GBS/CIDP Foundation of Canada

Guillain-Barré Syndrome / Chronic Inflammatory Demyelinating Polyneuropathy

Support, Education, and Research

News & Views

Issue: 11 *Fall/Winter 2012*

A Message from Susan Keast, Executive Director

Our fall newsletter is full of special information that I know will be of interest to you all. I hope you have all had a good summer and that our upcoming winter will be kind to each of us.

As we look ahead to the end of 2012 and to the new beginning of 2013, there is much going on in the world of GBS and CIDP. We are once again planning our National Conference which will take place on Saturday, April 27, 2013. So mark your calendars and watch your mail box for your invitation to attend. It is a time to connect with others whom we have known for many years, and to look forward to meeting new members. It is always so special to let new patients and their families know that they are not alone, and that they now belong to our precious family. Make sure that you bring your questions to the conference as its a day to get answers and to learn more about what is happening in our wellness and how to gain a better quality of life from better treatments, earlier diagnoses, and more doctors and neurologists to connect with. No matter where you go in this world, there is a GBS or CIDP chapter where you can share experiences with others. No matter what our culture or language, we are all share in the same hopes and fears, and the need to reach out to others who have experienced both GBS and CIDP. We are all ambassadors in making others feel and know that we are there for them. Thank you to all of you who reach out to others, this is what makes our Foundation strong and working towards your better life.

I have just come back from the Texas US International Symposium where I experienced fellowship at its best. It is never an easy job putting a conference together, and so I would like to congratulate the Foundation International in the US who worked so hard at making 400 plus people very happy. The information is always overwhelming and it takes many weeks upon returning home to digest all that we have heard and been a part of.

It was wonderful this time to have two Canadian Doctors as presenters at this Symposium and so many thanks to both Dr. Angelika Hahn (from London, ON) and Dr. Douglas Zochodne(from Calgary, AB). We hope to be keeping in touch with both of them as we continue on into 2013. Both Doctors are involved in interesting projects that we will be learning more about.

We are also pleased to announce that Dr. Joel Steinberg who has written many of our GBS/CIDP booklets and the wonderful book – Guillain-Barré Syndrome – will be coming to Toronto to make the GBS presentation at our April conference. Bring your pen so that perhaps we can coerce him into doing some signing for us. I appreciate his time in coming to do this for us and he has also experienced having had GBS, so he knows first hand what you are going through. Our own Dr. Vera Bril will be doing the CIDP presentation and her assistant Dr. Hans Katzberg will also be taking a part in our Conference.

A Message from Susan Keast, Executive Director (continued)

The venue for this day will have some new people involved in workshops, so again please watch your mail for information that I know will interest you. Our many thanks go out again to our liaisons for the amazing work they do. Where would we be without their time and energy in giving back to others. They drive many miles to make visits to hospitals, they have meetings to share experiences and to meet others, and they raise awareness wherever they can. This is what we need, more people to lend a hand in raising awareness as we are still a very rare disorder that needs to get the word out. Each person can take an important role in making sure that "your Foundation" will grow and prosper and you will know that you have helped so many others with GBS and CIDP as well as their families.

Please read all the liaison reports from those around the country who have met and made connections in their area. If you are thinking of doing something in your area, please contact Gail Kammer, our Regional Director for any questions or information you might need.

Our future for the Foundation has never looked brighter and are very excited in moving forward. Thank you once again to those who have sent in their stories. Each one is so valuable not only of your experiences, but to the message that they bring to others. Whether it be a tough time for you or a bright and hopeful outcome, we celebrate all your victories and very much share in all your sorrows. We are always here to help.

Susan Keast, Executive Director

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GBS/CIDP Patient Survey

by Vera Bril, MD

A survey of GBS/CIDP patient's was undertaken in early 2011 and ended in January 2012. The survey was open for 240 days and 79% of individuals responded to the survey. Given this high response rate, it was possible to extract some important information that is shared in this report.

In this survey, the patients took the lead in responding (>90% responders were patients). Caregivers or family members completed the surveys on behalf of the other participants. Of those responding, 2/3 were women, and the majority (80%) were over the age of 50. There was a fairly even split between those who had GBS and those with CIDP. Three-quarters were diagnosed within 3 months, the great majority (86%) by neurologists, and by neuromuscular physicians in 30%. Patients in this survey had their disease for many years: 40% for longer than 10 years and for 6-10 years in about 15% with no real difference between those who had GBS and those who had CIDP.

89% reported having very severe disease early on. When asked about current status, 19% reported that they were in remission, and 16% had only mild disease. However, 42% reported that they had moderate impairment and another 15% had ongoing severe or very severe limitations. So, in this group, more than ½ had neurological impairment interfering with their lives. At the time the survey was done, about 1/4 were not working primarily due to their disease, but 17% reported no effect on their ability to work. 1/3 reported that they were in remission and not being treated currently.

