# GBS/CIDP Foundation of Canada

Guillain-Barré Syndrome / Chronic Inflammatory Demyelinating Polyneuropathy

*Support, Education, and Research*

# *News & Views*

***Issue: 2016*** ***Fall/Winter***




## *A Message from Donna Hartlen, Executive Director*

We end 2016 with a special edition of 'News and Views', dedicated to our members. What is a better way to get to know those that we serve than by hearing their stories or telling you about those that give back as volunteers to the community?

I am so pleased to have several articles, from GBS, MMN, Miller Fisher, and Caregiver members, which give us some raw insight into the emotional roller coaster, day-to-day inconvenience, and the courage each has shown to move forward in life. We thank those that attended our Educational Afternoons, say our good-byes to two very special volunteers, and welcome two new Medical Advisory board doctors.

We look forward to the spring newsletter that we believe will be more heavily weighted with medical articles.

In our last edition, I wrote about the different activities going on throughout the rest of spring through the fall. The main point of discussion was a patient survey for both foundation and medical information and that it would be a pilot in Alberta. Members called or emailed to be next in line. Thank you for your interest to participate and I apologize for the delay. We need a website, software, and hosting to be able to accomplish this task. This is a top priority for the foundation in 2017 and will be the steppingstone of being able to expand Canadian services. We hope to have more news in the spring.

I would like to thank our members, volunteers, directors, Medical Advisory Board, and sponsors for your support and efforts in 2016 and from my family, to you and yours, I wish you all the best in 2017. **Happy Holidays!** **Sincerely, Donna**

*GBS/CIDP Foundation of Canada*
*creates*

## *The Walter Keast Award*

Awarded by nomination annually to an individual in the GBS-CIDP Canadian community that exhibits an exemplary commitment, one that resembles Walter's dedication to patients and families through his many years of volunteer work for the Foundation.

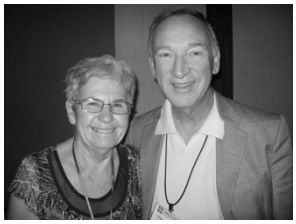
## *GBS/CIDP Foundation of Canada Is Pleased to Announce the Designation of Two Canadian Neurologists To our National Medical Advisory Board Team*

***Dr. Rami Massie*** is a neurologist at the Montreal Neurological Hospital specialized in neuromuscular disorders. After completing his residency in neurology at McGill University, he completed an EMG/Neuromuscular diseases fellowship and a peripheral nerve fellowship at Mayo Clinic in Rochester, Minnesota. He worked for four years at Sacré-Coeur Hospital in Montreal before coming full time to the Neuro. His clinical activities consist of seeing patients in the EMG laboratory, in the ALS clinic and in the neuromuscular clinic, with a particular interest for disorders of peripheral nerves. He also works in the Montreal General Hospital Neuropathy Clinic. He is also responsible for the monthly Neuromuscular Journal Club, which brings together all the neuromuscular specialists in the province.

***Dr. Chris White*** is the head of the Calgary Neuromuscular Program. He has an undergraduate degree in biology and psychology as well as an MD from McMaster University in Hamilton. He then trained in neurology at Queens University in Kingston. After a neuromuscular and EMG fellowship at the University of Western Ontario he moved to Calgary to join the department of clinical neurosciences and has been there since 1997.

## *GBS/CIDP International Symposium—San Antonio, Texas, USA Submitted by Barbara Sherman – Liaison: London, ON*


Hats off to the organizers of the 14th International Symposium. They did a great job making this a very successful event. They managed to shorten conference time to two days instead of two and a half days and still keep us on schedule. We had very intense full days with sessions starting at 8:15am and finishing around 5:15pm. After that was dinner and social events to get to know each other and share stories. The experts were all there to lead different sessions, share their wealth of knowledge and answer your questions. For the first time they offered personal time with a neurologist if you were having difficulty with your disease and needed a consultation.



