



# CANADA

Multiple Sclerosis Society of Canada



## **A change of heart**

**Drug coverage expanded in  
Newfoundland and Labrador**

**Pilot program  
on progressive MS**

**Caring for  
young caregivers**



## Message from Yves

Over the past few months, I've been able to travel from coast-to-coast to meet clients, staff, researchers and others who are passionately involved in the MS Society.

Most of my travel revolved around the MS Society's strategic planning process, the first national effort in a number of years. What impressed me, wherever I travelled and whoever I met, was the exceptional commitment to make a great organization even better.

The first phase of the strategic planning process involved gathering broad input on the future of the Society through 19 consultations. The next task is to consolidate the information and to develop a first draft of strategic directions and objectives. Division and chapter boards of directors will have the opportunity to validate the first draft in September and October. The plan is to use the new strategic plan to guide our work beginning in September 2008.

My travels also allowed me to meet people who are

moving our cause forward and to see the Society's work in action. One example is Margaret Rideout, a remarkable woman with MS who was the public face of our Atlantic Division's successful campaign to improve drug coverage to Newfoundland and Labrador. My congratulations to Margaret and, as well, to Sarah Cowan, director of government relations and marketing communications, Sean Kirby, vice-chair of Atlantic Division, and all others who were involved. More on page 3.

In addition, the MS Society and related MS Scientific Research Foundation recently approved a number of research initiatives (page 5) including a large multi-centre study of minocycline. For the first time, we've funded a clinical trial of a potential drug therapy, the result of previous MS Society-supported research. The Canadian Network of MS Clinics, many of which are supported by the MS Society, will play a key role in the study.

It has been an extraordinarily busy and productive time for the MS Society. It is clear to me that we are making progress on all fronts and our resolve to end MS has never been stronger. ■

Best wishes,

Yves Savoie  
President and Chief Executive  
President, Ontario Division



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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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**Front Cover:** Atlantic Division representatives Sarah Cowan, director, government relations and marketing communications, and Sean Kirby, vice chair, hold up a Valentine's treat presented to Premier Danny Williams as part of their campaign to improve drug coverage in Newfoundland and Labrador.

## Next issue focus

In the next *MS Canada: 2007 Fundraising Celebration!*

The MS Society is in full events mode this summer and fall, and with that, the continued success of fundraising efforts is impacting client services, research and government relations work across the country. You'll read about those who have walked, cycled, read or sold carnations in inspired efforts to raise funds to end MS. ■



**An Easter "Hop To It" bunny was delivered to the Minister of Health and Community Services as part of the MS Society's intense campaign to improve drug coverage in Newfoundland and Labrador.**

## Improved drug coverage in Newfoundland and Labrador

The province of Newfoundland and Labrador holds the distinction of being one of the most kind, caring and nurturing places in the country, perhaps even in the world. Yet, until recently, it also held the unfortunate distinction of being the only province in Canada that did not provide universal coverage of drugs to treat multiple sclerosis.

While the provincial government covered the drug costs of people on social assistance, seniors and those in long-term care, the lack of universal coverage left an estimated 600 people with MS without access to their drugs. Many others were forced to go on social assistance, live in poverty or split their families in order to qualify for drug coverage.

A proactive strategy to force change was developed and endorsed by the Atlantic Division board in November 2006. "Advocacy Packages" which provided template letters, petitions and tips on working with the media, were sent to every member in the province. People were encouraged to book meetings with their Members of the House of

Assembly and send letters to the editor of their local newspaper.

To keep the interest of both the media and the public, the government relations team made use of significant calendar dates to highlight the issue. At Christmas, a news release proclaimed "Province gives lump of coal to MS patients"; on Valentine's Day, Society representatives presented Premier Danny Williams with a giant heart-shaped cookie iced with the phrase "Premier, Have a Heart"; and for Easter, they met with the Minister of Health and Community Services to present him with a giant Easter bunny wearing a t-shirt that said "Premier, Hop to it!"

"The message remained the same, but the delivery was lighthearted and non-confrontational," says Sean Kirby, vice chair of Atlantic Division. "We were clear that we wanted to work with the government."

