

# MS ONTARIO

Volume 22

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Summer 2007

## Shared stories

“I realize now that I am not defined by my job or my physical capabilities (or lack thereof). I can contribute and make a difference in a lot of different ways. More importantly, I have come to realize that it is not what happens to you, but what you do about it. I no longer look at my family and think "poor them". Instead, I think "lucky me" to be surrounded with so much love and support.”

*Read the rest of Jennifer's Story and other thoughts from people affected by MS on our Believe web page at [www.mssociety.ca/believe.htm](http://www.mssociety.ca/believe.htm).*



Kicking off our Carnation Campaign for MS Awareness Month in May on Parliament Hill are (l-r) Penny Moore, Ted Menzies, MP (Macleod, Alberta), Dr. Carolyn Bennett, MP (St. Paul's, Ontario), Alexa Deeble (Top Ottawa MS Read-A-Thon fundraiser), Nickolas Deeble, Nichole Johnston (Top Ottawa MS Read-A-Thon fundraiser), Christiane Gagnon, MP (Québec, Québec), Pauline Johnston and Peter Stoffer, MP (Sackville—Eastern Shore, Nova Scotia)

## 2007 WALK a step above



Congratulations to the thousands of WALKers and teams who made the 2007 Super Cities WALK for MS our most successful event to date. Over 35,000 people participated across Ontario, raising more than \$5.7 million in 61 events, to help end MS once and for all. Kudos go out to the dedicated committee members, TeamMS ambassadors and hundreds of volunteers whose commitment and dedication helped the 2007 events exceed all expectations. Monies raised will go towards helping the MS Society of Canada's mission to be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life. We look forward to seeing you in 2008!



# Chair's Corner

I am continually inspired by the people of Ontario who dedicate themselves to ending MS through their support of the MS Society. The Super Cities WALK for MS was held in 61 communities across the province and brought in a record-breaking \$5.7 million!

Hundreds of staff and volunteers worked behind the scenes of these community events to make them as participant-friendly as possible. And thousands of WALKers took to the streets – with the solid support of their sponsors - to raise awareness and funds for MS. I speak for all of us at the MS Society when I say thank you to everyone involved for giving so generously of their time and energy. This kind of cooperation and dedication to a shared goal makes a great impact on the lives of many. Funds raised will move our research initiatives forward, and provide vital community programs and services that make a daily difference for those with MS.

The inspiring success of our WALK events is sure to be followed by more of the same when the RONA MS Bike Tours get underway in the next few weeks. This busy fundraising season can be a challenge for our hard-working chapters, but we know it's all worth it when we see participants joining in, having fun, raising money and putting so much

passion into supporting our important mission.

Another inspiring event that recently brought us together was the Ontario Division Leadership Retreat in Toronto on March 31. We had an excellent turn-out of chapter representatives for an engaging day of brainstorming for the national strategic planning process, now underway in every MS Society division. It was my pleasure to host the session, which gave me the welcome opportunity to meet up with many of our chapter volunteers and staff, and watch unfold a high level of participation from the group.

The impact of these strategic planning sessions, which are built around a highly consultative process to ensure all voices are heard, will soon be felt in communities across the country. Yves Savoie and the national board of directors will consolidate the input by the end of 2007 to build on the Society's six decades of success and chart a new course to move further, faster, toward realizing our mission.

On behalf of the Ontario Division board of directors, I extend warm regards to all members, staff and volunteers, and wish you a happy, healthy summer.



A handwritten signature in black ink that reads "Tad Brown". The signature is stylized and fluid.

Tad Brown,  
Chair, Ontario Division Board of Directors



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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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## Upcoming publications:

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.

All MS Society publications are available online in Portable Document Format (PDF) and in print, unless otherwise indicated. To order print copies call your chapter or the division office at 1-800-268-7582.

The following publications will be available during the summer of 2007:

### **Insuring Your Future - 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 insurance coverage.

### **A Guide for Caregivers – New, adapted from the National MS Society (USA)**

This publication provides information on some common practical issues faced by caregivers. It also includes a resource list.

### **Urinary Dysfunction: A guide for people with Multiple Sclerosis – New, adapted from the National MS Society (USA)**

This resource provides a comprehensive explanation of MS-related urinary problems. Detailed descriptions of diagnostic testing, management strategies and commonly prescribed drugs are included.

## **Chilling out in summer heat**

Body temperature is usually around 37 degrees Celsius or 98.6 degrees Fahrenheit. When it rises due to environmental temperature, intense exercise or fever, the hypothalamus sends a message to the sweat glands to return the body to its normal temperature. When this happens in people with MS, impulse transmission is disrupted more than usual and can aggra-

vate neurological symptoms.

