A Message from Susan Keast, Executive Director

Spring is here again, full of hope and new things going on in the medical community for the health and well being of our patients and their families. Its the time of year that I love to report all that has been going on over the winter. Each one of you are the reason we work so hard to make sure your health is at the top of the list.

As you know our mission of "support, education and research" is our commitment to you. We listen to you and try to move in the direction that will help you the most. We are in the middle of getting the information put together from our survey that you all took part in and in the fall newsletter we will have that data for you. I do appreciate learning from the survey, that most of you enjoy our newsletter and said that your connection to others through the newsletter and what you learn was the most important.

We work hard with our medical professionals to help you know and understand your GBS, CIDP and variants. New treatments are becoming available, more doctors are joining our Foundation to help in your wellness. Their support of what we do makes us a strong working team. The support of our pharmaceutical companies shows not only their support in what we do, but their belief in you and their aim is to see you get well.

We now have an Education Committee that is reaching out to raise awareness in all areas, but particularly in rural areas, and in hospitals where our diseases are still very much unknown. We all know too well what it is like to go to an emergency room and be sent home many times being told that whatever we think we have is all in our heads. Each one of you can help in this education and awareness. Doctors in small towns need to know what GBS and CIDP are, and what the treatments are so that everyone has a fair chance of getting well and returning to their normal lives.

Please note that we are asked often to recommend the best rehabilitation centre where our patients can get the best physiotherapy. If you would like to pass on information from your rehabilitation centre, please email us so that we can provide this list to others. It is very important that the facility recommended has helped other GBS, CIDP and variant patients. Remember when sending in your rehab centre name, please ask their permission to let you do this. Having centres recommended from "outside any city limits" is needed so that those who live in other areas, of any province, can receive the best of care.

Also in this newsletter, we are introducing you to the Canadian Blood Services. I am sure you are wondering why this would be important to us... please read their article, it is very interesting.
A Message from Susan Keast, Executive Director (continued)

We will be working closely with Canadian Blood Services so that we can bring you the most up to date information on what is new, how things work for you and again help to raise awareness about blood products. In Canada the pharmaceutical companies and Canadian Blood Services want to work with you to make sure that everything is helping you in the way it should. If for any reason something is not working right in your treatment, or with your hospital, and/or clinic where you get your treatment, please let us know or your doctor know. This is the only way we can get to the bottom of things.

Remember we work as a team for the good of all.

The stories that you send in to share are so helpful to others. Patients and families realize that they are not alone. Keep sending them in, your accomplishments are amazing. Nothing is more exciting than when we visit patients and watch them take their first steps, move a finger... Each one of us can remember the delight in knowing that we were on our way to recovery. We watch with pride all your accomplishments.

Now for those who have residual problems, or who are having difficulties with their GBS and CIDP because their lives are not returning to normalcy, and then there are those who get GBS several times, and while this is not common, it does happen. There are those with CIDP who need support and help for many years, so again we need to reach out to everyone to support and to let them know that they are not alone.

Please note the new addition to our Medical Advisory Board, Dr. Jiri Vajsar. We are so lucky to have so many wonderful doctors on our Board. We are grateful for their commitment to each of you as well as to the Foundation.

This newsletter is filled with some very important notices, so please read this cover to cover so that you don't miss anything.

This newsletter will appear on gbs–cidp.org/canada web site so that you can download it or read it on line. This same newsletter will also appear on gbs–cidp.org/french.

Booklets on the "Overview for the Lay Person" are now available in French as well as Spanish. Please let us know if you wish any of these.

Summer will soon be here and I wish each of you the Very Best. Be Safe and take care...

Susan Keast, Executive Director
keast@zing-net.ca

Addendum – Bob Benson

We have inserted the announcement sent to us by the International Foundation, about the passing of Bob Benson.

As most of you know the International Foundation was started by Bob and Estelle Benson because Bob himself had GBS. It is because of the generosity of both Estelle and Bob that our Foundation in Canada was able to become a reality. Our Foundation will miss Bob, his wonderful sense of humor and above all the support he has given to us to help us grow into who we are today.

