



# CANADA

AUTUMN/WINTER 2009



What you need to know about H1N1 | 5

3

**Smoking and MS**



4

**The disability poverty trap**



Multiple Sclerosis Society of Canada

**MSSOCIETY.CA**

Annual meeting of members, see proxy inside.

# Message from Yves



**G**ood health is a priority for us all. For Canadians affected by MS, the path to wellness involves more than treatment of the disease. Multiple sclerosis is a chronic neurological illness that creates variability, disability and

uncertainty. Frequently, it demands a significant amount of energy, tenacity, and courage to meet daily challenges. But this disease is just one aspect of health to those we serve. At the MS Society of Canada, we believe it is important to have a multi-faceted wellness program. Deciding to adhere to a healthy lifestyle or to maintain healthy habits is a choice especially relevant for people with MS who often feel they have little control over the disease.

In this issue of MS Canada, we are reminded to protect our overall health and well-being with choices such as healthy eating, not smoking, and some form of regular physical activity balanced with adequate rest. We will explore the H1N1 virus, an illness that is of concern to many Canadians, by sharing facts and small changes that can offer protection as we enter flu season.

You will also learn of several MS Society programs that are contributing to wellness for people with MS, their caregivers, and partners. Whether delivered in the form of an active living day or a

couples' weekend retreat, these programs support lifestyle balance as they focus on the combination of body, mind, and spirit.

We are also encouraged by promising new developments related to MS treatments. Ongoing trials of cladribine and fingolimod, both administered orally, offer new therapeutic options for managing MS. As well, Tysabri (natalizumab), used to treat relapsing-remitting MS, has now been approved for reimbursement in four provinces. These developments increase the range of drug therapies available to people with MS, enabling them to better manage the disease and, ultimately, their overall health.

As we near the end of the year and look towards 2010, all of these steps contribute to general wellness, which, among other benefits, provide hope that one can renew and refresh along the way. While we remind you to think twice before shaking hands this season, more importantly, we extend our very best wishes to you for a lifetime of good health and well-being. ■

Yves Savoie  
President and chief executive officer  
President, Ontario Division



## MS Canada, Autumn / Winter 2009

Published by the Multiple Sclerosis Society of Canada  
175 Bloor St. E., Suite 700, Toronto ON M4W 3R8  
Tel: (416) 922-6065 • Fax: (416) 922-7538  
Toll free: 1-866-922-6065 • Website: [mssociety.ca](http://mssociety.ca)  
Charitable Registration no. 10774 6174 RR0001

**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.

President and chief executive officer: Yves Savoie  
Editor-in-chief: Annette King  
Managing editor: Carol Kim  
ISSN 0315-1131 – Issued quarterly  
Canadian Publications Mail Product  
Sales Agreement No. 40063383



### Find us on Facebook

Become a fan of our page at [facebook.com/mssocietycanada](http://facebook.com/mssocietycanada) and join the conversation.



### Follow us on Twitter

Follow our tweets at [twitter.com/mssocietycanada](http://twitter.com/mssocietycanada) and stay up-to-date with the latest MS news and events.



## MS Answers

### Q: Does smoking cigarettes worsen MS?



**A:** There is now good documentation that smoking is linked to MS. Two large studies involving over 200,000 women in the US showed the risk of developing MS

was higher in smokers compared to women who have never smoked, after adjustments for age, residence and ancestry. Furthermore, another study showed that the probability of transforming from a relapsing-remitting course into a secondary progressive one is three times higher in smokers. In other words, smoking puts one at risk for developing MS and also in a position of worsening symptoms. If you are a current smoker, my advice would be for you to quit smoking immediately.

### Q: I recently signed up for personal training at a local fitness centre. I'm reasonably fit and have no physical disability, mostly just fatigue. What factors/information would be of value to a personal trainer in regards to an MS patient to more appropriately adjust our sessions?

**A:** Many personal trainers receive limited instruction on the unique nature of MS clients, so I would suggest that you initially go to see a local neurological physical therapist first to get you on the right track for your exercise program. 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. If your physical needs change, the trainer can encourage further input from the physical therapist in the future.

