News & Views

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GBS/CIDP Foundation of Canada
Guillain-Barré Syndrome / Chronic Inflammatory Demyelinating Polyneuropathy
Support, Education, Research, and Advocacy

National Conference
TORONTO

October 25 – October 26
Details Inside

Save the Date!

3100 Garden Street, PO Box 80060 RPO Rossland Garden, Whitby, ON, L1R 0H1
Canadian registered charity: 887327906RR0001 | 1-647-560-6842 | info@gbcidp.ca | gbscidp.ca
**Study Title:** An exploration of how patient stories inform health professionals’ knowledge and practice.

### Research on Patients Stories

- Do you live with a chronic illness?
- Are you interested in telling your story about how you prepare and tell your story to health practitioners?
- We are trying to understand better how patients’ stories inform health practitioners’ knowledge and practice.
- The study involves a 45-60-minute interview that is audio-recorded.

*Principal Investigator: Dr C. Watling*

For more information, please contact Wilma Koopman PhD candidate, Western University, Health and Rehabilitation Sciences

Telephone 519-685-8500 ext 35747
Or email wkoopma@uwo.ca

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GBS/CIDP Foundation of Canada
Subcutaneous immunoglobulin infusion (SCIG): A new therapeutic option for neurology patients

Submitted by Steven Baker, MD, FRCPC, CSCN

Intravenous immunoglobulin (IVIG) administration has been a fixture in the treatment of autoimmune neuromuscular disorders for many years. Subcutaneous (SC) administration, an alternative route of immunoglobulin administration, has become widely used in patients with primary immune deficiency (PID). Many studies and decades of experience in PID have confirmed the safety and efficacy of SCIG.

In recent years, SCIG has emerged as an alternative treatment for patients with neurological conditions such as chronic inflammatory demyelinating polyneuropathy (CIDP), multifocal motor neuropathy (MMN) and myasthenia gravis (MG). There are two fundamental differences between SCIG and IVIG that lead to most of the practical differences between the two routes. The first of these is the lack of a requirement for venous access with SCIG; the second is the relatively slow absorption of SCIG into the intra-vascular compartment. SCIG affords the freedom of home infusion and thus permits portability. This is particularly attractive for individuals who travel and would otherwise struggle with hospital IVIG appointments.

Until recently, Hizentra® (CSL) was the only SCIG product available in Canada. Gammanorm® (Octapharma) was available to select patients who could not tolerate Hizentra® under Health Canada’s Special Access Program (SAP). In October 2017 the Canadian Blood Services announced, as a result of the tender, patients would be required to transition to Cuvitru® (Shire). With almost 3,000 SCIG patients transitioning from Hizentra® to Cuvitru®, this is the largest SCIG transition seen globally. During the transition the Canadian Immunodeficiencies Patient Organization (CIPO) collected data on 882 patients that completed the transition from 10 PID clinics across the country. Of these 882 patients, 5.9% reported having a reaction to Cuvitru® during the transition from Hizentra®, and 3.4% had been, or were going to be trialed on another product. Initially, in the transition process, reaction rates were lower, around 1% – 2%, but as more patients completed transition, reaction rates increased. A copy of the complete CIPO report can be found at http://www.cipo.ca/wp-content/uploads/2018/12/Final-Report-IG-Transition.pdf

Available products have differences and as a result, there could be inter-patient variability; some patients may tolerate one product better than another. While in most patients SCIG treatment is well tolerated, in some it can be associated with adverse reactions. In patients with adverse reactions, a switch from one product to another may be needed. For those Canadian patients who have poor tolerability issues with Cuvitru® or who may discontinue the product for adverse reactions or other clinical reasons, a new SCIG therapy, Cutaquig® (Octapharma) has recently been approved by Health Canada which provides patients with an additional option. Cutaquig® has a low dynamic viscosity and requires a low pressure for administration, this could be especially useful for patients with hand weakness (i.e., MMN). The lower viscosity of Cutaquig® may, in some patients, translate into a more rapid distribution in the subcutaneous tissue. This could result in lower frequency and extent of local adverse reactions (swelling and pain at the injection sites), during and after SCIG infusions, as compared with higher viscosity SCIG 20% products.

McMaster’s Neuromuscular Clinic in Hamilton has gained considerable experience in transitioning patients from IVIG to SCIG. This mass conversion was primarily instigated by the need to off-load the outpatient infusion clinic, which began to experience administrative and logistical difficulties with the growing number of patients requiring and benefiting from IgG therapy. We have had no cases of symptomatic recrudescence and in fact two patients reported improved hand dexterity. Overall, our neuromuscular patients have had very positive feedback with SCIG and as such it has been an overwhelming success.

