hospital. On July 22nd I became so agitated with ventilator and soreness in my mouth, I kept trying to pull the tube out. It was then decided to take me off the ventilator, but I was unable to breathe on my own, even with the aid of oxygen. After two hours of trying, by which time I was soaking wet with exhaustion, I was put back on ventilation. The next day July 23rd a tracheostomy was done, I felt so much better without the tubing in my mouth. My daughters said it was nice that I was able to smile again.

On July 24th I could not believe it when I heard a neighbor in Canada having learned I had GBS had started decorating the trees on our street with turquoise ribbons (turquoise being my favorite color). Other neighbors continued tying ribbons around trees until the whole street had trees with turquoise ribbons on them. My family showed me a photo of decorated trees full of turquoise ribbons. This brought tears to everyone's eyes my eyes.

I was surprised once again when I heard two young girls on our street aged twelve and thirteen had started going door to door spreading the word that I had GBS, asking people to keep me in their thoughts and prayers and collecting money to buy me a gift. I felt very touched to think they had taken this upon themselves to do this, and I was extremely grateful.

During my stay at Addenbrooke's Stuart Pearson from the GBS association in the UK, together with his wife, visited me. Susan Keast whom my family back in Canada had been corresponding arranged this visit. Seeing Stuart who had been bedridden with GBS thirteen years

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ago, standing beside my bed happy and healthy, hearing his story, experience and recovery from GBS was, for myself and my family, living proof that full recovery was possible! His visit was so uplifting and a great source of encouragement to us all.

I was now beginning to get co-ordination back in my arms and hands and I was able to breathe for several hours on my own. On July 28th I was transferred back to Bedford hospital. On arriving I remember smiling and waving at the staff as I was wheeled in a bed back into the critical care unit. Doctors, nurses greeted me saying how amazed they were at how much I had improved in such a short time, I did not recognize many of the staff, but they all remembered me.

I now had good movement in my upper body, and was able to communicate by writing on a white board. I was now able to breathe on my own for longer periods of time. But I was still unable to move my lower body without assistance. I experienced terrible nerve pain in my feet, cramping, numbness and pins and needles sensation. I couldn't bear anything touching my feet because of the sensitivity. I was still receiving in bed physiotherapy, but when a team of three assisted me to sit up on the edge of bed, I felt dizzy and needed support like a baby. The following day they used a hoist to lift me out of bed into a chair to sit for a while. The day after they assisted me in standing on a rotor stand, I felt weak and shaky but I was standing, another achievement!

On August 1st, I was given a blue dye test, several hours later I was allowed to start sipping water via a straw. The same day the tracheostomy tube was capped off, and I was able to breath on my own, which was scary but wonderful. I tried using a voice box but I found this exhausting, as it made breathing difficult. I then tried mouthing words and could faintly hear my voice. It was such an exciting moment to be able to speak again.

In total, I had spent four weeks in critical care units. During this time I was visited everyday by my Mom and her partner, my husband and daughters. My brother had taken time off work in order to spend long periods of time with me. His wife visited me whenever she was able. I will be ever grateful for their wonderful support. I was now well enough to be transferred to a ward, that afternoon I was admitted to Howard Stroke Unit. A doctor who had treated me visited on August 2nd, he explained while hospitalized with GBS I had a swelling of the brain followed by an adrenalin rush which effected my heart (diagnosis Takotsubo Cardiomyopathy). He asked if I would give permission for a medical paper to be written on me as this was rare, and so I signed the papers.

The tracheostomy tube was removed on August 3rd. I was started on a pureed food diet, while still being fed via a feeding tube. Being in a regular ward I had so many visitors, not only close family but also all family members and friends, it was wonderful to see everyone. The catheter was removed August 5th and only the feeding tube remained. I was gradually getting more movement in my lower body and able to lift my legs on and off the bed to get onto the rotor stand then rotated by nurses to sit in a chair, wheel chair, or commode. I was beginning to feel less shaky and a little stronger.

On August 8th my family took me outside in a wheelchair. I cried tears of joy. It was my first time outside in five weeks. It had felt like an eternity. How beautiful everything looked: the trees, the grass so green, and the vibrant colors of flowers. It was wonderful to be back in the real world again, no longer confined to a hospital bed.

