



CANADA

AUTUMN 2008

endMS.ca

It's time. Give now.

3

Free education session
Living with MS Day

Montréal  08
SCLÉROSE EN PLAQUES MULTIPLE SCLEROSIS

7

A treatment is born
Phases of clinical trials



 Multiple Sclerosis Society of Canada

WWW.MSSOCIETY.CA

Annual meeting of members, see proxy inside.



Yves Savoie

Message from Yves

Dear friends:

Welcome to this important issue of MS Canada which marks the official launch of the **endMS** campaign. In the past few decades, Canadian researchers have made incredible advances in the knowledge and treatment of multiple sclerosis. Canada's leadership in the global MS research enterprise is acknowledged broadly. However, as top MS researchers retire, accelerated progress toward the end of MS is at risk. The need for action is real and urgent.

endMS is a bold new movement that will revolutionize the field of MS research in Canada and consolidate Canada's global leadership in MS research. Work has already begun in raising \$60 million to recruit, train, support, and retain the next generation of MS researchers in Canada, and to accelerate their research activities to find a cure and improved treatments for MS. The flagship of this investment is the new \$20 million endMS Research and Training Network. The Network will secure Canada's position as the premier destination in the world to train for and pursue a career in MS research.

Members of the campaign cabinet and regional cabinets across the country are working vigorously to meet our fundraising goal. Astral Media and CanWest Global Communications have joined the

endMS.ca movement as media partners; thanks to their efforts, the movement to end MS is growing everyday. You can be part of this movement as well. Take a moment to visit endMS.ca to find out how.

The endMS Research and Training Network, has among its goals, to expand opportunities for the rapid translation of research discoveries into benefits to people with MS. Clinical trials are an important way to translate basic discoveries into improved treatments. You can learn more about the different phases of clinical trials on page 6. Also, in the spirit of making research discoveries relevant to people affected by MS, the MS International Federation and the MS Society of Canada will host a free one-day international event in Montreal on September 16. It will provide a unique opportunity to hear from leading researchers about current issues in MS research, care, and treatment ranging from managing progressive MS to caregiving.

I thank you warmly for the important role you play in the movement to end MS! ■

Sincerely,

Yves Savoie
President and chief executive officer
President, Ontario Division



MS Canada, Autumn 2008

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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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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!



MS Canada is available online!
www.mssociety.ca

Living with MS Day:



Global Perspectives on Current Issues

Montreal will host the 2008 ACTRIMS/ECTRIMS/LACTRIMS meeting before an international MS community this fall. Before this prestigious scientific meeting, a valuable education session will be presented – the Living with MS Day for people with multiple sclerosis through the partnership of the MS Society of Canada and the Multiple Sclerosis International Federation.

This free education event will include educational presentations from leading experts from around the world, introduced by people with MS. Topics include: how MS starts, early treatment, cognition and emotions, managing progressive MS and caregiving. Questions from the audience will be

encouraged and a complimentary lunch will be provided.

Date: Tuesday, September 16th, 2008

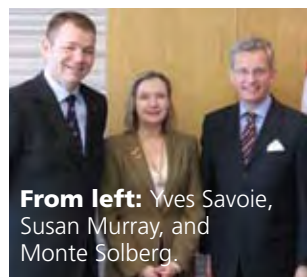
Location: Montreal Sheraton Hotel
1201, boul. René-Lévesque Ouest /
West, Montréal, Québec, H3B 2L7

Time: 9:00am to 5:00pm

To register, please email montreal08@msif.org, call 514-849-7591 or 1-800-268-7582 (for Quebec residents only). For further information, please visit www.montreal08.net ■



Income improvements atop Parliament Hill



From left: Yves Savoie, Susan Murray, and Monte Solberg.

The MS Society of Canada is asking the federal government for policy changes that would allow more people with MS to stay at work and remain part of their communities.

“These modest improvements would help people affected by MS, their families and caregivers gain the income for essential needs. Many people with MS are no longer able to work and family members who are caregivers often have to cut back on their own jobs to provide needed care,” said Lynn Hunter, chair, National Government Relations Committee.

In March and again in June, MS Society volunteers and staff met with key politicians including Monte Solberg, Minister of Human Resources and Social Development, to ask for immediate action. In June, the MS Society also launched an online advocacy campaign to enlist MS Society members and friends to send a message to their own MPs in support of MS Society recommendations.

The MS Society is asking the federal government for three important changes: make Employment Insurance sickness benefits more flexible to allow people to work part-time and receive partial benefits; make the Disability Tax Credit refundable; and allow spouses to claim the Caregiver Tax Credit. ■

2008 Research Teleconference

The national scientific and clinical advisor of the MS Society, Dr. Paul O'Connor, was the guest speaker during the 2008 MS Research Teleconference. On April 3, listeners from across the country had the opportunity to hear about the latest on MS research and ask questions

answered by one of Canada's leading neurologists.