To read the complete responses to these and other questions on living with MS, visit the MS answers website at [www.msanswers.ca](http://www.msanswers.ca). ■

## Being well with MS

**T**he MS Society's Atlantic Division recently launched Being Well with MS, a new funding program for people diagnosed with MS and their caregivers. The program offers financial assistance for clients to participate in activities or programs that will contribute to their emotional, spiritual, physical, mental or social well-being and rejuvenation.

Being Well with MS was specifically designed in response to a recent survey asking clients and families with MS about their needs and desires. An advisory group was struck, consisting of caregivers, health professionals and people living with MS to review the survey responses and determine the area

of greatest need and decide on a course of action. The result was a new program designed to help people feel well with MS.

To date, their office has received over 150 applications since June; far more than originally expected. "We are thrilled that people are responding so enthusiastically," says Dena Simon, president, Atlantic Division. "We're so pleased that the new program honours the choice and the voice of families living with MS in Atlantic Canada."

For more information on the Atlantic Division's Being Well with MS program, visit [www.mssociety.ca/atlantic](http://www.mssociety.ca/atlantic) or phone 902-468-8230. ■

# How did I get here? Caught in the disability poverty trap



By Sharon Segal - MS Society Volunteer

**H**ow did things end up like this? Here I am, in my fifties, having done all the “right things”, but I find myself living in poverty. Why is this happening?

It’s because I have a disability. I was diagnosed with multiple sclerosis almost 35 years ago. Given the unpredictability and episodic nature of MS, I had to seek out employment that didn’t require me to work a regular 40-hour week. Occasionally, I had to quit a part-time position or refuse a contract because of a relapse.

The result was lack of workplace benefits, no pension plan, reduced CPP contributions and

less income. However, these difficulties pale in comparison with what I’m dealing with now. A couple of years ago, I had to stop working altogether. Fortunately, I had been working for several years at a job with a benefits plan, so I was able to collect long-term disability (LTD). But I can’t supplement my income, because the insurance company that pays my LTD requires that I be totally disabled and unable to do any work. I can’t risk violating this requirement.

In some instances, my income is actually considered “too high”. While I receive marginally more than the scandalously inadequate provincial social assistance disability benefits, I don’t qualify for other financial assistance to cover expenses like repairs to my scooter or household assistance. Why? My paltry disability payments exceed the allowable income threshold.

This is just my story, but it’s one that’s repeated in many different ways by people living with disabilities in Canada. It highlights the absolute necessity for some type of disability income support program. Perhaps a good place to start would be to make the disability tax credit refundable (currently useless for many who qualify, because they have no taxable income).

*The MS Society is urging the federal government to make a number of changes to financially help people affected by MS, including making the disability tax credit refundable.*

*For more information on advocacy, visit [www.mssociety.ca/en/involved/advocacy](http://www.mssociety.ca/en/involved/advocacy). ■*

## Tysabri reimbursement

**O**n July 1, 2009, Alberta and Saskatchewan agreed to cover most of the cost of Tysabri (natalizumab) for people with MS, who have failed on two other disease-modifying therapies. As of September 30, Ontario agreed to reimburse Tysabri for the treatment of Rapidly Evolving Severe Relapsing-Remitting multiple sclerosis (RES-RRMS) in individuals who meet certain

criteria. This brings the total to four provinces that are now reimbursing Tysabri, with Quebec having agreed to cover the drug last year.

The MS Society looks forward to other provinces following suit with this reimbursement and will continue advocacy with other provincial governments in the hopes to see this realized. ■

# What you should know about H1N1

No one likes to be sick, and the prospect of Canada facing a level six pandemic can be frightening for many. For people living with MS, much like any chronic illness, the risk of acquiring the virus brings added stress and concern. By knowing the facts and taking simple measures in our daily routines, each of us can help protect ourselves and those we love.

## How serious is a pandemic?

A pandemic level six alert refers to an illness that is easily spread and that will affect a wide number of people. The word pandemic does not refer to severity of illness, but to numbers affected and how fast it is being transmitted. While a seasonal flu is

a yearly event, pandemics occur only two or three times a century, resulting in very limited natural immunity in anyone.

## What are its symptoms?

For the great majority of Canadians who will contract H1N1, the symptoms will be much like any other flu: headache, sore throat, fever, fatigue and cough and will resolve on its own in 1 to 2 weeks.

