GBS/CIDP Foundation of Canada

Guillain-Barré Syndrome / Chronic Inflammatory Demyelinating Polyneuropathy

Support, Education, and Research

News & Views

Issue: 15 ***Fall/Winter***

A Message from Donna Hartlen, Executive Director

It's hard to believe that in just a few short weeks we'll be ringing in a new year! As I reflect upon 2014, I am proud of the foundation's achievements. Thanks to the dedication of board members, doctors on our Medical Advisory Board, and liaisons, we have had another successful year!

This could not be possible without the generosity of all those that donated their time, resources or funds, to the foundation. We truly appreciate each and every donation and feel a great responsibility in choosing programs wisely, that reflect our mission of support, education, and research. Your charitableness has supported activities this past year such as, western regional conference, educational presentations, support group meetings, hospital visitation, distribution of literature to patients/caregivers, research Funding (IGOS), and advocacy. Thank-you.

In the second half of the year, we were invited by Muscular Dystrophy Quebec to attend their Neuromuscular Educational Day at the Montreal Neuro Institute, Montreal, QC. It is with many thanks that we were given this opportunity to learn from presentations, have a booth and meet patients, introduce our Quebec liaisons, and present the foundation and the services it provides. A special thank-you to Quebec liaisons Beryl Bergeron and Peter Levick for traveling to Montreal to introduce themselves to patients.

We have finally created our Canadian Facebook page. Search for 'GBS/CIDP Foundation of Canada' and 'Like' the page. We are pleased to provide, along with our web pages, another means of broadcasting events, news, and articles throughout the year. I hope to bring more personal stories to readers on this page. So get out your pens and pencils and submit your stories and let all of us embrace your victories and hold your hand as you face challenges.

As we leave behind 2014, the foundation is working eagerly on our plans for 2015.

The highlight of this upcoming year is our National Conference May 2, 2015 in Mississauga, ON. This conference will have a new flavour! Through the commitment and support of our Medical Advisory Board doctors, we will have our GBS and CIDP workshops and the foundation is very excited to add an MMN workshop. I had the pleasure of attending the Foundation International Symposium in Orlando, FL this year. I was overwhelmed by all of the research that is going on around the world and the national conference will highlight some of the great news in this area. I am very excited to announce that Santo Garcia, Occupational therapist by trade, and director of the

A Message from Donna Hartlen, Executive Director (continued)

Foundation International will do a presentation on Physio and Occupational therapy, including his signature 'Chair Aerobics'. Embraced by attendees of the symposium, it's not a presentation; it is an experience to behold! Conference invitations will be sent out in the New Year, and for more information, please see the announcement within this newsletter. **Don't miss it, save the date!**

Lastly, I want to say thank-you to our dedicated volunteers. We appreciate all your hard work over the last year. With their continued dedication, patients never have to feel alone in dealing with a diagnosis of one of our disorders.

If you would like to volunteer for the foundation and become a liaison, or support the foundation in other ways, please contact Gail Kammer, President and Regional Director, via email at gail.kammer@gbscidpcanada.org to help with any questions or more information about volunteering.

If you would like to 'Go Green' and reduce paper usage and the cost of printing, please send a request to donna.hartlen@gbscidpcanada.org to receive future newsletters via email.

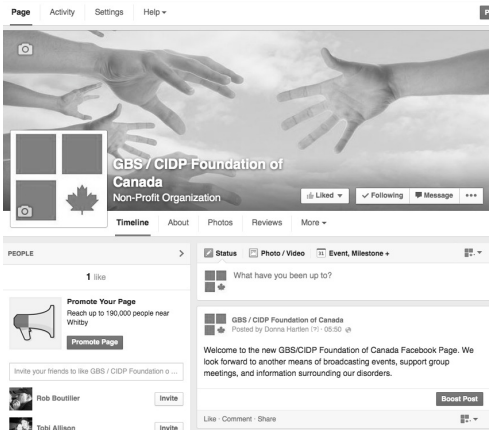
Our future shines brightly and we look forward to shaking things up in 2015! I wish each of you a wonderful holiday season and wishing all the best to you and your families in the New Year!

