

SUMMER 2009

## Kidz Klub: Adapting to changing face of caregivers



James and Jenna happily help their mom, Kim Latour, with daily chores.

Jenna and James were only 14 and 10 years old when their mother Kim Latour was diagnosed with multiple sclerosis. It was not long before their mother's diagnosis of MS would have an immense impact on their young lives.

When Kim couldn't hold a knife or lift a pan or a pot, her children stepped in to help with cooking. Jenna and James also pay bills, do laundry, get their mom dressed, and assist with tasks that would otherwise be effortless for Kim before the whole family began adjusting to living with MS.

"My children carry a burden of concern about my well-being

*continued on page 3*

### Walkers and cyclists **connect online**

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Share photos, stories, and receive updates about the MS Walks and RONA MS Bike Tours in Ontario. Find us on Facebook, twitter, LinkedIn, and our blog sites. More details on page 4.



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# Message from Yves & Linda

**C**ultivate innovation. This is an ambitious and essential concept at the MS Society of Canada. Emerging from our strategic plan, Momentum 2015, we recognize that we all must be able to embrace innovation to remain relevant and excel in our constant efforts to deliver on the MS Society's mission.

In this issue, we will be introducing you to some of our tremendous stories of creative and forward-thinking work. In client services, the Niagara Peninsula Chapter of Hope's initiative in support of young people caring for adults with MS recognizes and bolsters a quieter, less visible MS client. In research, you will read about how an internationally-renowned neuroscientist, Dr. Charles Tator, who has focused his lifelong work on neural repair in spinal cord injury, has recently been attracted to the field of MS where he is applying novel ideas to the potential for myelin repair using stem cells in MS.

We are also breaking new ground with our online strategies, which stretch from advocacy to fundraising. More publications are available on our website and for the first time, we are offering the opportunity to receive MS Ontario via email. Choosing to receive the newsletter electronically means you will be able to read it sooner, help us

reduce our environmental impact, and re-direct funds spent on postage to other mission-related activities.

Online innovation has also extended the MS Society's reach in its efforts to press governments to implement policies that are more responsive to the reality of living with MS. Social networking sites, such as Facebook have been harnessed to provide participants in the MS Walks throughout Ontario with the opportunity to connect, and create an online community well beyond the event season.

This spring, the MS Walk drew thousands of donors, participants, sponsors and volunteers. Those who fundraised had to be inventive this year as Ontarians faced an unprecedented economic slowdown. We thank you sincerely for your commitment, and for every step you took in the movement to end MS. ■



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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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# Are you prepared for an emergency?

**H**ot summer days can lead to rolling blackouts; when the power shuts down, elevators stop working, and air conditioning no longer provides relief from the heat. For those living with multiple sclerosis, there may be added concerns related to mobility and vision that may interfere with safety and security during a blackout. These and other emergency situations can occur without any warning. It makes sense to be prepared.

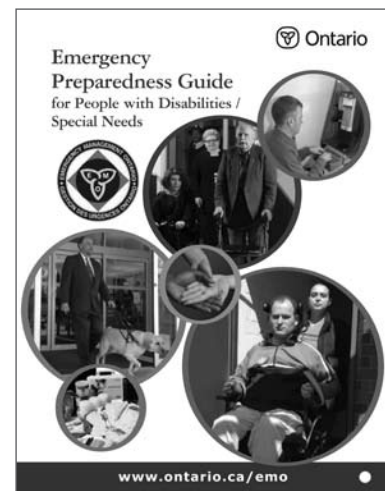
This past spring, the MS Society of Canada, Toronto Chapter held an education event about Emergency Preparedness. A Diversity Outreach Officer from Emergency Management Ontario gave a presentation introducing the publication *Emergency Preparedness Guide for people with disabilities/*

*special needs*, produced by the government of Ontario to benefit all people living with a disability in the province. Presently, 1 in 7 Ontarians have a disability and with an aging population, these rates are expected to increase.

The guide contains general and specific emergency preparedness tips for people with disabilities and emergency preparedness information for people with special needs. In particular, individuals and families are urged to take personal responsibility for being prepared and for being self-sufficient for at least three days following an adverse event.

If you would like to learn more about emergency preparedness and have access to the internet,

you can read the speaking notes or listen to the presentation hosted by the MS Society's Toronto Chapter by visiting [www.msociety.ca/Ontario](http://www.msociety.ca/Ontario). If you are a client who would like to receive Information Referral or Supportive Counselling services through the MS Society, Ontario Division, please call 1-800-268-7582 Ext 2306. ■



## Kidz Klub: Adapting to changing face of caregivers

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even when I am doing well. When the disease is at its worst, the pressure on our family is great. [On] many days, fatigue and muscle spasms limit what I am able to do”.

