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Message from Yves



Since our founding in 1948, the Multiple Sclerosis Society of Canada has dedicated resources and expertise to increase government response to challenges faced by individuals and

families living with MS. Despite considerable progress over the last decade, access to health care, income security, caregiver support, and accessible communities remain priority issues for thousands of Canadians affected by MS. As a health charity, we are devoted to advancing such issues by working with government at all levels in a non-partisan way.

This edition of MS Canada will introduce you to many activities that demonstrate our work in mobilizing for policy change. You will meet two Ottawa students who raised funds through the MS Read-A-Thon program and later visited Parliament Hill to present carnations to MPs in honour of MS Awareness Month. You will read about a petition with more than 4,000 signatures demanding action for better income security and the accompanying 1,000 emails from MS Society supporters to their MPs. We will also update you about our request to provincial governments to

make Tysabri, a disease-modifying therapy, eligible for reimbursement under public drug programs. These efforts build on the success of our Quebec Division which received the news in late 2008 that Quebec would be the first province in Canada to reimburse Tysabri.

We applaud the federal government for their commitment of \$15 million over 4 years to study the incidence, prevalence, and impact of neurological diseases in Canada. This announcement represents a critical first step to better understanding the experience of people living with MS, and the impact to families, communities, and Canadian society.

Reflected in this issue of MS Canada is our deeply held belief that lasting change occurs when we rally with one voice in pressing governments to be leaders in building inclusive communities. While many challenges remain, and the need for policy reform is more urgent than ever, we are gratified by the response from politicians at every level and from every party in their support for a better quality of life for Canadians living with MS.

We thank you for being part of the movement to end MS. ■

Yves Savoie
President and chief executive officer
President, Ontario Division



MS Canada, Summer 2009

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Our Mission: To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.

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Hear the latest on MS research from one of Canada's leading neurologist, Dr. Peter Rieckmann. Listen to the 2009 MS Research Teleconference audio recording at www.mssociety.ca/en/research or contact 1-866-922-6065 for a copy of the CD.



MS Answers

Q: I would like to travel to a sun destination. Since I have MS, I would like to know if this type of trip could cause an attack.

A: Many people with multiple sclerosis report that heat greatly aggravates their symptoms. It is not clear, however, why heat and high humidity levels cause this worsening of MS symptoms. MS is an individual disease that varies from person to person. For instance, some people may feel better

when visiting sun destinations, because the air is drier than it is in Canada. Also, if you normally react well to heat, then a rise in body temperature as a result of a trip to a sun destination might not trigger any neurological repercussions for you.

For tips about dealing with the effects of heat and to read the complete answer, go to www.msanswers.ca. ■

Ray of light under the sun



Martha of Quaqaq, Quebec has lived with MS since she was 9.

While it is the most common neurological disease affecting young Canadian adults aged 15 to 40, multiple sclerosis affects children, some as young as two years old. In a small Inuit village of approximately 300 people, Martha Ningiuruvik was diagnosed with MS in January 2005 at the age of 9. Having endured bouts of

nausea, weakness, a three week long hospital stay, and frequent injections for treatment, Martha felt completely isolated from other children in her community. She didn't know of any other children in the village who lived with MS.

When her symptoms began to subside, Martha longed to return to her usual routine and to enjoy all of the things she did before her diagnosis. With her mother's encouragement, she agreed to make a long journey from her remote town of Quaqaq, Quebec to the historic town of Perth, Ontario to attend the first ever Summer Adventure Camp for children and teens living with MS in 2007.

At camp, the kindness and support of staff and counsellors helped to ease Martha's apprehension of meeting other children and teens. She made

new friends without any trouble and shared fun and memorable moments hiking, canoeing, playing games, and doing crafts with them. The large gathering of young campers and staff by the lake on the final night is among her favourite moments. Although it marks the end of the week-long program, reflecting on the days at camp that night reinforces the value in meeting and interacting with other young people who live with MS.

Today, Martha is a vibrant teenager who leads a normal life without any symptoms of MS getting in the way. The experience of travelling from her hometown to Perth for the Summer Adventure Camp has even stirred her motivation to travel the world some day. Most of all, she is eagerly awaiting the chance to take part in the upcoming Summer Adventure Camp on August 15 to 21. It will be her third visit to the camp in Perth.

Martha is one of nearly 30 children who attend the Summer Adventure Camp each year. It is a program offered by the MS Society of Canada with the support of generous donors. The Summer Adventure Camp offers a safe, supportive, and fun setting for children and teens under 18 who live with MS to share their experiences freely. To learn more about the Summer Adventure Camp, visit www.mssociety.ca/en/help/camp.htm. ■

MS Society's continued strides toward good governance

Recognizing the importance of good governance, the MS Society recently completed a comprehensive governance review with the goal of continuing to strengthen our organization's effectiveness and enhancing our ability to achieve our mission.

