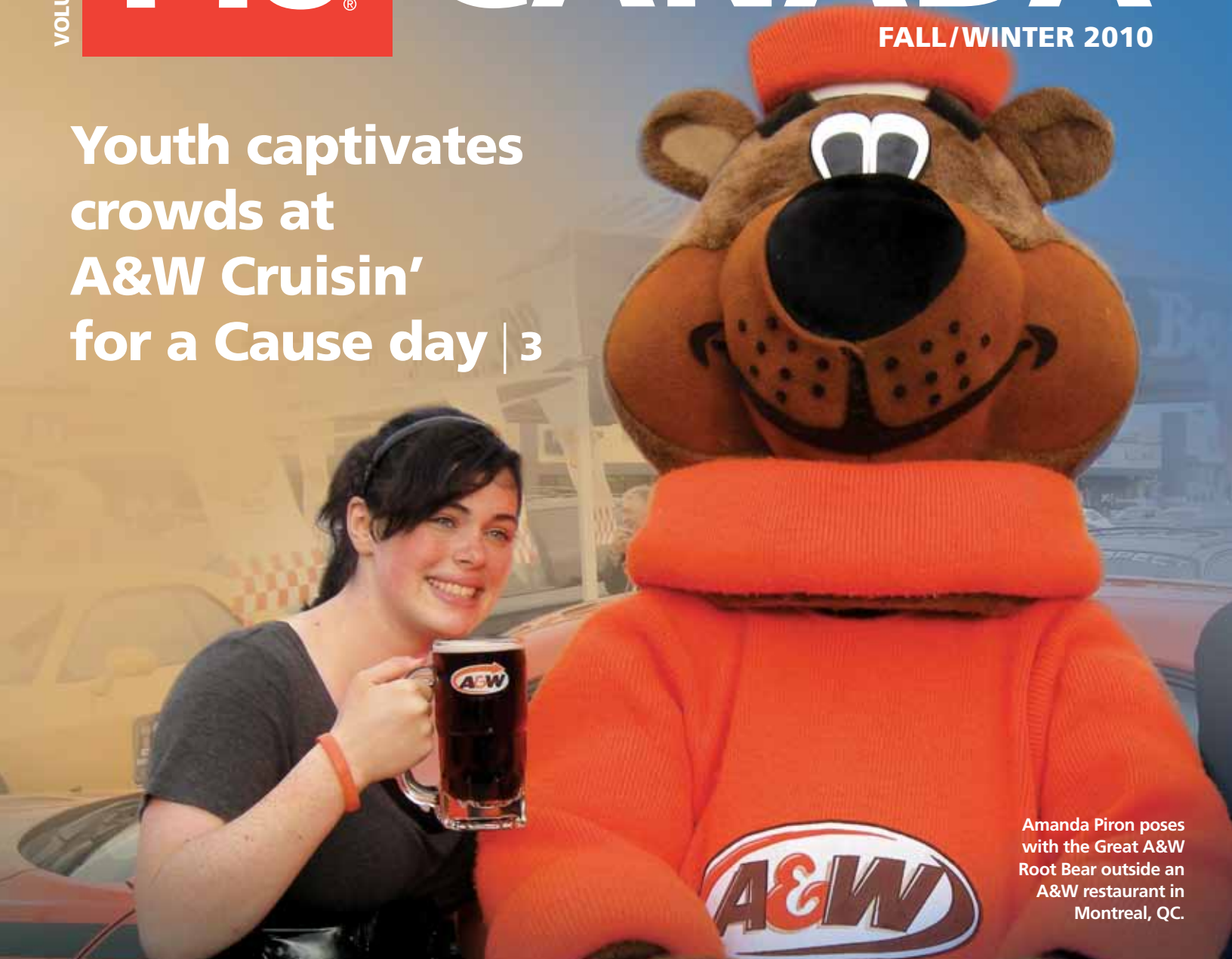


Youth captivates crowds at A&W Cruisin' for a Cause day | 3



Amanda Piron poses with the Great A&W Root Bear outside an A&W restaurant in Montreal, QC.