Janice Hon, Occupational Therapist, St. Michael's Hospital MS Clinic, says that people with MS should be aware of the effect of summer heat on their body and well-being. "It's important to avoid overheating as it may worsen existing symptoms," says Janice. "But that doesn't mean you can't still benefit from exercise or summertime activities. Simple lifestyle precautions can make a positive difference."

As the summer approaches, remember to:

- Dress lightly, eat cool foods and drink cool fluids.
- If an air conditioner isn't available, use a fan. A fan near an open window away from the sun will help in circulating cooler air.
- Cool baths or showers are refreshing; be sure hand rails and other supports are installed in the tub for safety.
- Try "cool clothing" - these are products such as scarves, bandanas, hats and vests that contain substances that can hold either cold or heat depending upon your need. Various kinds are available at pharmacies or at some department stores.
- Do your exercise in the pool (make sure it's not overly heated) so you can stay both fit and cool.

## **Tysabri update: Negative CDR review**

The Common Drug Review (CDR) process has recommended to provincial drug formularies that Tysabri (natalizumab) not be included in drugs for reimbursement. The main reason for the negative advice seems to be the lack of randomized controlled clinical trials comparing Tysabri to the four other disease modifying therapies.

The recommendation is not binding on provincial governments but is information they take into account in making decisions as to whether to list a drug and pay for it.

The Multiple Sclerosis Society of Canada is disappointed that Tysabri did not receive a positive recommendation from CDR and will be providing information to the Ontario government to assist it with its decisions about Tysabri that will benefit people with MS.

For more information about Tysabri, see the frequently asked questions document on our website: [www.mssociety.ca](http://www.mssociety.ca). Key word search "Tysabri".

# Government Relations and Social Action

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## Making a difference today

### Government relations workshop fosters local action



Working together at the Making a Difference Today government relations workshop are Yassemin Cohanin (left), Ottawa Chapter volunteer and member of the Ontario government relations and community social action committee, and Leanne Anderson, Ottawa Chapter client services manager.

The feeling that “we can make a difference today” was in the air at the end of the first government relations training workshop for chapters in late April.

Nearly 40 volunteers and staff from almost 20 chapters gathered in Toronto to learn how social action and government relations can and should be part of chapter activities.

After learning about the new Local Health Integration Network (LHIN), participants agreed the MS Society should become more active with LHINs, which will have a major impact on how health care is delivered across Ontario. Ontario staff will take the lead in developing a “LHIN how to guide” for all chapters and units.

A key goal of the workshop was to equip participants with the basic tips and tools to work with local government and government agencies. Chuck Rachlis and Chris Breen, two experts with many years of working for and with governments, did just that with

both knowledge and humour. Ian Greaves of Niagara Falls followed up with concrete examples of how his chapter uses local political contacts for all of its work.

“I was so impressed with the high calibre of work that many chapter volunteers have undertaken in the past that has made a real difference in their communities,” said John Clifford, chair, Ontario government relations and community social action committee.

“Cathy Topping inspired the entire room with her presentation about the Thumbs Up program in Elgin County which has businesses clamouring to be designated as ‘Thumbs Up accessible’. It was also great to learn from Carole Ward how her leadership led to the development of an accessible dental program in Halton region. We are definitely making a difference,” he said.

Presentations and photos from the Making a Difference Today workshop are posted on the MS Society website at [www.mssociety.ca/ontario](http://www.mssociety.ca/ontario).

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## New drug for pain may be useful in MS



Former Olympian Charmaine Crooks (right) with Deanna Groetzing, vice-president, government relations & policy, at the MS Society exhibit booth prior to a conference on neuropathic pain at the University of Toronto in April. Ms. Crooks is promoting greater awareness of this type of chronic pain which is related to damage to nerves or nerve conduction. The MS Society offered information about recent educational initiatives relating to pain and MS.

People with MS in Ontario who have neuropathic pain may have another treatment option. This is the kind of pain that develops because of damaged nerves or nerve conduction. This type of pain is experienced in many different ways: sometimes a continuous burning, aching or prickling sensation, or a painful response to normally non-painful things such as being touched lightly or getting dressed.

A new drug for some types of neuropathic pain is Lyrica (pregabalin). Approved by Health Canada in

2005 for treating neuropathic pain in diabetes and shingles, the Ontario Drug Benefit program will reimburse it for other conditions including MS under the exceptional access (section 8) process. Those who may qualify must have failed the use of both tricyclic antidepressants and gabapentin.

In addition, most private drug plans will reimburse the cost of Lyrica although each plan has their own criteria for approval. People who are interested should contact their own health care providers.

