

# GBS/CIDP Foundation of Canada

Guillain-Barré Syndrome / Chronic Inflammatory Demyelinating Polyneuropathy

*Support, Education, and Research*

## News & Views

Issue: 12

Spring/Summer 2013

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Tom Feasby, MD  
Serge Payer  
Kenneth Shonk, MD

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Susan Keast

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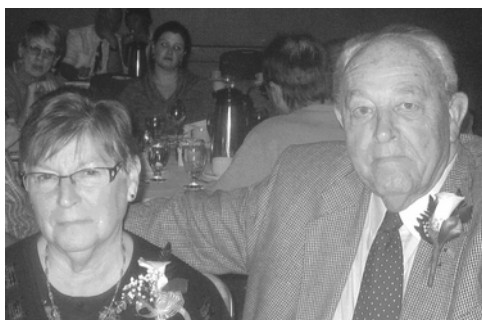
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Douglas Zochodne, MD

### *A Message from Susan Keast, Executive Director*

This issue of our newsletter is very special to me. First, I would like to say that we are so blessed to have such a wonderful group of Doctors with whom we work. Each one has a special talent and understanding that they bring to our Foundation and each is chosen because of their commitment and support not only to the Foundation, but to each of you as patients, and your families.



him on our Board.

We also added someone special to our Honourary Board, Dr. Tom Feasby. Many of you may know of him already as he was instrumental in helping our first GBS support group of Ontario get started many years ago. He is still very involved with GBS, CIDP and Variants and is now presently working on some very special research involving the "Long Term Outcome of GBS". We are delighted to have

We completed our National Conference at the end of April and I can honestly say that it was just fabulous. Many, many thankyou's go out to those who gave up their time to make presentations and give their time to each of you.

Due to a family emergency, Dr. Bril was not able to attend, and we sure did miss her, but a special thank you goes out to Dr. Hans Katzberg who gave the CIDP presentation and filled in for Dr. Bril. It was such a pleasure to have him. Everyone enjoyed meeting him and hearing what he had to say.

It was also such a pleasure for us to have Dr. Joel Steinberg and his wife Susan attend our conference. Dr. Joel has written so many of our GBS books and pamphlets and his caring and concern about each of you comes through in all that he does for us. He also had GBS, and so has a great understanding of all your hopes and fears.

I always look forward to seeing our liaisons from across Canada. They are special people who give back to patients and their families everywhere. Without them we could not exist. I know I mention this in every newsletter, but it can never be said enough. Each one, and our newer ones who have come on side, have such big hearts and they are there for each of you. Please connect with them, set up support group meetings and get together.

### *A Message from Susan Keast, Executive Director (continued)*

We are a family that reaches out to each other, so grab a coffee with them, make friends and find ways to continue to make this Foundation flourish.

Our conferences would not happen without the help and sponsorship of our pharmaceutical friends. Their care and concern about each patient and how they are managing is more apparent every time we have a conference. We thank Grifols Canada, and Octapharma for their support. They are always at the end of the phone to answer our questions, to make sure that all our needs are being met, and they also involve themselves in our conferences by providing enlightening presentations. Thank you to Steve Roblin from Grifols for his presentation at our liaison training day. Everyone had great questions for him and we could have kept him busy for many hours.

Thank you also to Rebecca Mills from New Brunswick who also came to help out at our training day and to do the presentation for our "Emotional Issues for Caregivers only". Rebecca has great insight and a way of getting right to the issues. Of course we could not manage at our conference without Wilma Koopman from the London Health Science Centre. Wilma did the presentation on "GBS emotional issues for patients only". Wilma has a great sense of humour as well as a deep understanding of GBS from her work with our patients. Barbara Sherman, a Director on our Board, handled the "Emotional Issues for CIDP patients only". Barb has CIDP and so has a personal interest in making sure that our patients are well looked after. This year we had Paul Lewis who is an Registered Massage Therapist (RMT). This was his first conference with us, and we are so grateful for what he brought to each of us. He discussed therapy, pain, and control of issues. I know that we will be seeing more of Paul and hearing from him often. People are reaching out to alternative methods to find relief in coping with their illnesses. Thank you Paul for bringing this information to us.

Thanks also to Dr. Ken Shonk who always makes us laugh by seeing the humour in coping. He has such great understanding of all our pain and fears as he also has CIDP. He has a sensitive side and acknowledges the seriousness of GBS and CIDP, but he also lets us know that with humour we can survive, we can cope and reach out to others, and often we can forget for a short while. We always look forward to having Ken and his wife Vicki attend, as they are very much a part of our GBS/CIDP Family.

Please read the listing of our support group meetings – some have already taken place and others are yet to come. We hope that you will attend if you can.

Now to the next important part of this newsletter. By the fall of this year we should be able to announce to you who the new Executive Director of our Foundation will be. Each of you will be in good hands and I know that you will give this person all your help and support. It has been my very sincere pleasure to have met so many of you over the years, to have watched you get well and to see your many accomplishments. I have felt like a family member in witnessing your achievements. I have been so lucky to have been part of such a fabulous group. We have been able to grow in amazing ways with our connections to our Doctors and patients, our research that is ongoing to help each of you get better, and of course our many phone calls, emails and visitations. I have sat with so many of you, laughed when we could, cried many times and held each of you very dear. I wish you not only the very best in your futures, but I know that the new Executive Director will fill this role in new and wonderful ways. You will all prosper and grow, and your family connections with the Foundation will continue to be as strong as ever. I have been involved with GBS/CIDP since 1993 and so it is time for me to move forward with my family. I will always be involved with health care as I am committed to making sure that people get the best health care they can. Walter has also spent all these+ years making sure that the books are balanced and that we have always been prosperous. Both Walter and I have been blessed many times over by this journey with each of you and so now we wish you well ... The Foundation will always have a special place in our hearts. Thanks to each of you as well as to our wonderful Board of Directors who have helped to make this Foundation a place for each to gain education and help. This has always been your Foundation, and we are just part of the Family.