In the end, the MS Society lobbied successfully for people with MS as well as for all people in Newfoundland and Labrador in need of any catastrophic drug.

On April 23rd, the government announced a significant expansion to the Newfoundland and Labrador Prescription Drug Program. The expansion is designed to assist people based on the cost of their drugs and their ability to pay. While people on social assistance will continue to have 100% of their drug costs covered, others will pay for a portion of their drugs based on a percentage of income. More information on how the program works is available at:

<http://www.releases.gov.nl.ca/releases/2007/health/0423n01.htm>.

The program expansion and improved accessibility for MS therapies will begin in October 2007.

For more information, go to the Atlantic Division's website at [www.mssociety.ca/atlantic](http://www.mssociety.ca/atlantic). ■

## Young caregivers

Generally we think of caregivers as adults between the ages of 30 and 60. Although this age range makes up the majority of MS caregivers, we are becoming increasingly aware of caregivers under the age of 18.

Caregiving responsibilities taken on by children and teens vary greatly from household chores to assisting with activities

of daily living such as bathing, toileting and eating.

Increased responsibilities at home can take a toll on school work, extra-curricular activities and socialization.\* Similar to adult caregivers, young caregivers may feel guilty taking time for themselves. For some, this may mean not participating in an after school club or sports team or declining an offer to 'hang-out' with friends after school.

*continued on page 6*

\*Young Caregivers in the U.S., Findings from a National Survey, Sept 2005. National Alliance for Caregiving in collaboration with United Hospital Fund.

## MS Society staff and board members donate to the mission



MS Society staff Lynn Laccohee, right, with volunteer Janet MacNeil at the closing ceremony of the Toronto Chapter, Ontario Division, and National Office Leadership Circle. Janet spoke about her MS diagnosis and her involvement with the Society.

The staff and volunteer board members of the MS Society of Canada are dedicated to realizing our mission through their commitment of time and talents.

Through an exclusive recognition club called the Leadership Circle (or Ensemble.stopSP in Quebec), staff and volunteer board members have the opportunity to financially contribute to our work. This sends a powerful message to our clients,

our donors and the community at large that we believe in our mission.

The Leadership Circle originated in Alberta and has now spread across Canada as staff and volunteers embrace the opportunity to support our mission in an additional way. We are very proud of the fact that from coast-to-coast, every division and the national office has a Leadership Circle campaign. Many of these campaigns boast 100% participation (or close to it) from staff and board members. This level of participation is tremendous and almost unheard of in the non-profit industry. Yves Savoie, president and chief executive of the MS Society of Canada comments:

*“Of the organizations I have been proud to serve, as both a volunteer and an employee, I have never witnessed the level of staff support at the MS Society of Canada... It is inspiring and Canadians with MS should know that they are supported by staff and leadership volunteers who truly believe in this wonderful organization and are working hard to end MS.” ■*

## Carnation Campaign kick off at Parliament Hill



We are pleased to announce that the 2007 MS Carnation Campaign launch held last May 9 on Parliament Hill was a success. Members of Parliament wore red

carnations on their lapels to kick off the annual fundraising event.

Ted Menzies (MacLeod, CPC), Dr. Carolyn Bennett, (St. Paul's, Liberal), Christiane Gagnon (Québec, Bloc), Peter Stoffer (Sackville-Eastern Shore, NDP) and MS Society representatives pinned carnation boutonnieres to MPs as they entered the House of Commons. Mr. Menzies delivered a statement about MS Awareness Month and the significance of the Carnation Campaign before Question Period.

Last year's top Ottawa-area MS Read-A-Thon students, Nichole Johnston from Roland Michener Public School, and Alexa Deeble from D. Audrey Moodie Intermediate School also participated in marking the occasion. ■

## Russell Peters supports the MS Society



Internationally-known Canadian comedian Russell Peters supported the fight to end MS at a recent Toronto show. “An Evening with Russell Peters and Friends” was a MySpace Secret Standup comedy event held at the Diesel Playhouse in downtown Toronto. The MS Society was invited to collect donations from attendees, resulting in a very enthusiastic response and \$1,000 raised.