GBS/CIDP Patient Survey (continued)

When asked about previous treatment of their neuropathy, 64% had received IVIG, 39% corticosteroids and 1/3 plasma exchange. Another 1/4 had tried homeopathic medications.

The CIDP and GBS patient groups were compared, but firm conclusions were not possible for individual items as the numbers in each group became too small for valid comparisons. About the same percentage of men and women had each diagnosis.

Time to diagnosis was a lot shorter for GBS with 58% reporting almost immediate diagnosis compared to only 4% of CIDP patients. Time to diagnosis was greater than 3 months for about 50% of CIDP patients and only 3% of the GBS group. So, it is clear that CIDP patients are not getting diagnosed quickly, particularly when compared with GBS patients.

For the worst state of disease survey item, there was no difference between GBS and CIDP patients in this survey. 52% of GBS patients compared with 46% of CIDP patients were in the most severe levels (3, 4 or 5) and these numbers are not really different.

For current disease status, about the same percentage reported having severe or very severe disease and slightly more patients with GBS were in remission or had very mild disease.

About 90% of CIDP patients have received IVIG compared to 55% of GBS patients.

20% CIDP patients treated with IVIG did not have a change in disease status compared to 2/3 of those not treated with IVIG, although the numbers were small. However, this would suggest that more of those on IVIG improved compared to those who did not receive this treatment. Of those on IVIG, 16% had marked changes in their clinical status compared to none of the patients who were not treated with IVIG. In the GBS group, the numbers treated with IVIG are too small to draw similar comparisons.

This survey had produced results that are thought-provoking. Many patients in this survey had suffered many years with their neuropathy. Diagnosis was delayed in those with CIDP when compared to those who have GBS. Although some patients recovered well, many still have major neurological impairments. Fewer than 1 in 5 patients report no effect on their ability to work, or taken the opposite way, more than 4 out of 5 patients have ongoing limitation in their ability to work after developing these neuropathies. Those CIDP patients treated with IVIG reported more change in status than those not treated with this immune therapy. We can understand from this survey that both GBS and CIDP have long-term consequences in most patients and that our current treatments are limited in getting people better and back to their usual lives.

Welcome to Chris White, MD

Dr. White, a neurologist practising in Calgary, Alberta is now accepting referred patients who have GBS and CIDP. We are truly grateful to have him available to care for our family of patients in this area of the country.

Association of New Brunswick Massage Therapists Annual General Meeting and Conference

On August 17, 2012 Stacey Jewett made a presentation at the ***"Association of New Brunswick Massage Therapists Annual General Meeting and Conference"*** at Saint John Trade & Convention Centre in Saint John, New Brunswick. Stacey was one of several presenters at the conference and discussed her journey with the disease, Guillain-Barré syndrome. In addition, she gave an overview of GBS; in particular, its symptoms, diagnosis, and recovery.

Thank you Stacey

(***Stacey Jewett – Liaison, New Brunswick, jewettstacey@gmail.com)***

Grifols Patient Open House

September 2012, Raleigh, North Carolina
by Linda Paul – Liaison, Ottawa, Ontario, bluesmeorloseme@yahoo.ca

In September I had the opportunity to visit the Grifols Patient Open House in Raleigh, North Carolina. The Patient Open House is attended by patients who use products produced by Grifols, including IVIG, as well as plasma donors. The event included receptions and dinners to meet Grifols executives and staff, other patients, and plasma donors. Over the two day open house, we were given presentations on the origins of the Grifols Company, clinical development, product safety, and the manufacturing process; as well as a plant tour, and a visit to a plasma collection centre.

The most interesting part for me was visiting the plasma collection centre and meeting the plasma donors. It was very moving to meet donors who enable us to get the treatment we need, and they were very interested in hearing about how the plasma is used in our treatments.

Most of the plasma used in Canada comes from the United States, where there are many plasma donation centres. Donors who donate whole blood can only donate every 60 days whereas plasma donors at plasma collection centres can donate up to twice a week. Some donors donate up to 100 times a year. Each donor is hooked up to machine with a pump and a centrifuge. Whole blood goes into the centrifuge, where the plasma is separated and goes into a bottle. The rest of the blood goes back into the donor. The process takes 1-2 hours until a 0.85 litre bottle is filled with plasma. The plasma is then processed in state of the art factories to make IVIG. Every 10 grams of IVIG prepared requires approximately three 0.85L bottles of plasma. This means that each monthly treatment of 30 grams of IVIG that I get requires the equivalent of donations from nine people, each giving up 2 hours of their time to donate.

In Memory of Sylvia Shipley

I first met Sylvia in 1994 while visiting patients afflicted with Guillain-Barré syndrome at Victoria Hospital In London, Ontario. At the age of 64 Sylvia had lived her life as a strong and very independent woman. The illness impacted her greatly. Sylvia had never been ill before and never fully recovered. During the 4 months in the hospital I would visit her weekly and our friendship grew from there. When Sylvia was released from the hospital her mobility was still limited and I continued to visit her weekly. The illness defined her in her later years but she never begrudged it.