We will always be grateful for the time he has given to each of us in helping this Foundation as well as the International Foundation become a Family of connected patients right around the world. His contributions to the world of GBS and CIDP are immeasurable and all of us who knew him will miss him not because of all that he has done, but as just "Bob", our friend.
Quality of Life in Chronic Immune Neuropathy
by Vera Bril, MD

Patients with CIDP have nerve injury because the body's immune system attacks the nerves producing symptoms such as pain, numbness, tingling and weakness. As a result of this abnormal immune activity and the nerve damage, people have varying degrees of disability. The disability interferes with different aspects of life leading to a change in the quality of life. For example, patients may not be able to work, may not be able to participate in sports or even walk properly, may not be able to participate in social activities at home or in their community, may have stopped hobbies that they enjoy, and many other limitations might be present. At this time, we don't know the best way to assess the quality of life in patients with CIDP as specific measurement scales have not been developed. Some general quality of life scales are used, but these are not specific and likely don't capture properly all the elements that affect patients with CIDP or other forms of immune neuropathy. It is important to understand how quality of life is affected in patients with chronic immune neuropathy in order to fully understand the impact of these disorders on people and on society. We need to fully understand all the limitations that face our patients. In the clinic, we ask the patient about feelings of pain, weakness, numbness and tingling.

We measure strength, reflexes, sensation, and walking ability. We measure nerve conduction studies. However we do not typically talk about quality of life in any detail.

It is important to have a specific quality of life scale for chronic immune neuropathies, but the scale used has to be proven to be valid, that means reliable and truly measuring disease elements as we think it will.

In light of the need for a specific quality of life measure, we agreed to join a multicenter research study about quality of life in patients with chronic forms of immune neuropathy, including CIDP, and variants such as MGUS. Ted Burns from the University of Virginia started the study, and we are really happy to be working with him on this very important project. In this study we ask patients to identify their most prominent feature of neuropathy such as clumsiness, imbalance, pain, numbness or weakness. Then the patient is asked to complete several questionnaires. One questionnaire talks about activities such as reading a newspaper or book, eating, brushing teeth, washing upper body, sitting on the toilet, making sandwiches, doing dishes, taking a shower, going shopping, etc. These activities are rated as impossible to perform, performed with difficulty or easily performed. This scale is called a Rasch-built disability score. We also are doing the Rand 36-item health survey that asks questions about overall health status now and compared

It is with deep regret that the GBS|CIDP Foundation International announces that Robert (Bob) Benson, the inspiration for our foundation, died on May 17 from cancer.

Bob, who had Guillain-Barré syndrome in 1973, founded the organization along with his wife, Estelle.

At his family's request, contributions in his memory can be made to The Robert and Estelle Benson Fellowship in Neuromuscular Neurology. Please call 610-667-0131
Quality of Life in Chronic Immune Neuropathy (continued)

to a year ago, and then asks about other activities and these are rated as limited a lot, limited a little, or not limited.

These include different activities grouped as vigorous and moderate as well as activities such as climbing stairs. The patient is asked about the ability to work and the type of work that can be done. The patient is asked about their mood and whether they are feeling worn out, tired, blue or lacking energy.

Together with the Rasch-built disability and 36-item Rand scales, we check a new scale call the "Chronic Immune Mediated Polyneuropathy Patient Reported Outcome 20" (= "CIPPRO 20") scale that has 20 questions and rates the responses at 5 levels as: not at all, a little bit, somewhat, quite a bit or very much. This scale asks about activities such as walking, family activities, occupational skills, use of hands and other activities. In the study, we will also do a standard assessment of physical impairment with the Neuropathy Impairment Score (NIS). The physician completes the NIS after examining the muscular system, reflexes, sensation and grip strength.

All of the tests and questionnaires are done at the beginning of the study and repeated after 4–6 months.

The study is being done in about 60 people altogether with 15 to 20 from Toronto. At the end of the study, all of the scales will be compared to determine which is the best and whether the specific scale, the CIPPRO 20, gives a more accurate determination of how the patient's quality of life is changed by their neuropathy. The quality of life scale is meant to measure problems faced by people with chronic immune neuropathies, and so is not meant for GBS.