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\$1 M committed for CCSVI clinical trials



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Tips on getting around in and outside your home



Multiple Sclerosis Society of Canada

MSSOCIETY.CA

Message from Yves



Let me begin by acknowledging that the past few months have been unprecedented for people touched by MS. The topic of chronic cerebrospinal venous insufficiency (CCSVI)

has generated new hope and optimism about the possibility of a new treatment. Since our last issue of *MS Canada*, much progress has been made in the quest for answers surrounding CCSVI and MS. One of the most significant developments is the MS Society's commitment to provide \$1 million to support a pan-Canadian therapeutic trial of CCSVI as soon as it is warranted. By allocating \$1 million in advance, the MS Society of Canada is acting as a catalyst to bring definitive answers to the question of CCSVI as quickly as possible.

Every day, I am buoyed by the many positive accomplishments of all the people who share a passion for our ultimate goal to end MS. It is with great pride that I call to your attention a new initiative entitled 100 Days of Celebration, which began in September and runs until the end of December. 100 Days of Celebration recognizes achievements within the MS community and provides a platform for stories of celebration to be shared across the country. Day one of our celebration showcases Mike Sherwood, an MS Society volunteer from BC whose confident attitude is truly worth celebrating. Mike tells people, "Over the years, I have come to a positive conclusion...I have MS, but it

doesn't have me!" We invite you to participate in this initiative by contributing your reason to celebrate to 100DaysofCelebration@mssociety.ca

In keeping with the theme of celebration, I am pleased to announce that A&W hosted its second annual nationwide Cruisin' for a Cause day on August 26, where \$1 from every Teen Burger sold was donated to the MS Society of Canada. Through the contagious enthusiasm displayed by A&W staff, the dedicated efforts of MS Society volunteers and the generous contributions from communities across the country, I am proud to report that the event was a monumental success raising over \$700,000 – nearly doubling last year's total. Cruisin' for a Cause not only helps maintain the momentum of ongoing research and client services initiatives, it also increases the level of awareness of how MS impacts people, families and communities across the country.

In closing, I would like to note that this issue also features a special insert on mobility highlighting topics that include the importance of accessibility and managing mobility as it relates to MS symptoms. We thank Biogen Idec for their support of this issue of *MS Canada* through an educational grant. I hope that you enjoy the pages that follow and that they provide you with a reason to celebrate over the coming months. ■

Yves Savoie
President and chief executive officer
President, Ontario Division



MS Canada, Fall/Winter 2010

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100 Days of Celebration

Over the years, I have come to a positive conclusion about MS and me, "I have MS, but it doesn't have me!" ~ Mike Sherwood

Youth captivates crowds at A&W Cruisin' for a Cause day

No matter how you serve it, Amanda Piron loves a good Teen Burger. In fact, the MS Society ambassador, MS Read-a-Thon presenter and MS Summer Camp mentor had a bite at five A&W locations as part of the launch activities for the 2010 edition of Cruisin' for a Cause. Joining her on a tour that went to Montreal, Kitchener, Calgary, Regina and Maple Ridge, were Paul Hollands, president and CEO of A&W Food Services Inc. and Ken Mayhew, chief development officer of the MS Society of Canada. Amanda captivated audiences across the country by sharing her story of being diagnosed with MS at an early age.

Destination after destination, Amanda mesmerized crowds with her energy, "How do I feel about MS? I feel ready!" Those who came out to Cruisin' for a Cause to enjoy a Teen Burger, to admire a classic car or perhaps to hug the iconic Great A&W Root Bear, left with more than they had bargained for. After hearing Amanda speak, they left with a renewed sense of hope and the desire to do more to help Canadians who live with MS.

On August 26, more than 700 A&W restaurants across Canada opened their doors for the second annual Cruisin' for a Cause day, which raised



Amanda Piron (far left) is joined by MS Society staff and Paul Hollands, president & CEO of A&W (third from left) in Maple Ridge, B.C.

over \$700,000 – nearly doubling last year's total of \$400,000. Countless Canadians became better aware of MS by participating in the event, which was summarized by Amanda as something "that engaged people on a community level but will impact the lives of people living with MS on a national scale." Thanks to Amanda and the tireless efforts of A&W and MS Society staff and volunteers across the country, the event was a major success. ■

Are you 15 to 25 years old and want to share your voice about programs and services that might better support you or someone you care about?