On June 14, 2011 Sylvia was hospitalized and diagnosed with lung cancer. Sylvia had no family and limited support. I would visit her daily until her death on August 19, 2011.

Sylvia lived a frugal life with very few possessions. She had a passion for all living creatures. Upon her passing she chose to recognize with a financial contribution the two organizations that she admired and impacted her life. The Humane Society, and the Guillain-Barré Foundation of Canada.

I believe we both recognized that without the illness we would never have met and I feel truly blessed to have had her in my life.

Sylvia's friend forever,
Marg Bacon

Addendum: GBS/CIDP Foundation of Canada appreciates the significant donation left to us by Sylvie. It is overwhelming to know that by helping her with her GBS, her generosity will help so many of us too.

Manitoba Support Group Meeting – April 29, 2012

by Bill & Louise Haskett – Liaisons, Brandon, Manitoba, bill13@mymts.net

We had what I would call a very successful meeting. Bill Turner and his wife Joyce, and Leah Hyrsak, Physiotherapist were very appreciative of our asking them to come out and join us for lunch. There were three of us that Leah had helped get through their ordeals. Leah said it was a very rewarding experience for her to see us all doing so well. Bill Turner said he didn't know what he did to deserve the invite, We told him that we appreciated the help he gave us in telling people about our support group through his feed back radio show. Including Bill and Leah and two children there was 14 people for lunch. Just hope they don't start bring all their kids!!

They were real well behaved though. We had one couple that never miss, unable to come. One new couple we got from the radio show that we never met yet were also unable to attend. We all told our hard luck stories and gave much praise to the people in the hospital areas and especially our family members and friends for helping us get through these tough times.

Nova Scotia Support Group Meeting – October 21, 2012

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

At last spring's Halifax Conference, a few of the participants voiced an interest in getting together more informally.

I held the first Nova Scotia Support Group Meeting on Sunday, Oct. 21 in Truro, Nova Scotia. Five couples from Nova Scotia and New Brunswick met at the Atlantic Superstore Community room to share their stories and offer support. My 19 year old Lauren again shared her story of "What it is like growing up with a Mum who has CIDP". The group agreed to meet again in Spring 2013. Hope to see some new faces then!

Saskatchewan Support Group Meeting – September 9, 2012

by Gail Kammer - Regional Director and Liaison, Saskatchewan, gail.kammer@gbscidpcanada.org

My Saskatoon support group meeting was held on Sunday, September 9th . Four people attended. I did not have many people but the knowledge those people learned was invaluable to them. We had Susan Shimla, from the Canadian Blood Services, speak to us, and give us a slide presentation about the making of IVIG. The hour presentation was very informative. Susan spoke of what the Canadian Blood Services does in the process of making IVIG. She stressed that the best thing that a patient could do is to encourage people to donate blood, since many donors are needed to make one treatment.

After Susan left, the remaining people enjoyed juice and fruit and talked about the presentation. One CIDP patient was very satisfied because he had many questions answered by Susan. I would highly recommend having a representative from the Canadian Blood Services speak at your meeting.

British Columbia Support Group Meeting – September, 2012

by Sherry Nejedly – Director & Liaison, British Columbia, sherry.nejedley@gbscidpcanada.org

Our support group meeting in April in Vancouver turned out to be a very successful one. Everyone was pleased to have met each other and learn of our stories. Ben Patchel of Grifols Canada Ltd was there to answer questions for IVIG and Tracy Ross (GF Strong) gave a small demonstration on exercise for home use.

We had people coming from the north, interior and the Island of B.C. Approximately twenty five people. Suzan Jennings (Liaison) and I were very pleased with the out come.

Thanks to Ben Patchel and Tracy Ross for your help. Also thanks to all the survivors for attending:

Doreen Reid, Caleb Sigurgeirson, Barb Brooks, Carol Gowan, Bill Baker and Claudio Cuesta, Joan Wittenberg, John Jennings, Terry and Terese Ohman, Norman Nast, Rhonda and Bryn Henry, Agnes Jackman, Pamela Miller, Cheryl Dean and daughter Rachell and Alison Cohee .

It was good to see old and new faces. On behalf of the Foundation thanks again and hope to be doing others in the new year.

Fort Worth Symposium – October, 2012

by Gail Kammer – President & Secretary, gail.kammer@gbscidpcanada.org (Regional Director, GBS|CIDP Foundation International)

Greetings from the Fort Worth Symposium! We had beautiful weather during our visit, although it did get cooler as the week went by.

Susan and I met many new people from other parts of the U.S. and Canada. New connections were made that may help our Canadian Foundation in the future. I look forward to the new possibilities for future foundation growth.

A walk-a-thon was held on Sunday morning. It was in the water park close to the hotel. It started in the dark, but by the end of the walk we were in the light and had made new friends. The small waterfalls was beautiful to see.