## Resources for MS caregivers managing advanced care

There are times when caregivers find themselves in a situation where they are no longer able to care for their loved one at home and must look to long-term care facilities or nursing homes for advanced care. This can be an extremely difficult decision for caregivers, the person with MS and family members to make, so it is very important that everyone involved feels comfortable and at ease with the health care team responsible for the continuing care.

To assist caregivers and health care professionals in keeping up-to-date in MS treatments and other related issues associated with MS, we would like to share several comprehensive publications written by noted MS professionals specifically for MS health care teams.

As a caregiver, family member or health care professional you may be interested in the following resources, or you may wish to pass them along to your colleagues or loved ones' health care team.

*Nursing Home Care of Individuals with MS: Guidelines and Recommendations for Quality Care* (Online resource): National MS Society, United States [www.nationalmssociety.org/docs/HOM/MS\\_nursing\\_guide.pdf](http://www.nationalmssociety.org/docs/HOM/MS_nursing_guide.pdf)

*International Journal of MS Care* (online and available in hard-copy from The Consortium of Multiple Sclerosis Centers) [www.ms-care.org/cmssc/Journal-of-MS-Care.html](http://www.ms-care.org/cmssc/Journal-of-MS-Care.html)

*MS: The Guide to Treatment and Management*, 6<sup>th</sup> ed (2006)

Demos Medical Publishing  
ISBN-13: 978-1932603514

*Nursing Practice in MS: A Core Curriculum* (2006)  
June Halper, Kathleen Costillo & Colleen Harris  
ISBN-13 978-1-888799-96-5

*Advanced Concepts in MS Nursing Care* (2007)  
June Halper  
ISBN-13 978-1933864150

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## Workplace giving works

The MS Society receives 96 per cent of its revenue from individuals, foundations and corporations, unlike many charities that receive ongoing government funding. One inspired way for corporations and their employees to support our work is through workplace giving, which offers great benefits to all involved. A company and its workforce has the opportunity to get involved in a wide range of activities for a very worthy cause, improve morale and give back to the communities in which they live and work.



Derek Wilson, manager, major gifts/planned giving (centre) accepts a cheque for \$10,910 on behalf of the MS Society of Canada, Ontario Division at the BMO Bank of Montreal Fountain of Hope Employees' Foundation Celebration of Giving on May 2. Presenting on behalf of BMO Bank of Montreal are Frank Techar – president and chief executive officer, Personal and Commercial Banking Canada and Marta Jones-Tromm – BMO Fountain of Hope allocations committee chair & Bank of Montreal central Toronto area manager.

Many Canadians, however, are not familiar with workplace giving. The **2004 National Survey of Giving, Volunteering and Participating** reports that just five per cent of total donations in Canada were made through workplace giving initiatives.

*“I feel that it is important for the corporate sector to demonstrate social responsibility by making contributions, and also by providing an outlet for its employees to channel their efforts towards productive means.”*

– Ryan Grundy, BMO learning facilitator and contributor to BMO Fountain of Hope

**How do workplace giving programs work?** Most workplace giving programs provide employees with a variety of donation methods, including fundraising events and payroll deduction programs. Some employers also match gifts made by employees to registered charities, which means by designating \$50 to the cause, your employer does the same, so \$100 comes to the charity. What a wonderful way to double your support!

**How can I get involved?** To become involved in workplace giving, contact your HR department to:

- Find out about your existing program and company policies, including details on payroll deductions, as well as volunteer opportunities.
- Determine if your company has a matching gift program.
- Ensure that the MS Society of Canada is on the list of registered charities for designation of donations.

Many Canadian corporations have workplace giving programs, including IBM and the Bank of Montreal, who have both supported the work of the MS Society for more than five years. Our thanks to the IBM Employees Charitable Fund, which has donated over \$155,000 to our work in Ontario and the BMO Fountain of Hope Employees' Foundation, which has provided almost \$100,000.

*For more information on how you can further support the work of the MS Society through workplace giving, please contact Derek Wilson, manager, Major Gifts/Planned Giving at 416-922-6600 ext. 2201 or [derek.wilson@mssociety.ca](mailto:derek.wilson@mssociety.ca)*



The MS Society was a recipient of the LCBO's Charity Donation Box program during the month of March, as MS Society coin boxes were displayed at more than 600 liquor stores across Ontario. The generosity of customers and staff resulted in total funds raised of \$7,200. Our great thanks to the LCBO for its commitment to charitable giving, and its customers for helping to end MS.

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## In the community with Yves

I am extremely proud of what I've seen in this great province in the short time I've been serving as president of Ontario Division. In the last weeks, I've been travelling to communities and getting to know the people who work hard to make this such an effective and vibrant division.

