



Connections

INFORMATION FOR PEOPLE LIVING WITH MS

To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.

Pedal up!

Biking to the Viking

August 28-29

Riding Mountain Challenge

September 12-13



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MS Society of Canada, Manitoba Division
100 - 1465 Buffalo Place
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It's almost time to put those pedals in motion! The 21st annual Rona MS Bike Tour will take place in two Manitoba locations this year.

Whether you're taking part in the ride and raising money for the 2010 Tour or have pledged your support to someone who is, you're making a profound difference in the lives of over 3,000 Manitobans living with MS. All the money raised supports breakthrough research as well as the many client services and programs MS Canada offers to those who need them.

Over 600 will ride from Stonewall to Gimli on August 28th and back on August 29th. The 80 kilometre ride goes rain or shine.

On September 12th, approximately 350 cyclists will make the 70 kilometre journey from the Parkland Recreation Complex in Dauphin to Clear Lake in Riding Mountain National Park. The cyclists will return to Dauphin the next day.

MS Society wants to once again express its thanks to RONA for its tremendous support of the Bike event again this year.

Volunteer!

From Stonewall to Gimli, and the 80 kms in between, cyclists have a lot of ground to cover – and volunteers are there to help them at every turn.

Over 250 volunteers are needed throughout the weekend to make this year's Biking to the Viking a success and opportunities are as varied as the venues. Members, friends families of participants and those just wanting to come out for a good time while lending a hand all make up our team of dedicated volunteers – and it's not too late to join them!



Available positions include Check In, Banking, Parking, Photography, Route Marshals, Rest Stops, Site Set Up and Take Down, Finish Line Cheering, as well as Rest Stop and Finish Line BBQ volunteers. Locations and shift lengths vary, and sitting positions are available.

Our Volunteer Coordinator, Brandy Schmidt, will be happy to sign you up or answer any questions you may have. Please email her at brandy.schmidt@mssociety.ca or call (204) 988-0919.



CCSVI and MS: A new hypothesis that warrants urgent study

The MS Society of Canada mission: **“To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.”**

We will continue to provide quality programs and services that meet the needs of people whose lives are affected by MS; to listen to your concerns and comments; to raise funds for services and research; and to be available when you need our support.

MS Society of Canada: Acting quickly to find evidence-based answers

We have heard from many regarding Chronic-Cerebro-Spinal Venous Insufficiency (CCSVI). We have been reviewing and monitoring the latest information to share with our members. We share the hope and optimism of all Canadians touched by MS. We have moved to initiate additional research needed to better understand the promise of a possible treatment.

Last Fall, we requested research grants to study the relationship between CCSVI and MS to identify its treatment potential.

The MS Society of Canada and the National MS Society (USA) have committed more than \$2.4 million to support seven new research projects focusing on the relationship between CCSVI and MS.

The MS Society has asked the Federal Government to do its part. In May we asked that \$10 million be allocated to the budget of the Canadian Institutes of Health Research specifically for CCSVI research. Health Minister Leona Aglukkaq has asked how to

advance this research. By funding research we are helping ensure answers about CCSVI are found as quickly as possible. If evidence shows treatment of CCSVI is a valid treatment option, we will advocate to make testing and treatment widely accessible for people with MS.

The need for controlled studies and clinical trials of CCSVI

The goal of controlled trials is to objectively evaluate outcomes. In controlled clinical trials, studies are designed to deliver results that control the variables. This way a positive effect of the studied intervention can be attributed to the treatment itself, and not to variables such as drugs or other treatments. It requires a study design which allows for sufficient numbers, randomized to the current treatment standard, or to the research treatment and a methodology which wherever possible includes measures which are as objective as possible and, wherever possible, evaluation by a ‘blinded’ evaluator who does not know whether or not the subject being studied has received the treatment.

What are the dangers of not waiting for controlled studies?

15 years ago, hyperbaric oxygen was strongly recommended as an MS therapy. The MS Society funded a controlled clinical trial, involving one group of people who inhaled oxygen under pressure while sitting in a hyperbaric chamber and a second group who sat in the chamber but breathed normal air. At the end of the trial, there was no improvement in function in those who received pressurized oxygen versus normal air. The result was the end to claims and speculation about the value of hyperbaric oxygen as a way of treating MS.