All performers wore red MS Bands of Hope wristbands, and each made a personal appeal for the audience to donate to the MS Society before leaving the theatre. Russell has a personal connection to MS, as his sister-in-law lives with the disease.

MS Society volunteers also collected \$600 in donations at Russell's two Air Canada Centre shows in mid-June. The MS Society's partnership with the MySpace Secret Standup show also resulted in the creation of an MS Society MySpace page at <http://www.myspace.com/mssocietycanada>. ■

## RESEARCH IN BRIEF

### \$15.8 million in research funding approved



**Dr. Luanne Metz from the University of Calgary is leading a study into minocycline, a possible treatment for the earliest form of MS.**

Annually, the Grants Review and Medical Advisory Committees of the MS Society are charged with identifying the most scientifically excellent and MS-relevant research proposals that are submitted for funding. Recently these committees met and recommended \$15.8 million in new funding, allocated for 35 operating grants and 70 research scholarships.

Among the highlights:

- **A randomized, controlled trial of minocycline in Clinically Isolated Syndrome (CIS).** For many people, CIS – the first onset of an MS-like symptom – represents the earliest stage of their living with MS. Researchers believe a new treatment option for this phase might be minocycline, a well-tolerated, oral, acne medication that has shown anti-inflammatory properties in animal models of MS. The study will involve 200 participants from across Canada and Dr. Luanne Metz from the University of Calgary is the lead investigator.
- **An extension of the bone marrow transplant project.** Funded since 2000, this second phase will focus on

monitoring and studying the long term outcomes following chemotherapy and bone marrow transplants in 15 individuals with progressive MS. Dr. Mark Freedman and Dr. Harold Atkins from the Ottawa Hospital are leading this study. Some participants have experienced increased mobility & function following transplantation and researchers will focus on the mechanisms associated with this improvement.

- **An extension of the genetic epidemiology of MS project, led by Dr. Dessa A. Sadovnick and Prof. George Ebers.** The study of genetics is a crucial piece of the MS puzzle. Utilizing one of the largest data sets of families with MS, researchers will continue to probe for insights in areas such as: the role of gender, maternal effects, the impact of genetics on disease outcome, the changing prevalence of MS and issues in primary progressive MS.

Dr. William J. McIlroy, national medical advisor for the MS Society comments on the recent funding approvals: “The MS Society’s grants program is funding an excellent mix of research looking at immunology, virology, MRI, health effects and myelin repair. Additionally, the MS Society and related MS Scientific Research Foundation continue to fund some of the world’s most cutting edge research.” ■

### Quality of life data examined

Two MS-related articles published in a recent edition of the *Canadian Journal of Neurological Sciences* highlights new data regarding quality of life when living with MS. Compared to the average Canadian, people with MS:

- Consult a medical doctor nearly twice as frequently;
- Are admitted overnight to a hospital 2.5 times more frequently;
- Consult mental health professionals 2.6 times more frequently.

In an accompanying editorial in the journal, Dr. Luanne Metz, a professor of clinical neurosciences at the University of Calgary and a member of one of the MS Society’s research review committees, urged that barriers to appropriate

treatment and care for people with MS be removed.

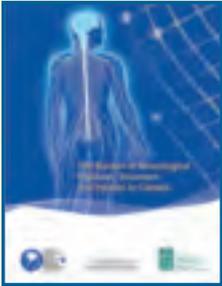
The studies also highlighted other societal costs:

- Employment rates in MS populations are lower than 50 per cent.
- A caregiver is needed by half of all people with MS.
- Over 70 per cent of people with MS need assistance with one or more tasks.

The two studies were led by Dr. Sheri Pohar from the Institute of Health Economics in Edmonton, and by Ms. Wilma Hopman and Dr. Don Brunet from Queen's University in Kingston. The Hopman & Brunet study was funded by the MS Society of Canada. ■

## GOVERNMENT RELATIONS & SOCIAL ACTION

### Report zeros in on cost impact of neurological diseases, injuries



The report *The Burden of Neurological Diseases, Disorders and Injuries in Canada* points out that neurological conditions have a significant economic impact, costing an estimated \$8.8 billion a year. It was released in June at the annual meeting of the Canadian Neurological Sciences Federation

(CNSF) in Edmonton.