This had to be scheduled ahead of time. Many of the neurologists were approachable, talking to different folks and answering their questions. In one session they talked a lot about the Zika Virus, and the number of new GBS cases that developed as a result. They are doing a lot of research around Zika. In another session where they talked about woman's issues they didn't have a speaker and it developed into one of the better sessions. Estelle Benson was delighted. → **Continued page 12**

## *A Life in Transition*
## *Submitted by Donna Sparkes, GBS Warrior*
## *Toronto, ON*

My GBS story begins Saturday morning, August 22, 2015. It was day two of an annual cottage weekend that was a highlight in what had already been a pretty spectacular summer. In June, after three years of sweat and sacrifice, I received my Master's degree. The first two weeks of August brought us to France for a wedding and reunion with my husband's family, which except for my unfortunate bout of food poisoning at the end, was rather fantastic. And just a couple of hours prior to leaving for the cottage, I had met with my business coach to begin building my new consulting practice. Now, to top it off, here I was spending quality time with some of my fabulous girlfriends. Life was pretty sweet.

As I climbed the stairs from my bunky to the main house that morning, I stretched out my strangely stiff calves. I couldn't remember doing anything strenuous that would make them feel so tight, but I shrugged off the oddness and looked forward to another day of delicious food, wine, conversation, and some serious dock time. Sitting in my Muskoka chair a little later, I reached over to flick an ant from my arm, but my fingers barely nudged it. So weird. I looked at my hands, opened and closed them, and stretched out my fingers. They felt slow and a bit weak when I made fists. What was going on? I tested my hands by grabbing a can from the ice bucket and popping the cap. I grinned… Well, at least I could still open a beer! I'm not much of an alarmist when it comes to health matters, and tend to have an "if it's bad it will get worse" approach. Unfortunately, things were about to get far worse.

By dinnertime I was having difficulty lifting my feet when I walked, and needed help cutting my steak. The next morning, I was marching rather than walking. When I went to the washroom my right leg buckled underneath me. My shin bones were buzzing, my calves felt like I had just run a marathon, and I couldn't even move my toes. When we left the cottage that afternoon I couldn't walk on my own and had to leave my car at the marina.

My friends delivered me to a very shocked and worried husband at about 7:30 pm. I insisted on waiting to see our family doctor the next morning, but when the next morning came it was obvious that I needed a hospital, so we called for an ambulance. A couple of hours later I heard "Guillain-Barre Syndrome" for the first time and was admitted to hospital soon after.

By Tuesday morning my limbs were almost completely paralyzed and it began to feel as though hot barbed wire was being pulled through my hips. But Tuesday also brought me a wonderful senior resident neurologist who was my kind of doctor. He performed a lumbar puncture and pushed for an urgent CT scan and MRI. Where others had been vague about what to expect, he answered my questions and gave it to me straight. He explained how my body's immune response was overreacting to my little bout of food poisoning and attacking my nerves. He laid out his prognosis, which wasn't pretty. Because my symptom onset was so swift and severe, he expected I would get far worse before I got better. He described how IVIG treatment would help slow the attack, but advised me to prepare for "the long haul".

After some prodding and googling I learned what "the long haul" was. Two to four weeks of decline into full body paralysis, reliance on a respirator and feeding tube, six to twelve months in a rehab hospital, months of outpatient rehab, crippling fatigue and nerve pain for who knows how long, with the potential for residual symptoms for the rest of my life. Now, how exactly does one prepare for that?

Well, here I am 15 months later, and I have learned a few things.

One, a prognosis is only a best guess. It is not a certainty. After two intensive nights of high-dose IVIG treatment, my decline halted and my body began to improve. No respirator. No feeding tube. On day eight I was transferred to a rehab hospital. In total I spent six weeks in hospital, not six months. Take that, long haul!

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## *A Life in Transition (continued)*

Two, psychological care is essential. Within three days I had gone from completely healthy to completely dependent -- it was sudden and it was scary. With GBS, decline is quick, recovery slow, and transitions tough. I needed help processing everything that was happening to me. In my opinion, the lack of psychological care as a fundamental, automatic part of GBS treatment is a huge gap.

Three, outpatient therapy must be scheduled before going home. During inpatient rehab I worked my butt off and made huge progress. As soon as I could use a walker and climb a flight of stairs I was transferred home with the expectation that outpatient therapy would continue the following week. However, my therapy was delayed for six weeks during which time I declined physically and psychologically. Make no mistake: this was the worst experience of my whole GBS journey.