Lyme Disease: The Great Imitator

This article was based on a presentation given to MS Society staff by Winnipeg researcher, Kathleen Crang.

Lyme disease (LD) is an infectious disease resulting from a bacterial *Borrelia* infection acquired through an arthropod/insect vector, primarily blacklegged ticks, but also flies, mosquitoes and others. The ticks are often so small that they cannot be seen by the naked eye. If untreated and left to the tertiary stage, LD can present with nervous system symptoms with a relapse-remitting pattern. Lyme disease has been misdiagnosed as MS around the globe, and the literature is rich with evidence that Lyme and multiple sclerosis are often difficult to differentiate. LD has also been misdiagnosed as lupus, ALS, fibromyalgia, chronic fatigue syndrome, depression and schizophrenia.

LD and MS occur in the same geographical parallels. It can cause demyelination, demonstrated by plaques on the MRI. Both can be characterized by relapsing-remitting flare-ups, fatigue and other neurological symptoms.

Early symptoms (days-weeks after infection) can include rash, fever/chills, headache and stiff neck. Symptoms that can appear at weeks-months are multiple rash sites, cardiac involvement and arthritis. Late symptoms (months-years) may be arthritis, rash, neuropathy (disease/damage of the nerves) and encephalopathy (disease/damage of the brain).



Diagnosis of LD can be confirmed by the appearance of a characteristic “bull’s eye” rash, but this does not always appear. Blood tests tend to be unreliable. There have been minimal lab-confirmed cases made in Manitoba since 1999. A clinical diagnosis is most often made. Early treatment with antibiotics is effective and important!



It is possible that some LD patients in Manitoba have been misdiagnosed with MS. Lyme disease needs to be considered when MS symptoms present, particularly when other multi-system symptoms such as cardiac, arthritic and skin problems also appear. An antibiotic trial is a low-risk telltale clue to Lyme disease and may be worth a try in these situations.

MS.

Client Needs Assessment Survey

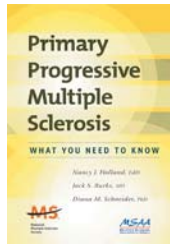
We want to take this opportunity to say **Thank You** to approximately one hundred members who took the time to complete and mail in the needs assessment survey sent out at the end of 2009. Your feedback helps us provide you with the programs and services that you need and want. In the coming year, we will be incorporating the results of the survey into our planning process so watch for new things to happen!

If you missed the chance to provide us with your feedback this time, we will be conducting further needs assessment surveys in the future. You are welcome to make suggestions and comments about our programs and services at any time by contacting a Client Services staff member.

MS.

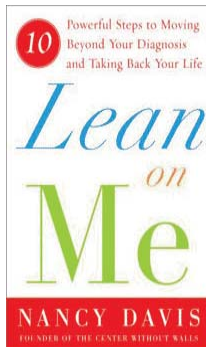
BOOKS

Primary Progressive Multiple Sclerosis: What you Need to Know by Nancy J. Holland, EdD, Jack S. Burks, MD & Diana M. Schneider, PhD; Dia-Medica 2010.



This book is part of a joint undertaking by the National Multiple Sclerosis Society and the Multiple Sclerosis Association of America to help meet the wide range of needs experienced by people with PPMS, their families and their health care providers. It addresses the physical, emotional and social impact of this less common form of MS. It also provides clear explanations of how MS affects the body's immune and central nervous systems, along with encouraging details about ongoing research and hope for the future.

This book is available from the Manitoba Division library. As well, a limited number of copies are available for members. To receive a free copy of the book and DVD, please contact Jan Hosking at 943-9595 or toll-free at 1-800-268-7582 or email at jan.hosking@mssociety.ca.



Lean on Me by Nancy Davis; Simon and Schuster 2007.

At the age of thirty-three, Nancy Davis was diagnosed with multiple sclerosis. Nancy learned about MS and created a new healthy lifestyle for herself. She shares her

personal step-by-step guide for taking charge of your own healthcare. Each step offers readers the strategies and strength to carry on when they are feeling overwhelmed and the

tools for actively seeking and receiving the best treatment. *Lean on Me* shows how to navigate the health care waters, find hope take positive action and celebrate progress. This is both an inspirational and practical book that you will find in the Manitoba Division library.



From the MS Clinic

New Physician joins the team!