In terms of the impact of indirect costs, multiple sclerosis was third following only stroke and Alzheimer's disease. The report looks at both direct and indirect costs of 11 conditions. Direct costs include money spent on hospital care, physician care and drugs. Indirect costs represent the dollar value of productivity lost due to long-term illness or premature death.

"The Multiple Sclerosis Society of Canada welcomes this report which shows that neurological diseases and injuries have a significant cost impact. In fact, it is likely the direct and indirect cost impact of MS is even higher than the

almost \$1 billion indicated since there were limitations on the data collected," said Deanna Groetzinger, vice-president, government relations and policy. "The report will be very helpful in our work with governments and donors and valuable in identifying information gaps to be pursued in future studies."

The report is available at [www.msociety.ca](http://www.msociety.ca) with key search words "cost impact" or at the Canadian Institute for Health Information (CIHI) website at [www.cihi.ca](http://www.cihi.ca).

### Canadians with Disabilities Act: Work proceeds gradually

During meetings in recent months with federal politicians, the MS Society explored what a Canadians with Disabilities Act could mean to people with MS. The MS Society has told officials that people with disabilities must have the opportunity to provide meaningful input into any legislation.

The major political parties have promised to bring in some type of disability act. Prime Minister Stephen Harper repeated the promise earlier this year and made specific reference to a Canadians with Disabilities Act. ■

## Young caregivers *continued from page 3*

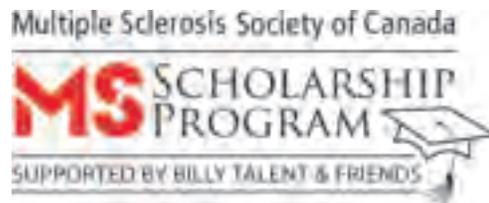
In some cases, the care recipient, adult caregiver or other family members may be unaware of the child's decision not to participate.

If your child provides care for you, another family member or a close friend, we encourage you to check in with them to see how they are coping. Here are a few suggestions for you and your young caregiver:

- Maintain open lines of communication; make sure the young caregiver has an opportunity to express their feelings about caregiving or anything else they may want to talk about.
- Encourage your young caregiver to bring friends home after school or on weekends if they are needed at home. This will also help educate their friends about MS.

- Let the young caregiver's teacher know about their roles and responsibilities at home. They will be more likely to make alternate plans or extend deadlines.
- Learn the warning signs of caregiver burn-out. Young caregivers need breaks to rejuvenate and re-energize as well.
- Ensure young caregivers have plenty of time to study and participate in extracurricular activities. Remember that your young caregiver is still just a kid so let them (and you) enjoy their youthfulness!

Please contact the MS Society of Canada at 1-800-268-7582 to learn about resources available in your area. For more information on caregiving, contact Jennifer Eades at [Jennifer.Eades@msociety.ca](mailto:Jennifer.Eades@msociety.ca) or 1-800-224-6309. ■



## Scholarship recipients selected

The selection process for the inaugural MS Society of Canada Scholarship Program, supported by Billy Talent and Friends, is complete and 61 students whose lives have been affected by MS will receive financial assistance for the 2007/08 academic year. The full list of students receiving scholarships, as well as their stories, will be available in the coming weeks at [www.mssociety.ca](http://www.mssociety.ca).

In the end, 141 applications were received and \$60,000 in scholarships was disbursed. Amounts ranged between \$500 and \$1000 depending on full or part-time status.

The scholarship program became possible when Aaron Solowoniuk, drummer for Juno award-winning punk rock band Billy Talent, came to the MS Society looking for a creative way to use his influence to help youth affected by MS. Aaron himself was diagnosed with MS when he was 22.

Aaron enlisted the support of Warner Music Canada, which donated \$50,000 based on first-week CD sales of

Billy Talent II. Billy Talent also hosted a benefit concert and donated an autographed drumhead for an eBay auction to raise money for the program.

