

# GBS/CIDP Foundation of Canada

Guillain-Barré Syndrome / Chronic Inflammatory Demyelinating Polyneuropathy  
*Support, Education, and Research*

## News & Views

Issue: 2016

Spring/Summer

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



Along with spring, the foundation is undergoing a time of transition and new growth. We are gaining insight into your needs as we connect with you one-on-one via the survey that has begun in Alberta, headed by Kim Brooks. Also along with last year's event evaluations. We are trying to responsibly implement program changes that better serve our membership.

We are currently working feverishly on the following projects and activities:

- Educational Afternoons: Educating and connecting with more of our membership across this vast country with smaller events – Ottawa, May 14<sup>th</sup> | Halifax, May 28<sup>th</sup> | Vancouver (Oct 22). Thank you to our Medical Advisory Board and local medical professionals that have volunteered their personal time. Registration is now open for Ottawa and Halifax!
- Canadian Walk and Rolls – You want to walk to support! Watch for locations this spring and fall.
- Mentoring new volunteers to get local support meetings up and running: The connections that are made with other patients and families in your communities are so important. Be a volunteer!
- Membership Survey: We estimate this survey to take about 15 minutes and all information will remain confidential. Please see the red flyer that breaks down the information we are trying to gain in order for the foundation to do a better job prioritizing your needs. Thank you to those that have completed the survey and chosen to be part of a larger voice! This survey is anticipated to run over many months.
- Educational In-services: Building awareness of the foundation and our disorders within the medical community through presentations to groups such as ICU, Rehab Wards, etc.
- Expanding on our Canadian literature
- The foundation and volunteers will continue to put patient and family support as our number one focus. Call 1-647-56-6842 or email [info@gbscidpcanada.org](mailto:info@gbscidpcanada.org)

Without the generosity of our entire membership and sponsors, our 2016 program and patient support efforts would not be possible. We truly appreciate your support.

I am pleased to announce the designation of two new board members, Kim Brooks, Alberta and Jane Field, Ontario. The foundation also welcomes Demetrios (Jim) Strongolos in his new role as President and Sharon Ratelle in her role as Secretary/Treasurer. Sherry Nejedly remains your Vice President. I look forward to working with each of you.

Please enjoy this edition of the newsletter and continue to visit [gbs-cidp.org/canada](http://gbs-cidp.org/canada) for updates. Happy Spring! Warmly, Donna



**University Health Network | Toronto General  
Hospital Centre of Excellence releases Canadian  
Statement on Zika Virus and Guillain-Barré Syndrome**



March 31, 2016

The GBS/CIDP Foundation of Canada is actively monitoring the link between Zika virus and an increased incidence of Guillain-Barré syndrome in affected regions.

A new study published in the *Lancet* examines the rates of GBS during a Zika virus outbreak in French Polynesia, from October 2013 – April 2014 (Cao-Lormeau et al. *Lancet* 2016). During this large outbreak, 32000 patients were assessed for possible infection (Gourinat AC *Emerg Infect Dis* 2015: 21; 84–6). Previously, Zika had been reported as a mild illness consisting of fever, rash, joint /muscle pain. However, new reports emerged of Guillain-Barré syndrome in 42 French Polynesian patients. Given a population of approximately 275,000, this represents an incidence rate of over 15 cases per 100,000 population – higher than the expected GBS incidence rate of 2/100,000 person-years. The study also showed that patients presenting with GBS had 59 times greater odds of having antibodies against Zika virus as compared with controls presenting to the emergency room with non-febrile illness – thus implicating Zika as the cause of GBS in these 42 patients.

