

# MS® 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.



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Manitoba Division

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100 - 1465 Buffalo Place  
Winnipeg, MB R3T 1L8

## The Money Trail

Have you ever wondered how the MS Society of Canada, Manitoba Division is funded? Where do we get the money to provide the wide range of programs and services that are vital to Manitobans whose lives are affected by multiple sclerosis? The dollars come from a variety of sources. A number of people think that the MS Society is funded by the government; however, government funding is not provided. Our financial support comes from our own fundraising activities, donations, bequests and grants from the United Way.

### Our Fundraising

In Manitoba, our special events are the largest contributor to our financial well being. These include the various MS Walks, Bike Tours, Hit A Ball programs, and other fundraising events. Our Fund Development team, Communications Manager and Volunteer Coordinator, along with hundreds of volunteers work at a feverish pitch through our special events season to plan and carry out some of the very best fundraisers in Manitoba, and across Canada for that matter! Our mandate is that the monies raised are shared equally between Programs/ Services and Research.

The events draw thousands of participants that translate into tens of thousands of donors to the MS Society. In addition to participants, volunteers who assist with the events also sign up sponsors, thus increasing our fundraising dollars. Teams are finding innovative ways to bolster their fundraising by holding large events such as socials and book sales.

### United Way

The United Way ensures an essential network of programs and services by providing support to nearly 100 agency partners in Winnipeg and many more

throughout the province. The Manitoba Division of the MS Society of Canada receives funding from the United Way of Winnipeg for programs and services that are delivered to residents of Winnipeg. There is a very involved and detailed application process that occurs every four years including an annual reporting structure that ensures that the funds are being used as designated. Thus far, the United Way of Winnipeg has been very satisfied with the performance of the Winnipeg Client Services and continues to provide funding for existing and new programs and services. Portage la Prairie and Morden are also recipients of United Way grants that support the provision of programs and services to people in those communities.



Client Services Coordinator Ellen Karr stands next to United Way awards won by Manitoba Division

The Manitoba Division office is committed to holding a United Way Campaign every year in October. This year, our office demonstrated 100% participation in pledging our support of the United Way.

### Donations and Bequests

A smaller proportion of monies come from donations that are made by individuals or

groups. Some of these are donations in memoriam or in honour of an individual or a special occasion. A bequest is a gift left in a will to a charitable organization like the MS Society of Canada. If you would like to make a donation to the MS Society, Manitoba Division, please call **Jan** at **943-9595** or **1-800-268-7582**.

If you are interested in more detailed information about the financial situation of the MS Society of Canada, Manitoba Division, you are welcome to read the 2009 Annual Report that will be available from the Manitoba Division office, and online, later this year. Another way to learn more about the Manitoba Division is to attend the Annual General Meeting that takes place in November each year.

**MS.**

## Living with MS

### MS Active Living Day

On Thursday, October 22, approximately 40 people living with MS in Manitoba gathered for a new and exciting program offered by the Manitoba Division in partnership with the Reh-Fit Centre in Winnipeg. The Reh-Fit Centre is a not-for-profit organization with a mission to enhance health and well-being through innovative health and fitness services in a supportive environment. The one-day event funded by a grant from Manitoba in Motion offered a combination of education, physical activity and social interaction with a focus on wellness and healthy active living. Keynote presentations on The Kaleidoscope of Change and Laughter for Healthy Living were well received. Each participant attended two break out sessions of their choice on topics such as Healthy Eating, Starting a Fitness Program,

Meditation, Energy Conservation and Chair Fitness. The day included refreshment breaks and lunch, all for a minimal cost.



There were plenty of different and challenging activities at the MS Active Living Day

Evaluations were almost all positive to glowing. As one participant stated, "An enjoyable way to spend the day and come away with helpful hints and practice to use on a daily basis." Manitoba Division staff were thrilled to see so many of our members having such a great time! We look forward to planning similar future events.