Join other youth and young adults living with multiple sclerosis, either with a diagnosis of MS or a personal connection to MS, to represent the voice and choice of your generation at the MS Society.

For more information contact:
mandy.joseph@mssociety.ca
or call 1-866-922-6065 ext. 3198

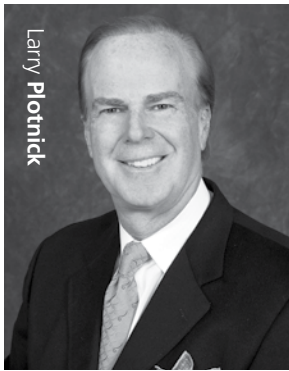
DAY 19



"Nobody can go back and start a new beginning, but anyone can start today and make a new ending."

~ Anna Wlodarkiewicz

Celebrating Larry Plotnick on his endMS success!



Larry Plotnick

Larry Plotnick first contacted the MS Society in September 2007. A few months earlier, his daughter-in-law, Joy, was diagnosed with multiple sclerosis. It was very difficult for Larry's family to accept that the energetic 35-year-old mother of two had been diagnosed with MS.

As the executive chairman of The UPS Store and a seasoned professional, Larry is always juggling several issues at a time and isn't afraid of big challenges. Despite a hectic lifestyle and a demanding career, he also involves himself in a variety of causes for his community, making his involvement with the endMS movement completely natural. In his view, taking part in a national campaign with an overall objective to raise \$60 million for MS research represents the kind of challenge that is tailor-made for him.

In the fall of 2009, Larry decided he wanted to contribute to the endMS campaign, so he and his family sent out messages by mail and email, inviting more than 600 people to support MS research through an online donation site Larry created. To-date, the site has raised over \$124,000! This amount was raised thanks to the support of more than 400 donors, many of whom were new to the endMS cause.

Larry is thankful for the time, energy and encouragement he receives from his family and

friends, especially his wife Jane, Stanley and Barbara Plotnick, Lisa and Jason Mars, Andrea Webber, and, of course, Joy and Michael and their daughters.

"We hope that our family and friends will help us raise money to support the research that will, hopefully sooner rather than later, find a cure for this potentially very debilitating disease," says Larry.

For more details about Larry's initiative, visit helpplotnickendMS.ca ■



We will never walk on the moon.

Be part of something monumental. Funded largely by the MS Society, Canadian researchers have brought the cure for MS within reach. Let's take this last step together.

endMS.ca
It's time. Give now.

1-800-361-2985

MS Multiple Sclerosis Society of Canada

100 Days of Celebration



DAY 28

"The Multiple Sclerosis Society of Canada has been a monumental part in helping Joyce live life to her fullest. Their support services have allowed her to live independently for many years..." ~ Sylvia Brownell, sister-in-law of Joyce Brownell

Promoting function, independence and mobility

MS symptoms can make it challenging to carry out daily activities, including getting around the home and going out. Perhaps leg weakness prevents you from walking from one room to another or fear of losing your balance keeps you from doing work around the kitchen. In a recent survey, over 78% of Canadians with MS said that mobility issues are a significant problem¹, affecting their working lives and relationships, and are a source of considerable frustration. This special feature will provide you with tips and techniques that will help you to maintain your level of function, independence, and mobility throughout the winter months.



Working with your healthcare team

If MS begins to impede your ability to complete routine activities, that's when it's time to involve your doctor to help you make a plan to manage your mobility-related symptoms. Your physician can also refer you to other healthcare professionals for help with specific problems. Together, your healthcare team can devise a plan that is tailored to your specific needs.

A physiotherapist can evaluate your mobility, balance, gait and posture and provide you with techniques and aids to improve them. The physiotherapist can also design a unique exercise program that targets the symptoms that you are dealing with.