Four, we can't always choose our circumstances, but we can choose how we respond to them. GBS sucks and recovery is tough, but crap happens to everyone, and I'm a part of everyone. I personally do not believe that "everything happens for a reason," but I do believe there is value in every circumstance. This experience will change you for better or for worse; the choice is yours.

My fight with GBS is not over and I continue to face some challenges. The financial impact has been tough. After investing so much in my degree, I am not able to work, and for various reasons I seem to fall through the cracks of all government assistance programs. Fatigue is another challenge, and is a symptom that is hard to understand. People want to visit and you can't. You want to do more, and you can't. As mobility improves, expectations begin to return (from others and yourself) that you just can't live up to. But my biggest challenge is staying motivated with physical therapy. Physiotherapy was really helpful, but after my allotted healthcare sessions were used, I was left on my own. And we can't afford private physiotherapy.

But I'm not complaining: mine is a life in transition. I may or may not be able to return to my career, but I can move forward from where I am. With the help of Make A Change Canada's Business Abilities program, I am creating RehabForBeginners.com where I aim to help others by addressing some of the gaps I experienced in my rehab and recovery. Stay tuned!

GBS/CIDP Foundation of Canada

Fondation Canadienne du SGB/PDIC

GBS/CIDP Foundation of Canada has been supporting patients and families since 2003 by the generosity of our members and sponsors. Your generosity has allowed us to grow, support, educate, connect, and, invest in Canadian Research. Thank You!

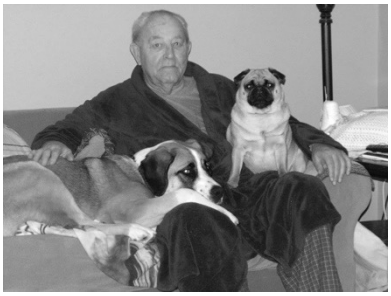
WE NOW NEED YOUR SUPPORT. In order to move forward with several important activities, we are counting on your generosity once again. With your gift of donation, you will be supporting the following foundation activities in 2017.

- Canadian Website, software, and hosting
- Minimum of three Educational Afternoons. London and Hamilton confirmed
- Patient Support
- Expanding Canadian Literature

**DONATE NOW – CanadaHelps.ca**

A donation receipt is given for donations of $10.00 or more

# *Walter Keast 1940 - 2016*



Walter passed away peacefully on October 5th, 2016 after a long battle with cancer. His family was at his side. Walter will be sadly missed by his wife Susan (daughter Pam, Son Rob, Daughter-in-law Kira and two well loved grandsons, Jake and Jamie). Walter and Susan were married in 1965 and they spent most of their married lives living in the country. Walter loved his dogs and also spending time with the miniature horses and donkeys. His great love was attending the hockey and football games of both his grandsons. He had also played hockey and football at Upper Canada College, reliving all this with Jake and Jamie brought him so much pleasure.

When Susan came down with GBS back in 1989 he was determined to find a way to help others. Not much was known back then and only a few dedicated people whom we were grateful to meet helped us find others who also needed help and support. Barbara Clark Smith was one person who helped gather people together to form the Ontario Support Group and with her help many support meetings were held so that we could all learn to cope. Many years later we joined the US Foundation International with Estelle and Bob Benson and with their help we were able to start a registered charity for GBS/CIDP Foundation of Canada. Since that time back in 2003, Walter was actively helping the foundation by doing the Foundation accounting and keeping everything in order. He remained a dedicated Foundation member until the summer of 2015 - 2016 when his cancer became his main challenge and his work with the Foundation had to end. He helped support so many of our patients and never missed an event. He cared about all those at the Foundation and always thought of them as family.

# *Maureen Kachmar*

After a long, but mostly pain free battle with Alzheimers and cancer, Maureen passed away with her husband Michael by her side on November 17, 2016. She is survived by her husband, her brother Murray (Susan) and her sister Glenys (Dave), her nieces and nephews, her sons, Warren (Arlene), Glenn and Reid and her grandchildren Anne, Taylor and Michaela.