*“Participating in public awareness exercises and life skills classes offered through the MS Society has helped to connect us with others facing similar challenges. My*

*children are stronger knowing they don't carry this burden without recognition and they are not alone”.*

There are many kids like Jenna and James who help provide care for a family member. They are called young carers. A young carer is someone under the age of 18 who helps out at home because a family member needs assistance in their everyday activities. Caring activities can include practical care, personal care, and emotional care.

The Niagara Peninsula Chapter of Hope created Kidz Klub,

a program that provides recognition to young carers for the valued role they play in supporting their family. Kidz Klub also provides education and information to kids about MS; practical skills training, peer support, social opportunities, recreational outings, and most of all, a chance to be a kid.

For more information about Niagara's Kidz Klub or resources for young carers, please contact the MS Society of Canada, Niagara Peninsula Chapter of Hope at 1-877-937-7772. ■

## Innovative fundraiser uses cutting-edge tactics



Michelle Di Rocco uses social media to fundraise

I first got involved with the MS Society because I'm an avid cyclist. I thought the RONA MS Bike Tours were the perfect way for me to apply my passion for cycling to a good cause.

One of the tools that is a part of my personal fundraising efforts is the social networking site, Twitter. Currently, I post (or

“tweet”) information about the MS Walk. As the RONA MS Bike Tours get closer, I'll use Twitter, and other social media websites like Facebook to raise pledges and give updates on my training progress.

Social media tools are incredibly valuable and effective because they reach a vast network of people that I might not know personally. They're also

non-intrusive – you're informing people without putting pressure on them to necessarily make a pledge. If even a small percentage of the people who receive the information decide to donate, get further involved or help to spread the word, you've absolutely gained something. The possibilities are limitless in raising awareness and creating buzz through these outlets.

People are anxious to make their voices heard, and this gives them a forum to do so. We no longer have to wait for mass media like newspapers and radio stations to announce news - now we can participate in the process. Moreover, we can have our opinions heard in reaction to that news. Social media is definitely here to stay.

Michelle Di Rocco is a Toronto based public relations professional. She has participated in the RONA MS Bike Tours since 2007 and is a member of its organizing committee. ■

## Stay connected!



Make a statement. Share your event photos and stories with others on our blogs.

MS Walk [www.EveryStepMatters.ca](http://www.EveryStepMatters.ca)

RONA MS Bike Tour [www.GearingUp.ca](http://www.GearingUp.ca)



Read and share our tweets at:

[www.twitter.com/MSWalk](http://www.twitter.com/MSWalk)

[www.twitter.com/MSBikeTours](http://www.twitter.com/MSBikeTours)



See what your friends and fellow event participants are saying and doing for the MS Walk and RONA MS Bike Tour.

Become a fan of the MS Walk and the RONA MS Bike Tour at [www.facebook.com](http://www.facebook.com).



Don't miss this chance to network with other professionals taking part in our events.

Join the MS Walk and RONA MS Bike Tour groups at [www.linkedin.com](http://www.linkedin.com).

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## WAMS gala funds career-launching grant for new researcher!

**A** new endMS Research and Training Network grant worth \$500,000 is available thanks to a group of women committed to ending multiple sclerosis. The 5-year Transitional Career Development Award will be given to an outstanding postdoctoral or clinical fellow to fund the last two years of their postdoctoral study, as well as their first independent MS or MS-related faculty position within a Canadian university or teaching hospital.

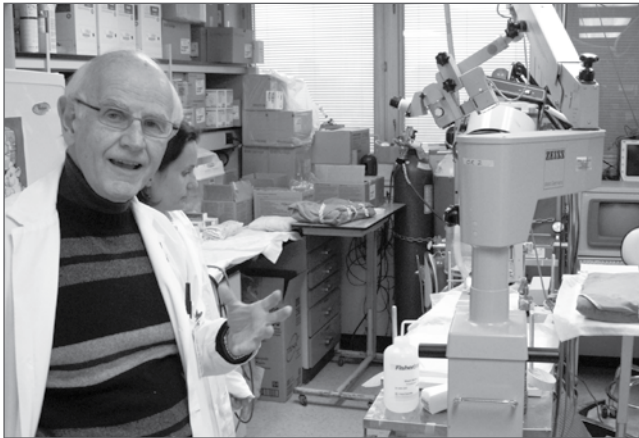
Funding for this grant is obtained from the Women Against MS (WAMS) program, which organizes events such as this year's WAMS Gala Luncheon that was held in May at the Royal York Hotel.

The success of WAMS can be attributed to its members, including former president of NASDAQ Canada and current president of R S Bell & Associates, Helen Kearns. This year, she was honoured by WAMS for her personal and professional commitment to end MS. Helen currently serves as vice chair, communications on the endMS National Campaign Cabinet.

Women Against MS was formed in Canada four years ago. To date, it has raised nearly \$1 million through various initiatives. ■

[www.womenagainstm.com](http://www.womenagainstm.com)

# Can injecting adult stem cells promote repair?



Dr. Tator (foreground) and Dr. Mothe at their lab at the Toronto Western Hospital.