After assessing your physical abilities, your home and work environments, an occupational therapist can recommend strategies and aids that will help manage your energy level so that you can maintain the skills you need for independent living.

¹**Impact Multiple Sclerosis Patient Survey.** Conducted June 4 to June 29, 2010 by an independent market research company.

Some of the more common MS symptoms that affect mobility include: problems with balance; dizziness and vertigo; poor coordination; weakness; spasticity (muscle stiffness) and spasms. Occupational and physical therapy, sometimes in combination with medication, can help to maximize mobility and function as well as help to avoid complications of immobility over time. No matter what symptoms you are dealing with, you don't have to manage them alone, so don't hesitate to include your healthcare team from the start.

Beneficial exercise

The benefits of exercise do not stop because of MS. Actually, exercise can improve your muscle tone, strength and overall endurance and can help reduce fatigue, spasticity and pain. Depending on your symptoms, your exercise program may include:

- Stretching to maintain elasticity in muscles and tendons.
- Range of motion exercises to maintain or increase joint flexibility.
- Strengthening exercises using weights, exercise machines, or resistance bands to maintain muscle strength, and help reduce fatigue by helping muscles to work more efficiently and tire less easily.
- Aerobics to improve endurance and cardiovascular function, which can, in turn, reduce fatigue.
- Yoga for flexibility and improved balance.
- Tai chi to improve balance and walking ability.
- Aquatic exercise for improving range of motion and strengthening muscles.

Helpful medications

When exercise alone is not enough to control your mobility-related symptoms, your doctor can prescribe medications that may improve symptoms that interfere with your mobility. These medications may include:

- Antispasticity medications to relieve muscle stiffness such as lioresal (Baclofen) and tizanidine (Sirdilud).
- Anticholinergics and stimulants for loss of balance.
- Antinausea medications for dizziness and vertigo.
- Amantadine, Modafinil, and Ritalin which help to reduce fatigue in some people.
- Injection therapy for severe spasticity.

Using adaptive equipment

For some people, they are able to maintain their function, independence, and mobility by making use of mobility aids and other adaptive equipment. The equipment helps them move safely and with confidence. Consider how the equipment below might increase your physical independence:

- Customized orthotics can improve stability, support weakened limbs, and help with spasticity.
- A cane enables you to stand when one leg is weaker than the other or for mild problems with balance.
- Walker for significant leg weakness and also support for maintaining balance.
- Wheelchair or scooter when excessive fatigue, unsteadiness or occasional falls keeps you from getting around in or outside your home.

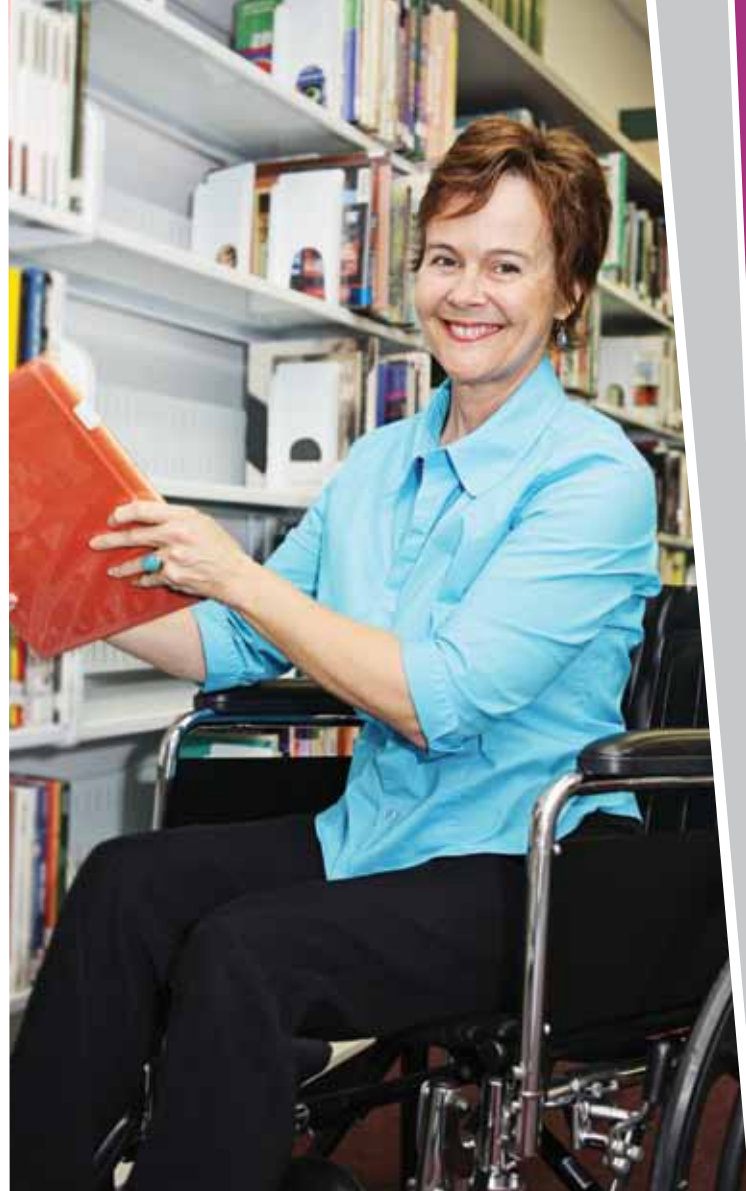
Tips on getting around in and outside the home