You can listen to the audio recording of the teleconference at www.mssociety.ca/en/research. For a copy of the audio CD, contact 1-866-922-6065 ext 2217. ■

endMS.ca A new campaign is launched

Canadian MS researchers have made incredible advances in the knowledge and treatment of multiple sclerosis; from the advancement of MRI technologies to the examination of childhood MS, Canadians have been at the forefront of MS research.

The fact is, however, that as MS researchers near retirement and a limited number of young scientists make MS their lifelong cause, progress toward discovery in the field of MS is at risk. This urgent need was recognized and the endMS.ca campaign was born.

What is endMS.ca?

The endMS.ca campaign is raising \$60 million over five years to support MS research in Canada. Its flagship investment is a new \$20 million entity called the endMS Research and Training Network, which is intended to recruit, train, support, and retain the next generation of MS researchers in Canada.

The first of its kind in the world, the endMS Research and Training Network is designed to increase the pace of discovery so that a cure can be found in the shortest time possible.

Funds raised through the endMS.ca campaign represent an immediate, dedicated investment to advance Canada's leadership position in MS research. The premise of the campaign uses a simple formula:



The best MS researchers + more MS research = an accelerated end to MS + better quality of life

As you read this, three new awards are being finalized to attract and retain students to the field of MS research. These awards are available for undergraduate, MD, PhD, and post-doctoral students dedicated to MS research. More initiatives are planned as the endMS Research and Training Network evolves.

Fundraising

In its early, "quiet phase" the endMS Campaign has raised well over \$20 million towards the \$60 million goal. High profile donations include a \$1 million gift from honorary endMS capital campaign chair and Scotiabank CEO Rick Waugh and his wife Lynne; and a Government of Alberta commitment of \$1.5 million. The MS Society will raise the remaining \$40 million in large part thanks to the commitment and leadership of an extraordinary campaign cabinet chaired by Sandy Aird.

Watch and listen for our ads

September 2008 marks the official launch of the campaign. Its launch coincides with a major shift in positioning for the MS Society of Canada. The term "endMS" deliberately enforces the fact that as an organization, we are committed to nothing less than the extinction of the disease. Of course, the provision of services, improving public education, and government advocacy remain key pillars of our day-to-day operations.

Another step closer to ending MS

Dr. Samuel Weiss, PhD, scientist and professor of Cell Biology & Anatomy and Pharmacology & Therapeutics at the University of Calgary received this year's prestigious Gairdner International Award. Weiss was nominated for discovering neural stem cells in the adult brain. This discovery has enabled scientists to investigate how to stimulate these cells to heal the brain. Currently, Weiss is researching brain cell regeneration in brain

diseases and spinal cord injuries by focusing on multiple sclerosis and stroke. It is expected that this work will provide answers on how therapies can be developed to repair damage to the nervous system caused by MS.

The MS Society of Canada congratulates Dr. Samuel Weiss on joining the ranks of other distinguished scientists from around the world as a Gairdner awardee. ■

A series of compelling ads that highlight the vision of ending MS can be seen and heard across the country. On the occasion of the launch of the endMS.ca campaign, two major media companies have offered their help:

- Astral Media has donated \$1 million worth of advertising through its television, outdoor, radio, and online properties.
- CanWest Global will publicize the endMS campaign through its television, newspaper, and online properties.

To get a feel for how we are articulating the endMS dream, visit www.endMS.ca. The website has many interactive tools such as blogs, photo and video uploads, and a function for you to share your own MS story, too.

How can you help?

Ending MS will require the attention of the entire MS community – from researchers, to donors, to volunteers, and members. Visit www.endMS.ca to learn more about and to make your contribution toward this bold and exciting campaign. ■



Molecular genetics and stem cells get financial boost

Recently, the grants review and medical advisory committees of the MS Society and the MS Scientific Research Foundation met and recommended \$9.4 million in new funding, allocated for 17 operating grants and 51 research scholarships. The funded applications represent the most scientifically excellent and MS-relevant research proposals received.

This year's highlights are:

- **Molecular genetics – led by Professor George Ebers, Oxford University and Dr. A. Dessa Sadovnick, University of BC.** The DNA in a small known region of susceptibility will be sequenced in individuals for comprehensive analysis. The investigators believe this will bring them much closer to unraveling the underlying causes of MS.
- **Stem cell injection to promote repair – led by Dr. Charles Tator, Toronto Western Hospital.** This innovative study will examine new techniques to deliver adult stem cells to mice that have experienced demyelination or have an MS-like disease. Researchers hope the procedure will promote repair of damaged myelin.

The MS Society has proudly funded over \$117 million in research in its 60 years of service. ■

A treatment is born The phases of clinical trials

Research moves through several distinct phases before a finding in the lab becomes a treatment in the marketplace. In all phases, the analysis of data after the closing date of the trial is extensive and can take many months

before the trial can proceed to the next phase. While this process can take many years, it is essential in order to ensure that treatments available to people with MS are safe and effective.

Preclinical study

Researchers conduct studies in the lab. Should a strong rationale and methodology for experiments with human subjects emerge, then the preclinical study will move to a Phase I study.