Maureen was born in Winnipeg and grew up in Fort Rouge. She enjoyed sports in her youth and was a lifelong artist as well as being skilled at many different crafts. Maureen also faced challenges. She experienced polio, Guillain-Barré Syndrome, Alzheimer's and cancer twice. Maureen took great joy in helping others. Her career as a social worker included work with children, seniors and the differently-abled. Her care of others included extensive volunteer work and her legacy will include decades of work with the Guillain-Barré Society.

Maureen had been involved with the Canadian and International GBS/CIDP Foundations, both as Regional Director, and then as a Director here on our Canadian Board of Directors. There was always time for patients and she spent many hours either on the phone, in person, as well as email. She attended every conference we had and always helped to get things put together. She also attended every symposium in the US and shared so much information in how to make things better for all. Maureen was dedicated to make sure that all patients had the help they needed to make their own lives better.

# *Educational Events 2016*

Many thanks to all that attended our Educational Afternoons in 2016 in Ottawa, Halifax, and Vancouver. Our educational events could not be possible without the help of medical professionals and our volunteers. We recognize the following individuals for their volunteer participation in the success of these events. Ottawa: Dr. Pierre Bourque, Dr. Elizabeth Pringle, Linda Theoret, Linda Paul, Demetrios Strongolos Halifax: Dr. Timothy Benstead, Dr. Ian Grant, Dr. Christine Short, Deb Bernasky and family, Jennifer Knee, Georgann Payne Vancouver: Dr. Kristine Chapman, Dr. Gillian Gibson, Dr. Kristin Jack, Dr. Jamila Madhani, Deborah Bernasky, Kim Brooks, Jane Field, Jason Kent, Sherry Nejedly, Caleb Sigurgeirson, Demetrios Strongolos

Ottawa

Ottawa


Halifax

Vancouver

Vancouver

** Visit our Facebook page for more photos from the events, GBS / CIDP Foundation of Canada**

## *Upcoming Events*

***Please visit gbs-cidp.org/Canada for details and updates on Canadian events***

**Toronto Support Group Meeting – Sunday, Jan 22, 2017** (Special Guest – Dr. Hans Katzberg)
**London Educational Afternoon – Saturday, May 6, 2017** (Dr. Kurt Kimpinski, more to come…)
**Hamilton Educational Afternoon – TBA** (Dr. Steven Baker, more to come…)

# *My MFS/CIDP Journey*

***Submitted by Doreen Reid***

According to several articles I have read about Miller Fisher Syndrome the prognosis for recovery is excellent with most patients making a full recovery within a few weeks or a few months. And then there is my experience…

I am a Prairie girl born on March 13, 1919 in Saskatchewan where I lived for 81 years. I graduated as a registered nurse in 1941 from Regina Gray Nuns' Hospital and served as a Nursing Sister in the Royal Canadian Medical Core during World War Two. I continued with my nursing career after my marriage until I retired at the age of 58. In 2000, I moved to British Columbia to be closer to my two sons and their families. I began having a few health problems such as two TIA's in 1999 and a bit of a heart problem. In September of 2007, I made a decision to move to a Seniors' Residence (an old folks home). It offered independent living and also a care wing. I was still active in the community as a member of Eastern Star and involved in several bridge groups, often playing eight times a week. I was still driving and even made a few trips back to Saskatchewan driving by myself.

Suddenly at the end of January of 2008, my right eye (lower lid) became incredibly painful. My daughter-in-law said I had two little white spots on my lower lid. I immediately went to see a doctor and was given eye drops for an eye infection.

The next morning I had pustules on my right eyebrow. My first thought was shingles, so I went back to the doctor who now prescribed an antiviral medication. But it was too late and I had developed a very severe case of shingles. Was this misdiagnosis because of ageism? I wondered. I was 89 years old.

And so began my life changing journey with this MFS and later CIDP. I also developed a severe case of thrush in my mouth and throat; which I believed was causing difficulty in my swallowing and talking. With the help of a care aid I was determined to remain in my suite. I became very weak, and after having several falls and when I could no longer speak and swallow I decided I had to go to the hospital. This was in the middle of February.

