

A Message from the President



Yves Savoie

It's always been a point of pride for me to be a part of a vibrant and forward-thinking MS community. From the 100,000 Canadians living with MS to the dedicated volunteers, donors and friends who support the Multiple Sclerosis Society of Canada, it's an honour to be a part of this period

of progress and promise.

Dr. Karen Lee, a driving force behind the roundtable discussions you'll read about in this issue, is someone whose passion for ending MS inspires us all. Dr. Lee is currently working to engage the MS community from every angle – patients, researchers, donors and friends – and her efforts have resulted in some of the most productive, inclusive conversations we've had in recent memory.

Greater input from the MS community is helping us raise the bar for MS research that will have an even greater impact. Thanks to the invaluable participation of people touched by MS, donors and researchers, together, we are celebrating a turning point in our approach to research. Research, we believe, should be collectively driven. Voices from the frontlines of MS must have a say.

As a supporter of the MS Society, you are an essential part of the progress we make inside and outside the laboratory. I hope that the advancements you read about in this issue of **Progress Report** bring you hope, and inspire a renewed commitment to our life-changing work together.

Thank you,

Yves Savoie
President and Chief Executive Officer
Multiple Sclerosis Society of Canada

Enhanced Collaboration Drives MS Research Forward

Without a doubt, Canadians living with multiple sclerosis are deeply invested in the future of MS research. With research outcomes having the power to affect their lives in the most personal of ways, it's no wonder the MS community is as engaged as ever in the world-class research being funded by the Multiple Sclerosis Society of Canada.

In a recent initiative spearheaded by Dr. Karen Lee, Vice President of Research at the MS Society of Canada, Canadians with MS and researchers sat down together for a series of group discussions as part of our ongoing efforts to identify and articulate the research priorities that have the most meaning to our community.

"I went into the conversations thinking that everyone involved would have really diverse interests," says Dr. Lee. "But in the end, we were all aligned."

"When I think of where we are today with research, we've come a long way."

– Dr. Lee

As we focus on building an ongoing, inspiring dialogue between the research community and Canadians with MS, we're excited to enter a new era of research – an era marked by enhanced collaboration and strong bonds of solidarity in our quest to end MS.

Building Momentum and Sustaining Hope

"When I think of where we are today with research, we've come a long way," says Dr. Lee. With momentum building as more and more promising news emerges from laboratories nationwide, the future is looking brighter by the day.

Three years ago, for

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Dr. Karen Lee
Vice President of Research, MS Society of Canada



Your Monthly Gift Can Help End MS

Join us today as a Partner in Progress

Making a monthly gift to help end MS is quick and easy – and it makes a world of difference. For the 100,000 Canadians living with this debilitating disease, every day is uncertain. Your gift, given reliably and securely each month, will help fund the research and support services that build a stronger future.

With 92% of our funding coming from generous donors like you, your monthly gift couldn't be more important. A \$7 or \$10 gift means so much. For us, it means a

stable source of funding and the ability to plan ahead.

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Visit us at www.mssociety/monthlygiving to join us as a **Partner in Progress**.

Thank you so much for your ongoing support.

MS in the News

Health Canada Approves TECFIDERA

Health Canada has approved Tecfidera (dimethyl fumarate, Biogen), a first-line oral therapy that has shown to reduce relapses and disease activity in MS.

Taken twice daily, Tecfidera was shown in clinical trials to significantly reduce relapses and disease activity on MRIs, and in one trial it reduced progression of disability. Health Canada's approval was based largely on results of two large-scale phase III studies of Tecfidera capsules, called Define and Confirm, which were conducted in people with relapsing-remitting MS. For further information on this and other updates, please go to www.mssociety.ca/en/help/msupdates/.

Identifying and Targeting Culprits of MS

MS Society of Canada Operating Grant recipient Dr. Nathalie Arbour and Master's studentship awardee Fatma Zaguia, both from the University of Montreal, have collaborated with leading scientists around a study which aims to identify a specific group of white blood cells that may have a role in MS.

The study looked at levels of different cell surface proteins on CD4 T cells that may contribute to the death of oligodendrocytes – the cells which produce myelin. They achieved this by collecting blood from patients with MS, and conducted a series of cell-based experiments to determine whether molecules such as NKG2C are associated with the toxic activity of CD4 T cells.