In these difficult economic times when governments look for any areas where they can cut costs, it is very important to be able to demonstrate to all health care providers, the Canadian Blood Services (and Heme Quebec), and the Ministry of Health officials holding the purse strings that chronic immune neuropathies have a major impact on quality of life and that appropriate treatment reduces disability, and improves quality of life. The CIPPRO 20 promises to provide a valid way to capture quality of life information in patients with chronic immune neuropathies.

We are honoured to welcome Dr. Jiri Vasjar to our Medical Advisory Board

Jiri Vajsar, MD, MSc, FRCPC, is an Associate Professor, and Clinical Director of Pediatric Neurology, Department of Pediatrics at The Hospital for Sick Children, and University of Toronto, Canada. He has a long standing interest and expertise in pediatric neuromuscular diseases including juvenile myasthenia gravis, autoimmune neuropathies, muscular dystrophies, congenital myopathies as well as in pediatric EMG. Together with Professor Dr. Darcy Fehlings from BKR they have completed and published a study dealing with long-term outcome of pediatric Guillain–Barré syndrome.

Thank you CSL Behring Canada for making this newsletter possible with an unrestricted educational grant
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.CanadaHelps.org website to make your donation.

Differentiating Acute CIDP from GBS - A Diagnostic Dilemma Eased by Recent Studies

by, Steven K. Baker BA, BEd, MSc, MD, FRCP(C)
Associate Professor
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Neuromuscular/Neurometabolic Disease Clinic
Hamilton Hospital Assessment Center Chair in Neuromuscular Rehabilitation
McMaster University

Guillain–Barré nervous system (PNS). Sensory, autonomic, and motor fibers are affected, however, it is the dramatic disability associated with the latter that generally draws the most clinical attention.' From a temporal perspective GBS reaches a clinical nadir within 4 weeks and is monophasic. This is an important distinction from the chronic form of the disorder (i.e., acquired PNS demyelination) termed chronic inflammatory demyelinating polyneuropathy (CIDP) because treatment is different. The disease course of CIDP is generally more indolent than GBS and produces disability over a longer time-course.

The onset kinetics of this condition typically transpire over a minimum of 8 weeks and can either be progressive or relapsing–remitting (analogous to multiple sclerosis which affects the central nervous system).

In this context, when a patient presents with a history of gradual deterioration (i.e., 8 weeks) with electrophysiologic evidence of demyelination, CIDP cannot be confused with GBS. However, in up to 15% of cases CIDP presents in an uncharacteristically rapid fashion—termed acute-CIDP (aCIDP). Initially misdiagnosed as GBS, subsequent relapses and/or ongoing need for IVIg prompt a revision in the diagnosis.
Differentiating Acute CIDP from GBS - A Diagnostic Dilemma Eased by Recent Studies (continued)

To complicate matters, GBS can recur (rGBS) rendering definitive diagnostics difficult at the time of first relapse. Given that both GBS and CIDP respond to IVIg, the standard treatment, there is no immediate therapeutic disadvantage for the patient. However, CIDP is steroid-responsive (whereas GBS is not) and frequently requires long-term immunosuppressive therapy. Therefore determination of the correct diagnosis, early in the disease course, will facilitate prognostication, optimize treatment decisions, and significantly influence health-related quality of life.

Two recent studies have addressed the question of how to distinguish GBS from aCIDP, or alternatively, rGBS from CIDP. The Dutch GBS Study Group found that aCIDP patients, in contrast to rGBS patients, have (1) 3 exacerbations compared to 52 for rGBS patients, (2) less clinical disability at presentation, (3) less cranial nerve involvement, (4) less respiratory compromise, (5) slower motor nerve conduction velocities, (6) demyelination without pure axonal loss, and took longer to reach both (7) their clinical nadir at onset (median duration: 16.5 vs 8.5 days), and (8) their first exacerbation (median duration: 51 vs 18 days). There was a trend for aCIDP patients to have more active denervation compared to rGBS patients (p = 0.06). No differences were found in antiganglioside antibody reactivity, cfs protein levels, terminal motor latency prolongation, or conduction block.