Meet Dr. James Marriot. In July, the Neurologist began his work at the MS Clinic.

Dr. Marriot comes to the MS Clinic excited about this opportunity in Manitoba.

Having most recently been at St. Michaels Hospital in Toronto on a Fellowship, Dr. Marriot's primary responsibilities here will be to revamp and move forward with the clinical trials program at the Winnipeg based clinic. This would include such things as either investigating or initiating treatments and therapies for people with MS.

Dr. Marriot says clinical trails may include how factors such as diet, disease modifying medications and behaviours can affect people with MS. He looks forward to ensuring the MS Clinic in Manitoba is active in being a centre for new therapies for people with MS.

Dr. Marriot is a native of Burlington, ON. He received his Medical degree from the University of Ottawa, before moving onto his Fellowship at St. Michaels in Toronto.

Welcome to Manitoba Dr. Marriot!



Canadian Patient Summit

by Shirley Atkins

As a representative of the Manitoba Division of the MS Society I attended the first Canadian Patient Summit held in Toronto in March. There were over 100 patients plus an additional 100 stakeholders representing the provinces and regions of Canada. Some of the chronic conditions represented were MS, ALS, cystic fibrosis, lung disease, cancer, diabetes, asthma, arthritis, osteoporosis, adult congenital heart disease, spinal cord injury and paraplegia. Some of those interested in the proceedings included the Canadian Pain Coalition, aboriginal associations, public health/long-term/hospice associations, pharmaceutical companies, Alzheimer Society, MS Society and the Canadian Association of Wound Care who hosted the conference.

Conference chair, Karen Philip, outlined the conference challenges and theme as “it’s not about us without us”. In other words, patients need to be at the table with policy decision-makers. Currently there are choices in the economics of health care. The strong united voice of patients can influence those choices.

Keynote speakers included Deb Matthews Minister of Health for Ontario and Mark Stabile economics professor at the University of Toronto. Panel presentations included hospital administrators and professors as well as patients and politicians.

Patients detailed their own inspirational stories: How can I overcome obesity and diabetes in the north where no fresh foods are available and milk costs \$8 a jug? What can a patient do when professionals are more concerned with legalities rather than a patient’s chronic pain? How can we get help for arthritis in Halifax

where there is a shortage of rheumatologists? Why did a mother die of MS at age 55 in an old folks home? What about her daughter who also has MS, spending \$20,000 a year for medications while looking after her 10 year old daughter?

Workshops such as “living well when there is no easy access to health care” were lively. There were additional idea sessions divided by provinces and regions including the more remote parts of Canada. Patients voted on key issues to improve health care policy. Some of those issues included a patient led/patient based advocacy group that would encourage government action, and the idea of one patient/one record (electronic health card).

The plan for the Summit is to compile information from across the country, identify the most important issues affecting patients and then to present those issues to different levels of government. This year patients were heard. Next year politicians will be invited to tell us about their accomplishments. **MS.**



Shirley Atkins (right) with Deanna Groetzinger, Vice-President, Government Relations & Policy MS Society of Canada

Government Relations & Community Relations

United Way of Winnipeg Partnership



The United Way of Winnipeg has approved our request for a sustainable grant of \$366,000. Their generous support will be disbursed over a three year period. The grant will help to ensure that persons living with MS will have access to client-centred, continuously improved programs and services that will enable them to achieve the highest possible quality of life while living with the daily challenges that MS brings. We thank the United Way for this grant that will support programs and services in the Winnipeg area.

Supporting Persons Living With MS at Parliament Hill

In May, Darell Hominuk, MS Society Director of Client Services and Jennifer Moszynski, Vice Chair of the MS Society Board of Directors met with Members of Parliament, Kirsty Duncan, Anita Neville, Patrick Brown Steven Fletcher in Ottawa to address specific legislative changes that would support persons living with MS. A number of income support changes that would benefit people living with disabilities and chronic diseases were recommended, including caregiver support, Employment Insurance flexibility and the Disability Tax Credit. MPs were also urged to increase funding into CCSVI and MS research, at a time when some Canadians with MS continue to seek diagnostics and treatment for CCSVI elsewhere. Manitoba Division looks forward to continuing to work with MPs to shape a more inclusive and accessible Canada.