Since September 2015, there has been an ongoing outbreak of Zika virus in Brazil and other countries in Central and South America. Nine countries have reported either increased rates of GBS, or detection of Zika virus in patients suffering from GBS (<http://www.who.int/mediacentre/news/statements/2016/zika-ec/en/>). For example, in El Salvador, there were 46 GBS cases reported between Dec 1, 2015 and January 6, 2016; while typically, there are 14 cases per month nationwide. As a result of this spike in GBS cases, the GBS/CIDP Foundation of Canada is committed to ensuring that our own local and provincial health systems are well informed and prepared to deal with this epidemic. In addition, we hope to be able to provide support and expertise to the most affected areas of the world. Currently, there have been very few Canadians identified who returned to Canada sick with zika virus. None have developed GBS.

GBS/CIDP Foundation of Canada is a non-profit organization supporting individuals and their families affected by Guillain-Barré syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), and variants through, support, education, research, and advocacy. The foundation has a 16 member Medical Advisory Board comprised of the Nation's leading peripheral neuropathy experts in research and patient care. For information please visit [gbs-cidp.org/canada](http://gbs-cidp.org/canada).

**Recommendations have been provided by the Global Medical Advisory Board of the GBS|CIDP Foundation International, and are as follows:**

- a) Education will be needed to alert those infected by Zika of the symptoms of GBS so they may seek healthcare early. The GBS|CIDP Foundation has materials on its website.
- b) Education of first responder healthcare workers will be needed as the complications of Zika include a number of diseases clinically similar to GBS and diagnostic confusion might arise.

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

***University Health Network | Toronto General Hospital Centre of Excellence releases Canadian Statement on Zika Virus and Guillain-Barré Syndrome (Continued)***

- c) Early neurologic consultation including nerve conduction studies will be needed. Differentiating GBS from other illnesses including primary Zika infection itself is important as a recent study suggested that early neurologic consultation can improve outcomes in GBS.
- d) Hospitals will need to be prepared for GBS patients, some of whom will have long stays in the Intensive Care Unit.
- e) Resources will be needed to provide the proven treatments, IVIg and plasma exchange.
- f) Resources will be needed for additional rehabilitation required after the acute illness.
- g) The IGOS Zika protocol, modeled on the successful IGOS protocol ([www.gbsstudies.org](http://www.gbsstudies.org)) should be in place before the epidemics start to capture data.
- h) Serological confirmation of Zika virus should be done in all cases of GBS with additional testing for the other triggers that may also lead to GBS such as dengue, chikungunya, C. jejuni, EBV, CMV, and hepatitis A/B/C/E.
- i) Biospecimens such as sera, urine, and spinal fluid should be saved and stored according to pre-specified protocols for future studies as this provides an unparalleled research opportunity to understand GBS and bring new treatments forward.
- j) Through the World Federation of Neurology, the American Academy of Neurology, and other organizations, neurologists should be engaged and prepared to see these patients and collect the important data.

Authorized By,  
Dr. Vera Bril



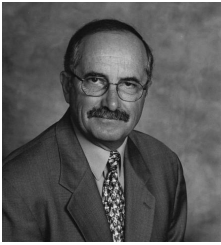
***Barbara Clark-Smith***  
***March 30, 1930 – January 20, 2016***

Barbara Clark Smith, age 85, will be sadly missed by her husband of 62 years, Albert William Smith, and loving children. The foundation wishes to extend our deepest condolences.

Barbara's career began in the 1950's as a legal secretary. She moved on to real estate as a salesperson and then as a Broker with the Toronto Real Estate Board. In 1983 she became ill with Guillain-Barre Syndrome (GBS) and eventually started a support group for GBS with the assistance of an executive group and five neurologists from across Canada who specialized in the disorder. In 1986 the GBS Support Group of Canada became a chapter of the Muscular Dystrophy Association of Canada, and Barbara was the Charter President for sixteen years. She was dedicated to her support group and continued to be involved, as it evolved, into the GBS/CIDP Foundation of Canada when it became a registered charity. For her extraordinary work in this area she received an award from the Department of Health and Welfare Canada and a Meritorious Service Medal from the Honorable Romeo LeBlanc, Governor General of Canada in 1997.