Dionne et al. extended these findings noting that the inflammatory process tends to affect the sensory PNS more in aCIDP than GBS. For example, prominent sensory symptoms, sensory ataxia, severely impaired vibration sense, and mitigation of pinprick in a length–dependent fashion occurred more frequently in aCIDP. Additionally, autonomic dysregulation accompanied GBS (70%) more often than aCIDP (13%). Similar to the Dutch study, the need for mechanical ventilation due to respiratory compromise was more frequent in GBS (37%) vs aCIDP (7%) as was facial weakness (i.e., CN VII; 57 vs 20%) and the presence of an antecedent infection (77 vs 33%). No sensory electrophysiological data as assessed by sural sparing, sensory ratio (sural + radial/median + ulnar), or A–waves could distinguish aCIDP from GBS.

Despite the significant differences between aCIDP and GBS that were highlighted in these 2 studies, no biomarker, clinical scoring scheme, nor regression equation can reliably differentiate these mimic immune-mediated neuropathies. Therefore, clinical acumen must continue to govern treatment decisions. Nevertheless, these data do call for increased surveillance in a patient who presents with predominant sensory symptoms and slower motor nerve conduction velocities without respiratory, cranial, or autonomic involvement. Such patients should receive additional information regarding signs and symptoms of a recurrence in order to mitigate disease progression and expedite rescue therapy. If a relapse does occur it is more likely to do so earlier in rGBS (<3 weeks) than in aCIDP (<8 weeks).

Finally, a discussion of rGBS is somewhat incomplete without addressing the role of vaccinations— particularly influenza. A recent collaborative paper from the Kaiser Permanente Vaccine Study Center and the Centers for Disease Control and Prevention addressed the issue of rGBS following vaccination. Briefly, 550 cases of neurologist–confirmed GBS were identified over an 11–year period (1995–2006). Follow–up data was collected until 2008. Eighteen of 550 (3.3%) patients had onset within 6 weeks of receiving trivalent influenza vaccine. Of these, 2 were revaccinated without recurrence. Only 6 of 550 patients experienced rGBS and none had exposure to any vaccine in the preceding 6 weeks. However, 5 of 6 patients reported antecedent infections (3 respiratory, 1 strep pharyngitis, 1 gastrointestinal). Importantly, of the 550 GBS patients 107 received a total of 405 doses of TIV over the follow–up period and no cases of rGBS were documented. Currently, the Advisory Committee on Immunization Practices recommends against vaccinations in anyone who developed GBS within 6 weeks of a previous vaccination. This recommendation does not extend to those with a history of GBS not associated with previous vaccination. This position is supported by the above study but due to the small sample size and the potential errors in charting definitive larger–scale follow–up studies are still needed.
Differentiating Acute CIDP from GBS - A Diagnostic Dilemma Eased by Recent Studies (continued)

References


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Canadian Blood Services

it's in you to give

Did you know that for every person in Canada who suffers from GBS or CIDP, approximately 93 people are needed to donate the blood required for a single course of treatment? Amazing as that may sound, it's true.

Last year, Canadian Blood Services collected close to one million units of blood, and processed it into the components and products that are administered to thousands of recipients each year.

One of those blood products is intravenous immunoglobulin (IVIG), a blood product manufactured from a concentration of antibodies from donors' plasma—a protein–rich component of blood that supports the immune system and helps control excessive bleeding.

It takes many donations to manufacture one treatment of IVIG for a GBS or CIDP patient. The average patient requires roughly 140g of IVIG in a treatment series, which means that it takes the blood donations of about 93 generous blood donors to treat one GBS/CIDP patient.

How you can help

As it can take many units of blood to help one patient, Canadian Blood Services is rallying communities across the country to come together – Rally Together to Save Lives – as a way to show that collectively, blood donations have a positive impact on people's lives.

If you are a friend, caregiver or family member of someone with GBS or CIDP, please make an appointment to donate blood, and ask others to join you. Consider hosting an In Honour clinic for the person you know needs blood and blood products.