Continued Next Page →
With new patients needing IgG therapy our approach is to initiate IVIG and if there is demonstrable clinical benefit after several infusions then convert them to SCIG.

The availability of multiple SCIG products, in the growing market of SCIG applications, ensures patients will have the ability to transition between them in the event of untoward side–effects.

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**Spring Schedule**

**Get Your Teams Ready!!!!**

Links to all of the walks will be available on [www.gbscidp.ca](http://www.gbscidp.ca) on April 8, 2019.

**2nd Annual Calgary Walk and Roll**

South Glenmore Park, Calgary, AB  
Saturday, May 25, 2019  
10am Registration  
Questions? [mailto:klange@gbscidp.ca](mailto:klange@gbscidp.ca)

**Halifax Walk and Roll**

Halifax Location TBA on April 8, 2019 *Hoping for Harbourfront*  
Saturday, May 25, 2019  
1pm Registration  
Questions? [mailto:nedwards@gbscidp.ca](mailto:nedwards@gbscidp.ca)

**Montreal Walk and Roll**

Montreal Location TBA  
Saturday, Jun 15, 2019  
10am Registration  
Questions? [mailto:nedwards@gbscidp.ca](mailto:nedwards@gbscidp.ca)
New study to investigate a potential new medication for CIDP

The ADVANCE-CIDP™ 1 Study is looking at a potential new treatment (an investigational medication) for patients with chronic inflammatory demyelinating polyradiculoneuropathy (CIDP). It will assess if the investigational medication could help to prevent muscle weakness in the upper and lower limbs. The investigational medication is an immunoglobulin (made from proteins found in the body called antibodies) and is given as an infusion under the skin every 2, 3, or 4 weeks. It may be possible for you to do this yourself.

About the study

The study will involve about 170 patients at approximately 90 study centres worldwide. If you take part, you may be involved in the study for up to 14 months. Study participation may offer:

- less time spent at the infusion centre/hospital compared with standard intravenous (IV) therapies, with a shorter average treatment cycle for the complete dose
- the potential to be able to give the investigational medication to yourself at home
- receiving therapy less often than other immunoglobulin infusions, with fewer needle sticks on average
- study treatment and study-related care at no cost

As with all medicines, the investigational medication may come with risks, which may not all be currently known. There are more factors to consider before deciding to enrol in this study, including potential risks and benefits of the investigational medication. Should you be eligible to participate in the ADVANCE-CIDP 1 Study, your study doctor will fully inform you of the potential risks before you enroll.

Study participation

The study is now enrolling. You (or someone you know) may be able to take part in the ADVANCE-CIDP 1 Study if you (or they):

- are 18 years of age or older
- have been diagnosed with CIDP
- have been receiving treatment with immunoglobulin infusions at a stable dose, every 2– 6 weeks, for at least 12 weeks (3 months)

There are more factors to decide if the study is right for you, which you will also need to match in order to join the study.

All study-related medical care will be provided by a team of experienced doctors and nurses. If your CIDP symptoms do not get worse during the first 6 months of the study, you and the study doctor can decide if you want to enter into the optional extension study, where you will have the chance to keep getting the investigational medication for up to 2.5 years.

You can find out more about the ADVANCE-CIDP 1 Study at www.ClinicalTrials.gov for NCT03549270. You can also contact the study team directly to learn more about the study using the details below:

Dr. Anita Florendo-Cumbermack, LHSC, University Hospital, 519-685-8500 ext. #33129

ADVANCE-CIDP is a trademark of Baxalta Incorporated, a wholly owned, indirect subsidiary of Shire plc.
Save the Dates!!

Friday Evening, Oct 25, 2019
Patient Social and Fundraiser

Full-Day Conference
Saturday, Oct 26, 2019
7:30am – 5pm

Confirmed Speakers so far:
Dr. Steven Baker (McMaster Hospital)
Dr. Vera Bril (Toronto General Hospital)
Dr. Hans Katzberg (Toronto Western Hospital)
Dr. Jiri Vasjar (Sick Kids Toronto)

Location – Greater Toronto Area
We will have more details in the spring newsletter.
We are currently selecting a Toronto Airport Hotel that will suit the needs of our members.
“I don’t think this is musculoskeletal,” the physio said, 
“Otherwise I wouldn’t be able to bend your leg like this. 
You’d be screaming. I think you should ask your doctor for 
a nerve conduction test. You should be able to get one 
pretty quickly.”
I did have two mildly deteriorating disks. But I had been 
having increasing difficulty walking. I climbed stairs by 
using the railings to pull myself up. I fell twice going up 
curbs. Once I was unable to get out of my bathtub. I was 
tired. My back hurt — a lot — whenever I moved. I didn’t 
bother buying tickets for the Toronto Film Festival, 
although I always went. I walked through my house with 
one hand on a piece of furniture or on the wall. The 
medical term, I learned later, was “cruising the furniture.” 
I phoned my family doctor, who thought the test a good 
idea. The next morning I received a call asking if I could 
get to an office at the hospital in two hours. A friend said 
she could take me. Two months later that same friend 
would bring me home.