## *A Doctor With CIDP For 28 Years*

*Submitted by Dr. Kenneth Shonk*



I have been asked to write an article about my experience with CIDP over the last 28 years. It was actually in April of 1988 that I first developed my symptoms and coincidentally they started about 2 weeks after a hepatitis B shot. I had been disgustingly healthy up to

this point with missing one week of school in Grade One with the chickenpox and not having another sick day for almost 40 years. I was your typically stubborn male who ignored the tingling and numbness in my legs until I also developed muscle weakness. I was helping to coach my son's hockey team and at the practice I skated onto the ice, fell down, got up and fell down again. I was not Wayne Gretsky but I had played hockey for several years and when I had to crawl off the ice I realized that something was amiss. I had all kinds of ideas about what was wrong with me and they were not the optimistic kind. I have looked after a fair number of doctors as a family physician and sometimes their anxiety levels are higher than normal because they know all about the worst case scenarios. I had myself with ALS and a few other doomsday diseases.

Knowing that a doctor who treats himself has a fool for a patient and a fool for a doctor, it was time to seek expert help. The first neurologist I saw did not know what I had either so I felt better about my ignorance. He did however make the appropriate referral to London where I saw Dr. Hahn. I think she had me pegged with CIDP within a few minutes. At this point I was unable to walk and in a wheelchair. I will freely admit that even as a doctor I had never heard of CIDP. I did not feel so bad when Dr. Hahn informed me that it was quite a new diagnosis and if I remember correctly she said that there had only been 15 cases diagnosed to that date. ( I certainly stand to be corrected here as I am going back 28 years) I began describing my symptoms in medical terms and was instructed to use non-medical terms. By using medical terms you tend to favour the terms that correspond to your predetermined diagnosis and this can lead to misdiagnosis. I was admitted to Victoria Hospital where I had trained as a student and even presented at neurology rounds. The doctor truly becomes the patient.

I had a number of plasmaphoresis treatments and was

started on a high dose of prednisone. When I returned to see Dr. Hahn in a couple of weeks I was now walking with a cane and I did a little Charlie Chaplin routine for her. Remembering that I was in a wheelchair on my first visit, Dr. Hahn was worried that I had become manic on the prednisone but my wife informed her that this was normal for me.

I was also asked to mention my sideline interest in humour, which incidentally started at about the same time in 1988. I have been speaking about humour publically now for 28 years and have completed over 900 presentations to just about any group that you can mention including several of the GBS/CIDP Conferences.. I am continually amazed at the diverse groups interested in this topic. A few years ago I spoke at the International Plowing Match here in Roseville and three days later spoke at Grand Neurology rounds at the University of Alberta in Edmonton. I did clean the manure off my shoes before heading to Edmonton! I have observed that while speaking I usually don't notice any of my CIDP symptoms other than my balance deficits. Mind over matter?

I have had at least a half dozen relapses of my CIDP and even as a physician I have been unable to pin down what triggers them. I am to have a reassessment next week in London. Wilma Koopman has put up with me for all of the 28 years and has had to listen to my lousy jokes. Which allows me to tell you about the 104 year-old lady who was asked what was good about being 104? She quickly replied: " No peer pressure."

Adjusting to my CIDP symptoms has been somewhat of a challenge. I was the male athlete of the year in Grade Thirteen (albeit a rather small high school) and to not be able to run or even walk very fast is certainly an adjustment. Fortunately I was able to play hockey, slow-pitch baseball, basketball, windsurf, sail, kayak, ski, and white water canoe for the years before my illness. I have continued to canoe on a smaller scale and on my own I have found that cycling and swimming do not require a lot of peripheral balance.

I have also been fortunate in that my wife and I have done a lot of travelling early on and I would encourage younger

## *A Doctor With CIDP For 28 Years (continued)*

people to take those trips when you are young and healthy enough to truly enjoy the experience. Don't leave everything for the retirement years. My wife and I have also recently moved to a retirement community and now have a bungalow with a walk in shower, wide doorways and lots of handrails in case things get worse. Having a daughter who is an Occupational Therapist doesn't hurt either.