The doctor in the emergency room kept examining my face and throat and finally said, "It's not the thrush, it's not the shingles, she's paralyzed!" After a series of MRIs, scans and blood work, I was diagnosed with Miller Fisher Syndrome. The only treatment I was given was a course of prednisone. There was no mention of an IVIG treatment. I had no physiotherapy, and no explanation about my condition and how severe it was. I had no follow up after my initial treatment and was told that I would be fine in just a few months. I was put on a diet of thickened liquids gradually moving on to a puréed diet. The paralysis progressed down my body to my legs and feet also paralyzing my bladder so I had a Foley catheter for quite a long time. My bowels also became paralyzed, and to this day they have not fully recovered. As a result I take a cocktail of laxatives every night. A couple of episodes of impacted stool have kept me vigilant.

While I was at the hospital I was taken to the gym on a regular basis and was assisted by two staff members to learn to walk again. I remained in the hospital till the 30th of March when I was discharged and returned to the care wing at my seniors' residence where I remained until the end of May. Then I was able to return to my own suite requiring the help of a care aid for a couple of months. I almost wore out the carpet in the hallways with my walker trying to continue walking to regain my strength. I gradually improved to the point where I was able to attend bridge tournaments at Harrison Hot Springs and with other groups closer to my home. I was able to travel to Palm Desert spending quality time with family there as well as on the lower mainland. I became very active in the community within the residence becoming the President of the Resident Council, which was formed in late 2009. (I remained president of the council until 2016). I also organized a bridge club and a knitting group. Our project for the moment is knitting sweaters and caps for babies in Rwanda. I received a Provincial Award in 2014 from the Simon Fraser University Gerontology Research Centre. This was a senior's leadership award → **continued next page**

## *My MFS/CIDP Journey (continued)*

for service to seniors in the community.

During this period I was dealing with residual issues. My right eye continued to be troublesome resulting in many visits to the ophthalmologist and requiring steroid drops. Until a year ago I saw my dentist every three months for cleaning to help keep my gums healthy. I have found that stress will trigger a relapse.

In June of 2013 my oldest son died unexpectedly of a heart attack. My close-knit family was devastated. As the only senior family member left, I needed to be strong. This has been a very difficult time and still is, but we do learn to live again. With every tear we shed, we learn.

By the end of 2013, I became very ill. It is very hard to describe, but I had a general feeling of malaise; I had no appetite; I lost weight; I was weak and tired. Also, I had more trouble with my gums and more shingle pain above my right eye. At this time, I was taking a blood thinner as a precaution after having two TIAs back in 1999. Because of this the capillaries around my lower legs and ankles would continually break down and bleed, resulting in blood under the skin. The skin on both legs broke down resulting in open areas. These had to be dressed and cared for by my care-aid. They took many months to heal.

I had some trouble walking and speaking and swallowing and was put back on a prednisone regime. I continued to go to the dining room using my power wheelchair and continued to partake in some activities. In the fall of 2014 I attended the GBS/CDIP conference with my daughter- in -law. In the question period I asked, "Could one have a relapse of Miller Fisher Syndrome?" I was told, "Yes, you can even 5, 10, or 15 years later."

My GP made a referral for me to see a neurologist. My appointment was on May 20th, 2015. During our discussion, I was told they did not expect me to leave the hospital back in 2008. Why was I not told? Why was my family not told? Then to my great surprise I was told I now have CIDP. To say the least, I was shocked, we both were. There was no mention of a follow up or help with any of my activities. Since then I have had two episodes of shingles controlled by the antiviral medication which I now take every day. I still have trouble walking and my walker is never far from my side.

My health improved and remains fairly stable. In October, my daughter-in-law and I attended an information afternoon regarding GBS and CIDP. I have attended all these meetings since 2008 and have found them of great value. Generally the age range for these conditions is from 8 months to 81 years. I guess I changed that. I was 89 when I was first diagnosed. The liaisons for the Foundation in BC, Suzan Jennings and Sherry Nejedly, have been a great help to me. In addition I have enjoyed many visits with Gail Kammer in Saskatchewan.

As a result of this meeting, a referral has been made for me to see Dr. Kristine Chapman, who is the director of The Vancouver Hospital Neuromuscular Disease Unit. I am looking forward to my visit with Dr. Chapman. At the moment I am back on prednisone. I think this relapse was caused by stress after having a hernia repair.