This research paves the way for the development of MS therapies that will specifically target CD4 T cells flagged by the NKG2C molecule, leaving other components of the immune system unharmed.

Risk and Reward in Stem Cell Study

Drs. Mark Freedman and Harold Atkins from the Ottawa Hospital Research Institute conducted a phase II Bone Marrow Transplantation (BMT) trial that included 24 patients who underwent intense chemotherapy followed by transplantation with the patients' own bone marrow stem cells. Following treatment, investigators observed diminished relapse activity, absence of tissue damage observed on MRI, and significant improvements in brain function. Positive results yielded from this high-risk but effective procedure prompted a follow-up investigation to gain a better understanding of the mechanisms behind the treatment.

A follow-up study, conducted by Dr. Amit Bar-Or from McGill University, revealed that a distinct group of T cells were absent in patients following stem cell transplantation. Dr. Bar-Or postulates that diminished activity of these T cells may account for the absence of new relapse activity. This finding enhances our understanding of MS, and could lead to modifications to stem cell therapies to achieve long-term remission while minimizing risk.

Living with MS

Pain Management and Increasing Restful Sleep

For people living with MS, chronic pain and sleeping problems are potentially serious issues that can drastically impact quality of life. In 2012, the Multiple Sclerosis Society of Canada and the National Multiple Sclerosis Society (USA) developed the 2012 North American Education Program (NAEP) on Managing Pain and Sleep Issues in MS.

The program DVD and accompanying publication feature presentations by top MS doctors from Canada and the United States who delve into issues ranging from how to talk to your doctor about pain and sleep to personalized treatment options. The program, offered through MS Society facilitated self-help and support groups, allows participants to break into groups to reflect on presentation topics and discuss symptoms, treatments and concerns in a supportive environment.

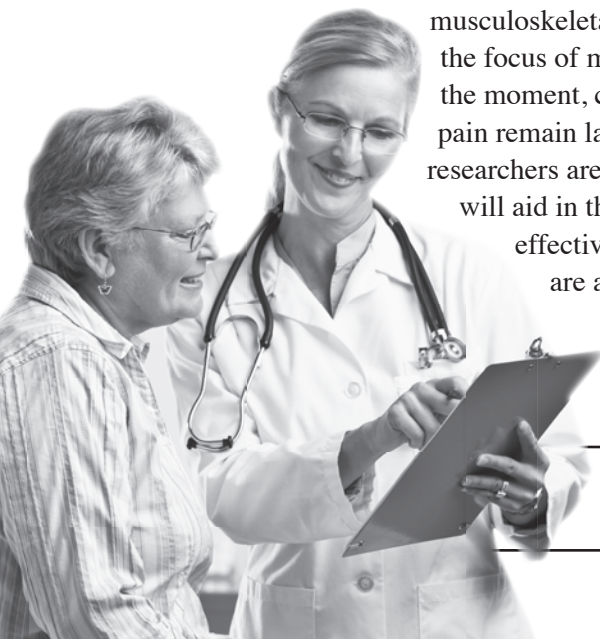
Talking About Pain is the First Step

Many people experiencing pain struggle to articulate their symptoms to their doctors. Pain, after all, can be difficult to put into words; quantifying it can be even harder. Throughout the program, participants learned about helpful techniques for documenting pain, such as keeping journals and notes to help identify patterns and triggers. Program participants were also encouraged to speak candidly with nurses who are involved in their treatment. *“Start with the nurse,”* advised Heidi Maloni, PhD. *“He or she can help you frame in a succinct way what to tell the neurologist about your pain.”*

Key presenters, including people living with MS, also discussed three categories of treatment options for MS-related pain. While there is no treatment regimen that applies to all individuals, a combination of medication, non-medicinal interventions, and complementary & alternative therapies are available and should be discussed on an individualized basis.

Fortunately, MS-related pain – both nerve pain and musculoskeletal pain – is currently the focus of much research. At the moment, causes behind MS pain remain largely unknown and researchers are pursuing answers that will aid in the development of more effective therapies. Researchers are also investigating better

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2013-2014 Annual Research Grants Competition

The National Board of Directors of the MS Society of Canada is pleased to announce the winners of the 2013-2014 Annual Research Grants competition. In total, 16 Operating Grants, 18 Postdoctoral Fellowships, 29 Doctoral Studentships and 3 Master Studentships were awarded.