**MS.**

## Spend the holidays with us!

The holiday season is coming to the Manitoba Division. As always, we want to make this time of year special for our members with many enjoyable events:

### Portage la Prairie

Herman Prior Centre – Crocus Room  
Date: Wednesday, December 16th, 2009  
Time: 7:00 – 8:30 pm

### Morden

Morden Friendship Centre – Meeting Room  
Date: Tuesday, December 15th, 2009  
Time: 7:00 – 8:30 pm *continued p4*

### Steinbach

Steinbach 55 Plus Centre – Fireside Lounge  
Date: Thursday, December 17th, 2009  
Time: 7:00 – 8:30 pm

### Teulon

Teulon Memorial Hospital – Boardroom  
Date: Friday, December 11th, 2009  
Time: 11:30 – 1:30 pm

### Lac du Bonnet

Lac du Bonnet Legion  
Date: Thursday, December 3rd, 2009  
Time: 11:30 – 1:30 pm  
Please call **Nadine** at **471-0402** if you plan on attending any of the above events.



### Westman Chapter

Christmas Pot Luck Luncheon  
Riverbank Discovery Centre, Brandon  
Date: Saturday, November 28th, 2009  
Time: 11:30 - 2:30  
Please call **Cindy** at **(204) 571-5671** if you plan on attending.

### Winnipeg

Fort Rouge Leisure Centre, 625 Osborne Street  
Date: Wednesday, December 9, 2009  
Time: 7:00 – 9:00 pm  
Please call **Deanna** at **988-0905** if you plan on attending.



## Research News

### Care Given to People with MS by Family Members Presents Unique Challenges

**Study funded by National MS Society points to need for respite and mental health support for family caregivers**  
September 2, 2009

#### Summary

A study focusing on family members of people with MS with moderate to severe physical disabilities highlights the unique demographics of this population and their need for support.

#### Details

**Background:** Studies suggest that at any one time, an estimated 30 percent of people with MS require assistance and care at home, and that about 80 percent of that care is provided by informal, unpaid caregivers who are usually family members. This type of care is important if it helps people remain in their homes rather than move to a nursing home.

**Study Design:** 530 people, each of whom provided the majority of informal or unpaid care for a person with MS, were surveyed. The study survey focused on caregiving involving people with moderate to severe physical disabilities.

**Results:** The vast majority (78%) of informal caregivers were spouses, over half of them husbands. Forty percent reported that another caregiver was involved and half of these were a child. Thirty percent also reported that they had one or more paid caregivers, housekeepers, aides or nurses. Nearly half

reported providing more than 20 hours of care per week. This care ranged from household chores such as grocery shopping, preparing meals and managing finances, to personal care such as giving medicines or injections, assisting with bathing, etc.



The impacts of their informal roles as caregivers were significant. Over 40 percent of caregivers who were employed reported that their caregiving duties had caused them to reduce the amount of time they worked at their jobs over the previous year, and 77 percent who were employed had gone to work late, left work early or took time off because of their caregiving responsibilities. Ten percent of survey respondents reported that they could not work at all because of their caregiving responsibilities.

Among the challenges mentioned most often by informal caregivers, over half said they needed help finding time for themselves and nearly half needed help managing emotions and physical stress. About 26 percent of those surveyed felt that they would benefit from treatment or counselling from a mental health professional, but only about one-third of

those who identified this as a need had sought this help.

Despite the many challenges faced by informal caregivers, the overwhelming majority of survey respondents said that they were happy to help, that they found caregiving rewarding, and that they were proud of the care they provided.

The investigators compared characteristics of informal caregivers for people with MS against those of a US national study of informal caregiving not specific to the MS population, and found several aspects that make informal care providers for people with MS unique:

- MS is a chronic disease, and caregivers cared for the individual with MS for an average of 13.2 years, compared with the national average of 4.3 years.
- About 50 percent of the MS caregivers reported spending 20 or more hours per week providing care, versus 25 percent in the national study.
- MS caregivers were more often male spouses who lived in the same home as the person needing care; on the national level, most caregivers are females who do not live with the person needing care.
- MS caregivers were older, at an average of 60 years of age, compared to the national average of 46 years of age.