First: Diagnosis
Not long into that nerve test, the doctor said, “You need 
an MRI. I’m going to find you a bed.”
I felt a huge sense of relief. There was something wrong 
with me, and now they were going to find out what it was. 
I gave myself up to the system. The pain medication 
worked but there wasn’t much sleep. Someone kept 
waking me up to breathe into some contraption. Others 
came and took vials of blood. And the lead neurologist 
and the residents and students congregated around my 
bed and asked me questions. I came to think of them as 
Dr. Mama Duck and all the doctor ducklings. Had I had an 
infection of any kind? A vaccination? Where had I been? 
When did I start to get weak? How? Where was the pain? 
What was it on a scale from one to ten?
And they tapped my arms and legs and had me resist as 
they tried to pull them. Arms were normal; legs had no 
reflexes and barely any movement. I did not feel the 
tuning fork or pricks on my toes, feet or legs.
I’d had no vaccination and no infection that I could 
remember – but they were asking about the past six or 
eight months. The next day I had the MRI. I had no idea 
they were so noisy, like trucks picking up garbage.
The MRI showed something. Next day’s brain scan came 
up normal. Then it was the weekend and the lumbar 
puncture would have to wait until Monday.
I had too much time to think. What if I had cancer, one of 
the possibilities mentioned, and died? What if I never 
walked again? I lived in a house with stairs. I owned it with 
another woman who lived in the other half. If I could never 
go home what would happen to her if I had to sell? I had a 
two-person communications business that operated from 
the house. How would I be able to serve our clients, get 
new business and keep enough money coming in? I was 
61, not willing or able to retire. I was executor and 
decision-maker for a friend who had terminal cancer. I 
had three cats. I wasn’t prepared for this.
On Monday two ducklings came to do the lumbar 
puncture. One duckling appeared a couple of hours later, 
grinning. “Well, we know it’s not cancer,” she announced. 
“We’ll know more later, but I wanted you to know that.” I 
thanked her.
Late that afternoon, Dr. Mama Duck and all her brood 
appeared. My autoimmune system was working overtime 
and destroying the myelin that is the sheath that covers 
the nerves, in my legs. Thus, the messages from my brain 
couldn’t get through and the legs weren’t working. The 
now deconditioned muscles in my legs and core were 
probably the cause of the pain in my back. They would 
give me a dose of immune globulin intravenously each day 
for the next five days. The immune globulin, which comes 
from other people’s blood, would make my own 
antibodies stop attacking the myelin. Then I could leave 
hospital. I’d be able to walk again, no problem. I was 
lucky. I had a mild case of this CIDP, or perhaps it was 
Guillan–Barré Syndrome. The time of onset was not clear. 
But the treatment was exactly the same, so we’d find out 
in time. They left, pleased with the good news. They may 
have said more, but if so I was unable to take it in. I was 
lying in a hospital bed, unable to use my legs, and it’s a 
mild case? It didn’t feel mild. 
IVIG started that night. A physiotherapist showed up every 
day to start exercises. It was only from him that I learned I 
would go to a rehab hospital for a couple of months. The 
ducklings had done their job and diagnosed me, and I was 
tolerating the treatment. They did take me as a subject to 
grand rounds. It was satisfying to know that several 
experienced neurologists had seen my file. I learned that if
**CIDP: Eight years and walking – Con’d**

It came back it would only come back to what it had originally attacked. My arms would remain unaffected. And I finally learned to pronounce the full name – chronic inflammatory demyelinating polyradiculoneuropathy. After 10 days in acute care, an ambulance transferred me to a rehab hospital.

Second: Recovery

Then followed days of physiotherapy in the morning, occupational therapy in the afternoon, and walks through the hallways. In between I tried to keep up with my regular work. Writing and editing needed a laptop, a phone and internet access, but not legs. Progress was slow, but steady. My first taste of independence came when I got my own wheelchair and I could get myself into it. Now I could go to the bathroom by myself. I could go for coffee. I learned to do a wheelie. I got blisters on my hands.

My first step wasn’t as exciting. It was more of a lurch. After the six-step walk, a nap. I was exhausted. The back pain diminished. I learned to use a walker, then two four-footed canes. I learned to climb a curb with a walker and to climb stairs with a cane. We had to get up and down a flight of steep stairs before we were allowed to go home.