Another way to help support the blood system is through volunteering. Our volunteer opportunities make the experience even more rewarding—nothing is more gratifying than knowing that the time you contribute saves lives.

For more information, or to book an appointment, visit our website at www.blood.ca or call 1 888 2 DONATE (1-888-236-6283).
The Making of Plasma Products

Events around the Country

Support Group meetings:

British Columbia - April 14\textsuperscript{th} – contact Sherry Nejedly at shernej@gmail.com

Alberta – April 21\textsuperscript{st} – contact Fran Thornitt at scotlind@telus.net

Manitoba – April 29\textsuperscript{th} – contact Bill Haskett at bill13@mts.net

Nova Scotia – May 29\textsuperscript{th} – Eastern Canada and Quebec Conference – contact Susan Keast at keast@zing-net.ca

Saskatchewan – June 3\textsuperscript{rd} in Saskatoon – Contact Gail Kammer at kamm1989@hotmail.com

Ontario – Meeting to be announced in Ottawa, summer of 2012

All areas of Canada have been busy with visitations to patients and their families. We are so lucky to meet so many and to give them support. What a wonderful experience it is to watch each person succeed in their goals of wellness.

If you wish to meet with your liaison, please give them a call to see when you can have a meeting or just a one on one visit.

Remember, we are here for you.

Thank you to each of our liaisons who give their time to help you get better.
What's happening in Alberta
by, Fran Thornitt

Things have sure been revving up in Alberta during the past year. In one year we have gone from one member to almost 30! What really gave us the boost was having the Edmonton Conference last fall. We had a large number of our new members show up there and have continued to grow since then.

With the help of great volunteers, like Marilyn Rose (caretaker) and Charlie Cahill (CIDP) and the wishes of many more, we were able to get our support group off the ground. We held our first meeting in January and are all looking forward to our next one on April 21st. We have decided to hold four meetings a year. We have twelve members as of now and are hoping to add a few next time. I am also hoping to entice a speaker soon.

We have also started a mini-library so that members can borrow books by other caretakers and patients. I hope to include articles from medical journals, etc. for patients to read as well.

It's been a great year! We are hoping that this next year will be even better!

My Personal Battle with CIDP
by, Fran Thornitt

Handicapped, disabled, invalid. These are words that I would never have applied to myself until March of 1998. A few weeks before I had had a bladder infection and then I woke up one morning and found that my right toe was numb. I didn't know that this was the beginning of a lifelong battle with my body, my mind, and my very life.

The numbness continued upward over the next few weeks. I became steadily weaker; so weak that even a walk through light snow with my dog became impossible. I thought that perhaps everything was linked to the clinical depression that I was going through.

They sent me home on the 6th day. By that time, I could walk a bit and had feeling returning to my hands and arms. I struggled with fatigue and spent my days in bed as much as possible. I was at home alone as my husband, Ed, was working. We couldn't find anyone to come in and sit with me. I was terrified of falling and did so on a regular basis.

I try to send out one newsletter a month to all our members via email. That's a Gail Kammer idea.

I try to bring everyone up-to-date with what's happening with GBS/CIDP in Alberta, and Canada as well as other bits of news about these conditions.

I gave a presentation on "The Life of a Patient With CIDP" in Calgary last fall to about 250 nurses, physiotherapists, and a few doctors. It was well received, but we would like to do more education in hospital and media settings. That is our next goal along with helping more people with GBS/CIDP.

We now have a temporary liaison, June Adams, in the city of Edmonton. Charlie Cahill is our new support person and works hard for our foundation.

My problem was that I was so weak I sometimes couldn't get up and had to lie there for hours waiting for Ed to come home from work at noon or at supper to get me up on my feet and back in bed.