“I’m thrilled that it’s been so successful in its first year, and am confident that this program will make a difference in the lives of young people facing the challenges of this disease,” says Aaron.

Jon Temme, vice president of client services and research for the MS Society of Canada says: “We are thrilled with the results of the scholarship program. I give full credit to Aaron for his resolve and ability to get others involved. We now can respond in a very tangible way to a need that has long been felt by many.”

The next scholarship competition will accept applications between January 15 and April 15, 2008 with funds being distributed in August, 2008. ■

## First-ever progressive MS program piloted in Manitoba

The MS Society prides itself on providing programming to enhance the quality of life for people living with MS. To do this, we must first listen to the needs of our clients and determine what specific kinds of programs and services best meet their requirements.

Members living with progressive forms of MS expressed a need for more information about this type of disease and the MS Society responded by developing a series of specialized programs.

### Waiting list

Multi-session programs were developed for both primary progressive MS (PPMS) and secondary progressive MS (SPMS). In total, 70 individuals and their caregivers attended the Winnipeg sessions and waiting lists have already started to form for the next series.

Individuals and their caregivers were provided with up-

to-date and relevant information on progressive MS, treatments, care and research. Sessions were hosted by MS Society client services staff, a neurologist and a family therapist.

### Positive feedback

The feedback was extremely positive and it was clear that there was a significant need for this kind of programming. “This was very informative,” said one participant. “It was good to talk to others with progressive MS. We’re very grateful to the MS Society for this session.”

Based on the great demand, plans are already underway for two more PPMS programs and at least one more SPMS session. Word-of-mouth and media attention helped spread the word about this initiative that is among the first in North America to focus on progressive forms of MS. ■

# Upcoming publications



**Our warm thanks to Heather Kertzer from Ontario whose work appears on the Insuring Your Future cover. Heather's work is called Le Café.**

The MS Society of Canada offers a variety of publications focusing on the many aspects of life with MS. These publications are available for those affected by MS, and include topic areas such as general information, managing MS symptoms, health and wellness, MS and family, managing practical issues, MS and caregivers, and young persons with MS.

MS Society publications are available online in Portable Document Format (PDF) from our website:

[www.mssociety.ca/en/information/pubs.htm](http://www.mssociety.ca/en/information/pubs.htm).

To order print copies free of charge, call your chapter or division office at 1-800-268-7582.

In late summer, three new publications will be available to you:

### *Urinary Dysfunction and MS\** –

A comprehensive guide to MS-related urinary problems, this publication includes detailed descriptions of diagnostic testing, management strategies, and commonly prescribed medications.

### *Insuring Your Future: Your guide to life insurance and multiple sclerosis* – Updated

Once diagnosed, it is often difficult for people with MS to obtain insurance. This booklet provides easy-to-understand information about life insurance and describes strategies for acquiring life insurance as well as alternatives to life insurance coverage.

*A Guide for Caregivers\** – This guide provides information on practical issues faced by caregivers. A resource list is included. ■

\*New, adapted from the National Multiple Sclerosis Society (USA)

## The questions you have ... answered!

Knowledge is power. A new education series will feature Dr. Rosalind Kalb, associate vice president of the Professional Resource Center at the National MS Society in New York, and author of numerous articles and books addressing practical issues in MS. It will focus on providing a platform for questions and answers, as well as for sharing tips and strategies for managing MS. This two hour session will feature a short introductory presentation from Dr. Kalb who will then be joined by a local neurologist to form a panel to answer your questions.

Location	Date	Call to register
Halifax, NS	September 8	800-268-7582
Montreal, QC	September 9	514-849-7591
Winnipeg, MB	September 29	204-988-0906
Toronto, ON	September 30	866-274-1483

For more information please call the numbers listed above or visit [www.mssociety.ca](http://www.mssociety.ca) and enter key search word “education”.

This education series is offered free of charge and is made possible by the fundraising efforts of the MS Society of Canada and its supporters. ■

## MS CANADA

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)



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