This comparison underscores the need for support for family members and other informal caregivers of people with advanced MS since, compared with US national averages for other conditions, caring for a person with MS often entails years of care in the home by an older spouse coping with the many challenges and symptoms that come with this chronic disease.

## Government and Community Relations Financial Future Planning

The Registered Disability Savings Plan (RDSP) is a tax-deferred savings plan that will help an individual with a disability to save for their long-term financial security.

Contributions to a RDSP will be eligible for the Canada Disability Savings Grant. There is also a Canada Disability Savings Bond for persons with a lower net family income. To be eligible for the RDSP, a person must be a resident of Canada and eligible for the federal Disability Tax Credit.

Currently, the Bank of Montreal (BMO Financial Group), Royal Bank of Canada and Imperial Bank of Commerce offer the RDSP. For more information or to set up a plan, please call the financial institution near you. In the next year, it is anticipated that more financial institutions will issue the RDSP.

To obtain more information, visit these helpful resources:  
[www.hrsdc.gc.ca/en/disability\\_issues/disability\\_savings/index.shtml](http://www.hrsdc.gc.ca/en/disability_issues/disability_savings/index.shtml) and  
[www.plan.ca/homepage.php](http://www.plan.ca/homepage.php). You may also call **1-800-O-Canada** (1-800-622-6232).

## Caregiver Tax Credit

As mentioned in the previous newsletter, Judy Wasylycia-Leis, MP for Winnipeg North, has agreed to sponsor a private member's bill which would allow spouses to claim the federal caregiver amount. This resulted because of the meeting Vice Chair of the MS Society Board of Directors, Jennifer Moszynski and MS Society Director of Client Services, Darell Hominuk had with

her in May in Ottawa. Darell and national Vice-President of Government Relations, Deanna Groetzinger later followed up with Ms. Wasylycia-Leis by teleconference over the summer. Ms. Wasylycia-Leis now has motion M-412 before Parliament calling for this change, and she continues to work with the Parliamentary Library drafters for additional improvements. The MS Society is broadening support for this effort with other health charities.

## Tysabri Update

In September, Ontario became the fourth province to add Tysabri (natalizumab) to the list of MS drugs that can be reimbursed for people with MS. Ontario has joined Saskatchewan, Alberta and Quebec in making Tysabri a second-line treatment therapy option. Currently, the MS Society is advocating for the inclusion of Tysabri on the Manitoba Drug Benefits Formulary.

Tysabri is used for the treatment of persons with relapsing-remitting MS. Listed as a monotherapy by the Common Drug Review, Tysabri reduces the frequency of clinical exacerbations, decreases the number of active brain lesions identified on MRI scans and delays the progression of physical disability.

**MS.**

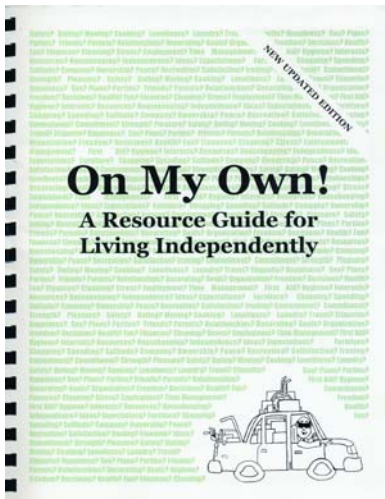
**endMS.ca**  
It's time. Give now.

