

# Progress Report

Vol 18 A PERIODIC NEWSLETTER FOR OUR LOYAL CONTRIBUTORS

**SPRING** 2014

### **A Message from the President**



already made tremendous progress on behalf of the 100,000 Canadians living with MS today. Thanks to you, the MS Society is funding world-class research – like the collaborative

Together, we've

Yves Savoie like the collaborative study on B-cells – to search for better treatments for MS.

To gain important insights from people living with MS, we recently implemented the Listening to People Affected by MS initiative to better understand the challenges persons with MS face. We also held a Research Priorities session to develop future priorities for research efforts with input from people with MS, their family members, donors, volunteers, clinicians, and researchers.

I'm heartened by the promise the future holds as well as by the strength of your leadership as a friend of the MS Society of Canada. Thank you so much for your solidarity in these days of incredible hope and promise.

MS may be threatening the health of our loved ones, but it's no match for our combined time, energy and generosity. In working together, 2014 will be a year of many inroads against MS. I'm very much looking forward to all that we'll surely accomplish together.

Thank you.

Yves Sayoie

President and Chief Executive Officer Multiple Sclerosis Society of Canada

### **Collaborate for a Cure**

With the support of the Multiple Sclerosis Scientific Research Foundation, three MS researchers from esteemed Canadian universities are on an ambitious path to uncover the role of a little-known fragment of the immune system in MS. This team of world-leading Canadian researchers is pioneering a collaborative research study on B-cells – cells within the immune system – that may lead to major breakthroughs and innovative therapies to treat this disease.

### Shifting Focus from "T" to "B"

In MS, the immune system mistakenly recognizes and attacks the protective myelin sheath in the brain and spinal cord. This



Dr. Amit Bar-Or



Dr. Alexandre Prat



Dr. Jennifer Gommerman

observation spawned much research into the full impact of the immune system, specifically the white blood cells, on the development of MS. To date, most of this work has focused solely on the T cell, a type of white blood cell whose errant activity has been observed in people with MS. As a result, treatments for MS have been developed to target T cells, and have so far led to marked improvements in patients. However, these therapies are only partially effective and have harmful side effects. This led researchers to search for other culprits of MS that need to be targeted in order to fully treat the disease.

Recently, another white blood cell in the immune system has been identified as a major contributor to MS: the B cell. The B cell, like the T cell, has been shown to promote inflammation in the central nervous system and has also been discovered in brain tissue of people with progressive MS, raising the possibility that B cells may contribute to disease progression and worsening of disability. New evidence shows that administering therapies which remove B cells from the body leads to a

### **MS** in the News

## New relapsing-remitting MS oral therapy approved

Health Canada has approved oral therapy AUBAGIO® (teriflunomide) for the treatment of people with relapsing remitting multiple sclerosis (RRMS) to reduce the frequency of relapses and to delay the accumulation of physical disability. A research trial showed that this therapy reduced the annualized relapse rate by 31% in people with RRMS. In addition, MRI data showed significant reduction in tissue damage in the brain.

## Gaining a better understanding of myelin repair

MS Society Doctoral Studentship recipients Ryan O'Meara and John-Paul Michalski, who work under the leadership of MS Society-funded senior researcher Dr. Rashmi Kothary at the Ottawa Hospital Research Institute, published an article in The Journal of Neuroscience which helps to understand the process of myelin production.

In MS, myelin is damaged by the immune system, and so determining how the lost myelin can be replaced is critically important to prevent nerve damage and accumulation of disability. Myelin is produced in the nervous system by cells called oligodendrocytes. In the article, O'Meara and colleagues reveal the important role of proteins which are essential for oligodendrocyte development and activity. Armed with this valuable information, Dr. Kothary's team can begin exploring ways of activating these critical proteins which will, in turn, enable oligodendrocytes to produce new, healthy myelin in people with MS.

# How Getting Fit Can Help Combat MS



Many research studies have shown that an active lifestyle may be helpful for people with MS in reducing their fatigue, improving their mobility, and enhancing their overall well-being.

"The rate of MS in Canada is among the highest in the world," says researcher Dr.

Latimer-Cheung. "Evidence indicates that engaging in exercise has the potential to improve and/or maintain functional ability, aerobic fitness, strength, fatigue and depression among people with MS. Unfortunately, many people with MS are physically inactive."

### A life-improving exercise guideline

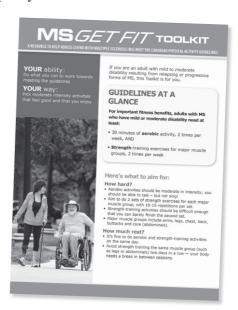
To help solve this problem, a research team lead by Drs. Amy Latimer-Cheung and Kathleen Martin Ginis conducted a systematic review of 54 studies related to MS and exercise, which lead to the creation of the Canadian Physical Activity Guidelines for Adults with MS, and accompanying easy-to-use *MS Get Fit Toolkit*.

"We identified the minimum amount of exercise and developed the guidelines from there," says Dr. Latimer-Cheung. "We want to ensure people living with MS have a good quality of life."

