

SPRING 2011

Ontario government **makes strides on CCSVI**



Yves Savoie with Ontario minister of Health and Long-Term Care Deb Matthews

In keeping with recommendations of the MS Society of Canada, on March 1st the government of Ontario announced the creation of an expert advisory group to advise on follow-up care and treatment of Ontarians with MS who have undergone CCSVI treatment abroad, and pledged to support the federal government if it moves to create a national multiple sclerosis registry for people living with MS.

The MS Society is pleased the Ontario government responded to our request to ensure that appropriate and timely medical care be available to those who undergo treatment for CCSVI and that it understands the potential that a registry holds for helping researchers to better understand MS and its impact on people's lives.

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Happy Feet

When life gets us down, we might rent a comedy or seek comfort in family and friends to soothe our souls. Catherine McCormack, mother of two and living with MS for 13 years, trains six days a week to become a world-class race walk champion.

“Race walking is one of the most difficult events in track and field,” says her coach Stafford Whalen; “you need the strength of a middle distance runner, the flexibility of a gymnast and the endurance of



Catherine McCormack

continued on page 4

Annual meeting of members on April 3, see proxy on page 7.

Message from Yves & John

Thousands of MS supporters will put their best foot forward this spring as we kick off our fundraising season with the MS Walk in communities across Ontario. In this edition, you will read about the passion, commitment and impact of our volunteers, friends and supporters as they stride toward the finish line in the movement to end MS.

Chronic cerebro-spinal venous insufficiency (CCSVI) continues to generate great excitement. On the cover and on page three, we highlight the Ontario government's commitment to establish a panel to make recommendations on best practices in follow up care for those who seek CCSVI treatment and to support the federal government if it creates a national MS registry.

We also feature MS Ambassador Catherine McCormack. Catherine's rise in race walking has been truly remarkable. She combines her love of competition with her goal of raising awareness of MS. Read about Catherine's successes on the cover and page four.

Equally committed and keeping the pace to endMS are Dave Bergeron and Rueben Devlin. With a close personal connection to MS, Dave is the driving

force behind Reel & Deal, a unique fundraising event he started to help provide much needed services to people affected by MS in his community. Rueben, a top fundraiser and a member of the Ontario Division endMS campaign cabinet, pedals tirelessly, year after year, in the RONA MS Bike Tour to raise money for MS research.

Our chapters and units are always one step ahead in supporting those affected by MS in communities throughout Ontario. We hope that you will be inspired by Linda Houle-Robert's story on page six, which tells of her passion for healthy living and the wellness program she developed in collaboration with the MS Society's Ottawa chapter.

Doing your best is to never stop trying. Our supporters and members embody this sentiment wholeheartedly. Together, step by step, we are moving closer toward a future free from MS. ■



Yves Savoie
President,
Division Ontario

John Clifford
Chair, Ontario board
of directors



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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“With each step I take, from the moment I get out of bed to the last one getting in, I am grateful that I am alive and well.”

Bridget Kelly, 17, lives with MS

Act on CCSVI

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“People with MS who choose to seek treatment abroad for CCSVI deserve timely access to post-treatment, follow-up care,” said Yves Savoie, President & CEO. “This is why we have called on all provinces and territories to address this important issue.”

In addition to follow up care and the creation of MS registries, the Society has called on governments to earmark funds for a pan-Canadian therapeutic trial on CCSVI, so an immediate infusion of funding will be available when such a trial is developed and approved. The MS Society earmarked \$1 million to support such a study.

We are also working with governments to determine the level of evidence required to publicly reimburse any potential treatments for CCSVI in people with MS, and we have asked governments to move quickly to reimburse testing and treatment if this level of evidence is established.

The federal government has established an expert scientific working group on CCSVI that will monitor and analyze CCSVI research, including the preliminary findings of the CCSVI research funded by the MS Society and its U.S. counterpart.

On the provincial front, the government of Saskatchewan committed \$5 million to support clinical trials; the government of Manitoba earmarked \$500,000 for clinical trials if and when such trials are warranted; the government of Newfoundland and Labrador funded an observational study on individuals who have undergone treatment abroad; and the government of Alberta promised up to \$1 million for an observational study, and committed to fund a clinical trial of the CCSVI procedure, if and when it is safe and ethical to proceed.

The MS Society applauds these initiatives and will continue its work to ensure that governments take further action on CCSVI. ■



WAMS

Women Against Multiple Sclerosis

Women Against MS Gala Luncheon

May 6th 2011, 11:45am-2:00pm
Fairmont Royal York, Toronto

Guest Speaker: **Lisa Ling**
Acclaimed Journalist on the
Oprah Winfrey Show and CNN

Honouree: **Janice Fukakusa**
Chief Administrative Officer
& Chief Financial Officer of RBC

VIP Tables: \$3,000 Tables: \$2,000 Tickets: \$200



E caley.bornbaum@mssociety.ca
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“ I have never seen MS as a hopeless cause. We engaged the struggle and we must continue until a cure is found. ”

Jake Doherty, donor and husband of late wife, Monique, who lived with MS

Happy feet

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a marathoner. Happy Feet,” his nickname for Catherine, “wants to train harder and faster than required. These are attributes that make a Canadian Champion.”