Ms Wasylycia-Leis Launches Bill to Extend Caregiver Tax Credit to Spouses of Persons with Disabilities

The MS Society of Canada congratulates former Winnipeg North MP Judy Wasylycia-Leis for launching a private member's bill that would allow spouses access to the federal caregiver tax credit. (shown at a news conference at the home of Lynn and Wayne Waterman). Although Ms Wasylycia-Leis has



since resigned, the Bill will proceed to the next step. The Bill also has the support of Hamilton Mountain MP Chris Charlton.

Health Care Professionals & Members Conference

Date: October 18, 2010

Location: Caboto Centre—1055 Wilkes Ave, Winnipeg

For more information, please call **943-9595** or visit

<http://mssociety.ca/manitoba/Client%20Services%20events.htm>

Meet Nadine Konyk, Rural Client Services Coordinator for Manitoba Division. Nadine is in her sixth year at the MS Society and is responsible for programs and services in rural areas within a 150 km radius around Winnipeg. Nadine is currently sharing her time with the Winnipeg office working on projects such as researching innovative ways of connecting via technology which can be utilized throughout the province to provide efficient ways of delivering programs and services. **For more information on programs in your area, please contact Nadine at (204) 988-0904 or 1-800-268-7582 or by email:**

nadine.konyk@mssociety.ca



Nadine Konyk, Rural Client Services Coordinator for Manitoba Division.

MS Society Self-help & Support Groups in Manitoba

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|------------------------------------|---|
| Teulon Support Group | 3rd Friday of each month, 11:30-1:30 |
| Lac du Bonnet Support Group | 4 times /year, Thursdays 11:30-1:30 |
| Selkirk Self-Help Group | Bi-Monthly, Mondays 7:00-8:30 |
| Portage la Prairie Self-Help Group | 4th Monday of each month, 7:00-8:30 |
| Morden Support Group | 2nd Tuesday of each month, 12:30-2:00 |
| Steinbach Self-Help Group | 2nd Tuesday of each month, 6:00-7:00 |
| Beausejour Self-Help Group | Last Wednesday of each month, 6:00-7:00 |

For information on these groups call Nadine Konyk at 1-800-268-7582 or 988-0904.

Westman Chapter

| | |
|-----------------------------------|--|
| Deloraine/Hartney Self-Help Group | Last Tuesday of each month, 1-3 pm |
| Brandon Out & About Support Group | 3rd or 4th Wednesday of each month, 6-8 pm |

For information on these groups call Cindy Stumme at 571-5671 or 1-800-268-7582.

Parkland Chapter

For groups in this area call Robin Searle at 622-2940 or 1-800-268-7582.

PRIMARY-PROGRESSIVE MS SUPPORT GROUP

- 4th Thursday of each month, 1-3 pm

SECONDARY-PROGRESSIVE MS SUPPORT GROUP

- 2nd Friday of each month, 1-3 pm

NEWLY DIAGNOSED GROUP

This is a program of education and support for those recently diagnosed with MS. It consists of four modules and two videos aimed at giving individuals facts about MS and tools for everyday life. **For information call your local client services staff or toll free 1-800-268-7582.**

Winnipeg Aquafitness Programs for Persons with MS: Can We Make Them More Accessible?

By: Katie Kitchen and Kaley Nicoll, Student Occupational Therapists, University of Manitoba

As part of our coursework for the University of Manitoba's Master of Occupational Therapy Program, we were interested in how people with MS are accessing the City of Winnipeg aquafitness programs. We were curious if people with MS had difficulties participating, what the challenges were and what made it easier for people to participate.

Aquafitness programs consist of exercises performed in water with a specially trained instructor. The City of Winnipeg offers them for persons with MS at Bonivital and Sherbrook pools. A review of research to date revealed that physical activity, particularly water-based physical activity such as aquafitness, offers physical, psychological and social benefits to persons with MS.

To gain an understanding of the barriers and facilitators to participation in local aquafitness programs, we talked to eight people with MS who had, or were, participating. Many spoke of increased flexibility and strength, as well as feeling as though they had something in common with others in class. All felt there were social benefits to participating in classes, including interaction and social outings.

All individuals spoke very highly of their instructors and other pool staff, including lifeguards, which are important factors in easing fears related to safety within the pool environment. Individuals in our discussion want to see more people with MS able to participate in aquafitness programs.