Donna

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

'Like' Us on Facebook

We are pleased to announce that the 'GBS /CIDP Foundation of Canada' Facebook page is now available. Keep up-to-date on events, support group meetings, and information pertaining to our disorders. Search for the page using the title above and 'Like' the page!



CIDP in Diabetes Patients

By Dr. Vera Bril and Dr. Ari Breiner

As many patients know, the diagnosis of CIDP remains a challenge, because there is no blood test or imaging study (such as MRI) that can accurately diagnose the disease. In many cases, the diagnosis is delayed considerably due to the lack of a single, simple test to confirm that the patient has CIDP. At this time, physicians rely on the expertise of the neurologist or neuromuscular specialist, in combination with the results of nerve conduction studies, to determine if someone has a demyelinating condition such as CIDP, or the more common axonal form of peripheral neuropathy. The challenge of CIDP diagnosis is much more difficult in patients who also have diabetes. In diabetes patients, abnormalities on the nerve conduction studies may be caused by diabetic peripheral neuropathy, but resemble very closely the changes in CIDP, and also diabetes patients could have a combination of neuropathies at the same time. In other words, diabetes patients may have both CIDP and diabetic neuropathy. Unfortunately, physicians can be very uncertain of the exact diagnosis in diabetes patients. For this reason, patients with diabetes have been excluded from past CIDP clinical trials. However, we know that diabetes patients with CIDP do improve with treatment, similar to those without CIDP. So, it becomes really important to make sure that the diagnosis of CIDP is not overlooked in those with diabetes.

At the Toronto General Hospital (University Health Network), we looked at patients with CIDP and compared a group with diabetes to a group without diabetes. These were patients who had been seen over the prior 20 years, or so. We found that the numbers responding positively to treatment were the same whether or not diabetes was present. What amazed us in this study was that we only treated about 50% of those with CIDP and diabetes compared to 90% of those with CIDP without diabetes, a definite bias that was completely unexpected. Clearly, in many patients, we are blaming the neuropathy on diabetes and not on CIDP.

So, now we are starting a study to more accurately examine the response of patients with diabetes and possible CIDP to treatment with IVIg. **Dr. Ari Breiner** and **Dr. Vera Bril** are leading the study, and Grifols Therapeutics has provided funding for the study to be done. We think that some patients with diabetes and demyelinating changes on nerve conduction studies will respond positively to treatment. If this result is found, then the implication is that CIDP is being under-diagnosed in diabetes patients because of the confusion over the meaning of the abnormalities on nerve conduction testing. We hope that the results of this study may help to better understand the overlap between diabetic polyneuropathy and CIDP and to improve treatment in diabetes patients who suffer from neuropathy.

If you have diabetes and peripheral neuropathy, and there is uncertainty about possible CIDP, please do not hesitate to contact Eduardo Ng (research manager) or Dr. Ari Breiner and Dr. Vera Bril at 416-340-3898 to determine if you are eligible for participation in this study.

The Foundation would like to thank all those who have made donations. We could not manage without you. Tax-deductible receipts will be given for all gifts of $10.00 or more.

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GBS and Lung Health

By Dr. Alex Chee

Weakness of the breathing muscles is a common complication of neuromuscular disorders including GBS/CIDP. Although the lungs themselves are not affected by the disease, the muscles that control lung movement can be weakened, impairing gas exchange and increasing the risk of lung infections. Respirologists (lung physicians) are often involved in the care of the patient with GBS/CIDP in different stages of the illness.

