

A Message from the President



Yves Savoie

Inspiration seems to be the theme of this issue... and it's because of you that we have such good and inspiring news to share.

From the call to action for all Canadians to advocate for better income security for those with MS and their caregivers, to the personal stories of students whose lives have been affected by MS, there's something stirring about each of the updates we're offering you this month.

These are exciting times at the MS Society of Canada and I am thrilled that in this issue we can share information with you about new therapies that give MS patients more choices for their care.

And I'd be remiss if I didn't mention that we're currently reviewing applications from some truly talented researchers to study the potential of chronic cerebrospinal venous insufficiency, or CCVSI as a cause of MS.

Thank you so much for the hope and help you give to the estimated 55,000 to 75,000 Canadians living with MS. We're getting closer to ending MS for good, with your help.

Your support means the world to them, and to the MS Society.

Yves Savoie
President and Chief Executive Officer
Multiple Sclerosis Society of Canada

Increased range of MS therapies offer new hope to patients

MS therapeutic strategies are offering a better range of treatments for patients, reports Dr. Paul O'Connor, director of the MS Clinic at Toronto's St. Michael's Hospital and the MS Society of Canada's national medical and clinical advisor.

More importantly, Dr. O'Connor reports that at least five promising therapies are on the road towards approval, with two that may be just a few years away from being available.

"That will be a major step forward," says Dr. O'Connor. "What we need is a range of therapies so we can select the one best suited to the patient's specific needs."

Five drug therapies are approved in Canada for the treatment of some forms of multiple sclerosis (MS). Four of these medications — Avonex[®], Betaseron[®], Copaxone[®] and Rebif[®] — are immune modulating medications. The fifth — Tysabri[®] — is a selective adhesion molecule inhibitor.

In large clinical trials, all of these drugs have been found to have a direct influence on altering the course of MS. In cases where MS patients have had an inadequate response to, or are unable to tolerate other approved MS therapies, infusion therapy may be called for.

This type of therapy is conducted in a clinic setting, and "seems to reduce the incidence of relapses by two-thirds," says Dr. O'Connor. The availability of new treatments is increasing steadily thanks to continuing research in Canada and throughout the world.

"I think the progress we have made to date in early diagnosis and the ability to modify the progress of the disease holds great hope for the future," he says. **"Therapies that restore quality of life to MS patients are indeed a great step forward."**



Spring Events

This spring there are a host of ways to get involved! You can buy a product from an MS partner and feel good knowing that a portion of your purchase goes to the MS Society. Or you can take advantage of the beautiful weather and join a local MS Walk.



The MS Walk is the Society's largest event fundraiser involving over 70,000 participants and volunteers in more than 160 communities across Canada. So step up, and register to join walkers in your own community. To find out where and when your local walk will take place, go to www.mswalks.ca. Or call 1-888-822-8467.



On May 8th, Mr. Lube will donate \$5 from every job to MS Society of Canada so make your appointment today!



The 2010 Carnation Campaign is just around the corner: May 6th to May 8th. The MS Carnation Campaign is the Society's longest-running fundraiser and thanks to our dedicated team of volunteers, it is also one of our most successful awareness events.

Because women are diagnosed with MS three times as often as men – and because so many Canadians with MS are mothers – the campaign takes place just before Mother's Day each year.

Call (800) 268-7582 to volunteer.

Meet our deserving 2009 scholarship recipients

Any Canadian under 25 who is personally affected by MS, or has a parent with MS, is qualified to receive a post-secondary school scholarship.

"I know the financial burden of the medicine... the financial burden of not being able to work...so this is a way for us to help," says Aaron Solowoniuk of punk rock band Billy Talent. Aaron has lived with MS for more than 10 years, and is the founder and a major supporter of the MS Scholarship Program.

I think when you meet a few of our 2009 scholarship recipients you'll agree that they are more than deserving of their honour.



"Seeing my mother struggle every day inspires me to make a difference in the world."

Akosua Affum, Delta BC
University of Victoria,
Health Info Sciences

"Having a mother with MS has given me a new perspective on life. Since my mother's illness I appreciate the daily challenges facing people with disabilities.

"I compare this education with a new garden. As a garden starts off with unattractive plain soil, so were my views on disabilities, unpleasant and missing the full story.

"Seeing my mother struggle every day inspires me to make a difference in the world. As it takes time, patience, and care for the garden to grow, so I hope my experiences will fertilize my garden of character."



"It has taught our family how to appreciate things that people take for granted."

Jeremy Thiebeau,
Riverview NB
St. Thomas University,
Education

"This disease may be a burden sometimes, but our family tries to look at it in a positive light. It has taught our family how to appreciate things that people take for granted every day, like brushing your teeth, cutting your fingernails, typing, and other physical abilities that my mother has experienced difficulty with.

"Most of all, we look at how it has brought us all closer together as a family."



“I would love to have the opportunity to spread the message that MS isn’t the end of a normal life, just the beginning of a new one.”