Family support is also extremely important and we are fortunate in having all three children and the nine grandchildren within 30 minutes of our new home. I actually get as much pleasure out of watching the grandkids hockey, baseball and soccer games as I got when I played myself.

I think that my overall message is that your life does not end with a diagnosis of CIDP and that you need to focus on what you can do and not on what you can't do. Take that anger, frustration and depression and channel that energy into what you can still manage to do. I would also

encourage you to be willing to laugh at yourself. If you can truly laugh at yourself it means that you are comfortable with who you are. I tend to fall a fair bit because of my proprioception loss in my legs. I recently made a trip to the bank and it was a snowy and icy day. On the way to my car I passed an older lady who I thought really shouldn't be out walking and as I passed her I stepped in a hole and went down very unceremoniously on my butt. I had a flicker of anger and then I started to laugh at my own stupidity.

My overall message is that we were given the ability to smile and laugh for a reason and a lot of us just don't use it often enough.

As Jeanne Banks said: "LAUGHTER WILL HELP INNOCULATE YOU AGAINST THE GRUMPS AND WILL DECREASE THE NUMBER OF SCOWL MOVEMENTS YOU HAVE EACH DAY."

Yours laughingly,  
Dr. Ken Shonk.

### *Ottawa Senior's Centre Health Fair Linda Paul Liaison | Ottawa | Ontario*

Linda tended a table for GBS-CIDP and had the chance to meet friends of GBS patients, pass along disorder information to a patient not yet diagnosed with onset of some weakness, and did general awareness. Thanks!



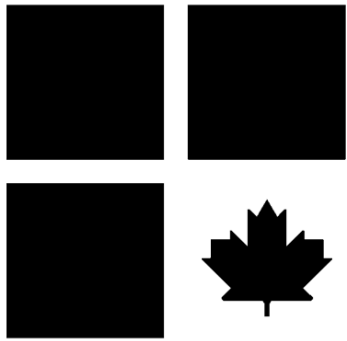
### **Every Little Bit Helps!**

*Many Thanks to local Whitby  
High School Students*

*Simeon Angelovski  
Raikem Dawkins*

**For the preparation of our newsletter  
envelopes for the mailing and  
distribution of this spring/summer  
newsletter.**

**Great Job Gentlemen!!**



# GBS/CIDP

## Foundation of Canada

*Serving patients with support, education, and research*

## Educational Afternoon

Ottawa Educational Afternoon  
Saturday May 14, 2016  
1pm-5pm

\* Registration Open – No At Door Entry  
Confirmed: Dr. Pierre Bourque  
Lynda Theoret

Halifax Educational Afternoon  
Saturday May 28, 2016  
1pm-5pm

\* Registration Open – No At Door Entry  
Confirmed: Dr. Timothy Benstead  
Dr. Ian Grant

Vancouver Educational Afternoon  
Saturday, Oct 22, 2016  
1pm-5pm

\* Registration - September  
Confirmed: Dr. Kristine Chapman  
Dr. Gillian Gibson  
Dr. Kristin Jack

**\*\*We are pleased to offer the ASK THE EXPERT session at each event\*\***

**Registration:** More detail on the each afternoon's agenda and registration forms are now available [www.gbs-cidp.org/canada](http://www.gbs-cidp.org/canada) and registration forms will be sent out to patients that are on our mailing list in each region within this newsletter. For questions, please call 1 (647) 560-6842 or email [info@gbscidpcanada.org](mailto:info@gbscidpcanada.org).