The same day I was reviewed by ITU team and deemed fit for medically escorted air travel to Canada, on arrival I was to be hospitalized and continue receiving physiotherapy and occupational therapy. Back in Canada preparation for my return was being made by my sister and brother in-law, along with my GP and the support.of Susan Keast. I was to be admitted to Toronto Western Hospital, under the care of Dr. Bril. We were all to travel home together I was so relieved and happy my husband had said he would not go home without me!

During this whole ordeal I had lost twenty-four pounds, I now weighed one hundred pounds. By August 12th I was eating normal food, enjoying savory foods

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immensely but unable to tolerate anything sweet, unusual for me as I had a sweet tooth before! August 13th the feeding tube was removed, the last of the tubing was gone, I felt free again!

Aug15th was to be my day in hospital. An escort nurse arrived from Tampa, USA. I was so excited to be going home, but I felt nervous about traveling. It was hard saying goodbye to everyone, especially my Mom, brother and family, but we were all so relieved and happy I had made a remarkable recovery, it had been a nightmare of a summer, but it had ended happily.

August 16th, our flight home to Canada went well. We were picked up from Bedford hospital at 4:15 am and drove one and a half hours to London Heathrow airport. I was boarded onto and off the plane in a wheelchair. Our flight took seven hours, our daughters travelled regular class, while the Nurse, my husband and myself travelled business class, I was able to lie down, and my husband assisted the nurse as needed. After eleven hours of traveling I was finally back on Canadian soil, exhausted, but happy. My close friend was there at the airport to greet me and take my family back home, reality had finally set in. I was one step closer to going home, and it was a very emotional moment! Our flight took seven hours, our daughters travelled regular class, while the Nurse, my husband and myself travelled business class, I was able to lie down, and my husband assisted the nurse as needed. After eleven hours of traveling I was finally back on Canadian soil, exhausted, but happy. My close friend was there at the airport to greet me and take my family back home, reality had finally set in. I was one step closer to going home, and it was a very emotional moment!

The same day I was admitted to Toronto Western Hospital. During the next few days was examined by different doctors. It was decided I needed to be transferred to a neurological rehabilitation hospital to receive physiotherapy and occupational therapy, which was not available there.

On August 20th I was admitted to Bridgepoint Hospital at which time I was only able to stand a short while and walk a few feet using a walking frame. I received daily physiotherapy and occupational therapy. I was able to go home for the weekends. My first weekend home was a very emotional one. I was in tears when I saw the trees decorated with ribbons. Then I received a visit from the two young girls (who had gone door to door spreading the word I had GBS) and their families. I felt even more emotional upon realizing how much time, effort and hard work these girls had put into everything they had done for me. They presented me with the speech they had said door to door. A wooden chest beautifully decorated with inspiring words, full of turquoise ribbons, that one could pin onto their shirt, which they had made in return for a donation. They held a huge banner welcoming me home, two turquoise wreaths and $420.00 that they had collected. These were all wonderful gifts and I felt deeply touched by the generosity of people who donated, but I realize that it was the girls' hard work that inspired everyone to contribute.

Once again I received numerous visits from family and friends. Six weeks later on October 2nd I was discharged from Bridgepoint. I required no more physiotherapy and was given a home exercise program to follow. I had made wonderful progress, as I was now walking independently and able to climb up and downstairs. I was so happy I could walk again, how alive I felt!

I could not have received better medical, physical and emotional care from doctors, nurses, physiotherapists, staff etc. in the UK and Canada. We truly believe the wonderful care I received played a huge part in my recovery, and are thankful to everyone who assisted with my recovery! The hospital staff in UK believed the support of my family played a huge role in my recovery. In fact they said they had never seen so much support from a family before. I had a tremendous support system family, friends, neighbors from the UK and Canada, and GBS society in the UK and Canada. So many people praying for us, sending get well wishes, visiting, flowers, gifts, and cards, I am so thankful for all that people have done.

My Experience abroad with Guillain-Barré Syndrome (continued)

Today is November 6th It has been four and a half months since the on start of GBS, I am still experiencing nerve sensations and pain in my feet but as each week passes the sensations and pain are becoming less intense. Also my taste is still not back to normal I am unable to tolerate the taste of anything sweet. But, I have come a long way and it is early days yet!

I have been home six weeks, how wonderful it is to be home again with my family and dog, sleeping in my own bed and achieving new things as each week passes. I have made a remarkable recovery and I feel truly blessed to have been given a second chance of life.

Notes