**Susan Keast**, Executive Director

## *Please welcome the newest members to our Boards*

### *Honorary Board*

***Thomas E. Feasby, MD, FRCPC***



Tom Feasby is a Professor of Neurology and the past Dean (2007–12) of the University of Calgary Faculty of Medicine. He graduated from the University of Manitoba and trained in Neurology and research at the University of Western Ontario and the Institute of Neurology, Queen Square UK. He trained in health services research at the RAND Corporation in Santa Monica, CA. As department chair, he helped build the Department of Clinical Neurosciences at the University of Calgary into a national leader. He founded Calgary's internationally acclaimed Stroke Program. From 2003 to 2007 he was the Vice President Academic Affairs at Capital Health in Edmonton and Associate Dean Clinical

Affairs in the Faculty of Medicine and Dentistry at the University of Alberta.

Dr. Feasby is a neurologist and specialist in neuromuscular disease and has made significant contributions to the understanding and treatment of the demyelinating neuropathies, especially Guillain-Barré Syndrome. His current research focuses on the appropriateness and effectiveness of healthcare interventions, such as carotid endarterectomy, intravenous immunoglobulin and MRI. He has published over 100 scientific papers and has written op-ed essays in leading Canadian newspapers. His work has been supported by the Canadian Institutes of Health Research, the MS Society of Canada and the Muscular Dystrophy Association of Canada. He has chaired the Board of the Association of Faculties of Medicine of Canada, served on the boards of leading organizations such as the American Neurological Association and the Institute of Health Economics and currently serves on the boards of the Michael Smith Foundation for Health Research in BC, the Multiple Sclerosis Society of Canada and the Institute for Public Health in Calgary.

### *Medical Advisory Board*

***Angela Genge, MD, FRCPC(C)***



Newfoundland born, Dr. Angela Genge completed her medical degree at Memorial University of Newfoundland. She completed her Canadian and American certifications in Internal Medicine and Neurology prior to completing a fellowship in neuromuscular diseases. She joined the staff of the Montreal Neurological Institute and Hospital in 1994 and became Director of the ALS Clinic in 1998.

Dr. Genge was appointed Director of the CRU in December 2004 and has expanded both the number and scope of clinical trials in neurological disease. Since her arrival, the CRU has grown in both depth and breadth and includes trials in neurosurgical conditions and brain tumors. With this, the CRU staffing has increased and an infusion center has been added for special projects. The future holds promise in successful treatments for ALS, brain tumors, muscle diseases, and primary progressive MS.

Her involvement in clinical research began while still a resident in Neurology. She began assisting Dr. Gordon Francis, the founding director of the CRU at the Montreal Neurological Institute in early trials in both Multiple Sclerosis, and NeuroAIDS. She became involved in ALS research in 1995 and has since expanded to become one of the leaders in international ALS clinical trials.

Her clinical interests in neurology continue to be focused on ALS and neuromuscular diseases. She is continuing to work on expanding the CRU to include clinical trials in orphan neuromuscular disorders, ALS, as well as increasing the MNI clinical research presence in all neurological and neurosurgical domains.

***Medical Advisory Board (continued)******Kurt Kimpinski, MD***

Dr. Kurt Kimpinski has recently joined the Department of Clinical Neurological Sciences at the University of Western Ontario within the Neuromuscular Division. Dr. Kimpinski obtained his MD from Dalhousie University and specialized in neurology at Queens University before undertaking neuromuscular fellowships at London Ontario, and the Mayo Clinic at Rochester, Minnesota. Dr. Kimpinski has specific interests in peripheral neuropathy and runs a regular inflammatory and hereditary neuropathy clinic in London. This clinic sees a wide range of patients with neuropathy including a large group of patients with CIDP and GBS. Dr. Kimpinski's clinic offers Quantitative Sensory Testing and Clinical Autonomic Testing as well as Nerve Conduction Studies/Electromyography through the EMG lab at the University Hospital in London, ON.

***Hans D. Katzberg, MD, MSc, FRCP(C)***

*Neuromuscular Medicine*

*Assistant Professor of Medicine (Neurology), University of Toronto*



Dr. Katzberg obtained his MD from the University of British Columbia and did his Neurology residency at the University of Toronto, where he served as chief resident from 2006–2007. He has obtained fellowships in EMG/Neurophysiology and Neuromuscular Diseases from Stanford University, where he also completed a Master's in Clinical Epidemiology. He returns to the University of Toronto as a clinician investigator to join the Prosserman Family Neuromuscular Clinic at the Toronto General Hospital / University Health Network.

Dr. Katzberg's research interests include outcomes research in peripheral neuropathy as well as treatment of immune mediated neuropathies and neuromuscular junction disorders such as myasthenia gravis.

***Douglas Zochodne, MD, FRCPC***

Dr. Douglas Zochodne is a Professor in the Department of Clinical Neurosciences and Director of the Neuromuscular Clinic (adult) for the Faculty of Medicine, University of Calgary (U of C). He also serves as the Director of Clinical Neurophysiology (Adult EMG) for Alberta Health Services.