In the many stories of GBS and CIDP that I have read there is a common thread of determination that this disease will not define our lives. This is not who we are or what we are. We are a group of people with this strange disease that changes on a whim. Without the loving and caring support of family, friends and the wonderful support of the staff at my residence, this journey would have been much harder. It has not been easy and it is not over; however, being an avid bridge player I have learned that in life as in bridge we play the hand we are dealt. I am now looking forward to celebrating my 98th birthday.

**Note: I have a nephew who has been diagnosed with CIDP and an English cousin who is now deceased, who had GBS.**

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

# *MY MMN Story*

***Submitted by Jack Konings***

Hello. My name is Jack Konings and I have Multifocal Motor Neuropathy with conduction Block (MMN).

In about 1996 I started noticing difficulty holding onto things with my right hand. I also had mild shocks in my lower right arm. I consulted my family doctor who sent me to various specialists over a one-year period. One of these specialists was Dr. Giles, a neurologist in Cambridge, Ontario. She did some strength tests and did a rudimentary EMG. This diagnosis led her to believe that I might have MMN. She referred me to Dr Hahn, a neurologist at London Health Sciences/University Hospital. Dr. Hahn also performed strength tests, blood work, and scheduled an MRI and a comprehensive EMG. These tests confirmed the MMN diagnosis.

The treatment prescribed was to try intravenous immunoglobulin (IVIG). A dose of 70 grams 5% solution was started. This was done by Bonnie Hogan, RN, at the IV Therapy Clinic at University Hospital in 1998. The first dose was spread out over 5 days at a very slow rate. After confirming that I tolerated the IVIG I was put on a 6-week rotation of 70 grams. The only side effects were mild nausea and headaches. These treatments took about 7 hours.

I saw Dr. Hahn and Nurse Practitioner Wilma Koopman annually to monitor my progress. It was eventually determined that a 4 week rotation of the same dose was more suitable.

After about a year, because of the travel time involved, I asked to have my infusions done in Cambridge. Because of the excellent reputation of Dr. J. Gowing, this request was allowed and I started receiving my IV treatments at the Medical Day Care Clinic at Cambridge Memorial Hospital. I continued with the 5% solution until a 10% solution became available. This reduced the infusion time dramatically and I was able to get my infusion in about 4 ½ hours at a maximum rate of 200 ml/hr.

In 2006 I decided to have a catheter port surgically implanted. This allowed the nurses to use a special right angle needle to access my bloodstream. The decision to install the port was made because of the level of scarring in my veins after repeated IV pokes over the years. The last straw for me was when I was poked 6 times in the same arm before a suitable vein was found.

I was still going to London annually for my check ups until Dr. Hahn retired. I then went back to Dr. Giles in Cambridge and eventually to Dr. D Stewart.

In the spring of 2016 I attended a GBS/CIDP seminar in Ottawa and was shown a new way to self infuse called subcutaneous immunoglobulin (SCIG). I had heard of this procedure previously, but hadn't considered it until I heard the excellent presentation by Lynda Theoret, RN. I was sold.

My main reason for considering SCIG was the cost of flights back and forth to and from Florida where I go for a few months in the winter.

After consulting Dr. Stewart in Cambridge he referred me to Dr. Kimpinski, a neurologist at London Health Sciences/University Hospital. After an initial consultation with him and Wilma Koopman it was determined that I was a candidate. Government approval was also obtained.
I received my first infusion on October 7th. This was a 25% dose administered by myself under the supervision of a nurse from the drug company that supplied the IVIG. The next infusions were on my own with my wife as supervisor. The IVIG used is a 20% solution that is administered via the fat (subcutaneous) tissue in the stomach. So far all is going well.

How has MMN affected my life? There have been very few changes. I am no longer able to lift heavy objects that require both hands. My dexterity is limited for some tasks, such as cutting meat at dinner, cutting fingernails, using normal scissors etc..