I came home in early November with a walker and made it up the front stairs into my house, grinning. Although there was a hospital bed waiting for me on the main floor, I made it down the stairs into my own bed, reveling in the quiet and the dark – and my very own private bathroom. I had several weeks of physiotherapy as an outpatient, working to improve leg and core strength. A major step was learning to get up off the floor – that meant I could take a bath.

The increased exercise brought leg cramps, often while sleeping. Standing relieved them, but it was a scramble to get up. I left a four-footed cane by the bed. They stand up by themselves so you can find them immediately. The myelin comes back, although not entirely as good as new, but it takes a long time. For me, it was almost two years. For the first year, the advice was not to push past exhaustion so as not to damage the nerves. So, when I was tired I sat.

I worked at home exclusively during the first year, not doing any on-site projects although I did manage two business trips, accompanied.

One year exactly after the hospital stay, I went to the film festival, using two canes and seeing only a few films. The following year I used only one cane, and saw my usual quota of 20 films in 10 days.

Accepting help

A long-time friend visited me in rehab on Thanksgiving weekend, with some turkey. We walked down the hall, I using my walker and she wheeling my chair behind me. I sat down for a little rest at the window at the end of the hall. She sat in a regular chair. We ate the turkey. She said, “You have always been so fiercely independent. It must be really hard to accept help, let alone ask for it.”

“Well, I’ve learned that people really do want to help,” I replied. “You just have to tell them what you need.”

One, who lived near my vet, brought me cat food. Another shopped for clothes for me. Another regularly took my walker and me to the movies. Others took me shopping. One accompanied me to medical appointments and took fastidious notes. Many came for lunch or dinner, bringing the meal. A client who lived near the rehab hospital printed things for me and dropped them off. My assistant paid my personal bills as well as the business ones. She even renegotiated my cell phone plan. My neighbours did my laundry. And my housemate looked after the cats.

I hope I always remembered to say thank you.

Third: Living with CIDP

Now, eight years after diagnosis, I need to use railings most days. I use a cane outside of my neighbourhood. It also gets me a seat on transit, and it’s useful when I encounter stairs that have no railing. And it helps when it’s a long walk or a long time standing. I still hesitate at the top of down escalators. And I’m a beat slow catching my balance when I turn, trip or slip. I avoid ice and I pay attention to where I put my feet. I have done one European vacation on my own.

I attend a weekly exercise class that concentrates on the basics of sitting, standing and walking, and I still go to the physio who first noticed it was nerves. Almost all my reflexes are back. And I can feel the tuning fork on my toes and that horrid steel instrument the neurologist uses on the soles of my feet. It takes me a while to unkink if I sit for more than an hour. I catch more colds. I get tired more often. (Some of these

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**CIDP: Eight years and walking – Con’d**

things might be due to aging, I’ll admit.) I still get leg cramps, but not as often. I can’t wait in line for more than 20 minutes or walk for more than 45. However, I can add to that if I sit for a few minutes.

I get my IVIg for two days every five weeks and do not schedule anything major for the day after. The treatment leaves me tired. The biggest worry is finding a good vein. We tried to extend the time between infusions but only a couple of days beyond the five weeks I got that walking-through-hardening-concrete feeling. We also tried lowering the dose, which also didn’t work. The present schedule does.

The doctors were right. My case was mild, and it remains only in my legs. Life is organized around my IVIg schedule. But, as I tell myself, all my friends of similar age have something to live with too, like arthritis or high blood pressure. CIDP is just a little more dramatic, and certainly far more rare.

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**Whitby Walk and Roll – Jan 26, 2019**

Many thanks to all of the teams from the GTA, Southwest Ontario, and as far north as New Liskeard, and the Saskatoon team. Congratulations, YOU made the walk a success!

You raised, $12,500.00 to help continue our programs!!
Vancouver Educational Afternoon

Thank you to our presenters, volunteers, sponsors, and our attendees. Without you, we could not provide these events for our community.
My GBS Journey (Acute Peripheral Axonal Polyneuropathy)
Submitted by Rosemary H.

In the winter of 2004/2005 I paid a visit to my GP for some routine item. During the visit he asked me if I had had the flu shot for that winter. I told him “no” and I didn’t want it. I had never had the flu shot and had resisted it, remembering the tragic aftermath of the Swine Flu immunizations of the ’70s. However, he pressed me and I said, “Will I get sick from it?” He said “No”. So I gave in. I never thought more about it until several months later.