**Cost:** Registered \$20 (Free parking available for Ottawa and Halifax)

## ***Your Oral Health***

***Submitted By Dr. Seema Kumar***



*Dr. Seema Kumar is a general dentist practicing in Ontario. She completed her BSc. with honours along with her Masters in Pharmacology from the University of Toronto. Dr. Kumar graduated from the Faculty of Dentistry at the University of Toronto (class of 2006). Following her dental studies, Dr. Kumar enrolled in a General Practice Residency programme at the Harvard School of Dental Medicine. She currently owns her own practice in Stouffville. [www.innovatoravenuedental.com](http://www.innovatoravenuedental.com)*

Oral hygiene is an important part of overall health. Looking after your oral health can often get neglected when there is a tendency to focus on other needs related to chronic and debilitating diseases, such as Guillain-Barre Syndrome (GBS) or Chronic inflammatory demyelinating polyradiculoneuropathy (CIDP). Still, healthy teeth and gums are essential for preventing infections that may cause GBS symptoms to increase, promoting proper digestion and nutrition and improving the enjoyment of food and social activities.

Part of looking after your oral health should include regular visits to the dentist, however people with mobility challenges may find visits to the dental office difficult. In this case, diligent routine homecare can help prevent dental problems.

A good dental routine involves:

- Brushing twice a day – after breakfast and before bedtime
- Using a fluoridated toothpaste
- Flossing daily
- Using a tongue scraper or brushing the tongue daily
- Eating a well-balanced diet without too many sweets
- Rinsing out the mouth after meals and sugary drinks
- Keeping mouth hydrated with frequent sips of water
- Scheduling regular dental visits, usually 6 months apart
- Any bleeding gums, tooth or jaw pain, or tooth sensitivity should be promptly reported.

When you do visit your dentist, let him or her know of all medications you are taking, including blood thinners. Your specific dental needs and medical condition will help dictate the course of treatment necessary as prescribed by your dentist. Also before making the trip to the office, make sure the office is accessible and knows in advance about any special needs you have. Try to book your appointment at the time of day when you are less fatigued and make sure you have time to rest after the appointment.

There are several symptoms of GBS that can interfere with adequate care of the teeth and gums. Fatigue, weakness, pain and sensory changes (numbness, tingling, and/or pain) in the hands can all challenge a person's efforts to brush and floss adequately.

The following strategies and assistive devices can help:

- Use toothbrushes with built-up handles (or cut a small slit in the sides of a tennis ball and slide it onto the handle of the toothbrush); use flossing tools; consider electric toothbrushes and flossing devices.
- Sit to brush and floss, if standing at the basin is tiring. Since nighttime is when food and bacteria have time to cause cavities, try flossing in bed.

*(Continued Page 10)*

## *What Are You Waiting For?*

### *Travelling with CIDP*

*by Director Jane Field, Toronto, ON*

I have always loved to travel, to experience other cultures, other landscapes, other ways of living. When I was 21, I travelled with CUSO, a Canadian volunteer organization, to Nigeria to teach English at a secondary school. I learned so much while I was there, far more than I could ever have taught my students. But one thing I found myself unexpectedly learning about was Guillain Barré Syndrome. Over a period of a few weeks I lost sensation and strength, first in my legs and then in my arms as well. I was very lucky that my respiratory system was not compromised that time. I returned to Canada and spent a year in rehab learning to walk and function again. When I was better I went back to Nigeria to resume teaching, assuming I had put GBS behind me. I continued to teach and I continued to travel.

Eight years after my first GBS attack I had just returned from a summer in Nicaragua where I was helping to put electric lights in a school. Suddenly I was once again paralyzed, this time even more severely, requiring a respirator and 7 months of hospitalization followed by another year of outpatient therapy. At the time I was told this was a second attack of GBS, unusual, but possible. I didn't recover quite as well the second time and relied on a wheelchair for mobility for the next 15 years. But I still wanted and needed to travel. In fact, as soon as I was discharged from my 7 month stay in acute care before beginning outpatient rehab, I booked a flight to Mexico and headed off alone with my new wheelchair for a week by myself at the Pacific Ocean. It was wonderful. In the following year I returned to Nicaragua to help in a home for disabled children and discovered a very wheelchair accessible volcano in Costa Rica on the way. Next I went to Europe as a mother's helper, yes, in my wheelchair – it's surprisingly easy to keep track of a two year old when she is happily riding on your lap! But, oh those old cobblestone streets do present a challenge.