Become a part of our goal to end MS.  
Donate now by calling the MS  
Society, Manitoba Division office at  
**943-9595 or 1-800-268-7582.**

## Book Reviews

### On My Own! A Resource Guide for Living Independently

by Canadian Abilities Foundation



This resource guide is designed to prepare people with disabilities for the transition to living independently. It covers everything from finding a place to live and setting up your new home, to throwing a party, to getting that

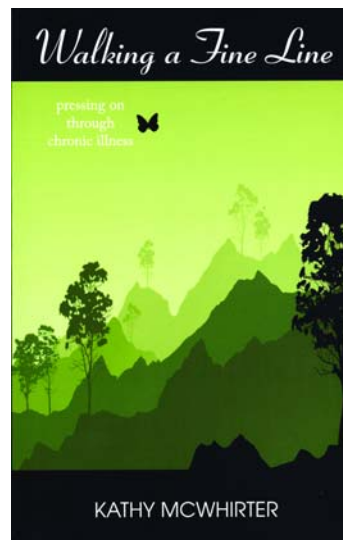
stain out of the carpet after the party! There are chapters on safety in the home, looking after yourself, housekeeping, cooking, getting along with others, time management and choosing your future.

This book is geared towards people just setting out on the path to independence. It is most suitable for young adults or those who have not previously lived on their own. Bonus is that being a Canadian book, the information and resources are all Canadian.

### Walking a Fine Line: pressing on through chronic illness

by Kathy McWhirter

This is the story of the author's journey through life with the added challenge of multiple sclerosis. The reader travels with her from the backwoods of Alberta where



she worked in Forestry and as a volunteer firefighter to the world of Special Education to "retirement" in Victoria, B.C. Along the way, while raising two daughters, she experiences many life changes including divorce, family losses and progression of her

MS. It is an interesting and easy read that many people, with or without MS, can relate to.

*Both these books are available in the library at the MS Society of Canada, Manitoba Division office at 100-1465 Buffalo Place.*

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### Watch for...

A new North American Education Program has just arrived in the Manitoba Division office. It is titled Clinical Trials: Solving One Piece of the MS Puzzle and includes a booklet and DVD. Various Chapters and areas of the Manitoba Division will be offering education based on this program in the coming months. Watch for further information.

**MS.**

## MS Society Self-help & Support Groups

### Winnipeg

These programs are designed to meet the needs for support and information for people with MS, family members, and others. All sessions are held at 1465 Buffalo Place unless otherwise specified.

<b>MS FRIENDS</b>	2nd Thursday of each month, 1-3 pm
<b>CHuMS</b>	3rd Thursday of each month, 1-3 pm
<b>MALE CAREGIVERS</b>	1st Wednesday of each month, 7-9 pm
<b>FEMALE CAREGIVERS</b>	1st Thursday of each month, 6:30-8:30 pm at various locations
<b>ON OUR OWN</b>	1st Friday of each month, 1-3 pm
<b>MOVING FORWARD</b>	1st Thursday of each month, 1-3 pm
<b>KILDONAN GROUP</b>	2nd Monday of each month, 1-3 pm at Kildonan Personal Care Centre, 1970 Henderson Hwy.

For information or to attend one of these self-help groups call Ellen Karr at 988-0917.

<b>PRIMARY-PROGRESSIVE MS SUPPORT GROUP</b>	4th Thursday of each month, 1-3 pm
<b>SECONDARY-PROGRESSIVE MS SUPPORT GROUP</b>	2nd Friday of each month, 1-3 pm
<b>NEWLY DIAGNOSED GROUP</b>	

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 on these groups call Nadine Konyk at 988-0904.

Are you interested in attending a four-session education and support program for people with Primary or Secondary-Progressive MS? These programs were rated highly by previous participants and complement the Primary and Secondary Progressive Support Groups. Call Ellen Karr at 988-0917 to put your name on the list.

### South East, South Central Chapters and areas outside Winnipeg

<b>TEULON SUPPORT GROUP</b>	2nd Friday of each month, 11:30-1:30
<b>LAC DU BONNET SUPPORT GROUP</b>	4 times /year, Thursdays 11:30-1:30
<b>SELKIRK SELF-HELP GROUP</b>	3 times/year, Mondays 7:00-8:30
<b>PORTAGE LA PRAIRIE SELF-HELP GROUP</b>	4th Monday of each month, 7:00-8:30
<b>MORDEN SUPPORT GROUP</b>	2nd Tuesday of each month, 12:30-2:00
<b>STEINBACH SELF-HELP GROUP</b>	2nd Tuesday of each month, 6:00-7:00

For information on these groups call Nadine Konyk at 471-0402.