The lungs are passive organs that require muscles for inflation and deflation. During normal resting breathing, the diaphragm is the primary muscle. The diaphragm's role is to pull the lungs from the bottom so that air can be drawn in through the mouth. Exhalation during quiet breathing requires very little work because after a breath, the natural tendency of the chest is to become smaller. The cycle of quiet inhalation by the diaphragm and relaxed exhalation is termed tidal volume. When you are lying down on your back, the diaphragm must work harder to push abdominal contents away from the chest so breathing becomes more effortful. Work of the diaphragm is also increased after a large meal as there is more abdominal content pushing against the chest.

More forceful inhalation requires the work of additional breathing muscles in the neck, chest and shoulders. In addition to the diaphragm pulling the bottom of the lungs down, these accessory muscles lift the collarbone and ribcage to pull open the upper lungs. These muscles work best when you are standing or sitting upright and have limited value when lying down.

Forceful exhalation also uses a different set of muscles. The abdominal muscles (ie.six-pack) along with muscles between ribs are activated in forceful exhalation during coughing. A strong cough involves both the ability to take in a large breath as well as the strength to let the air out with speed.

When first afflicted with GBS and in hospital, you may remember respiratory therapists repeatedly asking you to blow hard through a portable breathing monitor through your hospital stay. This spirometer measures both the total amount of air exhaled in one breath, the vital capacity. A proper vital capacity measures the amount of air you are able to maximally breathe in and out, using all muscles available. This measurement is used by physicians as a surrogate for respiratory muscle strength. A reduced vital capacity is concerning for two reasons: 1) Inadequate expelling of carbon dioxide and inhalation of freshly oxygenated air 2) Inadequate clearing of secretions via coughing. The primary role of the lungs is exchanging gases that the body uses and produces during regular function, namely oxygen and carbon dioxide. A low vital capacity and tidal volume are signs that the lungs cannot adequately exchange gases and physicians may decide that additional mechanical help of breathing is required. The lungs also function as gatekeepers against infections. Airways continually produce mucous to trap foreign particles. Small hair-like structures along the airways, called cilia, push the dirty mucous into the windpipe to be coughed out of the body. However, a weak cough means that the dirty mucous is not cleared, and the risk of lung infections (pneumonia) is increased. A low vital capacity and elevated carbon dioxide levels in the blood are signs physicians use to determine whether mechanical breathing is required to help support the body until the nerves supplying the breathing muscles recover.

Even as the breathing muscles recover it will take a long time to recover full respiratory function. The hospital setting exposes you to patients with other lung infections. Given that other patients were sick enough to need a hospital stay, lung infections acquired in the hospital may be more severe than an infection you would get in the community. It is important to maintain strict hygiene (washing hands, covering your face when you cough or sneeze, avoid touching your eyes and nose) in and out of the hospital setting.

There are a few factors that can reduce the risk of lung infections during recovery: 1) Good clearance of airway secretions: A strong cough helps clear mucous buildup and any foreign particles that can be trapped in the

GBS and Lung Health (continued)

mucous. Physical therapists can assist the cough and loosen phlegm with chest physiotherapy. 2) Diligent hygiene: Most germs are transmitted through contact or droplets. With influenza season upon us it is important to maintain good hand hygiene with hand washing and hand sanitizer. 3) 'Clean' living. There are intangible benefits to a healthy lifestyle including not smoking, and a balanced diet. 4) Vaccinations serve as a practice test to prepare your body to exposure to certain infections. In my line of work where I am constantly in close proximity to patients with lung infections, receiving a vaccination was an easy decision for me. If you choose to not receive an influenza vaccination this year, the first three tips become that much more important.

I wish you a healthy holiday season!

Alex Chee MD FRCPC
alex.chee@gbscidpcanada.org

Dr. Alex Chee is a respirologist at University of Calgary. He is intimately aware of the struggles of patients with inflammatory demyelinating polyneuropathy, after recovering from GBS himself.

Support group meeting Oct 1, 2014 Parkwood Hospital, London, ON

By Barbara Sherman, Director and Liaison GBS/CIDP Foundation of Canada

Wilma Koopman, Sharon Ratelle, Barbara Sherman, and Teresa Valenti teamed up to hold a support group meeting at Parkwood Hospital in London, ON. I think we had a successful meeting with 18 present, including us. We shared many things, but our focus centered on the most difficult things we had to deal with while struggling with this disease, and how we managed to cope with the issues that are very difficult. Everyone seemed glad to be a participant and share with others on common ground.