They identified a need for people with MS to participate in aquafitness programs. And they identified a need for one-on-one support to allow those with more severe symptoms of MS to participate.

Bonivital and Sherbrook pool facilities each had factors which made participation a challenge including small change rooms and a lack of accessible parking. But participants found that stairs leading into the pool (compared to traditional step ladders) made it easier to participate. Transportation to and from the pools was also described as a challenge.

For several people who wanted to participate in our discussions, seeing the advertising for this study was the first time they had ever heard about the MS specific aquafitness programs. This suggested a need for increased advertising of the programs.

The information we gathered from the study participants has allowed us to develop recommendations about how to increase the accessibility of the aquafitness programs in Winnipeg. The information we gathered was shared at the U of M Independent Study Research Symposium, where our peers, instructors and members of the community attended. We have further plans to share this information with Handi-Transit and the MS Society, Manitoba Division. We plan to assist stakeholders in looking at ways implement the recommendations from our study.

We enjoyed learning about aquafitness programs and appreciated the insights from all of our participants. Ellen Karr and staff at the MS Society of Canada, Manitoba Division, were instrumental through the duration of our study.

Active Living with MS

Over the past year, Client Services, Manitoba Division has heard your requests for more sessions related to healthy active lifestyles. Living with chronic illness or disability does impose some limitations on what you do and how you do it, but it does not mean that you cannot participate in activities that are fun, social and lively.

In October 2009, we held the **MS Active Living Day** in partnership with the Reh-Fit Centre. Around forty people participated in this one day event that included activities and presentations ranging from “How to start a fitness program” to “Healthy Eating” and “Managing Fatigue”. 89% of attendees found the program to be extremely beneficial. Most enjoyed the day. “An enjoyable way to spend the day and come away with helpful hints and practice to use on a daily basis.”

In May 2010, approximately fifty people came to the MS Society to enjoy a barbecue and to participate in **Achieving Independence: Active Living with MS**. Members heard about and tried out the *Magic* adapted golf cart (pictured), the *Trail Rider*, specialized bicycles and gardening tools. There were presentations on disabled sailing and adapted water-skiing. Dale Bullied of Carmen’s Cruisers motivated participants with his story about building an adapted bike so that his friend with MS could be an active participant in the RONA MS 150 Bike Tour. Special thanks to the Active Living Alliance for Canadians with a Disability, Disabled Sail Manitoba, Freedom Concepts, Water Ski and Wakeboard Manitoba and Shelmerdine Garden Centre who demonstrated that many leisure activities are accessible or can be made to be accessible. All it takes is creativity, perseverance and the genuine desire to participate actively in life.

Over the year, many members participate in yoga classes offered through the MS Society. Others join the MS Aquatics programs at the Sherbrook and Bonivital pools in Winnipeg and others around the province. We are happy to report that four people participated in a session with Disabled Sail Manitoba and had an opportunity to sail out on the high seas at Fort Whyte in July. Good for all of you!

This year the Manitoba Division will continue to encourage members to join these activities as well as programs being offered at the Taoist Tai Chi Society, the Rady Jewish Community Centre, the Reh-Fit Centre, the Wellness Institute and fitness programs at locations throughout the province. To find out more about active living options for you, please contact the Client Services staff in your chapter/area.



FUNDRAISING
We Painted the Town Red!!

The 2010 Manitoba Lotteries MS Walk was a huge success! Thanks to the work of walkers and volunteers, Manitoba walks raised **\$709,541**.

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|------------------------|-----------|
| Flin Flon | \$13,453 |
| The Pas | \$14,476 |
| Parkland Eco-Challenge | \$20,694 |
| Lac Du Bonnet | \$21,511 |
| Steinbach | \$24,716 |
| Portage La Prairie | \$27,840 |
| Morden | \$28,119 |
| Westman | \$69,223 |
| Winnipeg | \$489,509 |