### Westman Chapter

<b>DELORAINIE/HARTNEY SELF-HELP GROUP</b>	last Tuesday of each month, 1-3 pm
<b>BRANDON OUT &amp; ABOUT SUPPORT GROUP</b>	3rd or 4th Wednesday of each month, 6-8 pm

For information on these groups call Cindy Stumme at 204-571-5671 or 1-800-268-7482.

### Parkland Chapter

For contacts in this area call Robin Searle at 204-622-2940 or 1-800-268-7482.

## Fundraising Events

### A Successful Year for Fundraising

2009 has been an exceptional year for the Development Department at the MS Society with bigger and better - and greener - events.

Our Manitoba Lotteries MS Walks received a 50% increase in title sponsorship with our new partner Manitoba Lotteries. The MS Society is now securing a multi-year deal for title sponsorship with MLC.

Incorporating the two Winnipeg Walk locations into one gave Manitoba the largest MS Walk in Canada title. The Brandon Walk had the largest growth in the province with 15% year-over-year growth and a 4% growth in team participation.



RONA MS Bike Tour Biking to the Viking growth has been phenomenal across the board:

25% growth in participants  
18% growth in gross revenue  
12% growth in team members  
7% growth in team revenue

Register today to make 2010 another great success for MS Society fundraising. Go to [mswalks.ca](http://mswalks.ca) to register for the Manitoba Lotteries MS Walk or [msbiketours.com](http://msbiketours.com) for the RONA MS Bike Tours.



## Hit a Ball for MS Drives

### Another Great Golf Season



This summer, over 10,000 generous golfers, sponsors and hard-working volunteers in 150 participating tournaments across the province helped

raise more than \$60,000 to end MS! The weather was a bit unpredictable, but we can always count on the generosity of Manitobans. Thank you for a fantastic year!



Volunteer Jessica Moreno with participants at the Manitoba Pharmaceutical Association Tournament

Congratulations to our 2009 Hit a Ball for MS Raffle Draw Winners:

**Wes Shewchuk**, Brandon - 1st Prize: Two tickets via WestJet anywhere in Canada or the mainland United States (excluding the Northwest Territories. Max. retail value \$2,000)

**Gerda Laninga**, East St. Paul - 2nd Prize: 3-PW Taylor Made Tour Burner Irons and Bag Stand (retail value \$1,500)

**George Woods**, Winnipeg - 3rd Prize: Golf Shirt, Vest & Box of Taylor Made NS2D Golf Balls (retail value \$100)



## 2009 TeamMS Success Stories



The TeamMS program experienced it's most successful year to date in Manitoba. This is directly reflected in overall fundraising totals proving team members really do raise more money, have more fun, and come back to

participate more often than those who walk or bike alone.



Team Quivering Quads dressed in their finest at the Top Fundraiser VIP party at Biking to the Viking

### Biking to the Viking RONA MS Bike Tour Highlights

2009 saw a 12 per cent increase in Team Participants and a seven per cent increase in Team Revenue, at this years Biking to the Viking RONA MS Bike Tour. Successes to celebrate along the way include the Greatful Tread from The Great-West Life Assurance Company. They raised almost \$16,000 in 2009 than they did in 2008 and are a 59 person strong team. Quarry Physio Quivering Quads almost doubled their 2008 fundraising total in 2009, a

statistic almost unheard of in the current economy. Congratulations to Team Captain Ruby Laughren and the rest of her Quivering Quads on this amazing feat. Midland in Motion once again leads the Bike Tour TeamMS pack raising almost \$60,000 in 2009 due to their dedicated top fundraiser Bernie Lofchick for raising just over \$35,000 alone.

### Manitoba Lotteries MS Walk Highlights

The Brandon Walk showed incredible improvement in their TeamMS program, experiencing a 20 per cent increase in Team Participants and a 21 per cent increase in Team Revenue. Lac du Bonet almost doubled their number of Team Participants. These communities both showed incredible team spirit and should take great pride in the steps they took to end MS.