In June of 2005 I was driving back to Ontario from Florida when the ill feeling I had had at the start of the trip caused me to stop at a hospital off the I95 to see what was wrong. To cut a long story short I had developed cellulitis in my upper right chest from an infection received from an injection in Florida for a sore shoulder. I called my husband who flew down to Charleston to drive me back to our Ontario home.

As instructed by the US hospital doctor I immediately saw my own doctor who sent me to our local hospital where I was admitted. An operation followed and the cellulitis treated and I was sent home with a PICC (Peripherally Inserted Central Catheter) line to feed me constant antibiotics. (Whilst in the hospital I was diagnosed with the superbug MRSA, which turned out to be a blessing for me in subsequent months.) During the two weeks following my discharge from the hospital I began to feel ill again and so desperately tired I could not keep awake while I was sitting in the waiting room at the hospital. The doctor who saw me sent me to the Emergency area of the hospital so that I could be admitted again.

After several hours of waiting for a bed I was placed in a makeshift area until a more permanent spot could be found. During these waiting hours I developed significant back pain and was only allowed over-the-counter painkillers. At some point someone decided I should have a spinal tap and according to the results the protein level was high – which is, apparently, a possible indication of Guillain–Barre Syndrome (GBS). Incredibly, there never seemed to be a follow-up on these results. The following morning my husband noticed that I had developed a rash all over my body that was presumably caused by the medication administered for the spinal tap. This would be the first of many occasions when I experienced serious reactions to medications I was given.

The next week or so was a blur of pain, medications and confusion. I remember being told to get up to have a shower. No problem, really, except when I stood up from the shower bench to get back to the bed my legs crumpled under me and a male nurse was called to get me up off the floor.

Days went by, mostly with excruciating pain in my legs, then periods of nothing after a pain medication was administered. One terrible night I called my husband, or someone called him for me, because I was literally screaming with pain and nurses would not come to help me. When my husband arrived the nurses sat stubbornly at their station ignoring his pleas to call a doctor. Eventually, after the other patients added their pleas to my husband’s, a doctor arrived. The doctor had the nerve to say that I only complained of pain because he – my husband – was there. My husband was outraged and told him that he was only there BECAUSE of the pain. In many other accounts of a GBS experience I do not see the mention of the terrible pain it can cause. Perhaps others have been treated more humanely.

In my case, the doctors finally prescribed sufficient medication to keep the pain under control but the nurses refused to acknowledge that they were misreading the doctors' instructions which would have allowed me booster shots as frequently as every 3 hours instead of once every twelve hours. The medications I was being given were taking away my appetite and I was eating very little. On one occasion one nurse threatened me by saying, “If you don’t eat up your food you will not get your pain medication”.

During these early weeks I was in a fog of pain and confusion but I do remember being seen most mornings by a different team of doctors and interns and I became known as the mystery woman. After the fall in the shower I was run through what I called the “conveyor belt of torture” to have a catheter inserted, and various other painful things that I was not able to remember. Afterwards, I did say bleakly to my poor husband, “Why did you let them do that to me?”

Continued next page
My GBS Journey (Acute Peripheral Axonal Polyneuropathy) - con’d

Over the next three weeks the paralysis crept down from my waist to my toes then up my body into my face. At this point, no one had even indicated to me, or my family, any guess at a diagnosis, despite the strong indication of GBS from the spinal tap. From the hospital notes I read that I was suspected of having Lyme disease, West Nile Virus, encephalitis and vasculitis (I have a scar on my ankle where a sample of possibly a vein was taken).

Weeks later, even after the neurologist had diagnosed GBS, another doctor came to me saying that he needed to do tests to see if I had lymphoma. My husband was furious with the doctor for not discussing it with him first rather than upsetting me when I was alone without a family member present. Furthermore, the system did not provide any continuity of doctors who saw me and each team of doctors wanted to develop its own theories of what was wrong with me. It seemed that I was an object of education and curiosity rather than a patient who needed to be helped.

When the paralysis moved to my face I began to panic, thinking that my brain was going to be affected. However, I read in the hospital notes which I paid to get after discharge that, "the patient asked to see a neurologist"!!!! I find it incredible that weeks after the paralysis had started no doctor had thought to bring in a neurologist. Paralysis -> muscles -> nerves = neurologist!!! Was it so difficult to connect the dots?

(As a laughable side note, I read one of the nurse’s comments around the time that I was almost totally paralyzed which said that the patient is “a very dependent person”.)

After my request to see a neurologist she arrived, gave my arms and legs a few taps, flipped open a book she was carrying and said. “Well the bad news is you’ve got Guillain–Barre Syndrome, and the good news is that most people recover from it.” My husband was so happy because now we had a diagnosis and therefore we could start appropriate treatment. The dithering of the other doctors during those early weeks lost precious time. I am permanently impaired because of it.