3 Things the Chronically Ill Wish Their Loved Ones Knew

by Toni Bernhard

Toni Bernhard is the author of the award-winning ***How to Be Sick: A Buddhist-Inspired Guide for the Chronically Ill and Their Caregivers*** *and* ***How to Wake Up: A Buddhist-Inspired Guide to Navigating Joy and Sorrow****. Her new book on chronic pain and illness will be published in the Fall of 2015. Before becoming ill, she was a law professor at the University of California—Davis. Her blog, "Turning Straw Into Gold", is hosted by Psychology Today. Visit her website at* ***www.tonibernhard.com***

GBS/CIDP Foundation of Canada would like to thank Toni Bernhard for permission to print this article.

Perhaps this piece should be written entirely in the first person because it reflects what I want my loved ones (by whom I mean family and close friends) to know about me. These are the people who've done so much for me, and I'm deeply grateful. I simply want them to know a few things about how I feel.

Because I've been hanging out online for over a dozen years with other people who are chronically ill, I feel comfortable speaking for all of us here. I recognize that when it comes to chronic pain and illness…and loved ones, one size doesn't fit all (as is true with all things in life), but here's what I think most of us want our loved ones to know about us.

1. The grief we feel over the life we've lost may re-emerge now and then…indefinitely.

One life event that appears on all versions of "life stress scales" is serious illness. It's considered a grief-producing event, as are other major life losses, such as the loss of a relationship due to separation or death.

Until I became chronically ill, I had no idea that the people I knew with ongoing health struggles were grieving. Now I know that there's a lot to grieve over—the loss of the ability to be as productive as we once were, the loss of friends, the loss of the ability to take part in cherished activities, the loss of independence.

Grief comes in waves, and so it can arrive unexpectedly. One moment, we can feel accepting of the changes in our lives. The next minute we can be overcome by sadness. And it can be triggered by a simple interaction. For example, I thought I was done grieving about my lost career.

It's been over a decade since I had to stop working due to illness. But then, one day, I ran into a former colleague. She began to describe all the changes that have taken place at the law school where I taught. To my surprise, a wave of grief overcame me, and I had to work hard not to break out in tears in front of her. This happened even though, were I to recover, I wouldn't return to my old profession.

The grieving process I've gone through as a result of chronic illness has been one of the most intense of my life. Odd as it may sound, it's been more intense than the grief I felt when my mother died. She lived across the Atlantic from me and so we rarely saw each other. She had a long, good life. I was sad to lose her, and, yes, I grieved, but it was not as intense as the grieving I've gone through over the upheaval in my life due to chronic illness.

2. We can feel as if we're letting you down even though you've repeatedly told us that we're not.

I have two close friends whom I try to see each week. Both of them have told me that if I'm not feeling well enough to visit, I should cancel and that I should not feel bad about it. And yet, whenever I have to cancel, I feel as if I'm letting them down even though I believe them when they say that they don't want me to feel bad.

Related to this feeling of letting loved ones down is that we may apologize for being sick and being in pain even though it's not necessary. I find myself apologizing to my husband, my children, and to close friends for not being able to join in activities with them, even though they're not expecting me to go beyond my limits and even though they don't want me to. → (Continued page 8)

GBS/CIDP Foundation of Canada

Serving patients with support, education, and research

National Conference

May 2, 2015 (8-5pm)