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## *One Mother's Experience*
### *Submitted by Barbara Rahder*

It was odd for my 26-year-old daughter Micha to schedule our weekly phone call for a time when she knew I'd be going out to a friend's. But I called at the appointed hour and Micha, who was a doctoral student in California, began by saying, "I've got some bad news." I could feel my body bracing. She told me she'd been to the campus health clinic earlier in the week and described her symptoms: pins and needles in her hands and feet, tripping, falling down, dropping things and, most recently, falling over sideways on her bike when her legs refused to pedal. But Micha played rugby. She biked over mountains. She could run for miles. How could this be? My heart was pounding and my mind racing. Micha described how the young doctor had turned pale and fled the room in search of someone more experienced, how the doctor's panic had frightened her, how she'd been referred to a local neurologist, and how she hoped she'd know more soon. Tears were streaming down my face as we spoke, but it wasn't until I'd hung up and driven over to my friend Anne's, that I collapsed, falling to my knees and wailing, barely able to get the words out to explain why I was so distraught. Micha knew that I would need the support of my friends to cope with her news and had scheduled our call accordingly. I wondered, not for the first time, who was the parent and who the child.

Thus began eight long months of tests and speculation, an agonizing wait for a diagnosis and potential treatment. As Micha's symptoms ebbed and flowed, each wave seemed worse than the last. I was barely functioning in my job, but had a loyal secretary and a few close associates who knew what I was going through and helped me stay mostly on schedule, at least at work. At home, I lost the ability to keep myself organized. I missed dentist appointments, showed up at the doctor's a day early, dragged the wrong bins to the curb, and forgot to pick up my in-laws at the airport. It wasn't that I didn't have a calendar. Somehow I managed to write down every single one of these appointments on the wrong day or at the wrong time. All around me, I was recreating the chaos I felt inside.

When CIDP was finally confirmed, and IVIG proved effective, the relief was overwhelming, however short lived. Within weeks, her symptoms recurred, worse than before. In the months and years that followed, Micha maintained a two-day once-a month cycle of regular IVIG treatment, but with a number of scary glitches along the way. At first, I'd get weepy whenever she had a treatment, but eventually I got used to the schedule and just felt a little raw on her treatment days. At the same time, I was in awe of my daughter's strength and maturity. Clearly, this illness wasn't going to stop her. It wasn't even going to slow her down.

Before Micha flew off to do her doctoral research in the jungles of Peten in northern Guatemala, we were assured that her student medical insurance would continue to cover her IVIG treatments while she was abroad. We knew that we'd have to pay out of pocket and then get reimbursed by her insurance, but lucky for her, I thought I had enough savings to cover this short-term expense. Micha also checked out the availability of healthcare services in Flores, Guatemala, where she'd be living, and arranged, in advance, to go to a local clinic where a doctor could provide treatment. But nothing worked quite as planned.

Shortly after she arrived, she caught the worst cold of her life. It cleared up miraculously fast as her immune system kicked into high gear. Within days, however, she was unable to climb the stairs to her apartment. Her first treatment went roughly as we'd imagined, but turned out to be less than half the amount of IVIG she actually needed. Instead of recovering, she continued to decline. Her neurologist, back in the US, prescribed large quantities of prednisone, but rather than helping, the side effects quickly became debilitating. Unable to sleep or concentrate or get around on her own, she phoned me in desperation. I persuaded her to fly back to the US for treatment. → **Continued next page**

The following month, Micha organized a full IVIG treatment for herself at a hospital in Guatemala City. She basically walked in, introduced herself to the neurologist, told him about CIDP and persuaded him to treat her. She received excellent treatment there. Twice. The first time, she was required to stay in the hospital overnight because they were unfamiliar with the disease and wanted to be cautious. Everything worked smoothly, so she was treated as an outpatient the following month. Having already paid out over $50,000, however, I was running out of savings and still had received no indication of when I would be reimbursed by Micha's insurance. We had to switch tactics. Instead of continuing to receive treatment in Guatemala City, I paid to fly Micha back to the US every month where her insurance paid upfront for her treatment. After a year and a half of fieldwork in the forests of Peten, and almost monthly flights back and forth to the US for treatment, Micha completed her research and returned to California to analyse her findings and write her dissertation.

At some point during the next year—as she was busy teaching, writing, and coaching rugby—she was informed that she was going to lose her health insurance because she would soon exceed her lifetime coverage ($400,000 US) under the students' plan. Initially they said they'd cut her off at the end of 2012, which was, in fact, the last treatment they paid for upfront. But in January, after they finally reimbursed me for the cost of her treatments in Guatemala, the insurance company moved her cut-off date from December to the prior September, claiming that she now owed them for three months worth of IVIG expenses!