I was always spilling things on the floor or the table. My husband has a lot of patience, but I could tell he just didn't understand. I couldn't do anything by myself. I tried to go back to work three days a week, but it was too much. I was forced to go on disability leave. The depression set in, now with its companion — anxiety. I went through each day in a shadowy existence. I would get up and use my walker to try and get to the kitchen to make a piece of toast and a cup of coffee. I would shuffle back to our room and lie in bed till Ed got home for lunch. Afternoon — same procedure. This went on for months. The computer was downstairs so I couldn't go down and research anything.
My personal battle with CIDP (continued)

I felt guilty because I couldn’t look after my children, who thankfully were teenagers, or my house. I relapsed in June 1998. They tried steroids as a treatment, but they didn’t work. I had aches and pains and burning on the soles of my feet. I had poor bladder control and had to use diapers. I had constipation. I was unable to concentrate, so I couldn’t read or follow the plot of a book or movie. I had sleep problems and horrible nightmares.

I cried for endless hours worrying about the future. I was still alone.

On Christmas morning of 1998, I was the first one up and I bent over to turn on the tree lights. I totally lost my balance and crashed headfirst onto the hardwood floor. It was the worst fall I had ever taken. Ed and I decided not to go to the hospital as we had a houseful of guests. I must have a very hard head as I did not develop any sign of a concussion. At this point I was being treated with WIG. Ed and I would have to travel to Edmonton for a two day treatment. Eventually, I was able to get my treatments at home in Whitecourt.

I had another relapse on March 1, 1999. Once again I could not use my legs or arms. It was then that I was given a permanent diagnosis ― CIDP. Again, no information was forthcoming. They increased the dosage of WIG up to three days. Finally, the dosage became three days every eight weeks and I continued to improve.

Now I felt that I had lost everything. I was forced to resign my job permanently on June 11, 2008. My old self was gone and in its place was a failed wreck. I couldn’t do any of the things I could do before. While I had GBS there was at least some hope and now all hope was gone. I couldn’t ride my horses anymore.

I couldn’t run 5km four times a week. I began to gain weight and slowly rose from my normal 135 lbs. to 230! CIDP changes your life forever. You will never be the same.

But you can find other reasons to go on and to give back. After I could go downstairs safely, I began to research GBS/CIDP. First I found the American Foundation and for the first time I started to understand what had been happening within my body. I registered my name and address with them. Soon I got a call from Maureen Kachmar, a woman who I believed saved my life.

We talked on the phone for an hour. She gave me tips on how to live with CIDP. Then she handed me over to the Alberta liaison who became a close friend. We would talk once a week in the beginning and she sent me valuable literature on how this condition worked. I wasn’t alone anymore. It was through Lila, the liaison, that I decided that I could give back and help other people so that they would not feel as alone and in the dark as I had. I had worked as a counselor in many elementary schools for twenty years, so I had the basic skill set. When Lila wanted to retire, she asked me if I would consider taking over. I said I would and now I am giving back and I have a purpose in my life. I am no longer useless.

While the road from GBS to CIDP to liaison has been a battle to negotiate, I feel that it has taught me a number of things. I have learned to be my own advocate and stand up for myself. It has taught me patience. I am a stronger person. I can handle things that I would never thought possible 14 years ago. I have met some of the most remarkable men and women who teach me constantly. While I still have to go for IVIG, I have accepted that and this condition called CIDP.

The Foundation thanks 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.
My memories of GBS/CIDP conferences 25 years ago this year
by, Frances Roulstone

When I was in recovery in the Hillcrest Hospital in the spring of 1986, and because of my background in social work, I told my physio that I was going to start a Support Group. She left the room and came back with a pamphlet that told me Barbara Clark-Smith had beaten me to it. That was my start in a very rewarding part of my life.

The following spring of 1987, the first get together happened when Dr. John Humphrey arranged for our little group to meet as part of the main meeting of one of his other groups. It was held at a hotel across from City Hall and I only remember Barbara at the table as it was our first live meeting, although we had spent a lot of time on the phone over that first year. I recall that Dave Bryce, I think as a teenager, was there with his parents. I don't remember the other lady but I did have time with Dr. John Humphrey who was a neighbour and I had worked in Neurology at Sick Kids Hospital, so we were good friends, as well.

As each following year went by the conferences got bigger and better. Susan Keast was very active from the beginning and Larry Brenneman. We moved around to different venues and more and more people came. It was always such a treat to see how much they enjoyed themselves and would go home, happy, having learned so much and feeling better, especially when they met Dr. Ken Shonk and his "Big Dog!"