Place:	**Toronto West Airport Hotel, Aerowood Dr, Mississauga, Ontario Just south of the 401, west side of Dixie Rd**	
Confirmed Workshops:	**GBS**	**– Dr. Kurt Kimpinski**
	CIDP	**– Dr. Vera Bril and Dr. Ari Breiner**
	MMN	**– Dr. Hans Katzberg**
	Treatments:	**– Dr. Vera Bril**
	IGOS Research	**– Dr. Tom Feasby**
	Ask the Expert	**– Attending Presenters**
	Physical and Occupational Therapy: Chair Aerobics	**– Santo Garcia**
Registration:	**More Details on the day's agenda and registration will become available on www.gbs-cidp.org/Canada in the New Year and invitations will be sent out to patients that are on our mailing list. For more information or to be placed on our mailing list, please call (647) 560-6842 or email info@gbscidpcanada.org**	
Cost:	**Registered $45**	

3100 Garden St, PO Box 80060 Rossland Garden, Whitby, ON L1R 1H0 (647) 560-6842

3 Things the Chronically Ill Wish Their Loved Ones Knew (continued)

I've decided that it makes me feel better to apologize. It's my way of saying to them: "I know that my inability to do a lot of things and the unpredictability of how I'll feel on any given day is no fun for you either."

3. Being chronically ill can be embarrassing.

I wrote about embarrassment in a piece called "Are You Embarrassed?" In it, I said that the major reason people are embarrassment-prone is that they've set unrealistically high expectations for themselves and then judge themselves negatively when they can't possibly meet those standards.

We don't have to look far to see the unrealistically high expectation and the negative self-judgment that are at work here: we don't think we *should* be chronically ill. We live in a culture that repeatedly tells us we need not be sick or in pain, even though in the United States alone, 130 million people suffer from chronic illness. My loved ones accept my illness and yet I still can find myself embarrassed in front of them about the fact that I've been sick for so many years.

Sometimes guilt creeps in, too, because I can feel as if I've let them down. There's no rational reason for me to feel guilty. None of my loved ones has ever said anything to me that suggests they think I've let them down, but there it is—guilt—the painful feeling that I've been bad. I've quoted Buddhist teacher, Jack Kornfield, before on this (in both my books in fact), but I have to quote him again: "The mind has no shame." He sure was right! All I'd add is that I hope you're able to hold his comment lightly and can even laugh sometimes at your shameless mind.

There's a second reason that being chronically ill can be embarrassing. In addition to the cultural message that tells us we can all be healthy and fit, I feel as if the state of my health should be a private matter. We keep many other intimate details of our lives private. Why not chronic pain and illness? The answer is that most of us don't have the luxury of keeping our medical conditions private. We have to explain to our loved ones why we can't do this and why can't do that; why we have to cancel plans at the last minute; why we have to suddenly sit down or leave a gathering early. And so, instead of keeping this intimate part of our lives private, we're forced to talk about it and that can be embarrassing.

Third, most of us cherished the independence that came with good health. We find it embarrassing to have to continually depend on loved ones to do so many things for us, from cleaning to shopping to supporting us financially. I know many chronically ill people who have been forced to move back into their childhood homes because they're unable to care for themselves or because they can no longer afford to live independently. Having to tell others that you had to move in with your parents can not only be a source of embarrassment, but even worse—shame.

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We appreciate so much all that our loved ones have done to educate themselves about our medical condition, to take care of us, and to support us. These are just three additional things that we want them to know about us.

Links to Online Articles of Interest

Guillain-Barre Syndrome 'We Thought We Were Watching Him Die by Michelle Ruby Brantford Expositor
www.brantfordexpositor.ca/2014/11/28/we-thought-we-were-watching-him-die

Suzan Jennings a GBS patient is highlighted in the Nanaimo Disability Resource Centre's Destigmatizing Disabilities
http://ndrc.info/destigmatizing-disabilities/

My CIDP Narrative

By Rohit Jaiswal

My journey began with a visit to my family doctor, as I suspect it did for most. It started in October 2012, with sharp shooting pains radiating from the tibia in my left leg in addition to burning and tingling in my feet. My former family doctor suggested stage-two cancer at first glance and ordered some blood tests. The following days felt like a month as I paced and obsessed about what I would hear at that next visit.

