



CANADA

SPRING 2010



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MS Society volunteer Kate Douglas (pictured holding sign) at a recent MS Walk event.

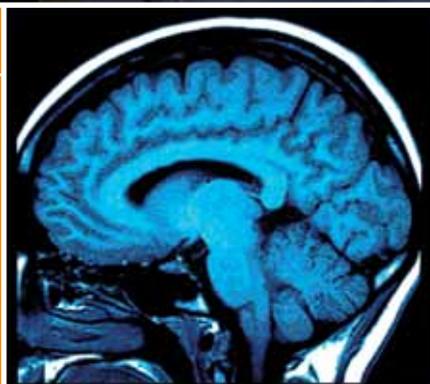
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MS Multiple Sclerosis Society of Canada

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Message from Yves



People who are affected by multiple sclerosis are the foundation upon which the MS Society of Canada is built and the driving force behind our mission. With tens of thousands of members and volunteers across the country sharing

a common goal to end MS, it is critical that stakeholders are engaged and involved in our activities. Each of us has the power to join the movement and make a difference.

In recent months, there has been a tremendous interest in news media reports about chronic cerebrospinal venous insufficiency (CCSVI). The MS Society shares in the interest generated by this treatment and by the possibilities that come with exploring a new avenue of research. We are proud of our steadfast commitment to funding the best science in the context of our CCSVI competition and in all of our other research competitions.

The launch of our online advocacy tool last year gave Canadians from coast to coast the opportunity to directly interact with government representatives about issues of importance to people with MS and their families, including increases in health research funding and improvements to programs that provide vital income security for people with disability who are

unable to work. The MS Society communicated with almost 10,000 constituents by email as we strove to shape government policies and programs impacting people affected by MS. We encourage you to register to receive regular alerts on a wide range of issues through the Advocacy section of our website.

As we celebrate National Volunteer Week this April, we thank Daniel Larouche for his valuable work as national chair over the past year and welcome Linda Lumsden to this position in 2010. Linda first joined the MS Society's Ottawa Chapter as a board member in 2000 and was later appointed as chair, Ontario Division board of directors in 2008. As national chair, she will continue to demonstrate her commitment and leadership to our vision and mission. All across the country, we recognize the ongoing efforts of volunteers who are making an impact, whether at fundraising events like the MS Walk, through outreach to government representatives, or at chapter offices serving local community members. It is through the spirit of our volunteers that the movement to end MS is made possible. ■

Yves Savoie
President and chief executive officer
President, Ontario Division



MS Canada, Spring 2010

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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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May 26 is World MS Day!
To find out how you can get involved in this year's events and activities, visit worldmsday.org.

Making your voice heard



Lynn Hunter,
chair, national
government
relations
committee

For many, joining the movement means having your voice heard. Last year, nearly 3,000 individuals from coast to coast joined the MS Society's advocacy campaign to persuade the federal government to make changes that will benefit people living with MS.

Starting in May 2009, during MS Awareness Month, people used an online advocacy tool to send messages to MPs.

The email messages urged them to increase health research funding and to boost income security by making the disability tax credit refundable, allowing spouses to claim the caregiver amount and making employment insurance sickness benefits more flexible.

When the parliamentary session ended in June,

297 out of 305 MPs had received at least one email message from constituents – that's 97.4% of all MPs!

"These are outstanding results. It tells us that the issues are compelling ones for the members, friends and donors. It also tells us the MS Society has incredible reach across the country in all areas: urban, suburban and rural, and that people are keen to become involved," said Lynn Hunter, chair of the national government relations committee.

This spring and throughout 2010, the MS Society will conduct advocacy campaigns to inform politicians about MS-related issues and what they can do to help.

To sign up for future advocacy campaigns, email us at advocacy@mssociety.ca. ■

Make income tax time work for you

Before filing taxes for 2009, check out the tax tips article on how to take advantage of credits and refunds on our website at mssociety.ca [keyword: tax tips].

MS awareness in full bloom

May is **MS** Awareness Month

Warmer weather is around the corner and that means MS Awareness Month will soon be upon us. Every May, the MS Society focuses its energies on generating awareness about MS and related issues to the public.

One highlight this year will be the annual research teleconference call. Every year, the MS Society facilitates a nationwide conference call that brings together one of Canada's brightest researchers to answer questions about MS. Over 150 phone lines were open last year to hear insights from University of British Columbia researcher, Dr. Peter Rieckmann.

This spring, volunteers and staff across Canada will host open houses, sell carnations, raise MS flags and participate in events geared towards raising awareness.

Another awareness month hallmark is the MS Carnation Campaign. Each year during the lead-up to Mother's Day, carnations are sold in public spaces to generate awareness of MS and raise funds for the cause. The campaign typically kicks off with a boutonnière-pinning event with MPs on Parliament Hill.