During the sessions, I heard some heartbreaking stories from patients and families. Made me feel thankful for where I am. It is easy to feel sorry for yourself until you hear another's story. There are many strong people that have to deal with life's misfortune and then they are hit with GBS or CIDP. It is amazing how strong these people are and are not bitter about the life they have been dealt. They just deal with it. They are indeed inspiring!

Ontario Educational Event & Support Group Meeting –September, 2012

by Barb Sherman – Director, barbara.sherman@gbscidpcanada.org

Barbara Sherman, Wilma Koopman RN(EC)NP, and Sharon Ratelle, liaison, organized an Educational Event and support group meeting at (LHSC) London Health Science Center on September 10. Forty people attended. Dr Kurt Kimpinski, a Neurologist at LHSC who has experience in GBS and CIDP made the presentation. Dr Kimpinski did an excellent presentation. He allowed people to interrupt him during the presentation to ask questions on something he said, and also allowed a big chunk of time at the end for questions. He didn't stop until everyone was satisfied. Everyone felt grateful for his cooperation in giving them the opportunity to express their concerns and ask their questions.

A big thank you to Sharon Ratelle who helped register guests and helped me with the break time and making cookies and banana loaf and coffee for everyone. We had a few bracelets and pill boxes from the Foundation to give out as small prizes . We are very grateful to Dr Kimpinski and Wilma Koopman for their contributions and dedication to the GBS/CIDP Foundation.

The Rest of My Life – Third Anniversary Celebration

by Linda Paul - Liaison, Ottawa, Ontario, bluesmeorloseme@yahoo.ca

Three years ago today, I woke up and was not able to move from the waist down. My lower arms and lower face were also numb. This was my third and worst relapse. Two months and two relapses after an initial diagnosis of CIDP, finally got treatment. IVIG worked right away, and by next day, I was able to lurch a few steps. Looking back, I didn't know what to expect. I expected to be back at work after Christmas, before my sick leave ran, within a year, before I was required to take medical retirement. I never expected that this would be a long term challenge. I used to be able to swing dance all night, rock climb, hike, walk for hours, and I miss those things. I am still on IVIG and haven't had another relapse I can now walk inside with a cane; to church, the convenience store, the pub and restaurant with a cane; and to the grocery store and senior exercise class with my walker. Longer distances still require a scooter but I am lucky to live in downtown Ottawa where everything is close by. I've done easy canoeing twice (and once ended up in the canal), snowshoed on the easy path with two canes, can dance several slower dances in one night (rather than hang onto climbing again, though I still have problems climbing stairs, and walking with my walker in a zombie walk (it's hard to be walking dead on a scooter). I have had so much support from my family, from dance friends, church friends, work friends, GBS/CIDP Foundation friends from the community centres and disabled exercise. When I get frustrated with slow progress, I remember how far I've come and look forward to more. a guy than the walker).

Some of my goals include rock climbing again, though I still have problems climbing stairs, and walking with my walker in the zombie walk (it's hard to be a walking dead on a scooter). I have had so much support from my family, from dance friends, church friends, work friends, GBS/CIDP Foundation friends and friends from the community centres and disabled exercise. When I get frustrated with the slow progress, I remember how far I've come and look forward to more. This has been a longer post than I intended, but I wanted to mark the 3rd anniversary of the rest of my life.

Happily Ever After: My Journey with Guillain-Barré syndrome

by Holly Gerlach, holly.gerlach@hotmail.com

In early 2011, my life was perfect. I was 26 years old. My husband and I had been married for a year and a half and I had just given birth to our first child, our daughter Casey. I had always wanted to be a mother, and now that I was one, my life felt complete.

But things quickly came crashing down on February 22nd when Casey was 3 weeks old. It started with a tingle in my fingertips, a pain in my neck, and a weakness in my legs that made me think I had a pinched nerve. But when I stood up in the middle of the night to nurse my daughter, and fell to the ground when my knees buckled, I knew this was not a pinched nerve, and I went to the hospital.

I was lucky that the doctors knew what they were dealing with. I had a spinal tap and its results led my doctors to officially diagnose me with GBS. I was started on IVIG, but I continued to deteriorate. Within 12 hours I could no longer walk. By the third day the paralysis had spread, and I could no longer breathe on my own.

I was admitted to the ICU and hooked up to a ventilator. Then, things got even worse. When inserting the catheter to start me on plasmapheresis, my femoral artery was ruptured and I started bleeding internally. I had to have emergency surgery to repair the artery. My family was told that I may not make it through the surgery, but thankfully, I did.

It's hard to believe, that I spent almost 3 months in the ICU. I was completely paralyzed from the neck down. At one point, my paralysis was so bad; all I could do was blink. I couldn't talk. I communicated with my family by using a communication board. I was fed through a tube in my stomach.