A task force, comprised of national board directors and supported by external experts, conducted the review in consultation with volunteer and staff leaders with experience at all levels of the MS Society. Its recommendations were approved by the national board of directors in November 2008. The recommendations address specific issues for the National Board as well as a number of measures to strengthen capacity for good governance at all levels of the organization. Nothing in the report's recommendations changes the structure of the Society in terms of its three levels: chapter, division, and national.

A newly-formed governance committee of the national board is putting these recommendations into practice. Governance

committees have also been created for most of the divisions and for some chapters.

We are proud of these important strides to strengthen the Society's governance practices and will share further updates on the outcomes of the governance review in future issues of *MS Canada*. ■

ANNUAL GENERAL MEETING

When: Saturday, November 21, 2009,
1 p.m. (EST)

Where: Marriott Bloor Yorkville,
90 Bloor Street East, Toronto

Questions: Contact Rosanne Portelance,
National Office: Rosanne.
Portelance@mssociety.ca
or 1-866-922-6065

Formal notice of and proxy form for the AGM will appear in the fall issue of *MS Canada*.

Feds commit \$15 million to major study of neurological diseases

The Neurological Health Charities Canada, in which the MS Society plays an active role, made significant progress on achieving a national brain strategy with the announcement of the federal government's research investment of \$15 million in neurological diseases.

Since the announcement was delivered on June 5, Canadians have applauded the news including Michelle Amerie, who has lived with MS for 27 years: "I am thrilled at the NHCC's announcement of this critical step forward in changing the lives of people with neurological diseases... As each of these neurological diseases is addressed, there is

greater hope for me and for others."

The four-year national population study will provide key information to improve current knowledge about the prevalence, risk factors, use of health services, economic cost, and impact of neurological conditions currently and projected over the next 20 years. A comprehensive report will be published in the final year of the study. It is expected that some of the findings "will help to guide our efforts to fund the best research and deliver programs that positively impact quality of life," said Yves Savoie, president and CEO, MS Society of Canada. ■

Mobilizing policy change

“I commend you on setting a clear strategy to work toward getting more federal money for MS research and to alleviate financial pressures felt by those of us who have MS,” wrote a Newfoundland woman who took part in online advocacy conducted during MS Awareness Month.

Throughout May, Members of Parliament heard about issues that are crucial to people affected by MS. During almost 30 face-to-face meetings in Ottawa, MS Society representatives urged MPs to improve income security programs for people living with MS and to increase health research funding.



Over 4,000 supporters signed a petition asking for action on income security.

Nearly 1,000 MS Society members and friends sent letters to MPs by email about the issues using an online advocacy tool. At the end of May, 11 MPs representing all parties, tabled a petition with more than 4,000 signatures asking for action on income security.

“I am pleased and humbled to see such terrific support from MS Society members and friends in letting their MPs know we need changes now,” said Yves Savoie, president and chief executive officer.

To sign up for future advocacy campaigns, send an email to: advocacy@mssociety.ca. ■

Drug reimbursement work continues

In some individuals with MS, no improvement is achieved after receiving current MS treatments. To fill the treatment gap, Tysabri (natalizumab), a new disease-modifying therapy, is now available. In February, the Common Drug Review recommended provinces reimburse Tysabri under certain criteria. Following this announcement, the MS Society is now urging provincial governments to make Tysabri eligible for reimbursement under public drug programs. ■

Special offer for MS Canada readers!



Abilities Magazine subscriptions are available to MS Society members at a discounted rate. For just \$14, you will receive four issues that provide

a unique perspective on travel, health, entertainment, profiles, family life and scintillating interviews.

Send a cheque or money order for \$14 noting that you read about the offer in *MS Canada* to: Abilities Magazine, The Canadian Abilities Foundation, 340 College Street, Suite 401, Toronto, ON M5T 3A9. Or order by credit card by phone (toll-free): 1-888-700-4476. ■

No Hill too high for young fundraisers

You can never be too young to have an impact on the life of a person living with MS. Two Ottawa students made an exceptional effort in their own drive to raise funds for MS by reading a lot of books and committing to their fundraising goals for the MS Read-A-Thon program.

Peter, a grade 2 student at Adrienne Clarkson Elementary School, read 42 books and raised \$1,519. Deana, a grade 5 student from John Young Elementary School, read 51 books – the most read in the MS Read-A-Thon program in the Ottawa area. The young fundraisers demonstrated to their fellow students that it is important to help people in their community in

their own way – an important message the MS Read-A-Thon imparts to students participating in the program across the country.

For their exceptional contribution, Peter and Deana were invited to visit Parliament Hill to shake hands with and present carnations to MPs arriving for their session during MS Awareness Month. They spoke excitedly about their MS Read-A-Thon accomplishments, but more importantly, conveyed to Canadian leaders their role in the fight to end MS.