To stay on top of MS Awareness Month activities or to get involved, please visit mssociety.ca or call 1-800-268-7582. ■

Leading the way for research in Canada



Dr. Cornelia Laule



Dr. Steven Kerfoot

Launched in 2008, the endMS Research and Training Network is a nationwide initiative developed to accelerate discovery in the field of multiple sclerosis in Canada. In January 2010, the network proudly announced the recipients of its inaugural endMS Transitional Career Development Awards – Dr. Cornelia Laule of the University of British Columbia and Dr. Steven Kerfoot of Yale University. The awards provide successful post-doctoral and clinical fellows each with \$500,000 to fund the last two years of their MS-focused fellowship and the first three years of their first faculty position at a Canadian institution.

Dr. Laule’s research at the University of British Columbia focuses on developing magnetic resonance techniques to study the pathology of multiple sclerosis. “Thanks to the endMS initiative, I am able to continue my career as an MS researcher in Canada,” says Dr. Laule. “This award will enable me to foster interdisciplinary research, mentor trainees and encourage teamwork between basic scientists and clinicians.”

After his studies at the University of Calgary, Dr. Kerfoot went on to train at Yale University in the field of B cell biology. With the support of this award, Dr. Kerfoot says he intends to “return to Canada to start a new lab as an independent

investigator and pursue my long-standing research interests in immunology, chronic inflammation and the central nervous system in order to shed light into the role that B cells play in multiple sclerosis.”

The endMS Network is funded by the MS Society-related MS Scientific Research Foundation and is the flagship investment of the \$60 million endMS capital campaign. Dr. Laule’s award was made possible by Women Against MS (WAMS), a collective of professional women dedicated to raising funds to end MS. Funded by long-time supporter and past member of the MS Society’s national board of directors, Dr. Kerfoot’s award was named the Garrett Herman endMS Transitional Career Development Award. ■

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CCSVI and MS

In November 2009, media outlets nationwide reported on chronic cerebrospinal venous insufficiency (CCSVI), a term used to describe a hypothetical situation in which the venous system is unable to efficiently remove blood from the central nervous system. According to the theory, this is related to the narrowing of small venous structures in the neck, chest and spine. Several physicians in Italy suggested that the treatment of blocked veins could alleviate the symptoms of MS. While exciting and interesting, the theory requires further validation.

With this in mind, the MS Society announced that it would launch a request for operating grants, specifically related to CCSVI and MS. It was a unique and unprecedented move that demonstrated the MS Society's desire to explore,

as soon as possible, a potential new avenue of treatment for MS. Canadian researchers responded to the call and will be submitting full grant applications. The anticipated funding decisions will be made on June 14, 2010.

The next important steps in this research involve assessing the frequency and prevalence of CCSVI in people with MS. If the results of this research demonstrate a possible connection between MS and CCSVI, researchers might then look at treating the condition itself.

Information about CCSVI and MS continues to evolve and new information will be posted as it becomes available. Please visit mssociety.ca/ccsvi for updates and a comprehensive question and answer section on this topic. ■

Join the movement to end MS



Since 2004, Kate Douglas has spent five months of every year offering her time and expertise as a volunteer coordinator for the MS Walk in Muskoka, Ontario.

After meeting several people with MS, Kate was especially struck by the stories of those diagnosed in the prime of their lives, at a time when they were just beginning their careers or starting families. Kate knew she had to do her part and decided to donate her volunteer management skills to the endMS movement.

As one of the original committee members from 2004, she recounts one of her most memorable moments. "I looked around the school gym at the sea of people and went, 'Wow I can't believe how many people are in this gym, ready to participate in the first ever MS Muskoka Walk!' It was quite overwhelming," says Kate.

What fuels her drive are the research breakthroughs made possible from funds raised by MS Walks, as well as the number of volunteers she sees coming back year after year. As Kate sees it, "I am confident that in the not too distant future the world will be free of MS, and that's the reason we all work so hard to raise as much money as possible – so this will happen in our lifetimes."

Join the movement! Register or volunteer for an MS Walk in your community at mswalks.ca. ■

Can Canada be the best place for caregivers?

This was the question participants tackled in late November 2009 at a two-day caregiver and poverty stakeholder forum hosted by the Multiple Sclerosis Society of Canada. The forum brought together a diverse group of health charity and non-profit organization leaders, researchers, policy-makers and government officials to examine the issues related to caregiving and economic security.

A family caregiver's efforts, understanding and compassion are essential in enabling their loved ones to live with dignity and participate more actively in society. However, providing care can have negative consequences for employment, with many caregivers needing to reduce their hours of work or quitting their jobs altogether to balance their caregiver responsibilities. In some cases, this can lead to economic insecurity and even poverty.

The forum went on to recommend policy changes such as improved income security for persons with disabilities, protection of caregivers' employment/income status and reduction of disability support costs. These recommendations took the form of either employment insurance reform to allow more flexibility in compassionate care leave, expansion of the Canada Pension Plan drop-out provisions or extension of the child disability benefit.

The panel noted employers also have a role to play. The emerging principle to support family caregivers is "customization" – the opportunity to adjust work without sacrificing job and career advancement. While some employers provide support to caregivers, others need to be shown how caregiver support can go hand-in-hand with successful business enterprises.