Dr. Zochodne attended the University of Western Ontario (UWO) in London, Ontario, majoring in Chemistry. He graduated from medical school in 1980 at UWO where he also completed a rotating internship, a year of internal medicine, and an FRCPC in Neurology in 1985. Dr. Zochodne then completed a Neuromuscular Fellowship at UWO from 1986 to 1988, following training at the Mayo Clinic, Rochester, Minnesota as an MRC fellow. After this, Dr. Zochodne established a peripheral nerve research laboratory and Neuromuscular Clinic at Queen's University in Kingston Ontario, before joining us at the U of C in 1992.

***Douglas Zochodne, MD, FRCPC (continued)***

The Zochodne laboratory has made contributions to the field of experimental diabetic neuropathy and peripheral nerve regeneration. In particular, its findings have emphasized the role of neurodegeneration in diabetic peripheral nerves. The Zochodne lab has published over 200 original articles and book chapters (excluding abstracts), including a new book titled, "The Neurobiology of Peripheral Nerve Regeneration" (Cambridge Press), published in the fall of 2008.

Dr. Zochodne is the team leader of a major (\$2.25M) Canadian Institutes of Health Research (CIHR) Regenerative Medicine and Nanotechnology team grant – with collaborators at the U of C in Neurosciences and Engineering (Rajiv Midha, Naweed Syed, Graham Jullien), the University of Alberta (Tessa Gordon, Ming Chan), and the University of Saskatchewan (Valerie Verge). In addition to CIHR grants and funding from the Canadian Diabetes Association (CDA), the Muscular Dystrophy Association of Canada (MDAC), National Institutes of Health (NIH), and the Natural Science and Engineering Research Council (NSERC), Dr. Zochodne is also recognized as a Alberta Heritage Foundation for Medical Research (AHFMR) Scientist. He has served as Editor-in-Chief of the Canadian Journal of Neurological Sciences (1999 to 2007), and was a recent member of the Institute Advisory Board of the Institute of Neuroscience (2003–2008), Mental Health, and Addiction (CIHR). He is also President-elect of the Peripheral Nerve Society.

***Kristine Chapman MD, FRCPC***

Dr. Chapman is a neuromuscular specialist at the University of British Columbia. She is the Director of the Vancouver Hospital Neuromuscular Disease Unit in Vancouver, B.C. After working for a number of years as an occupational therapist in neuro-rehab, Dr. Chapman attended medical school and did her neurology training at UBC, followed by a Neuromuscular Fellowship at Harvard.

Her areas of interest include autoimmune neuropathies, diabetic neuropathy, and identifying and treating neuropathic pain. Dr. Chapman enjoys being involved in medical education and is on the Canadian Neuromuscular Exam board for the CSCN. She has had the opportunity to invite patients from the BC Chapter of the GBS/CIDP Foundation with neuromuscular problems to co-lecture with her at the medical school, to help share their experience with young doctors.

Dr. Chapman is currently serving as the President of the Canadian Society of Clinical Neurophysiologists. One project of interest to the GBS/CIDP community that she is currently involved in, is the development of a program (together with the Provincial Blood Coordinating Office) to optimize utilization of IVIg in BC.

In her free time Dr. Chapman is an avid telemark skier, and loves to spend time in the mountains with her family. Her greatest satisfaction at work is the opportunity to work closely with her patients, sharing in their victories and challenges. She has very much enjoyed her involvement with the BC chapter of the GBS/CIDP Foundation of Canada to date, and looks forward to joining the Board.

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

## *Remembering Margaret*

It is so important that we remember our friends who started with us long before we became a registered foundation. Margaret was one of those special people who quickly turned her GBS into something positive. She became a loyal support person/liaison who gave back to others, always with a smile and a great sense of humour. She and her husband Carey never missed a support meeting or conference. She was always encouraging and totally supportive of what we do at the Foundation.

She became close friends with so many of us and she had a way of making others feel special. We will miss her but we also know how lucky we are to have shared in her life with her laughter, good advice, and strong support.

Our sympathies go out to Carey, and his and Margaret's children.

## *Margaret Katherine Stead, 1927 - 2013*



Margaret K. Stead, (Nee Smith) died peacefully on the 11<sup>th</sup> of July 2013, at the Montreal General Hospital after a short illness. She was born in Moncton, New Brunswick, on the 6<sup>th</sup> of June 1927. She was the oldest of six children born to Bowen Benjamin Charles Smith and Ethel Katherine Thomas. She grew up in Moncton and in Saint John, New Brunswick. She graduated from Saint John High School in 1944. In 1951 she moved to Montreal and entered the Montreal General Hospital nursing school, graduating in 1954. In 1966 she received a Bachelor of Nursing degree from McGill. In her 60's she attended the Argyl Institute of Human Relations and qualified as a psychotherapist. After working as a nurse at the