These modifications can help improve mobility

- wider doorways and hallways
- lever style instead of knob handles on doors and faucets
- crank-operated windows
- slide-out or revolving shelves
- lowered shelves, cabinets and countertops
- chairs with raised arms and seats
- ground-floor bedrooms
- raised toilet seats
- shower or tub chairs
- outdoors – an incline or ramp rather than a front step

For enhanced safety and support

- non-slip flooring, especially in kitchens and bathrooms
- non-skid backing on mats or double-sided carpet tape
- no loose rugs
- secured telephone and electrical cords
- furniture moved away from paths and walkways
- treads on uncarpeted indoor and outdoor stairs



- handrails and grab bars, particularly in stairways and bathrooms
- non-skid mats or adhesive strips in bathtubs

For winter safety

- lightweight boots with a thick, non-slip tread sole and wide, low heel
- ice gripper for walking on hard-packed snow and ice
- ice pick / retractable spike to attach to the end of a cane

Exercising safely with MS

Adapted from an entry posted on msanswers.ca

- Two Hour Rule: If you don't feel as good two hours after exercising as you did before you started, then you probably did too much.
- 'No Pain, no gain' does not apply to MS. Avoid overworking and causing excessive fatigue.
- Build in short rest periods, a minute or two, between each exercise to help you avoid fatigue.
- Exercise in a cool, air-conditioned environment of 20-22 degrees Celsius (68-72 degrees Fahrenheit). If exercising outdoors, try to exercise either early in the day or later in the evening to avoid the hotter weather.
- Drinking cold water or using cooling vests, neck collars, wrist wraps, or even wash cloths soaked in ice water can be used to cool the body when exercising.
- If performing pool exercises, the recommended water temperature is 26-29 degrees Celsius (80-84 degrees Fahrenheit)
- Find exercises that you enjoy!

For additional information on related topics, you can visit mssociety.ca where you will find resources in English and French such as:

- Everybody Stretch
- Multiple Sclerosis and Fitness

You can read them from your computer or contact an MS Society of Canada office to obtain a copy.



Did you know?

Some divisions and chapters of the MS Society have developed local resources such as financial assistance programs that provide limited amounts of funding for the purchase of exercise equipment and/or fitness memberships. In addition, some MS Society of Canada offices have their own lending libraries that loan additional books, CDs and DVDs as well as other MS related resources. To find out if there is a lending library in your area, contact the MS Society office nearest you.

\$1 M committed for CCSVI clinical trial

On September 16th, the MS Society of Canada's board of directors unanimously approved an allocation of \$1 million for a chronic cerebrospinal venous insufficiency (CCSVI) and MS pan-Canadian therapeutic clinical trial. The funding has been set aside to ensure an immediate availability of funds when such a trial is developed and approved.