When the receptionist called one week later to call me in, I felt nauseous. I could feel myself cautiously moving my feet one after the other as I walked into the red building by the mall; something I had done many times before without hesitation.

As I sat down, all I could hear was the pounding of my heart as my doctor stated in an uneventful voice, "test results were negative." A sense of euphoria engulfed as I processed the words. He recommended a visit to my endocrinologist for his advice and off I went still no further ahead with what was going on in my body.

I shared my escalating pain with my endocrinologist later in the same month. By this time the burning and tingling in my feet had reached an astoundingly uncomfortable level. The endocrinologist explained that after living with diabetes for 22 years, he wasn't surprised that I'd developed diabetic neuropathy. My symptoms worsened over the next few weeks. The pain in my legs had become unbearable, sensitivity spread to my chest and even the rubbing of my shirt had become excruciating and intolerable. My confusion intensified.

I met my new family doctor and asked for a referral to a neurologist. The wait began. I was eventually given an appointment for January 2013. It seemed like an eternity.

In the meantime, as my symptoms worsened and my anxieties escalated, I turned to the dreaded internet in search of answers. One week I suspected I had multiple sclerosis while another time I was convinced that I had Parkinson's. My speculation continued for weeks on end. A word of advice, don't always trust the Internet!

January finally arrived and I had my first meeting with my neurologist. I felt comfortable with her knowledge and bedside manners. My EMG (Electromyography) results were to be as expected. Poor conductivity aligned with the diabetic neuropathy. I couldn't shake my gut instinct. I felt that there was something more.

I returned to the Internet. I searched deeper. I wanted answers. There had to be others out in cyberspace that have my symptoms and possibly the answers I needed. By February of 2013 the numbness that was in my feet had spread into my hands and walking was progressively a problem. I started to feel defeated as my symptoms and sensitivity in my chest became unbearable. I had several nightly attacks when I felt that my body was shutting down.

After more EMG's and visits to my neurologist who now felt that diabetic neuropathy may not be the culprit. After she tested the conductivity of the nerves in my forehead, there had been a breakthrough. For the first time, I heard the possible diagnoses of myasthenia gravis and CIDP. I faintly remembered skimming through these names during my internet search but hadn't really delved deeper. A spinal tap shortly afterwards confirmed that a protein in my spinal fluid was elevated. CIDP it was. Eight months had lapsed by this time and I remember feeling relieved to finally have an answer.

My emotions were high. I had so many thoughts. Turns out, I had a surge of questions about CIDP, my family, career, future and next steps. There were plans…way down the road. I no longer wanted to wait. I started to talk to my wife about the car that I thought I wanted in ten years. Change of plans. I wanted it now along with a couple of trips that were on hold. She smiled and nodded, "do it."

I'd devoured every bit of information I could about CIDP and realized that the symptoms and treatments varied for individuals. The list of my medications was ever growing. I began IVIG treatments every four weeks at Credit Valley Hospital. At this point I couldn't walk unassisted and every

My CIDP Narrative (continued)

day was a challenge. I was hoping for a magic wand to rescue me. That didn't happen. It took three or four months before I noticed a change. Week four, prior to the treatment, was tough. My neurologist increased the frequency of IVIG to every three weeks and introduced a combination treatment and my life changed dramatically. Unfortunately, this was short lived, as I was experiencing liver failure, a severe side effect to one of the medications.

I spent Summer 2014 playing golf, an activity I couldn't do at all a year before. I travelled extensively with my family and enjoyed life around me. Although I still have pain in my legs, and suffer side effects from one of the medications, I can see my glass half full once again.

Through an Internet search, I came across an upcoming GBS/CIDP Foundation International Symposium, which connected me to an outstanding group of people. The warmth and understanding extended to my wife and me touched us. They have provided valuable information as well as emotional support.

I recently met with a leading neurologist who specializes in neuromuscular conditions in the Toronto Area. It was a productive meeting with positive suggestions. I will now begin a new treatment plan and will consider the possibility of enrolling in a trial to receive IVIG subcutaneously.