Montreal General, she enrolled as a nurse in the Royal Canadian Air Force Reserve 401 Squadron. She served for a year in 1958 at the hospital of Four Wing, RCAF, in Baden Solingen, Germany; holding the rank of Flying Officer. Sometime after her return to Montreal she became the first salaried employee of the newly established union, The United Nurses of Montreal, and negotiated the union's first contract. In the 1980's, she returned to the Montreal General Hospital, eventually becoming a nurse on its psychiatric ward. She also had a part time private psychotherapy practice. After contracting Guillain-Barré syndrome in her 60's she retired from nursing. While at home after the birth of her second child she became a founding director and the first president of the Québec Family History Society and an instructor in genealogical research. She was also a founding director and the first president of the Dorval Day Care Center (now known as the Centre De La Petite Enfance, Dorval). She is survived and dearly missed by her husband, Carey Stead, her two children, Katherine and Bowen (Lorna Maceachern), by her four sisters Shirley, (the late Werner Schmidt) of Medicine Hat, Alberta, Bernadine (Stuart Henderson) of Fredericton New Brunswick, Joyce (Albert Bamford) of Trenton Ontario, and Betty Ann (the late William Camp) Shelbourne, Nova Scotia, and by her brother, Bowen (Egolda Bowser) of St John, New Brunswick, and by many nieces and nephews and their children. Margaret cherished her family and took great joy in the news and conversations with all of us.

### *Going Green*

*We would like to reduce our use of paper. Let us know if you want to receive future newsletters and other information by e-mail.*

*If you do, please send us your e-mail address so we can update our records.*

## ***Octagam®, an established intravenous immunoglobulin (IVIG) therapy is now available in Canada***

***by, Lidia Cosentino***

Octapharma Canada is pleased to announce that as of April 2013, Canadian physicians and patients have had access to Octagam®10% through the Canadian Blood Services. While new to Canada, Octagam® has been in clinical use for 18 years in over 80 countries. The introduction of Octagam® provides to Canadian physicians and patients a safe and well tolerated therapeutic IVIG option<sup>1</sup>, with US and European clinical experience. Its long history dates back to 1995 when Octagam® was developed as the world's first room temperature stable liquid IGIV therapy.

Octagam® contains immunoglobulins (also known as antibodies) of type IgG and is administered intravenously (IV) in a hospital setting. IgG antibodies are found in all body fluids and are very important in fighting infections. IVIG therapy is usually given because you can either be born with an immune system that makes low levels of antibodies, or your system may make low levels of antibodies. In these immune deficient patients, IVIG is given to increase their antibody levels to prevent infections. It is also given in certain conditions called autoimmune diseases in which the immune system recognizes some of the person's own tissues as foreign substances and attack or destroy these tissues.

IVIGs are human plasma based products, derived from healthy human donors. Since IVIG is derived from human plasma, theoretically there is a risk of viral transmission; however, multiple steps are taken to ensure patient safety. The blood centers are strictly monitored and regulated by the Food and Drug Administration (FDA) and Health Canada. The individual donors undergo an in-depth screening process to determine that they have not been exposed to certain pathogens, such as the HIV or hepatitis virus. The plasma from all of these individuals is then pooled together, and then treated to isolate the antibodies (IgG immune globulins) and remove any other blood proteins or blood-borne pathogens. During the manufacturing process, viral inactivation and removal steps are included as an extra precaution. The end result is a highly purified immune globulin preparation that is then packaged and ready to be infused.<sup>1</sup>

The introduction of Octagam® will continue the Octapharma history of enhancing product choice and product innovation in Canada. We remain confident that Octagam®, through its global experience and record of tolerability, will contribute to enhancing patient care in Canada.

## ***Multifocal Motor Neuropathy (MMN)***

***by, Dr. Hans D. Katzberg MD MSc FRCP(C)***

Multifocal motor neuropathy, also known as MMN, is a inflammatory nerve disease affecting the myelin sheath, or insulation of nerves, similar to CIDP and GBS. It typically has a slow course over many years and affects the arms with weakness in the muscles that bend the fingers, however any nerve and muscle group can be affected. As is the case and other nerve conditions, the diagnosis is usually made by a careful assessment by a neurologist along with nerve testing (EMG), where a characteristic "blocking" of the responses to the nerves which go to the muscles is seen. Sometimes, additional testing with analysis of the spinal fluid and blood tests (in about 50% of cases, an antibody, GM1-ganglioside, is present) can help with the diagnosis. As in CIDP, this is a treatable condition, often responding to medicines which alter the immune system. One of these medications is intravenous immunoglobulin, or IVIG. This is a solution of antibodies pooled from healthy volunteers which can help to restore and maintain strength. Usually, this medication is given over 2–5 days in hospital in a specialized day unit and is administered on average every 4 weeks. A research study is currently ongoing at Toronto General Hospital evaluating a formulation of these immunoglobulins which can be given subcutaneously,

***Multifocal Motor Neuropathy (MMN) (continued)***

or under the skin, administered by patients themselves at home. To be eligible for the study, patients should have been diagnosed with MMN and be stable on a regular dose of IVIG. A similar study using this formulation of immunoglobulin, also known as SCIG, is taking place for patients with CIDP at TGH. For more information on both of these studies, please contact (416) 340-4800 extensions 7695 (Vilija Rasutis for the MMN study) or extension 3315 (Eduardo Ng for the CIDP study).