Forum participants were passionate and committed to creating a change in Canada's social mindset. They agreed that excessive financial burden should not be tolerated in Canada and economic security for caregivers to live a life they can fully value is a necessity.

The MS Society and other forum participants affirmed that Canada is capable of creating the conditions where caregiving is not only possible,

but valued as central to the Canadian social construct. They agreed to keep the spotlight on this important issue, which for so many is a labour of love.

The MS Society of Canada thanks Pfizer Canada for supporting the caregiver and poverty stakeholder forum through an unrestricted educational grant. ■



From left to right: Sherri Torjman, Caledon Institute for Social Policy; Dr. Janet Fast, University of Alberta & Hidden Costs/Invisible Contributions; Nora Spinks, Work-Life Harmony Enterprises

What the MS Society is doing to help

The MS Society of Canada is addressing the issues faced by family caregivers in a variety of ways.

Services: The MS Society across the country provides information about multiple sclerosis as well as resources, activities and support groups for caregivers to help effectively manage the ongoing stress that providing care can present. For more information, visit the Caregiver section under Living with MS at mssociety.ca.

Government relations: The MS Society is advocating the federal government to make changes to financially help people affected by MS, including allowing spouses to claim the caregiver amount as a tax credit and increasing tax credits for people with disabilities. For more information, visit the Advocacy section at mssociety.ca.



Q: What financial aids are available to people who can no longer work due to MS?

A: There are a few income sources that may be available to persons with MS, who are no longer able to work.

Long-term disability: If you have an employee benefits package, you may be eligible to receive long-term disability benefits. For more information, contact your human resources department.

Employment insurance: If you have made sufficient contributions to the employment insurance (EI) plan, you may be eligible to receive EI sickness benefits. Visit bit.ly/eibenefits for details.

Canada Pension Plan: If you have worked in Canada

and made contributions to the Canada Pension Plan, you may be eligible to receive Canada Pension Plan disability benefits. Visit bit.ly/cppbenefits for details.

Contact your provincial or territorial social services department about services available in your province.

A partnership between the MS Society of Canada and the Investor Education Fund (IEF) will produce a quality information resource that will include financial planning tips and tools, as well as guidance on money management to a broad range of MS clients. The resource will be available to the public in the late spring of 2010.

To learn more, visit msanswers.ca. ■

Multiple Sclerosis Society of Canada Notice of Annual General Meeting

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, June 12, 2010 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, 2009 to December 31, 2009;
- ii) Electing members of the National Board of Directors;
- iii) Appointing auditors;
- iv) 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, May 28, 2010. Attention: Rosanne Portelance.

DATED at Toronto, Ontario this 25th day of March 2010

Mr. François Coupal, Secretary



Multiple Sclerosis Society of Canada Proxy for Annual Meeting of Members, June 12, 2010

The undersigned hereby appoints Linda Lumsden, or failing her, Jim Casey, David Garton or François Coupal or _____ as proxy with power of substitution, to attend and vote for the undersigned at the Annual Meeting of members to be held Saturday, June 12, 2010 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 _____ 2010 _____
(Signature of member)

Please date, sign and return this proxy to the Secretary, Multiple Sclerosis Society of Canada, National Office, 175 Bloor Street East, Suite 700, North Tower, Toronto, ON M4W 3R8 by Friday, May 28th, 2010. Attention: Rosanne Portelance.

A role model in her community



Gayelene Bonenfant

Gayelene Bonenfant is a strong believer in the idea that it is better to give than to receive, and she's willing to put this belief into action. Gayelene first joined the movement in 2005 to end MS when her employer,

Athena Resources Ltd., became a generous donor to the Research Partners Program. Gayelene moved on to become involved with Persons Against MS (PAMS) in Alberta, as well as several fundraising events and the MS Ambassador's Program. Most recently, she became a member of the MS Society's Alberta Division board. In addition to her time and expertise, she made a

significant personal gift to the endMS campaign in December.

Gayelene's motivation is fuelled by her personal connection to MS and the many people she has crossed paths with over the years. "The main reason for my involvement is my sister, Merrilee, who was diagnosed with MS in 1999," says Gayelene. "But I literally cannot remember a time in my life when I didn't know someone touched by MS – it is present everywhere."

A role model in her community, Gayelene credits both her family and her community with her strong desire to give back. "I'm from a small community...where you learn to give back. I give what I am able to, both financially and in terms of my time and skill. To me, everyone has a unique opportunity to be a part of the solution – it's part of my personal philosophy." ■



To share your comment or story, please mail to the attention of Carol Kim or email to carol.kim@mssociety.ca.

To update your mailing address or subscription preferences, please contact your division office. Division contact information can be found at: mssociety.ca or you can call 1-800-268-7582 or email: info@mssociety.ca
To view this publication online, visit mssociety.ca/mscanada



The new Impact Report is coming!

Watch for this year's impact report (formerly annual report) in April at mssociety.ca.

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