Additionally, Dr. Ruth Ann Marrie of the University of Manitoba and Dr. Jacqueline Quandt of the University of British Columbia were awarded the Dr. Donald Paty Career Development Award. Dr. Marrie and Dr. Quandt will receive funding for three years.

Congratulations to all who received funding, and thank you to the many qualified applicants who participated in the competition. For more details, visit us online at www.mssociety.ca/en/research/researchdecisions.htm.

Congratulations

Our thanks go to the MS Society of Canada 2012 National Award recipients! Your leadership within the MS community and your commitment to ending MS is an inspiration to us all.

- **Norine Thomason,**
National Opal Award for Caregivers
- **Linda Lumsden,**
National Award of Merit, Member
- **Purdy's Sweet Day Glee Club,**
National Award of Merit, Non-Member

FACT: Pain resulting from MS is classified into two categories: Neurogenic (nerve pain) and Non-neurogenic (musculoskeletal)

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instance, oral therapies weren't available to Canadians with MS. Now, with Gilenya and Tecfidera, we have two. For patients who've been relying on painful injection treatments, oral therapies offer the hope and relief they've been waiting for.

Advances in repairing damaged myelin also inspire hope, as myelin repair, also known as remyelination, has the potential to restore function that has been lost to MS. With limited mobility affecting so many of the 100,000 Canadians living with MS, the promise held in myelin repair research hits incredibly close to home for all who live with the disease.

Research into progressive forms of MS is also showing tremendous promise. Though relatively few Canadians face progressive MS as an original diagnosis, relapsing-remitting MS often leads to a progressively debilitating disease form. Understanding all forms of MS equally is, without question, among our topmost priorities.

So too is research that is shedding light on the relationship between MS and depression, and the way in which doctors, patients and caregivers can come together to treat the whole person and not just the disease. MS is an emotional journey, and together we're finding ways to support Canadians as they navigate the inevitable ups and downs along the way.

Many Voices, One Community

Nationwide, the MS community extends far beyond those who are living with the disease. It is as strong as all the doctors, researchers, family members, friends and caregivers who are touched by MS day-in and day-out. As we've seen in Dr. Lee's group discussions, each of us brings so much energy and passion to our shared goal of ending MS. Each of us has valuable insight into the disease that will be instrumental in achieving future research advances.

"Helping researchers come up with new ideas is the best way to fight MS," says Patricia Rzechowka, a 24-year-old from Alberta who participated in one of the roundtable discussions.

Dr. Lee couldn't agree more. *"A person living with MS hearing directly from a researcher about their work is a powerful tool of hope."*

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ways to measure pain. With enhanced measurement capacity, doctors and people with MS will have a better framework from which to manage and treat MS-related pain. *"Pain research is in the midst of a renaissance,"* says Stephen G. Waxman, MD, PhD.

Strategies for Sleeping Soundly

When you're living with MS, a good night's sleep becomes even more essential. Poor sleep quality can affect balance and gait, leaving you susceptible to falls. Sleep also has a huge impact on emotional health and cognition.

A variety of MS symptoms, such as spasms, urinary frequency, restless leg syndrome, depression and anxiety may interfere with a good night's rest. Sleep apnea and restless leg syndrome are the most common sleep disorders found in people with MS. Program presenters offered plentiful "sleep hygiene" advice to help participants develop simple routines and habits that are conducive to falling and staying asleep at night.

Aside from lifestyle or "sleep hygiene" treatments, much conversation was devoted to sleeping treatments ranging from nighttime bladder management to special masks for sleep apnea. Participants were advised to avoid taking sleeping pills as a long-term solution to sleeping problems, as many sleeping medications lose their effectiveness over time and can even lead to addiction.

"Participants walked away with a renewed sense of hope"

Drs. Daria Trojan and John Kimoff of McGill University in Montreal, Quebec are just two Canadian researchers who are investigating the relationship between sleep issues, fatigue and MS. As researchers continue to pursue answers about MS-related sleep disorders, participants of the 2012 North American Education Program walked away with empowering information and a renewed sense of hope.



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