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***Canadian National Conference  
and  
Liaison Training Day  
April 26 & 27, 2013***



***Lesley Wichstrom & Steve Roblin  
from Grifols***



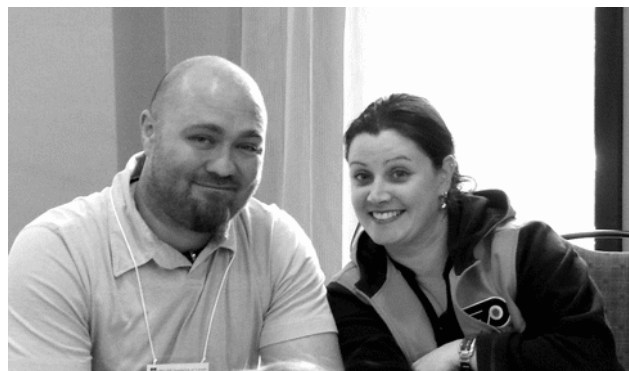
***Sharron Ratelle***



***Peter Levick***



***David Sleeth***



***Darryll Blencowe & Jennifer Shelton***



***Lauren Bernasky***



*Canadian National Conference (continued)*



*Hilary Dore and Jane Field*



*Megan Wood, Kathi Durst, Jennifer Shelton*



*Donna Hartlen, and her husband, Wayne Burke*



*Dr. Joel Steinberg*



*Canadian National Conference (continued)*



*Susan Keast & Steve Roblin*



*Dr. Kenneth and Vicki Shonk*



*Linda Paul & Leslie Wichstrom*



*Jo-Anne and John Baird*



*Antonietta & Rosa Dipietro*

*Canadian National Conference (continued)*



*Cynthia & Al Barber*



*Holly Gerlach, Gail Kammer, Marilyn Rose*



*Paul Lewis RMT, Dr. Angelika Hahn, Dr. Joel Steinberg, Dr. Hans Katzberg, Dr. Rebecca Mills*

*Canadian National Conference (continued)*



*Paul Lewis, RMT*



*Dr. Angelika Hahn*



*Mikelle Meaden , Wilma Koopman, Kelly Dadurka*



*Dr. Hans Katzberg*

## *From around the Country*

### *From British Columbia*

*by, Sherry Nejedly, Director*

First I would like to say that the Canadian Conference last April was a total success and would like to thank all the sponsors, participants, and families.

Out here in the west we are meeting with GBS/CIDP and variants patients and families while continuing to follow up with current and past patients.

I would like to congratulate our new liaison from Fraser Lake B.C. near Prince George, Rhonda Henry. She has been a great help supporting GBS and CIDP patients in the North. Also as some of you know, our liaison, Suzan Jennings is a great help on Vancouver Island.

We are hoping to have a long awaited western GBS/CIDP Conference here in Vancouver sometime in May of 2014. We will let you know when we know.

If any one needs any help we are always here for you.

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### *GBS/CIDP Awareness Picnic*

*by, Holly Gerlach - Liaison, Alberta*

Our First Annual GBS/CIDP Awareness Picnic in May was a great success! Along with the members of our support group, (and their families) we organized the event in less than a month! We were very fortunate that the weather was gorgeous, so we were able to sit out and enjoy the sunshine. We sold balloons, hot dogs, snacks, beverages,



and freezies, which were a huge hit with the kids. We had several different games, including wheelchair races, and one game where people had to pick up tiny beads and place into bowls wearing oven mitts, which really showed people how hard that is to do when you don't have those fine motor skills. The highlight of the day was when we released all the bio-degradable balloons into the air. It was great to see some familiar faces – people with GBS and CIDP that I have met

throughout my own journey – as well as meet some new people. Global News in Edmonton promoted the event prior to it and because of that we were able to reach several former patients that came out to the event and have now joined our support group. Overall it was great for awareness. We learned a lot about what worked (and what didn't) and we can't wait for next year to do it again!

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### *Support Meetings and Liaisons*

Deb Bernasky and Gail Kammer each hosted support meetings earlier this spring in Halifax Nova Scotia and Saskatoon Saskatchewan respectively. They were well attended and beneficial to the participants.

In mid-September we will be hosting a support meeting for CDIP patients in Toronto. We will let you know the time and place.

Also, we are looking for volunteers to become liaisons in Toronto and London, Ontario, and Vancouver Island, British Columbia.

## *Canada Cares Celebrates Caregivers Understanding Today's Caregivers*

*by, Caroline Tapp-McDougall*

Adults who find themselves struggling between the demands of aging adults and raising children are said to belong to the “sandwich generation.” This group of mid-lifers between 45 and 50 are also referred to as the baby boomers. They'll live longer than ever before, be parents having children later in life, and find themselves with dependent children living at home longer. As well, projections for the year 2056 suggest that the number of Canadians aged 65 or older will double to over a one in four ratio, and the proportion of seniors aged 80 and older will triple.

### *Who cares?*

While the majority of family care seems to be offered by women, more men are also finding themselves thrust into the caregiving role. In rural communities where professional support services may not be as readily available, care management becomes extraordinarily challenging. While most family members believe they are handling their responsibilities quite well at the beginning of their care journey, many become overwhelmed as their loved ones' needs progress. Caregiving affects people from all disciplines and all walks of life. Often, family life suffers, personal interests are compromised and the majority of caregivers agree that their careers and on-the-job responsibilities are affected. (In fact, 57 per cent of caregivers described their caregiving duties as being regular, with 21 per cent describing them as a daily commitment.) Many tell us that they spend up to 35 hours a week assisting a loved one and spend as many as four hours travelling back and forth; a very time-consuming commitment for a busy working person who is often a parent as well.

And, it isn't just close family members that are providing care. According to the *2007 General Social Survey on Family, Social Support and Retirement*, approximately a third of all caregivers were friends (14 per cent), extended family members (11 per cent) or neighbours (5 per cent).

### *In the workplace*

Many “sandwich generationers” who find themselves caregiving are still working, but each of them will not be involved in the same way.