The following year I visited Australia, New Zealand and Fiji. While I was there I was inspired to do a bungee jump in my wheelchair. I also went white water rafting and best of all snorkelling from a catamaran anchored overnight on the Great Barrier Reef. I didn't need to be able to walk to enjoy any of these pursuits.



#### **Bungee Jumping in Australia**

In 1997 I was teaching adult literacy in Toronto when one day I woke up very ill with gastroenteritis. I went to the hospital to be rehydrated and returned home 16 months later. The illness had triggered (apparently) a third episode of GBS. This was the worst yet and even upon discharge from the rehab hospital I remained totally quadriplegic. I was breathing on my own, but unable even to turn over in bed without help, let alone feed myself or do any personal care. Gradually I learned to accept attendant care as the foundation of my days, not the focus of my days. With attendant support I travelled to a conference in San Francisco, visited friends in Massachusetts and spent Christmas on my own in Burlington Vermont, just because it looked like a nice place to spend Christmas and one of my attendants was keen to accompany me.

In 2002 just when I thought I had life as a quadriplegic pretty well figured out, I met Dr. Hahn at University Hospital in London Ontario. She told me she was sure I had CIDP and that she could make me better. After close to another year in hospital and after 15 years in a wheelchair I was walking again. One thing about walking is that it is very convenient and travel is simplified considerably. During the next 8 years my partner Hilary and I did lots of travelling – to England to visit family, to



## ***What Are You Waiting For?***

### ***Travelling with CIDP by Jane Field (continued)***

the Maritimes and the west coast to visit friends, to Arizona, Mexico and Iceland. I relished my ability to climb rugged hillside paths, walk behind waterfalls and hike in the English countryside. It seemed I had put CIDP behind me too, though I continued to take Prednisone and Imuran to keep me stable.

Whilst visiting family in England in 2012; however, I contracted the Noro virus and it triggered a fourth attack of CIDP. Once again I was completely paralyzed. I spent a month in hospital in Bath and Bristol before I was stable enough to be flown home in a Lear jet with Hilary and a doctor, a nurse and a respiratory therapist. Not the kind of travel I would advise, though the Lear jet was fascinating. Then followed another seven months in hospital in Toronto.

I was discharged from Lyndhurst Rehab hospital in December of that year and immediately began planning a trip to Nova Scotia to spend Christmas with friends. Since I was still quadriplegic my partner could fly free on both Air Canada and Porter Airlines within Canada. My friend who is also quadriplegic rented a wheelchair accessible cabin on the Mersey River where we had a lovely Christmas together. The whole resort at The Mersey River Chalets is



**Boarding a boat in Costa Rica**

accessible. It was designed by several quadriplegic men so that in the summer even the canoes can be accessed with a hoist from the dock. Every cabin has a ramp and roll in shower. The thing about access is that once a place is



**Elephant Safari, Zimbabwe**

made accessible it works for everyone. Universal access is a concept worth promoting everywhere we go.

Following that trip we went down to Florida in February to spend a week with my brother. There we rented a wheelchair that could go on the beach and into the ocean, though I struggled with the force of the waves. So we took the wheelchair to a lake with no waves – just alligators to contend with. We also discovered that all beaches in Florida have a beach wheelchair that can be borrowed at no charge.

I have continued to get better since 2012, though not to the extent that I did in 2002. I still need a wheelchair for any kind of distance, though I am managing to walk with crutches around the house.