Now, look at this organization 25 years, coast to coast, wonderful. Barbara was given a National Award some years ago, Susan is on the Board of Directors of the Foundation and in 2004 Larry Brenneman gave me the honour of a "Lifetime Achievement Award" which is one of my most prized possessions. Dr. John Humphrey was the first in Canada to use Plasma Exchange and passed away much too young. There are still items about him on "Bravo" and he is not forgotten.

As an addendum to the above story, both Dave Bryce and I have known Frances from way back, long before we became a registered charity. Frances has always been committed to helping those with GBS and CIDP. She is originally from Toronto and then moved to Collingwood for many years, where she continued to help all patients and their families. Frances is now back and living in Toronto. These stories and memories are wonderful. They are the very beginnings of how we got to where we are today. Without the help of Barbara Clark-Smith and Frances Roulstone, where would we be? Dr. Shonk has always been a big part of each Conference bringing laughter and compassion to each, and then Larry Brenneman, who passed away much too soon, brought commitment, and time and talents to helping everyone he could. Dedication and devotion to our patients and their families is what makes us continue to reach out to others. I thank Frances for sending in these recollections. We need to stop sometimes and see where we have been and where we are going. Susan Keast

My GBS Story

by, David Sleeth, Liaison Kingston, Ontario david.sleeth@ServiceExperts.com

My GBS Story began in the early evening of February 8, 2010. After returning home from a short shopping trip, I found my lower back and the back of my legs feeling tender for no reason. When I awoke the following morning I was very unsteady. My Legs were rubbery and I needed to use the wall for support. I called my office and said I would be in later in the day once my legs returned to their normal strength little did I know at that time, I would not return to work even to a part time basis until 11 months down the road, and what a road it would be. After lunch, my legs felt like I had climbed the stairs of the CN Tower. Throughout the day, I had been working on my laptop and by dinner time, I had tingling from my elbows down to my fingers added to my rubbery legs. I was still trying to convince myself that those sensations would go away shortly even though the pain was starting to intensify.
My GBS Story (continued)

By 11:30 pm the pain ad magnified and the decision was made to head to the hospital. Just as the decision was made, I turned towards the bed to sit down and at that point my knees buckled and I fell beside the bed. As the triage nurses watched my wife struggle with me to get to the door of the emergency department, they felt they had another drunk on their hands. As we waited in emergency at Kingston General Hospital, I was put in a wheel chair which thankfully relieved some of the pain and discomfort.

After the emergency doctors While I was still in the emergency department the IVlg treatment was started. When we were told the diagnosis was Guillain Barre Syndrome we had no idea what we were in for as we had never heard of it before. It took me a week to learn how to pronounce it properly and another week to spell it correctly. The doctors were trying to pinpoint a possible trigger of GBS. The only information I could given them was that I had flu like symptoms over the past 7 to 10 days. These were not bad enough to miss work, but I felt a bit run down and lethargic. My legs were now paralyzed and I lost a lot of the mobility in my arms. My breathing performance was monitored for many days but I was fortunate the paralysis did not move up to my diaphram. Even though I was under a lot of medication including morphine, my main memory of the first few weeks in hospital was the high pain level and the super sensitivity in my legs and arms. When my legs were moved by a nurse, the pain would almost send me through the ceiling.

After spending two and a half weeks at Kingston General Hospital, I was transferred to St. Mary's of the Lake Hospital, our local rehabilitation hospital. We are so very fortunate to live in a city with such highly respected hospitals, caring nurses and doctors. When I was fitted for a wheel chair, I was required to answer a questionnaire. The final question that I was asked was what was my expectation of my stay. I told her, I wanted to walk out of this hospital. She nodded a couple of times without saying anything and she wrote that down. I think she knew that it was unlikely that was going to happen. Shortly after my arrival, a young woman wheeled into my room who also was recovering from GBS. She was diagnosed with GBS roughly two months before me. She was a great source of help to me. Our physio sessions were at the same time and I was continually asking her about this or that. After three weeks in St. Mary's, I was allowed to go home for an afternoon on the weekend in my wheel chair. When I needed to sign out you were again reminded of the severity of the illness. When it came to signing my name, I couldn't keep the pen in the signature box and my writing was not legible. On my first visit home for an afternoon, I used the sliding board from the wheel chair to our couch. Wow was that ever a nice feeling sinking down and finally enjoying the comforts of home again. Time went by quickly and before we knew it was time to go back to the hospital. Only one problem though, being rookies with a wheel chair and my wife and daughter struggled together and eventually pulled me up the sliding board and finally on to the wheel chair frame. I was then able to use my arms to life up my rear so that they were able to slide the cushion in from the back. After a good laugh, we headed back to the hospital.