Sometimes a colleague leaves suddenly due to a crisis such as a hospital emergency visit where they'll be called upon to attend to a parent who lives out of town. Or perhaps you'll encounter a team member who begins to come in late or requests shift changes so he or she can provide daily personal care for a sister, care which is comprised of intimate activities such as bathing and dressing. In 2007, nearly 40 per cent of female and less than 20 per cent of male caretakers provided personal care. Cooking and cleaning were provided by 60 per cent of females and 30 per cent of males, but men performed more outdoor tasks, like cutting grass or shovelling snow. Almost all caregivers, eight out of 10, need to assist with transportation, often compromising working hours.

Caregivers may also help with administration of medication. According to a specific and regular schedule, which might require adjustment to work hours or extra breaks during the day while offices are open.

### *The other care receivers*

Some caregivers care for a sick child or a child with special needs. Across Canada, 1.7 per cent of the children under the age of five and 4.6 per cent of children aged five to 14 have an identified disability (Statistics Canada, 2006).

These children may have difficulty in finding daycare. Statistics show that in nearly 50 per cent of cases, these parents, mostly mothers, are forced to alter their employment situations. In most cases, the effects on employment are understandably related to the severity of the child's disability. Many parents choose to leave work altogether, while others will refuse promotion or

## *Canada Cares Celebrates Caregivers (continued)*

adjust hours. In other cases, parents will need to work increased hours to meet their child's financial needs for specialty equipment, surgery, medication, etc.

Others still are caring for a sibling, cousin, or friend. A sister injured in a car accident or a friend struggling with cancer will also often need assistance. With a seemingly endless number of scenarios that can cause the need for a caregiver, it's a situation Canadians cannot ignore or avoid.

### *Avoiding caregiver burnout*

Life hands us stress on a regular basis, but adding caregiving responsibilities on top of it all can be overwhelming. Many caregivers can rely on their spouse, neighbours, siblings or friends for help. However, caregivers often try to mask their troubles, so it may be hard to tell who needs help if the person doesn't speak up. Sometimes actions speak louder than words

If someone starts coming in late, looks tired, is suddenly gaining or losing weight, becomes irritated or angered quickly, looks constantly worried or sad or complains of frequent headaches or pains, he or she may be suffering from "caregiver burnout". It's a common condition that results from the physical work, stress and responsibilities that come with the burden of care. Approaching the situation with understanding and compassion and taking a personal approach to each individual is the best way to help.

### *What help is available?*

Often caregivers feel guilty about not being able to do their fair share at work or feel badly that they can't spend more time with a loved one. Some may need to work with employers to shift their hours, reduce their commitment to part-time, or negotiate the flexibility of working from home or taking extra days off, especially if they are long-distance caregivers.

Know that caregivers often feel alone in their journey. You can help by:

- Referring them to a support group.

- Helping them to find information such as the Canadian Cancer Society, The Alzheimer's Society, Parkinson's Society Canada or any other relevant organization.
- Finding online workshops or services that provide care-planning and can help with identifying reliable local resources.
- Exploring options within the workplace, for caregiver leave or special benefits.
- Pitching in by making a meal, cleaning the house or doing the grocery shopping.

### *One size does not fit all*

Each caregiving passage will vary. A solution that may work for one person won't be suitable for another. A mother of a young child with a severe disability may need to work extra hours to pay for therapy, while others may need to alter their hours to fit their aging mother's care schedule or to have her move into their home.

As caregiving tasks differ, so does the length of time spent caregiving. One journey may be in crisis mode and last only a few days, while others involve a slow decline in a loved ones' physical and cognitive abilities over time.

Open lines of communication in an environment that fosters empathy and compassion and finding programs and services that meet their needs is key to being truly supportive. After all, isn't it time that Canada became caregiver friendly?

### *Canada Cares*

Canada Cares, [www.canadacares.org](http://www.canadacares.org), a not-for-profit organization dedicated to family caregiving—whether it's providing care for a child with a disability, a sibling with an injury or a senior who needs care at home. The organization, whose partners include Canadian Red Cross, Saint Elizabeth, We Care Home Health Services, March of Dimes Canada, VHA Home Healthcare, Invacare Canada, MV-1, and the Canadian Home Care Association is focused on establishing partnerships that celebrate both family and professional caregivers.

**Kevin McGaghey****Rothsay, New Brunswick, [mcgaghey@rogers.com](mailto:mcgaghey@rogers.com)**

I have been reading the GBS/CIDP newsletters for a number of years but I have never read about a case like mine, so I thought my experience might be interesting to other readers. I am a man close to 85 and I have shrunk a little. I would be about six feet tall; in my prime I was 6'2". I weigh about 200 pounds. I have weighed as much as 220 pounds and was very muscular. I am qualified in three mechanical trades, but rarely worked at them as I was usually a first line supervisor in the pulp and paper industry. I will leave it at that as I could write a whole page on my experiences and travels. I have worked from Port Hawkesbury, NS, to Port Alice, BC, and north to Prince George, BC, and many places in between.