The Winnipeg Walk saw a three per cent increase in Team Revenue despite the hesitation some participants had about relocating the Walk to River Heights. This is largely due to successful rookie teams who were eager to embrace the new walk and the new location. Special recognition is extended to Team Pharmacy, Pro-Fitness Posse, Together for Heather, and Not MS-ing Out for their amazing first-time fundraising efforts. These four rookie teams alone brought the MS Society over \$41,000 in new funds to end MS.

### Looking Ahead to 2010 – Help Out with “Signs of Appreciation”

There are a variety of reasons why people walk or bike in MS events. Some do it for the athletic challenge, some for a family fun outing. But after participating in an MS Society event the majority of people return to participate because of the cause. They feel a connection to ending MS. They value seeing tangible results for their fundraising efforts. And they learn how many people throughout Manitoba are directly or

indirectly living with MS when they ask for pledges within their social circles.

The MS Society wants to show our participants "Signs of Appreciation." Throughout the year we will be collecting visuals to display at our events showing how much people living with MS appreciate everyone's fundraising efforts. This can be a photograph with a thank you note, or a homemade banner autographed by members of a MS social club. You can come out to cheer at a rest stop or finish line, or you can volunteer to write a short thank you line on Team T-shirts that will be proudly worn on event day. People living with MS need not identify themselves in order to create a "Sign of Appreciation." Be creative and help us plaster our events with "Signs of Appreciation."



If you have an idea for a "Sign of Appreciation" or would like to submit a "Sign of Appreciation" to be incorporated into one of our events, please contact **Jani Sorensen** at **988-0913** or e-mail [jani.sorensen@mssociety.ca](mailto:jani.sorensen@mssociety.ca).

**MS.**

## Get Involved

### Become a Client Services Standing Committee Member

You can help build strong programs and services for persons living with MS! The MS Society, Manitoba Division is currently accepting applications for the appointment of committee members to the Client Services Standing Committee. We are seeking 8 candidates from within Manitoba who are community-minded with a sincere interest in the well-being of persons living with MS and their caregivers, and who want to make a positive difference in their lives. Committee members serve on a voluntary basis and work together in an advisory role to the Executive Committee and the Board of Directors of the Manitoba Division in matters specific to Client Services.

#### Qualifications

Interested applicants should demonstrate a suitable combination of the following:

- Volunteer, professional or consumer experience with services provided to persons living with MS
- An understanding of the trends and needs impacting persons living with MS in their community
- Active involvement in community activities
- An understanding of the general principles of an advisory role

#### How to Apply

For more information and an interview, contact **Darell Hominuk**, Director of Client Services at **988-0907** or toll-free at **1-800-268-7582**, or via e-mail at [darell.hominuk@mssociety.ca](mailto:darell.hominuk@mssociety.ca).

**MS.**

## 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 directly at the numbers below:

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

**Nadine Konyk**, Rural Client Services Coordinator, South Central Chapter - Morden/Portage, South East Chapter - Steinbach  
**(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 and Recreation Program Coordinator, Winnipeg  
**(204) 988-0905**

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



**Be a walker.  
Be an end to MS.**  
register for 2010  
[www.mswalks.ca](http://www.mswalks.ca)

 **MANITOBA LOTTERIES**  
**MS. WALK**

EVERY STEP MATTERS.



### **Contributors:**

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

Deanna Austin, Chad Falk, Darell Hominuk, Shauna Jurczak, Ellen Karr, Stephen Kennedy, Nadine Konyk, Brandy Schmidt, Robin Searle, Shelly Smith-Hines, Jani Sorensen, Cindy Stumme

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100-1465 Buffalo Place  
Winnipeg, MB R3T 1L8  
(204) 943-9595 or  
1-800-268-7582

Fax: (204) 988-0915  
[info.manitoba@mssociety.ca](mailto:info.manitoba@mssociety.ca)  
[www.mssociety.ca](http://www.mssociety.ca)

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