IVIG (intravenous immunoglobulin) treatment was started and we hoped I was on my way to getting better. This was not to be. The attending doctor reported to my husband that my kidneys were failing. My worried husband did some online research on IVIG treatments and found reports that they can cause renal failure in some patients. He ordered the doctor to stop the IVIG treatments – although more transfusions are usually recommended. A rather heated discussion took place between my husband and the doctor who denied that the transfusions were a cause of my kidney failure. The following day my husband took a report into him on the subject and the doctor admitted that my husband was probably right so the IVIG treatment was not continued after the fourth transfusion. My kidney problem was resolved.

Following the IVIG transfusions I began to lapse into periods of unconsciousness from which I could not be woken. My husband was usually the person who alerted the staff on this, or in some cases the Personal Service Worker that my husband had hired to be an extra person to look out for me in the hospital, seeing that on so many occasions I was not being taken care of properly. Possibly for this reason, and because my breathing test results were poor, it was decided that I needed to go on a respirator. I remember having a feeding tube pushed up my nose and being told to swallow the tube down into my stomach. After that….nothing. I was put into a medically induced coma, which my husband tells me was for about 10 days. At this point I was in ICU and this would be the first of three occasions when I would be rushed into ICU for having had a critical drop in blood pressure.

When I came off the respirator and was conscious again I was unable to speak. I wanted to tell my husband that the nurse wasn’t giving me my pain medication. I tried to write it down but all I could manage was a meaningless dribble of ink across the page. Then we tried for him to go through the letters of the alphabet and I would nod when he got to the letter I wanted. I got as far as “she won’t…” and my husband gave up because it was so frustrating for both of us.

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My GBS Journey (Acute Peripheral Axonal Polyneuropathy) – con’d

At this point I should relate that my husband, who runs his own IT company, was spending many hours with me and was often having me call him in the middle of the night because of pain. On top of this the doctors and nurses were not helping, particularly one doctor who displayed an arrogant attitude even though he seemed to know very little about GBS. The doctors seemed to be reluctant to hand me over to the care of the neurologist – who did know her stuff, so I never was (in this hospital) in the constant care of a specialist nor, as far as I am aware, did she ever attend me again.

However, after the period on the respirator, I was visited by another group of doctors called “The Pain Management Team”. Finally, I thought, someone realized that my PAIN was significant. However, I would have been more reassured if they had called themselves, “The Pain Elimination Team”.

Over these early months, at significant cost to my husband, I was attended to by a series of personal care workers, some better trained than others. One in particular, I was so grateful to. She would spend lots of time patiently rearranging the many foam supports around my body trying to get me into a comfortable position. She was like a sister to me and we talked a lot about her life in Iran before she came to Canada. She came on the night shift and I so looked forward to her arrival each evening.

After the IVIG and the Respirator episode and about two months into my stay in hospital I began to recover the use of my arms. To this day I still have two numb fingers in my left hand. I was able to haul myself further up the bed by hanging onto an overhead bar, but my lower half was still completely paralyzed. I was made to get into a bedside chair and table to take lunch but the effort to sit up was overwhelming and after a while I pleaded to be able to get back into bed. Toiletries were an ordeal, enemas, intimate personal care by a stranger, showers lying prostrate on some sort of platform, waiting in wheelchairs in uncomfortable corridors for CT Scans, ECGs, X-rays, MRIs and every other type of test you could think of. One doctor reminded my husband and me that the hospital had spent $25,000 on tests the previous night. Other tests, like nerve conduction tests were carried out. These were painful and when I was asked if I wanted to submit to another of these tests – which were informational only for the doctors and would not affect treatment – I declined.

Around the third month of my hospitalization, which was September 2005, I was encouraged to start physiotherapy. This was awkward and somewhat embarrassing while still encumbered with a catheter. I felt I was being pushed too hard and got the impression that the hospital was impatient with my lack of progress. I expect I was hurting their bottom line. (A great benefit of the Canadian medical system is that there were no extra out-of-pocket expenses because of my hospital stay and treatment. However, I felt the budgetary pressure.) On one occasion the physiotherapists were telling me to practice sitting on the edge of the bed and to lean down to pick up a bottle on the floor. The bed was high – my feet were not touching the floor – I knew I could not do it and that I would fall and I didn’t trust them to catch me before I hit the floor. I suspect that even able-bodied people would not be able to do this. I realized that I would have to put my foot down – figuratively speaking – and insist that they stop pressuring me. However, I was able to manoeuvre myself with the wheelchair they brought me so I welcomed the bit of freedom it gave to me to get around the hospital with the help of my “sitters”. I remember, in the wheelchair, experiencing how cold my legs were and I needed a blanket to keep them comfortable. I still have cold legs from residual nerve damage.