The Guidelines recommend that adults with MS who have a mild to moderate disability get at least:

- 30 minutes of moderate intensity aerobic activity two times per week; and
- Strength training activities two times per week

The Guidelines and the MS Get Fit Toolkit – which explains the benefits of physical activity and simple ways to get started exercising – are available online at mssociety.ca/physicalactivity/.



## **Advocating for People with MS**



Mobility, health, peace-of-mind – MS can rob people of so much. Beyond that, MS patients also face many social and economic challenges. That's why the MS Society of Canada advocates for people with MS to ensure they have the rights they deserve. Here are just a few of the issues that we're tackling head on:

### Catastrophic drug coverage for MS patients

Across Canada, people impacted by MS can face steep financial challenges in accessing treatments. While most provinces have taken steps towards establishing catastrophic drug programs, implementation of these programs is lacking in some areas. Together we must follow through on these vital programs.

### Support for people experiencing workplace challenges

People with MS often stop working due to inadequate transportation or because of insufficient accommodations and support at their jobs. We must advocate for change and a deeper understanding of the needs of people living with MS in the workplace, including the challenges of a disease that is often unpredictable and episodic.

### Help for those who can no longer work

Over time, up to 80% of people with MS can no longer work. Therefore the MS Society of Canada advocates for three key changes to federal programs:

- 1. Make Employment Insurance sickness benefits more flexible and useful for people living with MS.
- 2. Make it easier for people with MS to qualify for disability credits and benefits.
- 3. Make disability and caregiver tax credits fully refundable for low-income people to improve income security for caregivers.

Through our advocacy work in partnership with people impacted by MS, we hope to affect change within our social and economic systems.

To learn more and lend your support to our advocacy efforts, please visit 
mssociety.ca/advocacy.

## **Advocacy in Action**

For the last 15 years, Margaret has been advocating for better drug coverage in Prince Edward Island for herself and many others like her with MS.

"My doctor was clear about my needing treatment for MS," Margaret says. "But since I didn't have health insurance at the time and could not afford to pay for the medications, I could not be treated for my MS."

Margaret is a resident of Prince Edward Island, where, until October 2013, the 25% of residents without private health insurance were left vulnerable to the high cost of medications. Alongside the MS Society, Margaret took action to advocate for change.

Her actions are one of the reasons why the government of Prince Edward Island announced the development of a catastrophic drug



program. It doesn't require any premiums or fees to enroll, and it places no ceilings on drug costs or limits on participation. As of October, some Islanders are now paying as little as 3% of their income on medications, including those to treat MS.

Find out more about this program at mssociety.ca/atlantic.

# 1 DAY IN MAY...

## You can help end MS.

This May, you can help the MS Society to raise awareness about the experience of living with multiple sclerosis. Won't you join us.

### **PARTICIPATE**

## MS. WALK

EVERY STEP MATTERS.

Show Canadians that they don't have to face MS alone. To register, visit mswalks.ca/1dayinmay

### RAISE AWARENESS



Like our Facebook page to find out how you can support the 1 Day in May campaign. Facebook.com/MSSocietyCanada



Has MS helped you form a new and meaningful friendship? Tell us about it in a Tweet, and tag it #1DaylnMay.



Please join our advocacy efforts. Raise your voice and help make a difference. mssociety.ca/en/involved/advocacy.

### DONATE

Pick one day in May, and donate what you earn to help end MS. Go to mssociety.ca/1dayinmay to give.

To learn more, go to 1dayinmay.ca

## Collaborate for Cure... continued from page 1

dramatic reduction in relapses in people with MS.

That's why Drs. Amit Bar-Or, Alexandre Prat, and Jen Gommerman – from the universities of McGill, Montréal, and Toronto, respectively - have teamed up to unlock clues about this understudied, but critically important component of the immune system. They are now in the early stages of an extensive, multicentre study, entitled "B cells and MS: Who, What, When and Where". This collaboration will leverage critical resources and innovative technologies to fully explain the contribution of B cells in all forms of MS. This exciting collaboration holds the key to unlocking a new line of robust therapies that will specifically target the true culprits of this debilitating disease.

## Thank You for Everything!

## National Volunteer Week is April 6-12, 2014

More than 13.3 million people are giving their time, energy and passion to help make their community a better place. This National Volunteer Week, we want to thank each and every one of our MS Society of Canada volunteers.

From participating in our MS Walk and selling carnations for our Carnation Campaign to fundraising for our Friends & Family Drive and helping out at their local chapter, our volunteers are the lifeblood of our organization. We are so very grateful for their help.

## If you're not yet a volunteer, this is a great time to start!

If you'd like to participate in our Friends & Family or Neighbourhood Drives, you can find out more at

mssociety.ca/family&friends or call 1-800-361-2985.

Or, if you'd like to get involved with your local MS Chapter, simply contact your division office at 1-800-268-7582.

## **Get Involved this Spring**

### **World MS Day is May 28**

Access — or lack of it — is something that people living with MS know a great deal about. That's why the theme of this year's World MS Day is access — and the different types of access issues faced by men, women, and children with MS. Go to **worldmsday.org** to learn more.



EVERY STEP MATTERS.

#### Walk for a Cure

Want to change lives for the better? Participate in the MS Walk. This spring, you can help fund programs in your community and support groundbreaking research to help find a cure. Visit **mswalks.ca** for more information.



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