"We want to hit the ground running when a therapeutic trial is warranted and approved," says Yves Savoie, president and CEO of the MS Society. "Ensuring funds are available to support a Canadian trial will accelerate our ability to get definitive answers to the questions people touched by MS urgently seek."

The MS Society hopes to work with the provinces and the federal government to secure all of the funding for a therapeutic clinical trial. At the recent health ministers' meeting in Newfoundland, provinces and territories collectively stated that the issue of CCSVI is a top priority.

The MS Society has advocated for more research since the CCSVI theory became widely publicized in the fall of 2009. Already, \$2.4 million has been committed by the MS Society of Canada and the National MS Society (USA) to support seven research projects focusing on CCSVI and its relationship to MS. To learn more about our latest news on CCSVI and MS visit mssociety.ca/ccsvi ■

Vitamin D deficiency increases risk of MS

It is estimated that one billion people worldwide do not have sufficient vitamin D. Insufficient exposure to the sun and poor diet are associated with this deficiency, which is a known risk factor for bone softening diseases such as rickets. There is growing evidence, however, that a vitamin D deficiency also increases a person's susceptibility to autoimmune conditions such as MS.

Now, in a study whose funders include the MS Society of Canada and MS Scientific Research Foundation, researchers at the University of Oxford have shown the extent to which vitamin D interacts with our DNA. The findings suggest that the vitamin is able to influence our genetic makeup. The researchers found 2,776 binding sites along the length of the genome where a vitamin D receptor

(a protein activated by vitamin D) attaches itself to DNA and consequently influences what proteins are made from our genetic code. The binding sites were unusually concentrated near a number of genes associated with susceptibility to MS among other autoimmune conditions.

Although the idea that vitamin D plays an important role in our body's armor against disease is not new, the extent to which it interacts with our DNA is. "The body of evidence about the importance of vitamin D is building quickly and is exciting as vitamin D could be a readily modifiable factor in managing risk for the development of MS," concludes Dr. Paul O'Connor, national scientific and clinical advisor to the MS Society of Canada. ■

100 Days of Celebration



"Parents love when Read-A-Thon time comes. The program also teaches children to help others, think of what others experience, and helps to broaden their horizons." ~ Beth McDonald

Disability rights: check. Job: check.

Civil engineer, Denis Baribeau, proves performance at work is unaffected by MS symptoms.

“I worked hard to earn my bachelor’s degree in construction engineering. I was determined to keep my job and build my career.” Those are the fighting words of Denis Baribeau who faced job insecurities with the Quebec government when he became partially disabled as a result of a relapse from MS in 1996.

The biggest obstacle was to reverse the stereotype around disability and MS among his managers and colleagues. So, he took it upon himself to educate them by first engaging some in MS Society activities and demonstrating to others his ability to perform his job. “Some of my colleagues participate in the MS Walks, others donate to the MS Society actively or volunteer their time in one form or another. Through their involvement, they have altered their opinion of people with disabilities and of MS,” Denis explains proudly. While many of his colleagues supported him, however, there were still some whose perceptions could not be reversed. The only way to show that he could continue to work was by simply working, and then, working some more. It took years for Denis to raise awareness among his co-workers and managers and prove that

although his disability limited his movement, it had no impact on his job performance.

Today, while getting around in a wheelchair, Denis actively advocates for the rights of persons with disabilities with particular emphasis on accessibility. Following the advice of his locally elected official, Denis asserts, “don’t be afraid to come and ask for things because you elected them. If they don’t know what you need, they can’t get it for you.”

Denis was diagnosed with MS in 1986. When the relapse affected his mobility, he returned to work after only a short week off and remains employed with the Quebec government to date. He lives in Trois-Rivières with his wife, Julie, his strongest supporter, who for 12 consecutive years was a top MS Walk fundraiser (1997-2008) in Trois-Rivières. Denis remains actively involved with the MS Society, chairing the board of directors at its Mauricie Chapter and is also a member of the MS Society’s national government relations committee, a group of passionate advocates who work toward improving public policy in areas of income security, MS research, and accessibility. ■



MS Answers

Q : I recently signed up for personal training at a local fitness centre. My trainer raised the question of MS and how it would affect our training sessions. I’m reasonably fit and have no physical disability; mostly just fatigue. What additional information about balance, coordination, and core strength would be of value to a personal trainer to more appropriately adjust my sessions?