Despite having taken up the sport just two years ago, her goal to reach the podium for both the 2011 Canadian Track and Field and World Masters Championships is attainable. She placed 5th in the 20,000m race walk in the 2010 Canadian Track and Field Championships, beating her personal best. “I believe that I have been asymptomatic for four years because of sport. I do this to maintain the level of health I have now so I can be a mom to my two children,” she says.

Catherine’s athleticism is powered by her determination and courage to face challenges head-on, and there have been many: shortly after being diagnosed, and revealing her MS prognosis, she was let go from her marketing job of 7 years. In spite of this, she overcame her fear of judgement and moved on to a successful career in another industry, and has gone on to advocate for greater awareness of the disease in the workplace. Her younger sister also lives with a progressive form of the disease. Recently, Catherine was diagnosed with breast cancer. Despite the setbacks, she lives her best life. Her motto, “I have MS, but it doesn’t have me,” is what bolsters her determination. ■



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“I look forward to a day when we have new treatments, or even better, a cure, so others with MS can enjoy the quality of life that I’m savouring right now.”

Catherine McCormack, race-walk competitor,
MS Ambassador and lives with MS

Cycling is just the beginning



Rueben Devlin is cheered on by friends at the RONA MS Bike Tour

From his initial decision to volunteer for the MS Society of Canada, Rueben Devlin has selflessly put himself forward with the goal to help end MS.

His first initiative was cycling in the Toronto RONA MS Bike Tour in 2005, raising over \$2,500 in that year. He then enlisted his brother-in-law to join him and together they have raised ever increasing contributions. Now Rueben's wife, daughter and grandchildren all come out to cheer for them both.

When he heard about the endMS campaign, Rueben once again stepped forward as a donor. Not content to merely support the campaign financially, Rueben joined other leaders in the community to become a cabinet member, focused on supporting the endMS Research and Training Network and the researchers that it supports. Rueben views these dedicated researchers as the future pioneers in the movement to end MS. For this reason, he is determined to engage others to help raise much needed funds in this respect.

Rueben's wife and daughter have become proud members of Women Against MS and we expect his young grandchildren will soon be seen on the bike paths!

From fundraiser, to campaigner to spokesperson, Rueben has put his whole self forward in the fight to end MS. Thank you Rueben! ■

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“*The first year I rode, I rode because my own mother didn't believe that I could ride my bike for 75 kilometers.*”

Toosje Wright-Fulcher, RONA MS Bike Tour participant for 10 years and lives with MS

Reaching her potential



Linda Houle has completed ten marathons

Rising at 6am, Linda Houle-Robert runs eight kilometres to ensure a healthy start to her day. As a wife and a busy mother of two young daughters, Linda then assists her family with a healthy breakfast and spends the remainder of the day focused on a multitude of activities.

Linda is passionate about health and wellness. She is a person who lives, eats, and breathes health while living with the challenges of MS. With a sudden onset of numbness in her face and difficulties with her speech, Linda arrived at a hospital emergency ward ten years ago, where she quickly learned of her MS diagnosis. From that moment forward, Linda became an advocate for healthy living and proactive health care.

The impact of Linda's wellness activities reaches far beyond herself and her family, it also reaches deep into her local community. Linda volunteers with the Ottawa Chapter of the MS Society as a fitness

“Our generation – we have to be the ones to get out there to do something about MS.”

Julia Daniluck, diagnosed with MS at age 19

instructor for a weekly chair fitness class, writes a column for their newsletter and occasionally speaks at their events. Linda also runs marathons, completing ten in as many years; volunteers with a local skating club, swim club, coaches her daughter's soccer team and offers nutritional sessions to students at a local high school on how to eat properly to improve their athletic performance.

MS has impacted the way Linda looks at life. She savours all of life's little pleasures, especially the time spent with her children and her family. Linda particularly enjoys the opportunities to enhance the well-being of others through her nutritional and fitness programs. In essence, she is finding a balance between body, mind and spirit in a way that enables her to be her best each and every day. ■

How to prepare for a healthy MS Walk

By Linda Houle-Robert, B.Sc(Kin), M.A., B.Ed., PTS, RHN

1. Make sure you have a good pair of running shoes.
2. Start your walk training slowly. Gradually build yourself up starting with 5 or 10 minutes at a time.
3. Avoid drastic increases in time on your feet. Increase by 5 minute increments weekly until you reach 30 minutes of walking, 3 times a week.
4. Don't forget your water. Bring a stainless steel water bottle with you to the walk and try to drink continuously throughout the walk.
5. Eat a good healthy breakfast before the walk. A bowl of porridge with milk, a bit of maple syrup for some sweetness and slices of apples is a good choice. Sprinkle with some yummy cinnamon.