But the worst thing of all for me was that I couldn't be with my daughter. I barely had the strength or the energy to even look at her. Even the idea of having her on my lap made me claustrophobic and gave me severe anxiety attacks.

Happily Ever After: My Journey with Guillain-Barré syndrome (continued)

I couldn't be the mom I had always wanted to be. Thankfully, my husband was able to take paternity leave and took a leave of absence from work to care for her, and to be at my bedside every day.

I was dealing with pain and nausea, and I found it hard to believe that I was ever going to make it out of this alive. I was severely depressed, and I wanted to give up every single day. My family continued to pray for me. And after being completely paralyzed for 6 weeks, their prayers were answered, when I moved a finger. Slowly, the paralysis started to fade and I started to recover.

After 4 weeks my lungs were finally strong enough to breathe on their own again, and the trach was removed. I was released from the ICU. Without the tube in my throat, I no longer felt nauseous. I could finally talk again, although my vocal cords were damaged which left my voice low and scratchy. But my hands were getting stronger every day, and the muscles in my legs were showing signs of movement. Now that I could actually see myself recovering, I regained hope, and I started fighting harder than ever. And then therapy began. Because I was immobilized for so long, I lost 30 lbs. of muscle. And although by that point I was no longer paralyzed, I was extremely weak. In Physiotherapy, I spent time squeezing stress balls strengthening my hands, and eventually they were strong enough for me to hold cutlery, and drink out of a cup. Then I spent hours each day lifting my legs up in the air and pushing against my physiotherapist's hands to rebuild the muscles in my legs.

The weeks went by, and eventually, I was strong enough to stand, then strong enough to take a few steps, and then strong enough to practice walking with a walker. After 6 weeks, I was then transferred to a Rehab hospital for more therapy.

I spent 3 weeks focusing on my fine motor skills, and learned how to type and write again, and also on my leg strength, where I ultimately learned how to walk with a walker all on my own. And after over 4 month's total, I was released, and returned home to my husband and my daughter, who was now 5 months old.

Although I was home, my journey was not over. I still had a long road ahead of me, including learning how to walk with a cane, and ultimately, how to walk on my own.. I was still severely weak and every little thing took more energy than I could ever imagine.

But as the months went by, and with the help of physiotherapy three days a week, I regained my strength and mobility. I could do more and more every week, and I reached each of my goals as time went on.

It's been almost 2 years since I was diagnosed. I am back at work full time, and my daughter is now 2 and a half years old. I do have a few lingering effects, but they don't affect my life. My ankles are weak, I walk flat footed, my balance is lacking and my muscles are always very stiff. But considering how far I have come, I am extremely grateful as I know it could be worse.

After I was released from the hospital, I was constantly being asked what it was like to go through what I did, and it was impossible to share that with people in just one conversation. But I really wanted to share my story, so I started writing. And 9 months later, 200 and some pages later, my book, Happily Ever After: My Journey with Guillain-Barré syndrome, was complete. I am now determined to share my story as much as I can and help create awareness on this devastating disorder. Even though it was the worst experience of my life, I absolutely would not take it back. I am a different person now and I appreciate life so much more. I am grateful that I can walk again, I am grateful that I can be the mother I always wanted to be, and I am grateful to be alive. I live my life so differently now, I live life to the absolute fullest, I get out and do things that I've always wanted to do, and I spend a lot more time with those that I love.

If you're interested in seeing more on my journey, you can watch my video on You Tube, titled Holly Gerlach's Journey: From Guillain-Barré syndrome to Happily Ever. The video is a compilation of home movies of my time in the hospital.

