



CANADA

WINTER 2008

Election promise.

Tories to commit \$15 million to major study of neurological diseases.

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MS Answers replaces Ask the Expert

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MS Answers



WWW.MSSOCIETY.CA



Yves Savoie

Message from Yves

We are living in interesting times. The current global financial crisis has become a priority issues for people all over the world. While the effects of the crisis may be less severe in Canada, no one knows yet how deeply we will be affected by these changing winds. Canadians and those living with MS are rightly concerned about what these changes will bring in their own lives.

For the Multiple Sclerosis Society of Canada, there has never been a more important time for us to work diligently and effectively together. Meeting with divisions and chapters across the country, I am consistently reminded of the vital role the MS Society plays in providing services, programs and financial assistance to people and families affected by MS. As an organization, we must take solace in the fact, that we make a difference every day and offer hope to many. Our mission to deliver services to people touched by MS, to fund research and, ultimately, to end MS is only possible through the involvement of volunteers, donors and supporters willing to stay the course.

During the recent Federal election, the MS Society communicated with the leaders of all major parties and with candidates in many ridings to promote priority issues for Canadians with MS. Prime Minister Stephen Harper committed to working with Canada's major neurological health charities, including the MS Society of Canada, to provide \$15 million for a four-year population study of Canadians affected by neurological diseases.

The Society continues to enjoy the support of major corporate partners, among them Bayer, CanWest and Astral Media. Astral Media and CanWest have contributed significant advertising space to make possible the important public launch of the endMS.ca Campaign.

This past September, the largest gathering of MS researchers and clinicians took place in Montreal with more than 5,200 coming together to share information and learn about the rapid advances in the treatment of MS and the exciting pace of research discoveries. This event also helped to mark the 60th anniversary of the MS Society which was founded in Montreal in 1948.

As we navigate a changing world landscape, I am optimistic for the year ahead; the MS Society will remain responsive, prudent and fiscally strong. I commend all of you in working together to make the MS Society the leader it is today.

With your commitment and hard work, we will end MS! ■

Yves Savoie
President and chief executive officer
President, Ontario Division



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The Multiple Sclerosis Society of Canada is on Facebook!

Become a fan so you can share your MS-related photos, videos, news and stories with others. See you online!

endMS.ca
It's time. Give now.

Create your own personal endMS.ca Drive to join the movement to end MS. Go to endMS.ca and click on **DONATE NOW!**

Canadian research gets top exposure

This September, one of the key research highlights at the Montreal 08 World Congress on Treatment and Research in Multiple Sclerosis came from MS Society of Canada-funded researchers Heather Hanwell and Dr. Brenda Banwell. Their studies showed that children later diagnosed with multiple sclerosis had far lower levels of vitamin D than other youngsters. This gives some of the clearest evidence yet of vitamin D insufficiency as a key risk factor in MS. Vitamin D has long been known as a potential risk factor in MS, but these

were the first studies to show the effects in children.

Over 5,000 clinicians, researchers and basic scientists converged in Montreal for the largest conference ever held on MS treatment and research. There were over 45 platform sessions and more than 900 poster presentations covering the most important topics in the field of multiple sclerosis.

For more research highlights from the Montreal 08 World Congress, please visit www.msociety.ca. ■

Paediatric MS attracts pre-med student and Bayer award nod

While many students consider the summer months ideal for rest and relaxation, pre-med student Emily Ursell spent weeks at the Hospital for Sick Children in Toronto gaining research experience in the field of paediatric MS.

Emily is the daughter of Helen Kearns, a generous donor and committed volunteer to the MS Society of Canada. Helen serves as both a foundation director for the MS Scientific Research Foundation (MSSRF) and as vice-chair, Communications for the endMS Campaign Cabinet. With her mother's encouragement and knowledge of the Foundation, Emily, an undergraduate student at McGill University, seized an internship opportunity to work alongside renowned neurologist and researcher Dr. Brenda Banwell in North America's first paediatric MS Clinic.