NOTICE OF ANNUAL GENERAL MEETING OF MEMBERS: NOTICE IS HEREBY GIVEN that the Annual General Meeting (AGM) of the members of the Multiple Sclerosis Society of Canada (Ontario Division) will be held at the Sheraton Gateway Hotel at Toronto Pearson International Airport, Terminal Three, Toronto, Ontario on **April 3, 2011** at 11:15am for the following reasons:

1. Receiving the report to the members of the Board of Directors and the financial statements for the year **December 31, 2010** thereon;
2. Electing members of the Board of Directors;
3. Such further and other business as may be properly brought before the meeting.

Members in good standing who are unable to attend the meeting in person are requested to sign and date the form of proxy below and return it to the Multiple Sclerosis Society of Canada (Ontario Division) by March 29, 2011 at the address below. **To be entitled to vote at the AGM a member shall have been a member in good standing for at least the three-month period preceding the date of the AGM. Members in attendance at the AGM are required to provide photo identification.**

DATED AT: Toronto, Ontario, **March 11, 2011**, Karen Torrie-Racine, Secretary, Ontario Division Board of Directors

PROXY

This proxy is provided for use by members in good standing of the Multiple Sclerosis Society of Canada (Ontario Division) (the "Division") unable to attend the Division's Annual General Meeting on **April 3, 2011**. (the "Annual General Meeting").

PLEASE SIGN, DATE and RETURN this Proxy to the Division at the following address by **March 29, 2011** to the Multiple Sclerosis Society of Canada (Ontario Division), Suite 700, North Tower, 175 Bloor Street East, Toronto, Ontario, M4W 3R8 - Attention: President, Ontario Division.

The undersigned, being a member in good standing of the Division, hereby revokes all prior proxies and appoints Mr. John Clifford, Chair, or in his place, Ms Valerie Hussey, Vice-Chair or Mr. Niranjn Vivekanandan, Vice-Chair or _____, as his or her proxy to attend and act on his or her behalf at the Annual General Meeting and at any adjournment thereof as follows:

- (A) FOR the election as directors of the Division of the persons nominated by the Division's Nominations Committee.
OR
CHECK HERE ____ if you wish to abstain from voting for the election of directors.

- (B) In her or his discretion, with respect to amendments or variations to matters identified in the Notice respecting the Annual General Meeting or any other matters which may properly come before the Annual General Meeting.

The following are nominated to the Ontario Division Board of Directors from April 3, 2011 to the Ontario Division Annual General Meeting to be held in the Spring of 2013:

1. Robert Blais 2. Yassemin Cohanin 3. John Ellis 4. Elizabeth Flavelle 5. Don Forgeron
6. Kent Kirkpatrick 7. Tom Knowlton 8. Sandra Montague 9. Robert Messervey 10. Beth Nelligan
11. Karen Torrie-Racine 12. Marie Vaillant 13. Niranjn Vivekanandan

The slate of nominees and a request for additional nominations was published on February 21, 2011 in the Ontario section of the MS Society of Canada website.

The person designated in this Proxy shall vote in accordance with the specifications given herein and, in the absence of such specifications, shall vote in favour of the election of the directors nominated by the Nominations Committee.

DATED this _____ day of _____, 2011 SIGNATURE: _____

Please print clearly your name, address and phone number

Surname: _____ Middle Initial: _____ Given name: _____

Street Address: _____ Town/City: _____ Province: _____

Postal Code: _____ Phone number: _____ Chapter/Unit: _____

Reeling & dealing for MS



Many of us grow up knowing that family is our number one priority. So when a family member is diagnosed with MS, the effects of the disease are felt by everyone. For Dave Bergeron, watching his father, Terry, deal with the challenges that accompanied the disease affected him deeply.

“MS is a family thing and families are profoundly affected. Many people just look at the person who is ill but it’s not just that person who is affected,” explains Joan, Dave’s mother and dedicated caregiver to her husband since his diagnosis in 1992. “People don’t realize the isolation that families feel.”

Wanting to help people affected by MS in his community, Dave decided to fundraise for the MS cause by inaugurating a community fundraiser in 2008. The Reel & Deal fishing derby and poker tournament, an annual event that raises funds for

the MS Society’s York South, York North and York East chapters, has raised over \$215,000 to date.

“I do it for my parents,” says Dave, “I want to do my small part to help people living with MS, to make their day a little easier.” But it is in fact no small feat: Dave and his team give countless hours motivating others to give too.

One of the most rewarding Reel & Deal moments for Dave is watching an entire room full of people stand up to applaud Joan. “It’s about a bunch of people recognizing that people with MS struggle every day,” says Dave. “I hope to channel people’s energy into ending MS.”

The Reel & Deal event takes place on the first Thursday in July each year, and is held at Lake Scugog in Port Perry.

Want to register for the event or start your own fundraising event?

Contact Freya Potter Freya.potter@mssociety.ca or call 1-800-268-7582 extension 3157.



Share comments or stories:

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