My first experience with CIDP was about sixteen years ago when I was having trouble with my throat. My family doctor sent me to an otolaryngologist. The only problem she found was that my tongue was smaller on one side and crooked. She immediately sent me to a neurologist (this was in 1996). He diagnosed me with CIDP and gave me three weekly treatments of IVIG. This made me very sick and did not improve my situation at all. Also at this time another thing happened – I lost the strength to lift myself up with my left foot, so this gave me a slight limp. My last conversation with the specialist was that other treatments were worse than the disease and let's see what my body can do for me. I was 69 at this point. None of this slowed me down. By this time I was retired and doing more physical work on a family farm, such as cutting my winter's wood and growing my own vegetables. This went on for years – I seemed to go into remission and I was strong, so people told me, but I ran into trouble when I was 75. I was in the woods on January 29 with two trees down and the tractor stuck in a mud hole surrounded by two feet of snow. I was feeling poorly, so once I got the tractor out I decided to give up on my trees. Within a day or two I found out that I had the shingles. They were mostly located around my left eye. Although I had a rash, I saw three doctors before this was diagnosed. Finally a young female doctor at Emergency told me what was wrong.

This did not knock me down – I managed to do the work around the house and plow the snow, but I slept a lot. The doctor said I would be a long time recovering.

It was nine years ago this took place. I still have not recovered – there is always discomfort in that eye as well as a loss of vision and my eyebrow is sore, but my vision has improved slowly since. It is sometimes measured as 20/40 and has been 20/60, but it is still very valuable.

From then on my remission from CIDP was over. I lost the strength in my right foot to lift myself off the ground and my balance became poor, but not to the point that I had to stop. For three more winters I cut firewood. After that it was harder to work without my ankle strength and more dangerous. Then CIDP moved up into my knees. I was forced to give my heavy chores such as hoeing the garden and working in the woods. To keep myself busy I started building utility trailers in the backyard and maintaining my house – painting, electrical, plumbing –whatever needed to be done. I also spent a lot of time at the beach in the summer. It was hard to find winter things to do, but I had a small tractor and my neighbours were all older than myself, so I kept them plowed out and did whatever I could for them.

In 2007 my family doctor referred me to Dr. Benstead in Halifax, the nearest specialist in CIDP and GBS. After doing electromyography and nerve conduction tests, he wondered if my condition was actually CIDP or some other form of neuropathy. A nerve biopsy confirmed CIDP, but he felt any treatments he could give me at my age would be too dangerous.

I have been in contact with two other people who have had CIDP for a number of years – one is young woman of around 40 and the other is man roughly in his 70's. They have told me their symptoms and how they came down with it. They came down with it suddenly and were disabled and have slowly regained a little power. They complain of fatigue and the inability to walk very far and of using a crutch or walker to walk

**Kevin McGaghey (continued)**

and from my uneducated experience they sound as if they came down with GBS first and then recovered to CIDP, but this is just my own thought. At 84 years old, I can understand them better because I am feeling the same symptoms. Until two years ago I would say that I was a lot better than they were. I was still handling firewood and I still am, but with help from my wife.

I was very unfortunate to come down with polymyalgia rheumatica in the spring of 2012. With this all my muscles got sore but I was comfortable sitting down, so it took me a long time to realize I had an additional problem. I am being treated by a specialist who put me on a drug called Prednisone. After two days on Prednisone and a heavier dose than normal, most of the pain was gone. From then on when I had to do something, it was not with pleasure. I should be reducing the amount of this drug, but I have not been able to. This drug may also be worse than the condition because it affects the immune system.

I developed another problem about a year ago called acid reflux. This was blamed on CIDP. This interfered with the exercise program which I had been doing for many years and I would say this was a great loss to me. When I was diagnosed with CIDP by Dr. McLean, he thought from the EMG that this condition had started a long time ago. When I look back, I can say that I was about 42 years old when I first felt symptoms – one toe on my right foot would sometimes go numb.

This was especially noticeable after being out snowmobiling. There were other things that did show up that were minor like this for many years.

My family doctor had no idea what it might be except that it was a nerve problem and I ignored the minor problems. Most of my symptoms were on the left side. Sometimes my foot would drop while walking in rough terrain.

Prior to 42 years of age, I worked in the pulp and paper industry and most of that time was as a shift supervisor. I was exposed to a lot of chemicals such as chlorine, sulphur dioxide, carbon monoxide, and chlorine dioxide. My condition today is this – I am slowly getting to the point where I have to use a cane around the house and walking crutches otherwise. I can stand in one place if I have support with one hand and pile wood and I can walk without any support for short periods. Mechanical work is now difficult due to the loss of hand dexterity. I feel that I have been able to cope with CIDP because of my life style – I do not smoke or drink, I live quietly and have a healthy diet.

This seems rather long, but I could write a book on it. For example, in February 1964 I was caught in a tidal wave in Port Alice because of an earthquake in Alaska. If I couldn't have escaped the water by climbing a steel column, I would never have experienced CIDP.

***Announcement***

*The Foundation thanks all those who have made donations.  
We could not manage without you.*

*GBS/CIDP Foundation of Canada has partnered with CanadaHelps  
to facilitate donating electronically online.*

*Go online to [www.gbs-cidp.org/canada](http://www.gbs-cidp.org/canada)  
and you will see the following "Donate Now" button.*



*Click on the button*

*and you will be taken to the [www.CanadHelps.org](http://www.CanadHelps.org) website to make your donation.*

*Of course, we will continue to accept donations by cheque through the mail.*

## *My life with Guillain-Barré Syndrome*

*Céline Morin, from the beautiful Beauce County in Québec*

On December 15, 1998, when I first stood up, my legs felt like old rags and I also noticed that my hands were weaker. What's happening???

The previous week I had uncontrollable shivers, no fever but there was no way to warm me up. Finally, it went away on its own. The next day I decided not to go to work, I was too stiff but finally...I decided to go anyway. I was a bit tired but since we were getting close to Christmas time and that I had 3 young children, 7 years old, 5 years old and 2 ½ years old, for me it was normal to feel this tired. At that time I was working 3 days a week in administration. On December 14, I was hardly capable of finishing my working day; I was looking forward to some days off to rest.