## How can I stay safe?

“The best defense is a good offense” as they say. Proper hand washing, done frequently, is the single most effective tool in limiting contagion. Other strategies include getting enough rest, staying clear of others who are infected, avoiding crowds when practical and possibly getting the H1N1 vaccine. The regular seasonal flu vaccine will not offer the needed protection. For more information on the H1N1 vaccine, visit [www.phac-aspc.gc.ca](http://www.phac-aspc.gc.ca).

We know that once you have contracted this virus, it is contagious from 24 hours before you experience symptoms and for seven days after the onset of symptoms. That means there are plenty of opportunities to spread the virus, even when being diligent about prevention.

We all have a responsibility to do our best to limit the transmission of this virus. For more information about H1N1 and how to protect yourself, visit [www.mssociety.ca/en/flu\\_h1n1.htm](http://www.mssociety.ca/en/flu_h1n1.htm). ■

## Treatment update: oral medications



For those receiving and administering treatment for MS, there has long been interest in developing an oral therapy for treating multiple sclerosis.

Now, two drugs used for immune control in other diseases offer

hope of oral therapy options. Encouraging results for both drugs were presented at the American Academy of Neurology meeting in April 2009. Cladribine, a drug used for treatment of leukemia and lymphoma, and fingolimod, used to fight rejection in renal transplantation, have shown exciting results in phase III pivotal trials. As with current therapies, it is anticipated that use of these new medications will be limited to specified indications.

## 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  
internasional federasi



1.866.922.6065

[www.msglobaldinnerparty.ca](http://www.msglobaldinnerparty.ca)

# Partners in ending MS: A&W and Mr. Lube



A&W president and CEO, Paul Hollands (far right) and MS Society staff, Ken Mayhew and Wendy O'Malley, pose with the A&W Root Bear in Winnipeg.

In the movement to end MS, we cannot ignore the generous efforts of corporate sponsors to help us raise awareness and funds in support of MS research. This year saw two great partners, A&W and Mr. Lube, make a place for the MS Society as part of their companies' fundraising traditions.

A&W involved the MS Society in one of their most popular traditions, Cruisin' the Dub. Using the popularity of this event to raise MS awareness, the first ever, nationwide Cruisin' for a Cause event was held this summer, where \$1 from every Teen Burger sold was donated to the MS Society.

Another tradition lived on with Mr. Lube's third annual Founder's Day promotion last spring, where a donation of \$5 was made to the MS Society for every oil change purchased at any of their locations across the country. The event, which coincides with MS Awareness month, was created to recognize Mr. Lube's founder, Cliff Giese, and his contribution to the MS Society in support of wife, who lives with MS. To date, the campaign has raised \$91,000 in support of finding a cure. ■

## endMS anniversary

With over two-thirds of our goal raised, five regional research and training centres launched and a growing number of educational events aimed at MS researchers and trainees, the Multiple Sclerosis Society of Canada proudly marked one year since the launch of its endMS capital campaign.

## endMS summer school

The inaugural session of the endMS Research and Training Network Summer School took place in May at Université de Montréal, bringing together an interdisciplinary group of 32 trainees from across Canada.

These annual endMS summer schools will assist the endMS Research and Training Network in achieving one of its main objectives: fostering collaboration and providing education and training in the field of MS. Esteemed researchers, Drs. Nathalie Arbour, Alexandre Prat and Samuel Ludwin taught the course, which focused on the neuroimmunology and neuropathology of MS.

Events such as the endMS Summer School hold great potential for the future of MS research by bringing together established MS researchers and a new generation of trainees. ■

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

# Notice of Annual Meeting of Members

**N**OTICE IS HEREBY GIVEN that the Annual Meeting of the members of Multiple Sclerosis Society of Canada will be held at the Marriott Bloor Yorkville, 90 Bloor Street East, Toronto, ON. M4W 1A7, on Saturday, November 21, 2009 at 1:00 p.m. (Eastern Standard Time) for the following purposes:

- i) Receiving the report of the members of the National Board of Directors and the financial statements for the year September 1, 2008 to August 31, 2009; together with the report of the auditors thereon;
- ii) Electing members of the National Board of Directors;
- iii) Appointing auditors;

iv) Proposals to amend the by-laws of the MS Society of Canada

*The proposals to amend the by-laws of the corporation arise from the governance review process launched in September 2007. While these by-law changes were approved by the members at the time of the November 2008 AGM, Industry Canada has asked for further technical amendments to secure approval, as required, by the Minister of Industry Canada. It should be noted the current organizational structure of the MS Society of Canada (chapters, divisions and national office) is not affected by these proposed amendments.*

*Copies of the revised by-laws are available in both official languages upon request. For a copy, contact Rosanne Portelance, phone: 416-967-3003, toll free 1-866-922-6065, ext. 3003 or via email at [rosanne.portelance@mssociety.ca](mailto:rosanne.portelance@mssociety.ca)*

v) Such further and other business as may properly be brought before the meeting.