David Markus, Surrey BC
Simon Fraser University,
Business/Accounting

“Over the past ten years, my family and I have come to define what multiple sclerosis has come to mean for us.

“Although life changed for all of us, none compared to the changes my father had to go through. After being forced to take medical leave from his company, he did everything in his power to combat his illness. From the daily injections to the rows upon rows of pills in the morning, my father never once complained or let depression take over. This unrelenting optimism has impacted me in a far greater way than MS itself ever did.

“I would love to have the opportunity to spread the message that MS isn’t the end of a normal life, just the beginning of a new one.”



“Multiple Sclerosis is not going to take control of my life. I am.”

Lori Rasmussen, Merritt BC
University of Calgary,
Psychology/Com. Rehab

“On March 25, 2006 I was presented the diagnosis: Multiple Sclerosis. My mind took me back to the familiar story that I had been told as a child. My mother had been studying for final exams at university when she experienced her first attack.

“Four years later, I have accepted my diagnosis.

“I have learned that each day offers a new beginning. Some demand compromise – all are filled with opportunity. William Jennings Bryan once stated, “Destiny is not a matter of chance, it is a matter of choice. It is not a thing to be waited for, it is a thing to be achieved.”

“Multiple sclerosis is not going to take control of my life. I am.”

**“To live with MS,
you need to rely on
the people around you.”**



When Shirley Goldstein was first diagnosed with MS more than 32 years ago, she had no idea what the future would hold. “We thought it was like a death sentence,” recalls her husband Sidney. “We’d never heard of MS. It wasn’t advertised or talked about.”

One of the first things Shirley did after she received her diagnosis was contact the MS Society. She remained involved... as a fundraiser, as a supporter, and as an advocate... until the day she passed away on September 7th, 2009.

While she was proud of being an active, involved member of the MS Society, she was equally as proud of her role as mother to two children, Ellice and Jeffrey, and wife of 50 years to Sidney. She found particular joy in visits from her three grandchildren Mathew, J.P. and Kayla.

“I think that having MS made my family stronger,” said Shirley. “And I learned that to live with MS, you need to be strong – and you have to rely on the people around you.”

Despite her MS, Shirley was determined to enjoy life and always had an active schedule. She would regularly take her scooter and go to the mall to meet friends or family. She also regularly attended Tai Chi classes.

When this brave lady passed away she asked that donations go to the MS Society. We are deeply grateful for the support of the Goldstein family during Shirley’s lifetime, and to Shirley for showing us how to live with grace and dignity in the face of MS.

Multiple Sclerosis Society of Canada



*To support the MS Scholarship Program, contact
Mandy Joseph, Senior Coordinator, National Client Services
at 1-866-922-6065, ext. 2324 or you can email her at
mandy.joseph@mssociety.ca.*

You can make a month-in, month-out difference.

Have you ever considered supporting the MS Society with a monthly gift? It's easy and convenient.

And your consistent support will truly help to bring us closer to a cure.

As a monthly donor, you'll receive:



- A complimentary pen set as a token of our appreciation.
- Invitations to participate in our teleconferences on MS research.
- Newsletter updates keeping you informed about the ongoing fight against MS.
- Personalized name and address labels up to four times a year.
- What's more, you'll help us save the cost of printing and mailing the normal series of donation requests we mail throughout the year.

To learn more, go to www.mssociety.ca/en/give/monthly-giving.htm.

The Need is Now: Advocacy Initiatives on Behalf of Canadians with MS

As every Canadian living with MS knows, having this unpredictable and often progressive disease has a profound impact on a person's ability to earn a living.

Sharon Segal, who lives with MS and is an MS Society volunteer, knows firsthand how hard it can be to make ends meet.



"Here I am," she writes, "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. A couple of years ago, I had to stop working altogether."

Now, Sharon collects long-term disability but rules require that she can't supplement her income. She lives on the edge of poverty... yet does not qualify for other financial assistance. And her story is repeated over and over again throughout Canada.

That's why the MS Society is engaged in advocacy efforts to ensure that people with MS and their families have the opportunity to participate fully in all aspects of life.

Today, the MS Society is asking for governmental action to make a difference:

- Make Employment Insurance sickness benefits more flexible to allow people with MS or their caregivers to work part-time and receive partial benefits.
- Make the Disability Tax Credit a refundable benefit.
- Allow spouses to claim the Caregiver Tax Credit – right now this isn't allowed.

Changes like these will benefit every Canadian living with MS. But we need your help to advocate for the change we need.

JOIN US

Raise your voice to help shape the policies and programs that impact people affected by MS.

Write to your MP and advocate for better income Security for Canadians with MS. We've provided you with a sample letter on our website. If you don't know who to write to, we'll direct you to a parliamentary website where you can find out.

You can also sign up to receive updates, news, and learn about opportunities to take action at

<http://www.mssociety.ca/advocacy>



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