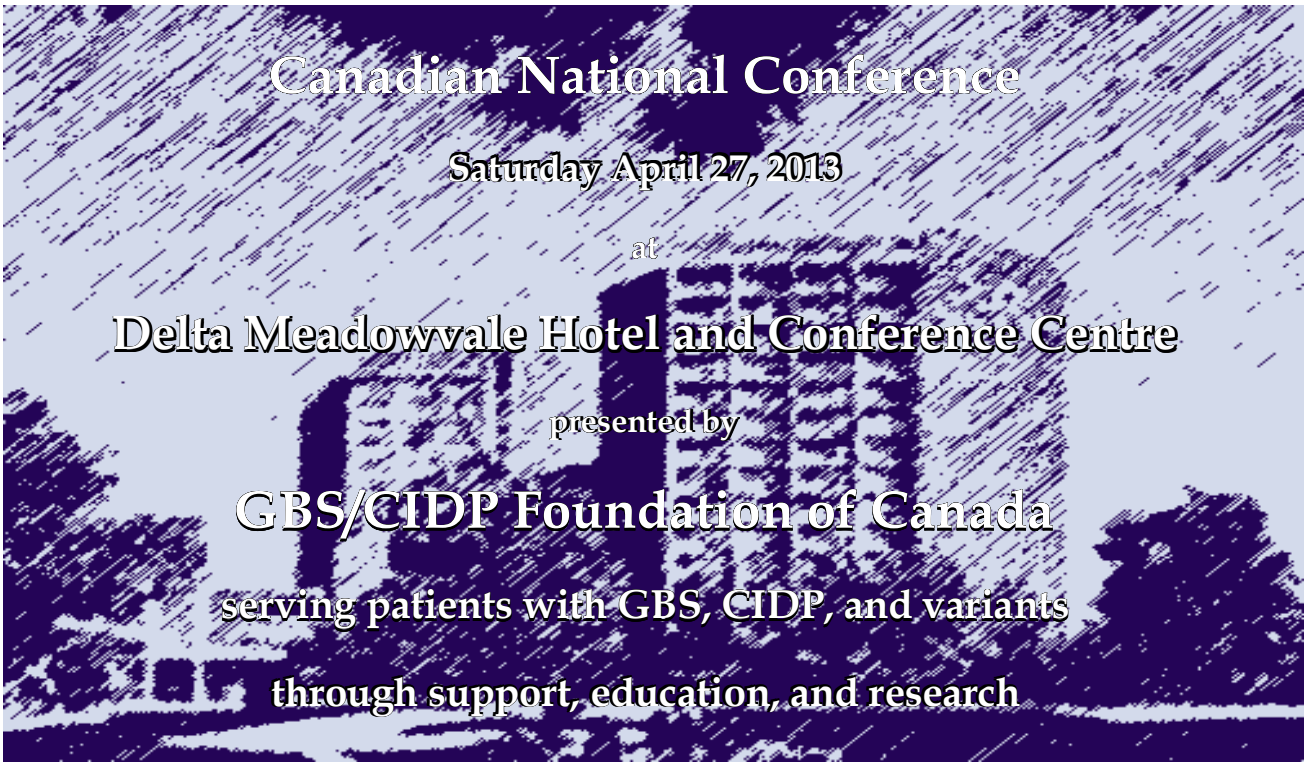
Announcement

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.
- CanadHelps 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 your year-end gifting. Tax deductible receipts will be given for all gifts of $10.00 or more.



Suzan Jennings – Liaison, Vancouver Island, British Columbia

Contact her at, suzanjennings@shaw.ca

Greetings fellow GBS & CIDPer's. As many of you know, my husband and I have retired to Parksville on Vancouver Island. Being that my husband is of retirement age and I am permanently disabled, we decided that we wanted to move somewhere that provided a nurturing environment for us, as we both enjoy volunteerism, but also somewhere that would be peaceful for our well being. I am excited to say that we have certainly found it. An exciting by-product of our move is that the GBS/CIDP Foundation of Canada has never had a liaison dedicated to Vancouver Island so I knew from the start; this would generate a huge challenge for me. As many of you can appreciate, when you acquire GBS or CIDP, your immediate world changes overnight. Over time, many regain most of their lost abilities but others, like me, are left with considerable deficits. I am sure many of you are sitting there right now bobbing your heads in agreement. After I went through the initial phases of being mad, sad, bitter, frustrated then came an overwhelming desire to 'make a difference'; just to be there for others, as they manoeuvre through their personal journeys.

This past September, my husband (*otherwise known as my driver)* and I arranged to visit Victoria, which is a 2.5 hour drive down the island where I made appointments with several patients and medical professionals including Neurologists and Physiotherapists. This picture below is of me with Marina, in the middle, who acquired GBS in 1986 and lived in Prince George then. She used to go around and put up posters, talk to doctors...all the things we as 'liaisons' do but she did not have a title. She had been just fine and then a few years ago, one of her legs started numbing again so she saw her doctor. It turned out that she was fine and was not having a GBS relapse, but felt that she needed support from the Foundation so contacted us. This was an especially important meeting for me because I was finally meeting Marina after dialoguing with for over 2 years.

In this picture, I am also with Louise on the right. We met for breakfast with Marina, who was a friend of hers, who had been diagnosed just this past July 2012. Luckily, she experienced a very mild case and stayed in the hospital for 10 days, did not require attending outpatient rehabilitation and took to the water for aqua therapy instead. As a retired school principal, Louise is focused and driven. She lives in Sidney with her husband and because she had trouble manoeuvring the stairs, they installed a chair lift for her in their home. On the morning of our meeting, her husband was not feeling well and did not want to disturb him so she drove herself for the first time! Louise has an extremely positive outlook and is just taking each day as it comes; just a lovely lady.

To my right is Lindie who has CIDP. She lives in a great family dynamic and I cannot stress the importance of "family power" here and we were so impressed with her mom Alice, father Richard and sister Sheree Like many, Lindie is having a real struggle dealing with all the side effects of CIDP. It just so happened that one of our own liaisons, Rhonda Henry, who also has CIDP, was going to Victoria and had arranged to meet with Lindie and her family. Thanks Rhonda!