There was a great opportunity in late March for me to meet up with chapter leaders at the Ontario Chapter Leadership Retreat. As Tad mentioned in his Chair's Corner in this issue of *MS Ontario*, the retreat was an energetic session that contributed greatly to the strategic planning process we're involved in nationally. The process will help us adapt to change and build resiliency and strength as an organization, as well as align and renew our commitment to serve people with MS in the country as efficiently as possible.

Ontario chapters and members of the Ontario Division Board will have an opportunity to be involved in this process again in September and October when we seek input to validate an initial draft of the Society's new strategic directions. This will make the strategic planning process as inclusive and complete as possible. So many of our board members have a deep connection to MS and are working tirelessly to strengthen our volunteer and chapter networks. I've had the good fortune to meet with many of them throughout the province, as well as researchers and clinicians in Ottawa, London, Kingston and Toronto.

Thoughts from everyone I've met have crystallized the mission for me. There are so many ways to achieve it in Ontario – through the excellent programs and services that every chapter and unit offers; the meticulous work being done toward a cure in laboratories and hospitals; the excellent health care offered at MS clinics; the education that's shared among our whole community; and the events that bring participants and donors together in the name of a loved one with MS.

At the Toronto Super Cities WALK for MS this

past April I saw clear evidence of the passion that abounds in the province. As I spoke to the crowd, sharing the stage with those who have worked for years to end MS, I saw sisters and mothers and daughters and husbands and sons and friends – all gathered on a cold day to say to someone special who lives with MS, *I'm here for you.*

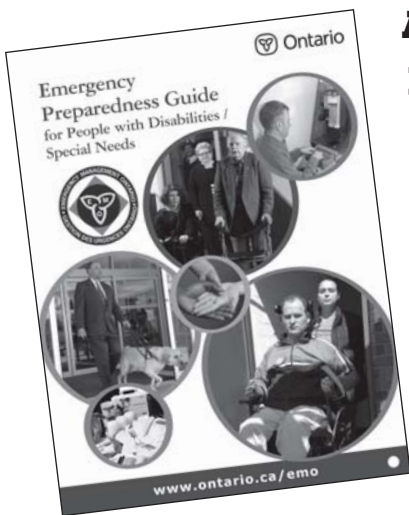
My best wishes to all.

Yves Savoie  
President and Chief Executive  
President, Ontario Division



Marcus Williams Photography / Per-Olof Osterling

**Yves Savoie helps kick off the Super Cities WALK for MS on a chilly April 15 at Toronto's Sunnybrook Park along with Mariette Poremsky, team captain of Biogen Idec. Mariette recruits over 250 members annually and has led her team to become the top Toronto WALK corporate team, top Ontario WALK team and the largest WALK team in Canada, raising almost \$200,000 since 2003. Congratulations and thank you Mariette and Biogen!**



## Always prepared

The Emergency Preparedness Guide for People with Disabilities / Special Needs was launched on May 11, 2007 and developed jointly by Emergency Management

Ontario (EMO), a

branch of the Ministry of Community Safety and Correctional Services, and the Accessibility Directorate of Ontario (ADO), part of the Ministry of Community and Social Services. Twenty stakeholder groups, including the Toronto Chapter and Ontario Division of the MS Society, were consulted for subject matter expertise and special insights. Appearing in the publication are (below, left to right), Lynn



Laccohee, manager of client services, Toronto Chapter, Barbara Feller, receptionist, and Toronto Chapter members Janet Macneil and Wendy George.

The publication is the most comprehensive emergency preparedness resource for people with disabilities and special

needs in Canada, providing vital information to the over 1.5 million Ontarians with visible and/or non-visible disabilities. It is available by calling the Ministry at 1-866-517-0571 or online at [www.ontario.ca/emo](http://www.ontario.ca/emo).

## RONA MS Bike Tour participants gear up for an exciting summer



Bike Tour finish line

In 2006, over 3300 RONA MS Bike Tour participants raised \$2.1 million in Ontario to end MS and this year, cyclists are gearing up again to surpass that amount.

They hope to raise over \$2.2 million!

There are five Bike Tours over five weekends in Ontario with one goal – to find a cure for MS. Cyclists in the RONA MS Bike Tour have no doubt that one day their goal will be realized and their friends and family will be there to cheer them on as they reach that finish line.

Proceeds from the RONA MS Bike Tours funds research into the cause and cure of multiple sclerosis as well as provides services to people living with MS and their families.

Bike Tours pass through Grand Bend – London, Ottawa, Niagara Region, Toronto and Brampton – Waterloo. Let's cheer on the over 3700 cyclists that will ***Gear up for this year's challenge!*** We know with their help we will end MS!

### Your subscription to MS Ontario

To update your mailing address or subscription preferences, please contact your chapter or the division office. Chapter 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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