The paediatric MS Clinic, founded in 1999, has grown exponentially thanks to funds provided by the MS Society through the MSSRF. Under the wing of Dr. Banwell, Emily contributed to the composition of two research papers on issues relating to paediatric MS. Her diligence and contribution to the second paper was recently recognized at the 43rd Canadian Neurological

Sciences Federation Annual Congress held in Victoria, B.C. where Emily received the 2008 Bayer Abstract Prize in MS Research Award for her excellence in original research in the field of multiple sclerosis in Canada.

Bayer Healthcare Pharmaceuticals, a long time supporter of the MS Society, is involved at local, provincial, and national levels. Scholarships like the Bayer MS Research Award are one of the most effective mechanisms that attract scientists early in their careers into MS research. Generous contributions made by corporations like Bayer allows the MS Society and the MSSRF to continue to be a world leader in MS research.

The MS Society of Canada's goal of attracting the next generation of researchers, scientists, and clinicians in order to accelerate research and ultimately end multiple sclerosis is well underway. "I believe that a cure [for MS] is within reach. The field of paediatric MS is valuable to the kids and is increasingly attracting researchers of exceptional caliber. I will strongly consider pursuing paediatric MS when I complete medical school in a few years," Emily concluded. ■

endMS.ca

Campaign gives hope



Like her mother, Andrea Butcher-Milne lives with multiple sclerosis. Being the second generation to be diagnosed with this disease, Andrea fears that her nine year old daughter, Anastasia, might one day receive the same diagnosis. “I know the impact that MS has on the whole family. Not just the person with MS,” explains Andrea.

This fall, for the very first time, Andrea felt a tremendous surge of hope when she heard Anastasia shout excitedly: “Mummy, look at this commercial!

Look, they’re going to end MS! See it can happen, mummy. See!” Every night, Anastasia expressed optimism each time the endMS ad appeared on Astral Media’s Family Channel.

endMS, however, is much more than a television ad. It is a bold new movement that will revolutionize the field of MS research in Canada. Funds raised through this campaign will establish the first endMS Research and Training Network in an effort to increase the pace of discovery and accelerate our drive to end MS. To be a part of this movement, take a moment to visit www.endMS.ca. ■

“Mummy, look at this commercial!
Look, they’re going to end MS! See it can happen, mummy. See!”

Astral Media raises its commitment to end MS

Astral Media Inc. recently announced that it will donate an additional \$2 million worth of advertising space to the Multiple Sclerosis Society of Canada. This amount is added to the original \$1 million commitment made earlier this year and gives the MS Society a unique coast-to-coast platform to raise awareness of one of the most common neurological diseases affecting young Canadians.

“Witnessing the enthusiasm and support that our initial announcement generated amongst

our employees, clients and partners, Astral Media is delighted to further its commitment to the MS Society of Canada,” said Ian Greenberg, president and chief executive officer of Astral Media Inc.

The exposure is unprecedented in the MS Society’s 60-year history. The MS Society is using Astral Media’s platforms to promote its \$60 million endMS research fundraising campaign. The ads direct potential donors and volunteers to www.endMS.ca. ■

Talented, young individuals with backgrounds in various scientific disciplines possess the drive as well as the potential to make an impact in the Canadian MS research community. Providing learning opportunities and financial assistance through the endMS Research and Training Network may help to attract and retain them to the field of multiple sclerosis.

Invitations were extended to select students to attend the ECTRIMS + ACTRIMS + LACTRIMS (European, American and Latin American Councils on Treatment and Research in MS respectively) Montreal 08 World Congress on Treatment and Research in Multiple Sclerosis in September, where the endMS Research and Training Network was publicly launched.

To facilitate each student's participation, a stipend of \$1000 from the endMS Network was offered to 70 attendees in order to cover the cost of the Network's teaching course as well as conference registration and travel expenses. Students who received the stipend included:

- Masters and PhD students currently funded by the MS Society of Canada
- Masters and PhD students involved in MS research but not funded by the MS Society
- Neurology Residents across Canada

In addition, the National MS Society in the U.S. is holding its 1st annual Tykeson Fellows Conference on Multiple Sclerosis from November 4th – 7th 2008, in Chicago. In an effort to increase networking among MS researchers, the endMS Network will organize travel arrangements and provide financial assistance to cover the costs associated with attendance for all post-doctoral fellows who hold MS Society of Canada funding as of November.