Members who are unable to attend the meeting in person are requested to date and sign the form of proxy below, detach and return it to the head office of the Society, 175 Bloor Street East, Suite 700, North Tower, Toronto, ON M4W 3R8 by Friday, November 6, 2008. Attention: Rosanne Portelance.

DATED at Toronto, Ontario this 23rd day of October 2009.

Ms. Geneviève Brouillette, Secretary-Treasurer



## Multiple Sclerosis Society of Canada Proxy for Annual Meeting of Members, November 21, 2009

The undersigned hereby appoints Daniel Larouche, or failing him, Robert B. Decker or Geneviève Brouillette or \_\_\_\_\_ as proxy with power of substitution, to attend and vote for the undersigned at the Annual Meeting of members to be held Saturday, November 21, 2009 and at any adjournment or adjournments thereof and to vote and otherwise act thereat for and on behalf and in the name of the undersigned in respect of all matters which may come before the meeting in the same manner the undersigned would do if personally present thereat.

DATED this \_\_\_\_\_ day of \_\_\_\_\_ 2009

\_\_\_\_\_  
(Signature of member)

Please date, sign and return this proxy to the Secretary-Treasurer, Multiple Sclerosis Society of Canada, National Office, 175 Bloor Street East, Suite 700, North Tower, Toronto, ON M4W 3R8 by Friday, November 6, 2009. Attention: Rosanne Portelance.

# Finding balance – **body, mind and spirit**

**S**trengthening the powerful connection between mind and body has been shown to improve a person's overall well-being. To encourage this development, the MS Society of Canada is pleased to offer a variety of wellness programs and resources across the country that focus on wellness in support of our clients. Below are a few examples of wellness programs delivered through our division and chapter offices:

## **MS Active Living Day – Manitoba Division, Winnipeg Chapter**

Taking place on October 22, 2009 at the Reh-Fit Centre, this exciting new initiative will allow people living with MS in Winnipeg the opportunity to experience a variety of wellness-oriented activities and education sessions in a comfortable, accessible and supportive setting. It is hoped that the experience will encourage participants to incorporate an active living philosophy into their daily MS management.

## **Couples Getaway – Alberta Division, Edmonton Chapter**

This weekend retreat is geared toward individuals with MS and their partners to get away and experience the natural beauty of Camp He Ho Ha located outside of Edmonton. The getaway aims to educate partners about the challenges of living with MS and help individuals discover a renewed appreciation for their partner in a supportive and relaxed setting. Sessions offered to couples include: Humour and Healing, the Challenges of MS for Couples, as well as income related topics.

## **The School of Movement – Quebec Division, Montreal Chapter**

Facilitated by a trained kinesiologist, this workshop enables people with MS to improve their quality of life with physical activity, as well as encourage a more active lifestyle. Activities include a warm-up/activation period, cooperative games, exercises and experimentation with the various components of walking, including: balance, coordination, strength, endurance and proprioception. The School of Movement is offered at various locations around Montreal in French and English.

For more information on these or other programs offered in your area, please contact your local MS Society of Canada division or chapter office at 1-800-268-7582 or visit [www.mssociety.ca](http://www.mssociety.ca). ■



To share your comment or story, please mail to the attention of Carol Kim or email to [carol.kim@mssociety.ca](mailto:carol.kim@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](http://www.mssociety.ca) or you can call 1-800-268-7582 or email: [info@mssociety.ca](mailto:info@mssociety.ca)



RETURN UNDELIVERABLE  
CANADIAN ADDRESSES TO:  
Multiple Sclerosis Society of Canada  
700 – 175 Bloor St. E.  
Toronto, ON M4W 3R8

Publications  
Mail Agreement  
# 40063383