In response, Micha did several things. First, she came back to Canada to re-enroll in OHIP (with a three-month wait for coverage under the mobile worker program). This allowed her to continue her studies in California, to apply for other types of emergency medical insurance in the US and, most importantly, to help organize to change the healthcare policy offered to University of California students. The students at Santa Cruz, Berkeley and other campuses wrote letters, created petitions, held protest marches and demonstrations, lobbied the UC Chancellors and members of the Board of Regents. And they got media attention for the plight of students, like Micha, whose studies were in jeopardy because of their lack of healthcare coverage. Micha spoke at rallies, met with officials, and was interviewed by CNN, among others.

During the three-month wait for her OHIP coverage, she struggled through a long period without needed treatment, at one point becoming bedridden and so weak that she was unable to feed herself. Ultimately, she had to have treatment regardless of the cost, so we solicited donations from friends and family and got support from a local medical charity, as well. Her rugby team provided homecare.

When her OHIP coverage began, Micha moved back to Toronto, as planned. To my shock and dismay, however, the earliest she could get an appointment with a neurologist was another four months away! This meant no way to schedule her regular IVIG treatment, as we'd anticipated. Our family doctor was unable to help. Micha's health was deteriorating and I became frantic, again!

Then, one night I went to the GBS/CIDP Foundation of Canada website, found Susan Keast's email and wrote to her. She responded that same evening and was tremendously helpful and reassuring. By the next week, Micha had an appointment with Dr. Bril and, soon after, was enrolled in a study. Unfortunately, the experimental treatment did not work for her and she had to drop out. It seemed we were back to square one! I know I emailed Susan again for help and don't really remember how things got resolved, but somehow Micha was able to go to Toronto Western Hospital for regular treatments after that. I am so thankful for Canada's healthcare system and also for Susan Keast!

As it turned out, the political organizing and pressure that students put on the University of California paid off, too. The Chancellors voted to change the students' health insurance plan, so that there is no longer any lifetime limit on their healthcare costs. Micha was able to return to UC Santa Cruz, complete her PhD, and is now an anthropology

→ **Continued next page**

## *MY MMN Story (continued)*

My hand tends to remain partially closed or clawed. Sometimes I lose finger control and my finger or thumb will shake. I have a brace for my hand that prevents my fingers from hyper-extending. It also lets my fingers straighten out more. Just as anyone does, I have learned to cope.

MMN can only affect your extremities so there are no good and bad periods as there might be in GBS or CIDP. Progression is very slow and held in check once IVIG treatment is started. I hope my story helps others recently diagnosed with MMN learn about its long-term prognosis. The most important thing to remember is that life goes on.

## *One Mother's Experience (continued)*

professor at Louisiana State University in Baton Rouge, where she continues to receive IVIG treatments for two days every month…at least as long as Obama's Affordable Care Act is still in place.

***Barbara Rahder and her daughter, Micha, are dual Canadian/US citizens. Barbara is a retired environmental studies professor.***

## *GBS/CIDP International Symposium—San Antonio, Texas, USA (continued)*

More sessions covered GBS, CIDP, MNN and variants, children and teen issues, Emotional issues for Caregivers and patients, vaccinations, managing residuals, stem cell transplantation, GBS modified therapies research, the power of mindfulness, a personal story, Research etc. They covered a lot of material. Like I said it was very intense. We took lots of notes and learned a lot.

Kelly Dadurka a physiotherapist from the London Health Science Centre and I manned a table with eight Canadians who attended the Symposium along with folks from Italy, South Africa, Germany, and the Netherlands. We each shared our stories, got to know each other, and plan to stay connected.

I have been to several International Symposiums and it is always a very rewarding experience to have the opportunity to go, to learn, and hear other folk's stories.

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**PLEASE CONTINUE TO VISIT gbs-cidp.org/Canada and our FACEBOOK page 'GBS / CIDP Foundation of Canada' for our current support group and event listings for up-to-date information on locations, dates, and times.**