At this particular event, the endMS Research and Training Network will sponsor a poster session, and thus support a forum in which fellows can engage in knowledge exchange with the intention of fostering collaborative relationships. ■

Prime Minister Harper promises \$15 million

During the federal election campaign, the Conservative Party of Canada announced plans to work with Canada's major neurological charities and to provide \$15 million for a four-year study of neurological diseases such as multiple sclerosis.

The MS Society of Canada applauds the promise and the specific identification of multiple sclerosis as one of the neurological diseases that Prime Minister Stephen Harper intends to include in this study.

“With the re-election of a Conservative government on October 14, the MS Society looks forward to working with the federal government to ensure the study proceeds as soon as possible,”

said Yves Savoie, president and chief executive officer of the Multiple Sclerosis Society of Canada. “People affected by MS and by other diseases and injuries of the brain and spinal cord need a comprehensive brain strategy, and this study will be a good first step.”

The MS Society is a member of Neurological Health Charities Canada (NHCC) that has been actively advocating for a national brain strategy. NHCC is a collective of organizations that represent people with chronic, often progressive brain diseases, disorders, and injuries in Canada.

Go to our website www.mssociety.ca to read the full story. ■

New disability savings plan in December

Individuals will soon have a new way of saving for the future for people who are severely disabled. By December, banks and other financial institutions will be offering the new Registered Disability Savings Plan (RDSP).

The RDSP was announced in the March 2007 federal budget as a way for families to assist family members who are severely disabled. It is a long-term savings plan that allows funds to be invested tax-free until withdrawal. In addition, the federal government will contribute grants and bonds to registered plans.

For the RDSP to be fully effective, provinces must exempt funds in an RDSP from the calculation of assets for social assistance programs. A number of provinces have taken that step, and the MS Society is working with other governments to persuade them to follow suit.

For more information, go to www.rdsp.com. In addition, in late January 2009, the MS Society will post more information about the RDSP as well as other tax tips at www.mssociety.ca. ■

Join the petition campaign **now!**

Throughout the summer and during the election, the MS Society carried out successful online MS income security advocacy campaigns. This fall, MS Society members and friends have the opportunity to sign a petition which will be delivered directly to Parliament.

The petition continues the request that the federal government make modest changes to current programs that will have significant benefit for people affected by MS.

- Make Employment Insurance sickness benefits more flexible to allow people 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.

To join the petition campaign, contact your MS Society division office by calling 1-800-268-7582 or go to www.mssociety.ca for the e-mail address. ■

Government relations highlights

- Successful online MS income security advocacy campaign reached more than 70 percent of Members of Parliament during summer 2008;
- Continuing advocacy activities resulted in all-party support for key MS income security issues;
- MS Society joined other members of the new Neurological Health Charities Canada seeking a pan-Canadian strategy for brain diseases, disorders and injuries. ■



is now **MS Answers**

In the spring of 2006, we launched *Ask the Expert*. It is an online forum where people with MS, caregivers, and others affected by MS can openly discuss MS related issues and obtain accurate answers to questions from subject experts that include neurologists, MS nurses, psychiatrists as well as other professionals in a range of disciplines.

Since its launch, the website has received on average three questions each day, which now total over 300 searchable questions in the current database. Interest for timely, credible, and relevant information about MS remains strong. People appreciate the ability to submit questions electronically and anonymously in either French or English.

This September, our *Ask the Expert* website was renamed *MS Answers*. The same quality, credible information can be found on the refreshed website with the addition of a new client-focused educational feature providing topic specific e-bulletins, which are uploaded to the site regularly. The first series of e-bulletins focuses on the topic of pain and MS, which is sent by e-mail to current subscribers. The e-bulletins are accessible through the *MS Answers* website as well.