I have mentioned the need for medications. I was taking about 10 capsules/pills in the morning and less than that during the day. On many occasions I was hallucinating or completely knocked out. When I was woken up I was always asked where I was. Sometimes I was in Bangkok, sometimes New Zealand, and sometimes Arizona, whatever. I talked nonsense with my family and apparently with the nurses, too, since they commented on it in their notes. I believed that my daughter had a close relationship with the nursemaid to Prince Charles…….really? … and had special invitations because of it. When my son and daughter came to visit me I believed that my husband had flown them to Bangkok to visit me and

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I chatted with them about it. I believed that I could see palm trees and a swimming pool from my hospital window and that white-coated waiters were serving hors d’oeuvres in the corridor. On another occasion I talked to the ICU nurse about the cats that were running around the walls and the one that was poking its head out of the paper dispenser.

At one point, when doctors were trying to drain my gall bladder, I asked for a lawyer because I thought I was going to die. In fact, at a time when I was in considerable pain, I asked my husband to do something to end my life. Fortunately, he ignored me. Whether or not this had anything to do with it or not I don’t know but a priest, vicar or other church-related person came to see me. I’m afraid I must not have given him a lot of attention because he never appeared again.

Towards the end of September I heard that I was to be moved to a different hospital. The rumor was that this was a palliative care institution and we were somewhat scared about this development. However, it turned out that only one floor of this new hospital was for palliative care and the rest was for rehabilitation.

My first room in the new hospital was shared with a patient who either had mental problems or was reacting to medications because she shouted, screamed and threw things around the room. Fortunately, the staff soon learned that I had MRSA and I was moved to a large private room at the end of the corridor. (I never experienced any symptoms from MRSA but it was probably why I was on the strongest antibiotic available to fight it. It was uncomfortable for my visitors since they had to wear gowns and masks, which made them overheated.)

What a relief this move was. The nurses, in general, were KIND. I still had problems with pain and it seems that their routine cannot be broken so, being at the end of their evening medication run, I was often in pain for up to five hours before they got to me. However, the gym was well equipped and the physiotherapists very good. But each time they tried to get me to stand up my legs would crumble under me. My lack of progress was attributed by some to be my laziness!!! I was pressed to get rid of my sitters, which I refused to do. In both hospitals there was a lot of hostility by some of the staff to me and to the sitters themselves and more than once I was questioned as to why I had them. In one instance, I asked the physiotherapist why I should get rid of them and I was told that it cost us, me and my husband, a lot of money. What a strange answer! I said that surely the expense to us was solely our affair and not that of the hospital staff. I never did understand their position. Perhaps, they saw it as a comment on their care.

In this second hospital I was attended by a neurologist – at last. I believe I had new medications and one was for nerve pain that made my hair fall out in clumps. I was continually searching my hospital gown for stray hairs that were making me itch. One day a sign-up sheet was circulated for the flu shot. I thought I had better sign up for it since I was in a place with lots of sick people. So I put my name on the list. A few hours later my neurologist came by to tell me I should not have the flu shot. It was only then that I made the connection with the first flu shot I had ever had some months previously and the GBS that I now had. I caught up with her – not literally – and told her about having had my first flu shot in the months previously and she said there was no connection since it was so long ago. Later, after discharge, I found a study report that said that there was a statistically significant increase in the incidence of GBS within 40 weeks of having the flu shot. She commented that she did not know this. Needless to say, I have never had another flu shot.

Getting dressed and ready for various activities was hard work. The 6-foot tall, muscular head nurse would sometimes help out. She would get my pants on me part way up my legs while I was sitting in the wheelchair, haul me up by my pants’ waistband to lean against her large frame, and shake me into them like a pillow into a pillowcase. We had a few laughs over that.

During this time I was attending sessions with the psychologist, occupational therapist and physiotherapists. After certain activities I had to do I started experiencing nausea and vomiting. I came to relate this to stress. There was a Continued next page ➔
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kitchen in the hospital set up on one of the floors so that rehabilitating patients could practice making themselves meals. During this exercise I threw up twice. Even talking with my doctor about throwing up caused me to throw up. On one occasion, after visiting my home with the occupational therapist to assess my living conditions, I again threw up. The occupational therapist said that we would have to remove the bed that my husband and I slept on and replace it with a hospital bed and a single bed, that the bathroom would have to be remodeled, all doors removed, kitchen modified, etc. I said, “You sound as if I am never going to get better.” No response. Still, I was not convinced that I was not going to get better. However, the shock was to come later.