Here I am with Bob, who after a very serious case of GBS, is now able to work part time as a personal trainer, and just recently, went on vacation to China with his lovely wife. Bob is a very determined man and refuses to become a victim and has fought his way back to recovery. Way to go Bob!

If you know of anyone on Vancouver Island that previously had GBS, currently is hospitalized or has CIDP, or if you would like to simply talk to me, please feel free to pass on my contact information. From me to you, *'keep on keeping on and just remember that you can only do what you can do!'*

My GBS Story

by Bob Cowen, Regina, Saskatchewan, bbcowen@sasktel.net

Like most people, I had never heard of GBS but that all changed on Feb.4/2002 three weeks before my 46th birthday. As I am now a survivor for 10 years, I will try and relay my story as best I can. Part of the reason for telling my experience now is for those who have not had as positive an outcome as the majority who have been inflicted with this syndrome.

Sat. Feb 3rd was a normal winter day which included partaking in a recreation hockey game. Woke up Sunday morning feeling a little sluggish in the legs which didn't seem out of the ordinary after playing hockey the night before. By mid afternoon the sluggishness elevated to a point where I knew something wasn't right. My legs became very heavy and my arms were affected as well. Coming from a small town, we knew the local Doctor quite well and gave him a call in the evening. He gave some indication (and was correct) that he knew what might be wrong with me. He told me to go to bed and if the condition was still present in the morning I was to go to emergency.

Very early Monday morning I woke up with legs 50% paralized, blurred vision and a feeling that my whole body was beginning to seize up. We(my wife and I) immediately got dressed and headed to the hospital. As is usual in the emergency ward things moved very slowly, and until I fell down in the washroom and was screaming in pain no one seemed too concerned.

By Sunday night I was in a bed on the neuro ward and had some tests including a spinal tap which confirmed I had GBS. By mid morning on Tuesday I began feeling like I couldn't breathe and the pain was unbearable. As soon as nursing realized I couldn't breathe I was rushed to ICU where a vent was inserted and this would be my home for the next 6 weeks. Part of my care in ICU was plasmapheresis and IVIG both of which seemed to have little effect. Life in the ICU was a heavy dose of morphine which took away some of the pain but no where enough to deal with pain like I have never encountered before. I was 100% paralized although I could move my eyelids to indicate yes or no by blinking. I have memories of family visiting and nurses caring for me but most of my time was spent in hallucinations which later took months to sort out what was real and what was only in my mind. Nearing the end of my six week ICU stay my drugs were reduced significantly so they could assess my condition. It was determined that I was ready to go to an acute care ward to continue my recovery.

For the next 6 months I was with it mentally but watched the clock intently waiting for my next dose of morphine to deal with my continuing intense pain. I had many visits from both physio therapists and respiratory therapists who worked hard at attempting to get me off the ventilator. During this period my only communication was with a word board and facial expressions. I believe it was about my 4th month anniversary when the respiratory people inserted a speaking valve into my vent. This simple act changed life greatly as I could now communicate with the hospital staff and my family. The trach stayed in for a total of 8 months. I should also mention that due to the caring of a particular ward manager I was given a burn bed (air filled) which helped tremendously with pain management. For the last 2 months of my 6 months stay in acute care I had daily visits to the physio therapists to begin stretching and sitting exercises. It was quite an accomplishment when I reached the 1 minute mark of sitting unassisted. It was now time to move on.

I was sent to Wascana Rehab Hospital where I spent the next 18 months. I believe it was my second month there when I lifted one arm off the bed. This was the first time I truly felt better things were meant to come. For the next 18 months there was slow but steady improvement as I persevered through 3 to 4 hours of therapy a day.

At 18 months it was agreed by all that I had achieved as much as I could at Wascana and it was time to go home. At this point I had reasonably good arm movement and improved core muscles and got around quite well in my electric wheelchair. My wife and I bought a condo and started our new life outside of the hospital system. At about two and a half years from onset, my wife and friends decided it was time for me to go back to work. I was very apprehensive about the whole work idea but it turned out to be a positive move and I continue to work as of today.

I can't and will never walk and my hands are non functioning but with a few adaptive aids I can use the

My GBS Story (continued)

phone and my computer which gets me through the work day and I can eat on my own.

I've been fortunate to have a wonderful wife and family who look after all my special care needs and helped me through the mental aspect of overcoming the hardships caused by this syndrome.

I encourage all of those who have been hit the hardest with GBS to keep battling and realize that even with physicals disabilities there can be great joy in life. I watched my 3 beautiful daughters get married and now have seven wonderful grandchildren to keep life exciting.

Carol Fay's Story

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Of course, we had to be on holiday when it happened. My husband Rod and I who live on Vancouver Island had just spent five wonderful days in New York and were four days into our trip to the Maritimes when I had to go to the ER in Charlottetown, PEI. For the previous four days I had been gradually losing my strength, beginning with my arms falling from my head as I was washing my hair in the shower. The ER doctor ordered blood tests. The results indicated nothing was wrong and I was to return the next day for a CAT scan. The CAT scan did not show that anything was amiss. But the ER doctor told me that he suspected Guillain-Barré and that he would do a spinal tap to confirm his diagnosis. He was right: the spinal tap indicated GBS. I was admitted to the hospital immediately and treated that same day with my first course of IVIG.