Users of *MS Answers* will be requested to complete a profile in order to receive timely information by e-mail with options to receive the message daily or weekly. They will also be surveyed as part of an ongoing effort to continuously improve the resource and to assist in the development of new topics and features for the website.

Visit www.MSanswers.ca to get the answers to your questions. ■

Youths get our support

“Don’t let something like MS get in the way of following your dreams...” were the encouraging and inspirational words of Aaron Solowoniuk via a pre-recorded video message that welcomed 26 youths at the second annual Summer Camp Adventure. Aaron, who has MS, is the drummer for prolific Canadian rock band Billy Talent, a major supporter of the MS Society’s Scholarship Program.

Children and teens from across Canada and the United States met for a week-long adventure in August at the Easter Seals Camp Merrywood in Perth, Ontario. Activities were fully accessible and designed to accommodate a wide range of interests and skill sets. The MS Society provided a fun and supportive environment for campers with collaboration from Easter Seals and The Hospital for Sick Children and the support of Billy Talent, the RBC Foundation, and an anonymous family foundation.

In addition to the Summer Camp Adventure, we were proud to offer a second year of scholarship grants in the amount of \$80,000 to 80 Canadian youths affected by MS.

Photos from this year’s camp and a list of scholarship winners are available at www.mssociety.ca. If you would like more information about the camp, paediatric MS, or resources available through the Young Persons with MS Network please call: 1-800-922-6065 or email: kidswithms@mssociety.ca. ■

By-laws propose change to size of national board of directors

A governance review process launched in September 2007 resulted in recommendations for changes to the Society’s national by-laws. The revised by-laws will be considered at the annual general meeting on November 22, 2008.

The most significant change is the reduction in the size of the National Board of Directors while retaining the balance of divisional delegates and members-at-large. The reduction in the size of the board will take place over a one-year transitional period. Another amendment will be the change of the fiscal year end from August 31st to December 31st. It should be noted the current organizational structure of the MS Society of Canada (chapters, divisions and national office) would be maintained.

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

Jazzing up dinner

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



Every year Shannon Smith of Toronto, Ontario themes her MS Global Dinner Party - this year's event was a Bob Fosse inspired night.

No one knew the theme until they arrived at the house - at which point each guest picked out a top hat, fishnet gloves, a sparkle bow tie and flirty fake eyelashes. A professional dance instructor, Nadine from Pulse Dance Works donated half of her fees to the cause and taught the ladies the Broadway dance to "Hey Big Spender" as everyone embraced the theme with open arms and jazz hands. Girlish games and prizes kept the donations, laughs and the event going until the wee hours of the morning. The night was filled with delicious food, drinks, dancing, fundraising and most of all fun!

Thanks to the support of her friends and family Shannon was able to raise twice the amount of her fundraising goal!

"It was a wonderful night for an incredible cause and I am happy to have been a part of the 2008 Global Dinner Party fundraising event," said Shannon Smith, Toronto, Ontario.

Get together with your friends, family, colleagues and community. Join Canada and 13 other countries worldwide that participate in the MS Global Dinner Party on the last Saturday in February to support the fight to end MS.

To register your event or for more information, visit www.msglobaldinnerparty.ca or call 1-866-922-6065. ■

It's time for the 'new' MS Walk.



The MS Society has stepped up marketing efforts for its largest fundraiser and announced last spring that it is renaming Super Cities WALK for MS to MS Walk. The new name, logo, tagline, colour scheme, public service announcements, and MS Walk activities will reflect a bold direction that aims to attract and empower event participants. Our hope is that MS Walk will engage more people in our mission,

increase awareness about the disease, and raise more funds for research, services, education and advocacy. It's about individual action and collective movement to end MS.

MS Walk draws over 70,000 participants and volunteers in more than 160 communities across Canada in the spring and early fall. You can sign-up for MS Walk online as a team or an individual, as well as learn about the latest resources and information at www.mswalks.ca. ■



To share your comment or story, please mail to the attention of Angeline Mau or e-mail 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 e-mail: info@mssociety.ca

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