One day I was informed that there was to be a family meeting. In attendance were my husband, my son, my daughter, my granddaughter, and my neurologist who ran the meeting, the head physiotherapist, the social worker, the occupational therapist and the psychologist.

The only thing I remember from this meeting is my neurologist saying to me, “You are probably never going to walk again”. After that I remember wheeling myself, in tears, as fast as I could to get back to my room. A nurse noticed the state I was in and came after me into my room. I told her what the neurologist had said, and she assured me that many people with GBS had left the hospital on their own two feet. I was greatly comforted. However, my husband and I were shocked and angered that the neurologist had come out with this statement in front of everyone without telling us beforehand. I believe that the psychologist had been a bit surprised by this approach too, because he spent quite a bit of time in a subsequent meeting trying to assess my feelings about hearing this so suddenly.

Time passed through October and November with daily visits to the gym. The therapist started me wearing braces around my ankles and tried to get me to stand up between the parallel bars. After a few days of failures I managed to pull myself out of the wheelchair, grab the bars and pull to a shaky standing position. Yeah! The therapist felt my thighs and said, – I could sense the relief under her breath – “You are starting to recover.” I was elated. I could see out of the hospital windows, now that I was standing. I could see how my top hung so loosely from my shoulders. I lost 51 lbs. during my entire stay. Over the months of November and December I progressed, with assistance, to a slow, staggering walk with one of those push/plonk walkers with the tennis balls on the front (or is it the back?) legs.

In early December I was given a discharge date. It was to be just before Christmas. When the discharge day arrived the taxi took us to our condo building in the middle of heavy snow. But here I was to rest, to sleep in my own bed next to my husband with a bag of medications, enough to set up my own pharmacy, it seemed.

Life at home was difficult at first. My husband would make me toast before rushing off to work. I would sit in my wheelchair staring out of the window, too tired to do anything. I couldn’t get to the bathroom on my own so I managed to wait until about 4:00pm and I would call him to come and help me. We had equipment so that I could get into the bathtub for showering.

My treatment wasn’t over. I was scheduled for twice- weekly appointments with the Rehab Centre for the next two years. I never missed an appointment except for two trips we took to Florida where the exercise of climbing up the 18 stairs of our condo seemed to improve me considerably.

I was fitted out with custom braces because of foot drop and I have never recovered from that. My other residual effect is tiredness that I understand is a common problem for GBS recovering patients.

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Six months after discharge I came down with some sort of infection. At this time I thought it would be advisable to stop the medications I was taking if I was going to take something else for this infection. So I stopped the painkiller, which was a morphine derivative. As soon as I did this I developed a cough and was so restless and trembling I could not sleep. On an emergency doctor’s advice I went back on the morphine-based drug. I had become addicted to it. Six months after that I was in Florida on my own and I decided to wean myself off this drug, which I did successfully by gradually reducing the dosage to nil.

How to summarize my experience? It was a nightmare for both my husband and I but we survived. First of all, my greatest gratitude is to my husband who gave me the most care and concern possible while dealing with his business responsibilities. My second is to the nurses of the second rehabilitation hospital and to my sitters, particularly my Iranian sitter, for their comfort and care. My children, of course, I am grateful to for their visits and help and to my family in England and the many friends who either visited or tried to visit me in hospital.

I came to trust the nurses of the rehabilitation hospital, not only for their kindness and humanity and for their experience and honesty with me. Friends have asked me if I am angry about what happened to me. My answer is always “No”, but what does anger me is the lack of information given out to patients and the public about the potential serious side effects of medications and inoculations. Providing the information should lead to earlier diagnosis and then better outcomes from GBS would hopefully result.

My life is fairly normal for someone of my age. I can’t do some of the things I would have liked but I have recovered more than anyone - except me - expected. I use a walking stick and braces for short distances, a walker and braces for longer distances and neither of those when I am at home. So I have to say, “Life is good”, all things considered.

Rosemary H.

2018 Walter Keast Award

It’s with great pleasure that we announce that Dean Lower is the recipient of the Walter Keast Award for 2018!

Dean was first diagnosed with GBS, and later changed to an acute form of CIDP. Just two weeks after discharge Dean presented his journey with GBS to the Neuroscience Nurses Educational Day. Shortly after he was invited to the University of Alberta to present his journey to the Neuroscience Department. As a Liaison Dean has spoken to and visited many patients. He participated in the Calgary Educational Day and was an integral part in the success of the first ever Calgary Walk N Roll. Not only did he help to plan and organize the Walk, he created a team and raised $5500.00 dollars. Congratulations Dean!