There is light at the end of the tunnel. Reach out to your network of support through any stage you are experiencing. My wife, Nina and children, Anysha and Shanav, have been emotional pillars throughout my journey. I thank the staff, especially Wendy and Lynn whose caring, professionalism, and support have far exceeded my expectations in Ambulatory Care at Credit Valley Hospital.

GBS/CIDP Foundation of Canada's Board of Directors Welcomes Two New Directors

Sharon Ratelle, Sharon has her BSC in Actuarial Science and Statistics after graduating from the University of Western Ontario, with Honors. She is currently building upon her education in project management and has been employed with a pension-consulting firm for the past 15 years. Sharon was diagnosed with GBS in 2006 while pregnant with her first child. She went on to have a normal second pregnancy and has two busy sons, 8 and 5 years old. She has been a long-time liaison since 2008 with the foundation, supporting Southwestern Ontario patients, and has been involved with several events over the years.

Wilma J Koopman, Wilma graduated from Hamilton Civic Hospitals 1973 (RN), and the University of Western Ontario (BScN, 1992; MScN 1998, Tertiary Care Nurse Practitioner Certificate 2000). She also completed the Postgraduate course in Neurological and Neurosurgical Nursing at the Montreal Neurological Institute in 1977.

Wilma worked as a staff nurse in Neurosciences at the Hamilton General Hospital upon graduation as an RN in 1973, moving to the Clinical Neuroscience Unit, University Hospital in 1975. Wilma was hired at University Hospital as the research nurse for the International GBS Plasmapheresis trial in 1981, where her career in Neuromuscular diseases began. In 1982, the Adult Neuromuscular Clinic Services Clinic was launched and Wilma was hired as the nurse coordinator and since 1999 as the Nurse Practitioner. She has collaborated on many research studies in the neuromuscular disease arena. She has authored and co-authored many peer reviewed articles and given oral presentations on GBS, CIDP, MD, and Myasthenia Gravis. She is certified in neuroscience nursing and is affiliated with professional nursing organizations nationally and internationally (CANN, AANN, and WFNN). She is also a part-time lecturer at the Western University, School of Nursing London Ontario.

Patient perspectives on Immunoglobulin Therapy Delivery From Out of Hospital into Home or Community Setting

by Vilija Rasutis RN – TGH - UHN

The past few years have been exciting in our Neuromuscular Department at Toronto General Hospital in regards to new studies and therapies that incorporate the use of immunoglobulin (Ig) to treat both CIDP and MMN. Intravenous immunoglobulin (IVIG) within the hospital setting has been the standard treatment for these patients for many decades. With limited resources, decreased beds and constraints in our health care delivery system, we have shifted our focus and attempts in improving our patient's quality of life by offering treatments (within a research protocol) outside of hospital (either in one's home or in a government funded care center - known to many as a CCAC center). The addition of subcutaneous immunoglobulin (SCIG) has offered alternatives as well through a recent study for patients with muscle disease. Twenty percent subcutaneous immunoglobulin is a more concentrated blood product formulated for administration under the skin and into the fatty tissue of the abdomen, thighs, back of arms or lower backside. Both formulations and reference to therapy has been exclusively conducted within a clinical trials framework.
Home based immunoglobulin (Ig) treatment offers potential benefits to patients and also helps to alleviate significant health care utilization stressors. The number one convenience factor for patients in considering Ig therapy within their home setting or in the community is the savings in travel time and associated costs with physically getting to the hospital, arranging for child/elder care and coordinating time off work amongst other related responsibilities.
Out of hospital health care allows for flexibility in scheduling, minimizes expenses and promotes autonomy. In some aspects of this type of therapy and most specifically with the subcutaneous Ig, patients are responsible for their weekly infusions and assume total care and accountability. This includes self-assessing for anticipated side effects, documenting each infusion and keeping in touch with the neuromuscular team every three months. Family and support systems play a strong role in the success and motivation of our patients, however our patients as a whole are a self motivated group as well as proactive in their care.