No one can say if I will continue to improve or if I may even have another full blown attack of my CIDP. Life is short. Thus in October 2015 Hilary and I travelled to South Africa, Zimbabwe and Botswana to fulfill a life dream for both of us to see animals in their natural habitat. We went on many safaris by boat and by land rover. We saw giraffes and hippos and rhinos and leopards and warthogs and cape buffalo, impala and elephants galore. The highlight was being able to ride an elephant on a safari. With much help to get on the elephant I found the ride gentle and easy. Much better than a wheelchair! It was truly a trip of a lifetime. I had researched tour companies on line and found a travel agent who specialized in arrangements for

## What Are You Waiting For?

*Travelling with CIDP by Jane Field (continued)*

travelers with special needs. It was the smoothest trip we have ever taken and one of the most accessible. After all, no one needs to be able to walk to ride in a jeep or boat or even on an elephant. Everywhere we went people were kind and eager to assist me. All the places we stayed at were accessible – even our tent in Botswana!

I didn't hesitate to return to England for Christmas this year despite my last experience there. I can't blame England for my recurrence of CIDP. We rented a wheelchair accessible van and I took my power wheelchair this time. This gave me a lot of freedom to explore the coastal path in Cornwall, which is beautiful any time of year.

In February 2016 we spent two weeks in Costa Rica where we saw different wildlife – monkeys, crocodiles, toucans, sloths and more. We ventured into the rainforest and onto the beach at the Pacific coast as well as into the thermal springs at the Arenal Volcano. The resort even had ramps

into the hot springs. In the rain forest we discovered a biological research station at La Selva that had inadvertently made 8 kilometres of trails deep into the forest wheelchair accessible. They built the paths to accommodate all the equipment they needed to bring in and afterwards realized people in wheelchairs could now experience the jungle. So they went further than that and made a raised yellow path down the middle so that blind visitors too can explore the rainforest.

People ask me if I am not afraid of having another attack when I travel. My reply is that I could have another attack at home. Why not go out and explore the world now to the best of my abilities? I may get back to walking and I may not. What am I waiting for?

### Go 'Green'

If you would like future newsletters digitally, send an email to [info@gbscidpcanada.org](mailto:info@gbscidpcanada.org)

## Your Oral Health (Continued)

- Allow a family member or personal assistant to help with tooth brushing/ flossing. We all need a helping hand sometimes!

Some medications used to treat GBS symptoms can cause dry mouth. Saliva helps to cleanse the mouth and teeth. A dry mouth is not only uncomfortable, it may cause bacteria to accumulate and may also interfere with chewing. You can minimize the effects of dry mouth by:

- Sipping water or sugarless drinks often
- Avoiding caffeine, tobacco, and alcohol
- Using lemon candies to stimulate the parotid glands (which produce saliva)
- Use of special products available from the pharmacy (eg. Biotene rinse/gel/toothpaste)

Your oral health is vital to your overall well-being, but you are not alone and can ask for help from your caregivers, support group and medical health professionals.

Disclaimer: This article was written to provide general dental advice. Nothing contained in this article is or should be considered, or used as a substitute for, **dental** diagnosis or treatment.

### Find us on Facebook

'Like Us' Search for 'GBS/CIDP Foundation of Canada'  
Another way to keep informed.

## *Toronto Area Support Group Up and Running*

**Toronto, Ontario, Sunday April 24, 2016, 2:00pm–4:00pm, Northern District Library, 40 Orchard View Blvd, M4R 1B9, Gwen Liu Meeting Room #200**

Our first Toronto Area support group meeting was held in October at the Northern District Library, 40 Orchard View Blvd. near Yonge and Eglinton. About 22 people with either CIDP or GBS and several friends and partners came out to talk about their experiences, ask questions of one another and lend support to each other.

At our first meeting we spent much of the time hearing each other's stories, and it became clear as we listened to one another that we would like to meet on an on-going basis, perhaps 4 times a year.

We had our second meeting on January 24<sup>th</sup> and even on a cold winter's day 18 people came out for small group discussions. We divided into three groups:

- *Coping with CIDP– treatments, daily living*
- *Dealing with the aftermath of Guillain-Barré Syndrome – residual effects, progress of recovery, daily living*
- *Caring for and supporting someone with Guillain-Barré Syndrome or CIDP. Impact on daily living, what kind of supports have you found or are you looking for?*

As we talked we were asked to be mindful of a few guidelines to enhance our discussions.