A : Your question brings up a wonderful opportunity for neurologically-trained physical therapists to collaborate with personal trainers when working with MS clients. First, a local neurological physical therapist can get you on

the right track for your exercise program. Issues around balance, coordination, and core strength can be the result of a variety of causes: spasticity, weakness, and vestibular dysfunction, among others. The causes of these problems can be isolated by the physical therapist to help devise a customized exercise plan for you. Once you are established into a rehabilitation program and have met your initial therapy goals, it is then a good option for you to transition to a personal trainer who can help you with the exercise program.

Read the full response at msanswers.ca, keyword search “personal trainer.” ■

An expression of hope

For some individuals, a diagnosis of MS can significantly impact their lifestyle. There may be changes to family roles and responsibilities, social or physical activities, and career paths.

Katie Gerke, a successful artist based in Calgary, can attest to these changes in her life. Since being diagnosed with MS, she has adapted her life choices to overcome many of the challenges she was faced with.

After high school, Katie trained and worked as a radiology technician for several years before deciding to travel abroad. Upon returning from her travels, she was diagnosed with MS. Despite the news, she pursued a post-secondary education and in 1996, she obtained a BSc in Computer Information Systems and began a new career as a software analyst.

In 2002, Katie was informed that she could no longer work. She struggled to absorb this information and worried about her future. Through overwhelming support from her local church, however, Katie found new hope, and embarked on a journey as an oral artist.

“I have lived with MS for 20 years and I have lost the use of both legs and both arms. I have lost the ability to express myself manually and have adapted to expressing myself orally. I just connect my heart, my mind and my emotions and push them down the length of a paintbrush to create something to share with others,” Katie explains.

She generously shared her painting *Midmorning Train* for use as the cover art for our new publication *Adapting: Financial Planning for a*



Life with MS. Today, Katie owns her own gallery, showcasing her undeniable talent (oralart.ca).

Adapting: Financial Planning for a Life with MS offers guidance on a variety of topics ranging from personal financial inventories and employment issues to coping with debt, investment portfolios and insurance information.

Financial planning for the future can be overwhelming and confusing. Thanks to a new partnership with the Investor Education Fund, the MS Society of Canada is working to provide families affected by MS with the necessary tools and resources they need to become better informed about financial management and ultimately enable them to make smarter decisions with respect to investing and managing their money.

Read the publication *Adapting: Financial Planning for a Life with MS* online by visiting mssociety.ca in the “What’s New” section.

Investor Education Fund is a non-profit organization that develops unbiased, independent financial information to help consumers make informed financial decisions. ■

MS 100 Days of Celebration



Listeners of CKRM Radio in Saskatchewan call in during the Christmas Music Dedication show requesting a song along with a donation for the MS Society. To date, the show has raised over \$250,000. ~ Lorne Harasen, creator and announcer of the Christmas Music Dedication show on CKRM Radio

What's on this fall and winter!

Host your MS Global Dinner Party this fall or winter. Every year, people around the world host dinner parties in support of MS research. The concept is simple: instead of spending money on a night out, each host asks their guests to make a donation in support of multiple sclerosis. Register today! We will even create an online account for you to assist in planning your event.



Join students across Canada as they read to end MS. Support their participation in the 2010-2011 MS Read-A-Thon! Go to msreadathon.ca to learn more.

This may be all you need to help us end MS.

Get together with your family and friends, colleagues and community. Support MS research worldwide in the fight to end multiple sclerosis.



multiple sclerosis international federation



1.866.922.6065

www.msglobaldinnerparty.ca

100 Days of Celebration



Want to share your reason to celebrate? Send your story to 100DaysofCelebration@mssociety.ca and it could be published on our homepage at mssociety.ca



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angeline.mau@mssociety.ca

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