A special thanks to the team captains and top fundraisers, who dedicated themselves to taking a few extra steps to end MS, by holding their own fundraising events like socials, BBQ's and book sales, in order to raise as much money as possible. On Walk day, they dressed up, carried banners and called out cheers as they painted the town red. Congratulations to all the walkers and to the 2010 Top Fundraisers:

| | | |
|--------------|-------------------|----------|
| Flin Flon | Tara Dewhirst | \$1,840 |
| The Pas | Robert Jackson | \$6,765 |
| Parkland E-C | Ray Lozinski | \$11,903 |
| Lac D-B | Paul Chapman | \$8,655 |
| Steinbach | Christine Janzen | \$3,045 |
| Portage | Vic Pople | \$1,950 |
| Morden | Scott Cherewayko | \$3,070 |
| Westman | Jessica Moskaluke | \$2,355 |
| Winnipeg | Colin Findlay | \$17,039 |

Top Rookie Fundraiser – Brian Lerner \$9,564

Top Fundraising Team – Mass Synergy
\$20,950

Provincial Top Fundraiser – Colin Findlay
\$17,039



Donate-a-Dollar in support of MS

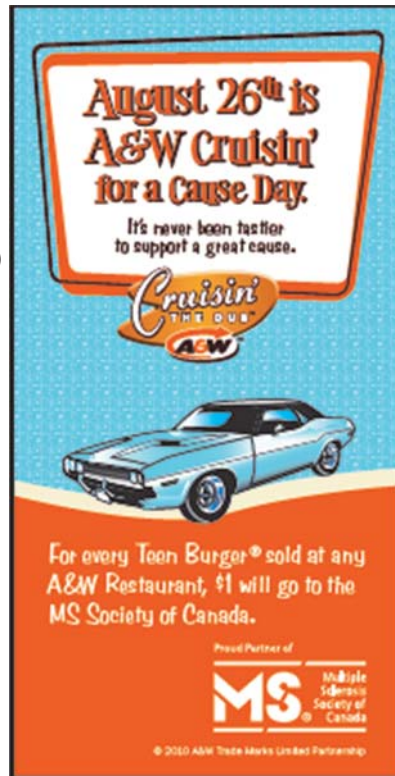
The MS Society and the Manitoba Liquor Control Commission are teaming to end MS.

The MLCC has chosen MS Society as one of its charity recipients for the **Donate-a-Dollar** program. The fundraiser encourages customers to donate a dollar at the checkout counter in support of MS programs and research.

The MLCC runs the Donate-a-Dollar program for one week in both spring and fall, featuring a different charity for each week. The MS Society is excited to be featured as the MLCC Donate-a-Dollar Charity for the fall campaign.

Don't miss a chance to help the MS Society and MLCC end MS by visiting a Liquor Mart September 13-19 and donating \$1. **MS.**

Buy a Teen Burger: Cruisin' for a Cause



Your dinner plans or lunch plans are set on August 26th.

For every Teen Burger sold that day, A & W is donating \$1 to the MS Society of Canada. It's A & W's largest joint partnership with a non-profit since A & W opened its first restaurant in 1956.



Manitoba Division Client Services Staff

Client Services is made up of staff and volunteers providing a wealth of knowledge, experience and commitment. Staff members provide services directly and assist volunteers in helping people with MS to help themselves. You can reach them via the MS Society's toll-free line: **1-800-268-7582** or at the following phone numbers

Darell Hominuk, Director of Client Services
(204) 988-0907

Nadine Konyk, Rural Client Services
Coordinator, (204) 471-0402

Cindy Stumme, Client Services Manager,
Westman Chapter, (204) 571-5671

Robin Searle, Client Services Manager,
Parkland Chapter, (204) 622-2940

Deanna Austin, Social & Recreation Program
Coordinator, Winnipeg, (204) 988-0905

Ellen Karr, Client Services Coordinator,
Winnipeg, (204) 988-0917

Support a Rider. Help gear up to end MS and donate to a rider for a Bike Tour in Manitoba. Details at...

www.ms biketours.com



Contributors:

Thank you to the following people for their contributions to this issue:

Shirley Atkins, Deanna Austin, Kathleen Crang, Darell Hominuk, Shauna Jurczak, Ellen Karr, Katie Kitchen, Nadine Konyk, Kaley Nicoll, Brandy Schmidt, Robin Searle, Duncan Stokes, Cindy Stumme

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Multiple Sclerosis Society of Canada, Manitoba Division

100-1465 Buffalo Place
Winnipeg, MB R3T 1L8
Phone: (204) 943-9595 or 1-800-268-7582
Fax: (204) 988-0915
info.manitoba@mssociety.ca
www.mssociety.ca

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