Peter and Deana are among over 30,000 Canadian students nationwide whose enthusiasm for the MS Read-A-Thon program gives hope to people living with MS. ■

Souls of your shoes

To help kick-off the MS Walk this spring, a unique contest named If My Shoes Could Talk was launched across the country. More than 90 Canadians proudly revealed their inspiring shoe stories that garnered a total of over 160,000 votes.

If My Shoes Could Talk MS Walk contest winners



1st: *My shoes express love*
by Chantal Houle
21,798 votes



2nd: *Success, dreams, and laughter*
by Roxane Guèvremont
21,240 votes



3rd: *Walk/dance like no one is watching*
by Fred Tufnell
16,512 votes

“After being diagnosed 5 years ago right before my 20th birthday and during my university finals I was ready to find a cure, and walk around the world for

this disease if I had to find it so I did what I could 5 MS walks later, along with \$25,000 towards a cure I'm doing my part and my shoes are tied tight along the way! Whether it was wearing them to university every morning to complete my Kinesiology degree, hosting MS steak nights and BBQ's they have been there. They sat patiently by the door while I shared my story for the MS Calendar of Hope in 2008 Miss April... My shoes carry me to the hospital to get help when I need it, and they carry me to work to help my clients deal with the muscle fatigue associated with MS. For the first time they will carry me to Camp Merrywood to volunteer at the kids camp this year! No matter how hard of a day I have those shoes never let me down and are ready to take on anything. They are my comfort and soul.”

Lacey Andreas, *If My Shoes Could Talk* contest participant, Saskatchewan

MS Walk is the MS Society's largest pledge-based fundraiser that takes place in 160 communities in Canada. Millions of dollars has been raised since its inception in 1991, with proceeds directed to ground-breaking MS research and to fund critical services for people affected by MS. ■

MS Society establishes five research and training centres

In a move intended to significantly accelerate the pace of MS research, the Multiple Sclerosis Society of Canada announced the establishment of five research and training centres involving over 100 established scientists and 250 trainees.

The entities, dubbed endMS Regional Research and Training Centres (RRTC), come less than one year after the MS Society launched a major fundraising initiative to alter the research landscape in Canada.

“The goal of these centres is to boost our capacity to conduct MS research through training of the next generation of MS

researchers,” says Yves Savoie, president and chief executive officer of the MS Society of Canada.

The five centres are funded entirely by the MS Society of Canada. Each centre will receive \$100,000 per year for three years to fund collaborative training and research activities.

Researchers and trainees affiliated with each RRTC will collaborate through conferences, regional workshops, online tools and inter-lab exchanges through which trainees will leave their host institution for a set period of time to train at another within the network. ■

All A&W restaurants across Canada to sell Teen Burgers for MS

In an effort to increase awareness of multiple sclerosis among Canadians, A&W has agreed to expand its Cruisin' for a Cause event to support the MS Society nationwide. This follows the resounding success of a similar event that took place at A&W restaurants in Saskatchewan last year. A dollar from every Teen Burger purchased on Thursday, August 27, 2009 at all 700 A&W restaurants across Canada will be donated to the MS Society. Funds raised on that day will help our efforts to raise greater awareness about the high incidence rates of MS among Canadians. Mark the date on your calendars and join A&W on August 27 to help end MS. It's a tasty way to do some good. ■



Enjoy our events this summer!

July

RONA MS Bike Tours

- 4-5 Sussex to Saint John (New Brunswick)
- 25-26 Grand Bend to London (Ontario)
Windsor to Wolfville (Nova Scotia)

August

- 9-16 MS Summer Camp for kids with a parent living with MS (Quebec)
- 15-21 Summer Adventure Camp for children and teens living with MS (Ontario)
- 27 Purchase an A&W Teen Burger today with proceeds going to the MS Society (all locations across Canada)

RONA MS Bike Tours

- 8-9 Ottawa to Kemptville (Ontario)
- 8-9 Cowichan Valley Grape Escape (British Columbia)
- 9 Vancouver Scenic City Tour (British Columbia)

- 14-15 Regina (Saskatchewan)
- 15-16 Brampton to Waterloo (Ontario)
- 22-23 Victoriaville Region (Quebec)
- 23 Niagara (Ontario)
- 29-30 Lévis Region (Quebec)
Stonewall to Gimli Biking to the Viking (Manitoba)

September

RONA MS Bike Tours

- 12 Waskesiu (Saskatchewan)
- 12-13 Hinton (Alberta)
Riding Mountain Challenge (Manitoba)
- 13 Kamloops Thompson River Ride (British Columbia)
Toronto (Ontario)

MS Walks

- 13 Quebec (Quebec)
Sherbrooke (Quebec)
Sorel-Tracy (Quebec)



To share your comment or story, please mail to the attention of Angeline Mau or email to angeline.mau@mssociety.ca.

To update your mailing address or subscription preferences, please contact your division office. Division contact information can be found at: www.mssociety.ca or you can call 1-800-268-7582 or email: info@mssociety.ca



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