**A**n innovative study, led by Dr. Charles Tator of Toronto Western Hospital, is examining new techniques to deliver adult stem cells to those that are missing myelin or have an MS-like disease. The novel aspect of this study is that researchers are using a simple spinal injection for the delivery of stem cells and that they are replacing adult tissue with adult

cells. Researchers hope the procedure will promote repair of damaged myelin.

Using animal models, Dr. Tator and his associate Dr. Andrea Mothe, extract neural stem cells from the spinal cords of healthy adult subjects, allow the cells to replicate, and transplant them to those that have experienced demyelination. The stem cells are implanted into the spinal fluid in the lumbar region rather than the spinal cord.

It is hoped that by transplanting myelin-producing cells, remyelination and neuroprotection will occur. In theory, the procedure could improve neurological dysfunction. Researchers hope that insights gained from this research on animals will increase the possibility of developing an effective therapy that will allow people to regain abilities lost to MS.

Dr. Tator's innovative project is funded by the Multiple Sclerosis Society of Canada. To read more about pioneering MS research taking place across Canada visit [www.msociety.ca/en/research](http://www.msociety.ca/en/research). ■

## *Serving MS carnations at Mandarin*

Mandarin Restaurants has strengthened its commitment to end MS by expanding its support of the MS Society for 2009.

The restaurant chain has purchased \$35,000 worth of carnations through the MS Carnation Campaign, which were handed out to their patrons at 21 locations across Ontario on Mother's Day weekend. Mandarin has also lent its support to the MS Walk in Toronto, providing lunch/dinner gift certificates to all participants and sponsoring several lunch items at the event. This summer, they will support the RONA MS Bike Tours as a key sponsor.



# Gap narrows between grassroots and tech-savvy advocates

*“It’s a privilege to be part of a team that works as one to change the lives of people affected by MS, an opportunity that would not have been as effective prior to the widespread use of computers,” said Jan Richardson from North Bay. “If you live in a Northern community you can have the same advocacy tools and information as someone who lives in an urban centre. Advocates do not have to work in isolation.”*

The MS Society ran three successful online advocacy campaigns in the past year, which encouraged Canadians to write or email their Members of Parliament (MPs) to champion income security for people affected by MS.

Thousands of Canadians contacted approximately 70% of 306 MPs on these issues. As well, thousands of Canadians participated in a follow-up, grassroots petition campaign presented to the House of Commons during MS Awareness Month in May.



By bringing together voices through grassroots and technologically enhanced advocacy, the MS Society offers people more ways to get involved. This involvement strengthens our collective voice.

Visit [www.mssociety.ca/en/involved/advocacy/](http://www.mssociety.ca/en/involved/advocacy/) to send a message to your MP. ■



## ***A&W Teen Burger sales help end MS in August!***

Plan to visit your local A&W restaurant on August 27 to support the MS Society of Canada. For the first time in Ontario, proceeds from each purchase of a Teen Burger on that day will be donated to the MS Society. Visit [www.mssociety.ca](http://www.mssociety.ca) for details.

A&W mascot Root Bear makes a statement at the 2009 Saskatchewan Blue Cross MS Walk.

# Fresh thinking in a tough economy

**T**he economic downturn has affected everyone. We are all tightening our belts, waiting to see when the economy will bounce back.

However, you don't have to let a slow economy stop you from supporting a cause that is important to you. Now is a perfect time to consider something called a legacy gift – a form of charitable giving that allows you to make a gift to the MS Society in the future without substantially affecting your income today.

There are dozens of ways to make a legacy gift. One of the most popular and simplest forms is leaving a bequest in your will.

Whatever stage of life you are at, we can help you find a legacy giving option that suits your circumstances. We've provided you with a description of the legacy gifts that are most commonly made by Canadians below.

If you're ready to make a legacy gift, talk to your lawyer or financial advisor to determine what option is best for you or contact Stephen Adler at 1-866-922-6065 or e-mail [stephen.adler@mssociety.ca](mailto:stephen.adler@mssociety.ca).

**Bequests** A bequest is a gift that you make to a charitable organization through your will.

**Life Insurance** You can take out a new policy or transfer ownership of an existing policy designating the MS Society of Canada as the beneficiary while you receive immediate tax relief on your premiums.

**Charitable gift annuities** This type of gift allows you to receive income while giving a sum of money to a charity.

**Charitable remainder trusts** In a Charitable remainder trust, you give an asset such as stocks, bonds, or real estate through a trust agreement.

**RRSPs or RRIFs** You can name a charity as a direct beneficiary for your RRSP, RRIF, or Canada Pension Assets and receive tax benefits as a result. ■

*The most popular legacy gift options are through wills and bequests because they do not affect a donor's current income.*



Share comments or stories:  
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