For the next 25 months GBS was to take me to five different hospitals. I was to be on a ventilator for 16 months, be on a tube feed for over 2 years, have my eyelids sewn together for more than a year. I was to be totally paralyzed from head to toe, and my strength would become almost non-existent. I would not be able to move my hands, let alone lift anything. But GBS affected my family even more. My husband and sons and their families saw me through the worst times in the ICU, the year in the Respiratory Unit, four months in the Health Care Centre and the final four and a half months in the Rehabilitation Unit. For them, the emotional turmoil of watching me descend into the depths of GBS and having to advocate on my behalf, as well as the sheer hard work of attending to the practicalities of my care and the expenses involved must have been exhausting. But in Charlottetown, we did not know any of this. After being admitted I was interviewed by both a doctor of internal medicine and a neurologist.

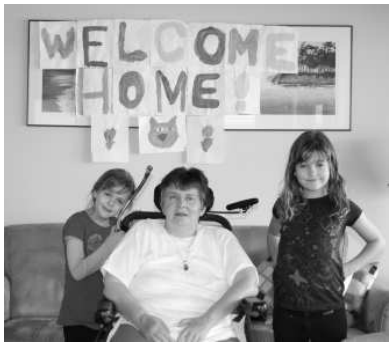
They wanted to be sure of the diagnosis and I felt that I was in very good hands. But I gradually got weaker. The first course of IVIG seemed to help a little, and Rod helped me walk down the hall outside my room. But the good effect wore off and despite a second course of IVIG I got weaker and couldn't walk or feed myself. I was in the Charlottetown hospital for over three weeks before I was taken back to Victoria, British Columbia in an air ambulance. Thank goodness for travel insurance!

Once back in Victoria I got steadily worse and within a week I was on a ventilator and in the ICU. I remember that during my three months in the ICU I experienced lots of terrifying hallucinations among the moments of reality. I kept my mind occupied by trying to recall poems that I learned by heart. I was able to communicate only blinking my eyes in response to questions. However, this became painful as the muscles in my eyelids became weak and I could not close my eyes. This was the beginning of a very painful period. I was unable to communicate to anyone that my eyes were sore, but my family noticed how bloodshot my eyes were and they could see the arc of debris at the bottom of my eyes caused by my inability to blink the dust away. My family raised the alarm, but it would be months before my eyes were sewn shut.

This was the best thing that happened and I will always be grateful to the ophthalmologists who took care of me, often coming in at night to check on me. My corneas were damaged however, and my eyesight is much worse than it used to be.

Carol Fay's Story (continued)

After three months, I was well enough to leave the ICU and I was transferred to the respiratory unit in another hospital. I was there for just over twelve months. It was here that I first began to get better. The nurses and the respiratory therapists were the best ever. I still remember them with great fondness, and I will always be grateful for their skills, patience, understanding and the support they gave to my family.



Two of my granddaughters welcome me home

On January 1, 2011 I was fitted with a Passé-Muir valve that enabled me to talk for the first time since September 2009. My husband came in to visit; the nurses placed themselves strategically behind him. I said, "Happy New Year." Rod nearly fell over, and the nurses were nearly crying with happiness. It was a moment to remember.

By the beginning of February, I was off the ventilator and it was now time to move to another hospital. I was taken to a Health Care Centre in my hometown. This made it easier for Rod to visit (he had rented a small furnished apartment when I was in Victoria). Rod bought a wheelchair van and he took me home for short visits. It was wonderful to be in my own home!

I began physiotherapy daily, and with the help of two dedicated physiotherapists, I began to improve – not that anyone would notice, but the physios charted the improvements. Their careful and precise observations were a contributing factor in getting me into a Rehab program at Nanaimo Regional General Hospital. I began Rehab in late May 2011.

I spent 18 weeks in Rehab. When I arrived there all I could do was lift one leg a little way. When I left I could do sit-to-stands, albeit with some difficulty (sit-to-stands are still a challenge for me) and I could walk with a two-wheeled walker. I could also feed myself with a spoon. I was allowed pureed food only as my swallow was still too weak for solid foods. My main source of nutrition was still via the tube-feed.

It took many weeks of therapy in the pool, and daily stints in the gym to get me to the point where I could come home. I was lucky to have a physiotherapist, an occupational therapist, a hand therapist, a speech language pathologist, a dietician, and two physiatrists who never gave up on me.

I have been home for eight months. I can now walk with a four-wheeled walker and no longer need a tube-feed. I feel my balance and strength returning, albeit ever so slowly. I feel so lucky that I helped by so many professionals, friends and especially my family.