On the morning of December 15, I had a very strange sensation of losing my strength in my legs and in my hands as well as an odd sensation in my entire body in general. Right away I decided to call my family doctor who came for a house call. He did not know what was happening and decided to contact a neurologist. He called back at the end of the day to check on me; I had lost more of my strength, standing up had become impossible and holding onto an object was a challenge. My husband drove me to the hospital for testing. With 3 young children and the holidays I did not have the time to be hospitalized. After the tests we came back home. My doctor was to communicate the results whenever they would be available; I thought medication would fix it all in a few days.

The next day, on December 16, only my left hand was still working but not too well. I called my family doctor again to come over for another house call, he explained to me that after talking to a neurologist, he was told I had the Guillain-Barré, (what is that????) and needed to be hospitalized but that I would recover from this disease. It was the first time he had a patient with the Guillain-Barré disease.

Since I had no muscular tone I was transported by ambulance to the nearest hospital which is approximately 20 minutes from my house.

They stabilized me and a nurse accompanied me for a transfer to another hospital to see a neurologist. I had no idea that a respiratory failure was possible; what we do not know does not worry us I guess. The neurologist confirmed the diagnosis, and they transferred me to another hospital for a plasmapheresis treatment. The neurologist said: "you will get better but it will take a long time, arm yourself with patience" he never said the word "definitively" but my husband and I thought so.

When we arrived at the hospital in Quebec City (approximately an hour from my house), neurologists came and met my husband and I to reconfirm the diagnosis. The following day this diagnosis was confirmed with the result from my spinal tap. On December 17, they started the plasmapheresis treatments (10 in total) and a very intense follow up, every 3 hours for blood work and every 6 hours for spirometry testing day and night. For a moment it was very critical as if I was going to get intubated but finally the results of the plasmapheresis treatment started to show up. After a 10 days stay and a loss of 20 pounds, they transferred me back to a hospital closer to my home town to continue my rehabilitation. Even though most people suffer from having their limbs manipulated, me it felt very soothing. I just had to wait for the axonal and myelin sheath regeneration.

Someone had to help me for eating, personal hygiene, turning me in bed etc... I had no muscular strength but my sensibility was normal. It is incredible the number of times we move in a small amount of time without even noticing it. Days were so long without moving and back then, there was no technology available like there is now.

### *My life with Guillain-Barré Syndrome (continued)*

On Tuesday January 3, I had my first try in physiotherapy, learning to sit on the bed side without support. I was like a 1 month old baby, it was discouraging.

On Saturday January 28, I had enough muscular tone to tolerate my first 24 hours leave from the hospital to go home. It was extremely demanding for my husband, I could not do anything by myself, not even eat and we could not use a wheel chair, it was not functional. He had to turn me over during the night and take care of the children. This first leave gave me a moral boost.

I also received a lot of support from my co-workers who relayed to come for a visit at the hospital. The physiotherapy went on for weeks. We could see some minimal improvements every week and I continued my 24 hours weekend visits home until I left the hospital. I was hospitalized for 19 weeks.

On Monday May 8, I was transferred to a rehabilitation center in Quebec City (IRDPO). It was not easy to be in this new environment and so far away from home, therefore a lot less visitors. The physiotherapy and occupational therapy were more intense and we could see a lot more improvement.

On Thursday July 6, we tried long orthotics AFO orthotics in the parallel bars. What a strange sensation to be able to do "your first steps" even though it was robotic. Inexplicable the joy and it was huge progress for me. With time we let go the parallel bars for the Canadian crutches. I also had to learn to go from the sitting position to a standing position with these orthotics. I had to revolve but my arms were not strong enough, after a few weeks I succeeded, another victory. I also learned to go up and down the stairs with these orthotics and as soon as I mastered the stairs I was allowed to go back home.

On September 15<sup>th</sup>, after 19 weeks of IRDPQ and a few weekend spent at home, it was the definitive, well deserved, return home after a total of 40 weeks away; the length of a pregnancy...I had some help at home and I kept exercising with some follow up as an outpatient at the hospital in my region.

The progress kept coming years after years. The long orthotics and the Canadian crutches were replaced by leg splints and 2 simple canes and gradually I slowly reduced the help at home.

A few years ago, I met a neurologist for another issue, and he informed me that I had the GBS with AMAN variant (Acute Motor Axonal Neuropathy).

24 years later, I receive help 4 hours a week at home for housekeeping tasks. I move around with the assistance of my tibiae orthotics because I have dropped feet. In my house I do not use my 2 canes but when I go outside I have to use them still. I must be careful to always lock my knees, the slightest flexion and it is a fall. I also use my wheelchair in my house to get anything that is low, for example to go get something on a lower shelf, get a dish out of the oven etc. If I need to do any medium to long range distance then I use my quadricarrier. I can drive a non-adapted vehicle. The strength in my hands is approximately 60%. I never went back to work. With young children I chose quality of life for my husband and I; it had no price. For 11 years I have been volunteering at our local library and I manage very well in my daily life. The architectural barriers are always going to be an issue, my quadricarrier is not powerful enough to climb stairs or cross a sidewalk.

It is essential for me to recognize the unlimited support of my husband who took good care of me and our 3 small children while still working. He and our children also survived GBS indirectly. Our life is continuing ....

#### *Disclaimer*

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