Specific parameters in handling the immunoglobulin, administering and understanding the side effect profile of the blood product is critical in managing our clinical trials studies outside the formal hospital setting. Nurses with specialized training and protocols specific to patients with neuromuscular disorders are key to linking resources and enabling this shift to occur while incorporating teaching tools that will maximize safety and efficacy of the treatment. Our results from a recent home based IVIG study demonstrated that home-based IVIG is safe and well tolerated as maintenance treatment in a select group of our patients with CIDP. All of our patients were very satisfied and supportive of the home IVIG program and 90% of patients preferred home infusion to hospital-based treatment. Another treatment with subcutaneous immunoglobulin has been favorably acknowledged as a choice therapy from the group of patients that participated in a recent study.

Implementation of out of hospital immunoglobulin requires close collaboration of health team members including the local blood bank. Understanding all participants roles and responsibilities including our health care system from a government regulatory perspectives is key in future success of this shift.

The following are a few "stories" that patients wished to share in regards to their immunoglobulin therapy either in the home or in a community (CCAC) center:

Patient D who participated in the 'home-based IVIG study' says:

"I have been receiving IVIG treatments every three weeks for 8 years and the home IVIG experience was the IVIG a la mode!!! It was by far an absolute treat. It afforded me the opportunity to receive treatment in the comfort of my own home. I could lie down if I needed to, or I could put dinner together and chase after my, then toddler. I was not put out

Moving?

Please do not forget to notify the foundation of any address changes you may have to ensure that you receive ongoing communications. Please contact by email at donna.hartlen@gbscidpcanada.org or by calling 1(647) 560-6842

Patient perspectives on Immunoglobulin Therapy Delivery From Out of Hospital into Home or Community Setting (continued)

financially either, as I did not have to pay the cost of transportation to and from the hospital or for parking for the day. Additionally, I did not have to make child care arrangements for my daughter. I was able to remain with her and spend quality time with her that is a savings far greater than money itself. Instead of dreading the pending IVIG treatments and all the planning that would be needed to prepare for them, I actually looked forward to them. The nurse that came to my home was not only extremely professional but also so warm and personable with an outrageous sense of humor. I really cultivated a wonderful relationship with her and looked forward to having adult conversation, and many a laugh. People with chronic illness often become more isolated from their friends and family and this opportunity was both welcoming and extremely therapeutic. The home IVIG experience, when you consider the many benefits including comfort, convenience, and emotional support, to name a few, was by far the best treatment time I have had in my IVIG history to date. I hope that this is the way of the future...it just makes sense"

Patient A who was also in the "Home IVIG study and currently participating in the 'pilot CCAC Centre for IVIG therapy' felt that although it was "great to have a nurse come to my home, it was a poor use of health care resources to have a 1:1 ratio of patient: nurse. Now I am receiving IVIG at a CCAC center (as part of a study) and feel that the facilities could get a lot more use if they were available evenings and week-ends".

Patient T who enrolled in the six month 'SCIG home study' enjoyed the two hours twice a week and the independence to do "his thing"; he felt more stable with consistent weekly infusions and learned to master the technique and overcome the 'apprehension' of inserting needles in his stomach.

Patient S enrolled in the six month 'SCIG home study' and has multiple travel commitments with his family. "In general, I found the SCIG process very convenient with respect to ease of application, portability, time management and flexibility to do what I please with my time."

As health care resources continue to be increasingly scarce in Canada, alternative rational and cost-effective treatments and delivery methods are critical, especially as new therapies emerge. We are excited to continue our quest for out-of-hospital treatment programs to improve access to care for neuromuscular patients with an emphasis on quality of care and most importantly, a focus on continuous improvements in quality of life.

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Should you wish to learn more about current and future studies for CIDP, please contact Eduardo Ng at 416 340-4184 (Study Coordinator for Dr. Bril)

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.