During my recovery the hardest part for me was learning how to walk again. I would sit in the lobby in my wheel chair and watch people walk by. Boy that didn't look very hard, but for me it took a couple of weeks to finally be able to move to a two wheel walker for my physio sessions. My knees were very, very weak. When I was trying to walk in the two wheel walker, I had two physio people on their knees beside me with their hands on my knees while my daughter pushed the wheel chair behind me ready for a collapse. Numerous times my knees would buckle and fortunately I was caught by the wheel chair. This was extremely frustrating and this went on for quite some time. I give a lot of credit to the 0.T staff at St. Mary's for getting me to where I am. They were tremendous in their care and there were some doubts as to how much of my mobility I would gt back. After my discharge, I had to wear specially made leg braces for two months afterwards. They were basically like a giant ski boot that came up to just below my knees. When my knees would buckle these AFO’s would kick in arid only allow my knees to drop an inch or so. Many times these prevented me from falling on the floor.
My GBS Story (continued)

One thing that really stands out in my hospital stay was watching the change of seasons from a hospital bed. I entered St. Mary’s late in February. I was in the bed closest to a large window which looked out into the backyards of a residential street. I witnessed the snow blowing in February and March, melting in April, the buds coming out in May and then leaves completely obscuring the view of the backyards in June. It was hard to believe that I was in hospital for that long a period.

Oh Yes, when I was finally discharged in June after three and a half months, being stubborn, I used the wheel chair to get to the front entrance where I then shifted to a two walker and I walked out the door to our waiting vehicle. A moral victory.

Finally 11 months after GBS and with continued physiotherapy, I started a gradual return to work program in January, 2011.

I was allowed to work eight hours a week which was increased monthly until finally being allowed to go back full time some 16 months after GBS another moral victory. But one of the biggest victories of all was starting to golf again in the late summer of 2011 using a riding cart. After using the power cart for 4 weeks, I was then able to walk the golf course pulling my golf cart. I don’t know how I would have survived this ordeal without the support of my family. In the beginning, my wife took a two and a half month leave from her career.

Our youngest daughter spent her reading week from university at my bedside. Our oldest daughter was out of the country when this happened. She returned just as I was transferred to St. Mary’s. I was in St. Mary’s for three and a half months and I had two physio sessions a day and she was there with me for all but four sessions over my entire stay. After my discharge our youngest daughter was my chauffeur for the summer. She would drive me to my physio and doctor appointments and wheel chair visits to my work place. I was also very fortunate to have the support of my co-workers and employer through the hospital visits and emails.

I am now 25 months past that initial diagnosis. I still have physio every week plus an at home program and I am still on some medication. I feel truly blessed that I was able to go from a wheel chair, then to leg braces and a 2 wheel walker, then to leg braces and a 4 wheel walker, then to a 4 wheel walker, then to 2 canes, down to 1 cane, then finally walking without any aids.

For those of you in the early stages of GBS, just remember as we were told at the Toronto Conference in 2011, that GBS stands for Getting Better Slowly. It takes a lot of hard work and patience with plenty of frustration, but as I look at it, I have GBS but GBS doesn’t have me.

Disclaimer
Information presented in the GBS/CIDP Foundation of Canada newsletter is intended for general educational purposes only, and should not be construed as advising on diagnosis or treatment of Guillain-Barré syndrome or any other medical condition.
Across the Country


Vancouver Support Meeting – April 14, 2012

Bill Hackett Support Meeting – April 29, 2012