1

Phase I trials

This phase determines safety of the MS treatment. In a small number of healthy volunteers or persons with MS, the clinical trial investigators try to understand how the human body reacts to the treatment under study.

2

Phase II trials

If the treatment is proven to be safe, studies begin to monitor the effectiveness of the treatment in people with MS. These studies can last anywhere from several months to several years, and involve larger numbers of people. The study is controlled, that is, the drug is compared with the standard treatment, or the placebo*.

3

Phase III trials

If an MS treatment is proven to be effective, a study is conducted involving hundreds of people. These multi-centre studies can take place in several countries, over several years. They enable investigators to better clarify the effectiveness of the therapy, and possible side effects.

4

Health Canada approval

Phase I, II, and III trials are necessary for approval from Health Canada. Approval from Health Canada typically takes over a year. Once approval is granted, the treatment is accessible by prescription.

5

Phase IV trials involve treatments that have been approved by Health Canada and are used by the public. These trials seek to gather more information about proven treatments so that they can be used more effectively. At this stage researchers collect detailed information related to dosage, risk factors, and achieving the best results with the treatment.

6

While a potential treatment's journey from laboratory to marketplace can often take many years, each study completed helps to increase our understanding of multiple sclerosis. Not only does this ultimately result in improved quality of life through more treatments and

a greater range of symptom management strategies, but it brings us closer, step by step, to ending MS. ■

Placebo - Inactive substance that has no treatment value. In clinical trials, experimental treatments often are compared with placebos to assess the treatment's effectiveness.

Multiple Sclerosis Society of Canada

Notice of Annual Meeting of Members

NOTICE 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 22, 2008 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, 2007 to August 31, 2008; together with the report of the auditors thereon;
- ii) Electing members of the National Board of Directors;
- iii) Appointing auditors;
- iv) Considering changes to the by-laws, including changes to the size of the National Board of Directors. (Details will be provided in the issue of MS Canada to be mailed in late October 2008.)
- 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 7th, 2008. Attention: Rosanne Portelance.

DATED at Toronto, Ontario this 18th day of August 2008.
Ms. Geneviève Brouillette, Secretary-Treasurer



Multiple Sclerosis Society of Canada Proxy for Annual Meeting of Members, November 22, 2008

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 22, 2008 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 _____ 2008

(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 07, 2008. Attention: Rosanne Portelance.



Media awards winners announced

The Multiple Sclerosis Society of Canada recently announced the winners of the annual John Alexander Media Awards. The awards recognize excellence in print and broadcast journalism.

Celia Milne received the print award for an examination of how MS researchers are trying to find the answers to why MS is more prevalent among women. The article was published in the Globe and Mail in July 2007.

Larry Read is recognized for *The Faces of MS*, a broadcast story about the Faces of MS: Public Education Project, an exhibit about Kamloops, B.C. residents affected by multiple sclerosis. CFJC News broadcasted the story in November 2007.

Entries for the 2008 awards are now being accepted. Submission deadline is on January 31, 2009. For more information, visit www.mssociety.ca/en/awards.htm. ■

Vitamin D study is applauded

The MS Society welcomed the news that the federal government will launch a study this fall investigating claims that a lack of vitamin D might be linked to the development of MS, cancer and heart disease, among other serious illnesses. In a letter to Health Canada, Lynn Hunter, Chair, National Government Relations Committee, offered assistance from the MS Society as the work moves forward. ■

Neurological health charities working together

The MS Society is a founding member of a new coalition, Neurological Health Charities Canada, which is focused on two vital issues: first, to convince the federal government to fund a definitive study on the extent and impact of neurological diseases and injuries and second, to urge provincial governments to include neurological diseases and injuries in their chronic disease strategies.

The group launched in June with a meeting with Minister of Health Tony Clement and a lunch reception for MPs on Parliament Hill. ■



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



Upcoming events

Ride of your life!

There is still time to register for a phenomenal ride through scenic and often spectacular parts of the country. You can be among the 10,000 cyclists who are expected to participate in the 22 RONA MS Bike Tours taking place this summer across Canada. Everything you need during the one or two-day tour will be provided including food, entertainment, road support crews, accommodations for overnight tours, and exciting incentives for your fundraising efforts.

Be part of the thrill and challenge yourself to complete your best ride ever! To find a tour that suits you, visit www.msbiketours.com or call 1-800-268-7582. ■

All booked up!



One of Canada's oldest and best literacy fundraising programs for children returns this fall. Your child may be one of 40,000 students who will participate in MS

Read-A-Thon, a program that has long been a tradition for schools to encourage academic and recreational literacy. You can empower your child to read books, magazines and newspaper articles so that more than \$1.2 million is raised for multiple sclerosis while your child develops reading skills. In fact, more than 1 million books will be read by students in 900 schools in Canada this year! And as always, there are fun prizes for them to earn as well!

Look for your child's MS Read-A-Thon student kit to get started! ■