- Remember we are here to encourage each other. Please keep horror stories and negative experiences to a minimum.
- Remember each of us could write a book on what we have been through or are going through. Try to keep details of your stories short to make time for everyone.
- Try to use our own experiences to offer helpful suggestions.
- Give every participant in your group a chance to ask questions and answer questions.

Each group reported back to the main group on what was discussed.

The GBS group discussed the need for on-going physiotherapy as outpatients and how to achieve that. For seniors a doctor's referral is all that is needed for OHIP sponsored physiotherapy, if there is a specific goal to work on. For younger patients it may not be so simple, but is worth exploring. They discussed ways of communicating with each other via Facebook and other social media.

The caregiver group discussed how important it is to fight for appropriate rehab. So often hospitals want to send patients off to long-term care when what they need is active rehab. It is helpful for a caregiver to try to be present when doctors come around and at physiotherapy or OT sessions when possible. In our healthcare system a lot of self-advocacy is necessary. Find allies wherever you can. It was mentioned that massage can be very helpful to patients, even just the lightest touch, as much as can be tolerated.

The CIDP group discussed getting physiotherapy as well. There is a web site for the College of Physiotherapists that could be helpful. One member provided a tip for shoes that are excellent for people with neuromuscular difficulties. They are New Balance Walkers. They also talked about IVIG treatments and medications that continue to suppress our immune systems with their different side effects.

We decided to meet again in the spring. Where possible we thought we would like to invite speakers to enhance our support group discussions. We have a great group going and have already been able to offer information and support in many ways to one another. One member made a comment that resonates with all of us. She said: " When one is

## ***Toronto Area Support Group Up and Running (continued)***

completely paralyzed that is when we know that we are so much more than our physical bodies. We find our true spirits."

I would like to acknowledge the support of Donna Hartlen our foundation's Executive Director, other liaisons Rohit and Nina Jaiswal, and Kathi Durst, for their help in getting to get the support group running.

Our next meeting will be April 24<sup>th</sup> from 2-4 pm at the Northern District Library. We are very pleased that Dr. Angelika Hahn will come to speak to the group and answer questions. You are welcome to join us if you can.

Jane Field

Director | Toronto Liaison | jane.field@gbscidpcanada.org

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**PLEASE CONTINUE TO VISIT [gbs-cidp.org/Canada](http://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. We look forward to more postings in the coming months, such as Awareness Walks prior to our Educational Afternoons !! Come Walk with us !!**

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### ***Kim Brooks***

***Director | Liaison | Calgary, AB***

I was diagnosed with CIDP in July of 2013. The 6 months leading up to that diagnoses was a true battle. Not only was I fighting my body but the health care system at the same time. After the diagnosis came the next battle, the road to recovery. As a patient I felt like I was the only one, I've heard this from so many of you.

I started as a Liaison with the Foundation in 2015, making contact with patients that had reached out to us for support. I was also involved in the planning of the Calgary Conference.

I'm currently working on the Foundation survey here in Alberta. This survey will update our contact information and help us to gain insight into our membership's support needs. I'm working my way through the Alberta list of patients. Please- if we only had each member's complete contact information, it would really help us move forward. Send me your name, email, and/or phone number to [Kim.Brooks@gbscidpcanada.org](mailto:Kim.Brooks@gbscidpcanada.org) and I will be in touch shortly.

Thanks to those who have already taken the time to answer my questions. Thanks as well for your patience while we get ourselves organized here in Alberta. Moving forward I would like to see support groups being held on a regular basis in both Edmonton and Calgary. We need to build a strong line of communication with both our membership and the medical community.

### **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, Chronic Inflammatory Demyelinating Polyneuropathy, or any other medical condition.**