

MS CONNECTIONS March 2008

Volunteer Legal Advocacy Program (VLAP) possibly coming to the Manitoba Division

What is the VLAP program? Coming from the MS Society, BC Division, VLAP is a program that provides members access to volunteers with legal and advocacy experience for legal advice and representation.

The program has two distinct areas. The advocacy section provides volunteers who can assist with issues relating to CPP disability, disability insurance, MS and human rights. Trained volunteers assist members with filling out forms, applications, appeals, meeting with employers to work out accommodation issues, and

applying for disability benefits, to name a few.

The legal representation section assists members in resolving legal issues with the help of lawyers who provide a pro bono service on behalf of the MS Society. Divorce, human rights and family law issues are just some of what members in the BC Division have had assistance dealing with.

Client Services staff report that members frequently call in about such issues and Ellen Karr, Client Services Coordinator, says that VLAP "will enable us to refer members to appropriate legal and financial resources that go beyond the scope of MS Society staff."

Development of new programs by the MS Society is guided by member interest. So, if this sounds like a program that you are interested in and would use, we need to hear from you. Please contact Susan Hologroski at susan.hologroski@mssociety.ca or 988-0901. If interest warrants, the next step would be to hold an information session.



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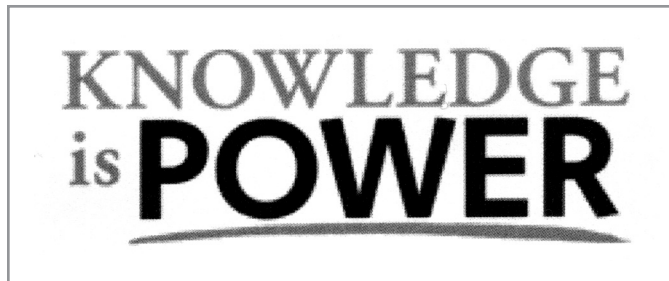
Editor: Stephen Kennedy

www.mssociety.ca

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:

- Jack Aldcorn..... Interim President
(204) 943-9595
- Tracy Brown..... VP of Client Services & Operations
(204) 988-0907
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Government Relations Manager
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(204) 471-0402
- Susan Hologroski... Manager of Information & Support Programming
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- Cindy Stumme..... Client Services Manager, Westman Chapter
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- 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



The **Knowledge is Power** (KIP) program is a free mail-out educational and support series for individuals starting to confront and cope with an MS diagnosis. KIP addresses common concerns and provides answers to frequently asked questions. Developed by the National Multiple Sclerosis Society in the U.S., KIP provides the reader with up-to-date information about MS. Receive a new volume every week for eight weeks in the comfort of your home. The topics include:

- What is MS?
- Dealing with your Diagnosis
- Working with your Doctor
- Treatments in MS
- Disclosing your Diagnosis
- Disease-modifying Treatments for MS
- The Impact of MS on the Family
- Maximizing your Employment Options

To register for the free mail-out subscription, call 943-9595 or our toll free number at 1-800-268-7582.

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Research News

Large-scale analysis from Nova Scotia suggests that disease-modifying drugs for MS are effective in reducing disability progression in people whose MS started with relapses

MEDICAL UPDATE MEMO

January 9, 2008

Summary

Murray Brown, PhD (Dalhousie University, Halifax, Nova Scotia) and colleagues developed estimates of drug effectiveness based on data from 590 people with MS treated with the drugs. Compared to estimated rates of progression before treatment, therapy was estimated to reduce progression in the EDSS by 90-105% over the course of the period studied in people with relapsing MS. The reduction in progression of the EDSS was 100-112% for patients with relapsing-remitting MS but only 8-22% for those with secondary-progressive MS. Although this study was

based on clinical observations and not on a well-controlled clinical trial, it provides much-needed evidence of the longer-term benefit of therapy.

Details

Disease-modifying drugs (DMDs) have been shown to reduce future disease activity for many individuals with relapsing forms of MS by reducing the frequency and severity of clinical attacks, the accumulation of tissue damage seen on MRI, and in some cases the progression of disability over the relatively short duration of the studies (usually approximately 2 years). However, research proving that these drugs can delay the progression of disability over the long term is lacking.

In this novel study (*Neurology* 2007 Oct 9;69(15):1498-507), funded by Health Canada, the MS Society of Canada, Nova Scotia Health Research Foundation and others, Murray Brown, PhD and colleagues used the Dalhousie MS Research Unit's database to track the course of 590 people with relapsing forms of MS. The database includes 25 years of clinical data on people with MS, including up to six years of data on people whose three classes of DMDs were paid for by Nova Scotia's Department of Health from 1998 to 2004.

The study population included 390 people with RR MS and 200 people with SP MS at an average of 8.9

years since disease onset. This study was “observational” meaning that the investigators were looking at this group of patients in a real-world setting and not in a controlled clinical trial. Annual disability (EDSS) progression was estimated for years before, during and after DMD treatment using statistical models.

The results suggest that the DMDs significantly delayed estimated EDSS progression in both groups combined by 90-105%. The effect was greater in those who began treatment and remained classified as RR MS in 2004 (100-112%) than in those who began treatment as RR MS or SP MS and ended up being classified as SP MS in 2004 (822%). Switching treatments was followed by significant estimated EDSS progression in those with SP MS, and stopping treatment also resulted in significant estimated EDSS progression in the group as a whole, although not significantly in RR MS and SP MS separately.

Aaron Miller, MD, Chief Medical Officer of the National MS Society, adds, “This study adds important information to our knowledge about DMDs, and hopefully will inspire future observational and controlled studies to further report on their ability to delay disease progression. These drugs remain the best defence available to reduce future disease course of MS.”

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Two year pilot study suggests that combination therapy with interferon Beta-1b and azathioprine may help slow the course of SPMS

MEDICAL UPDATE MEMO

January 11, 2008

Summary

A two-year study of azathioprine combined with interferon beta-1b (IFNB-1b) was carried out in 10 SPMS patients who had not responded well to IFNB-1b alone. The findings showed that:

- 1) combination therapy was safe and generally well tolerated;
- 2) annual relapse rate was reduced and there was a significant trend for EDSS improvement;
- 3) there was a significant improvement in neuropsychological tests after 2 years;
- 4) total lesion load measured by MRI decreased at 12 and 24 months.

Details

Combination therapy may benefit the subgroup of patients with secondary progressive multiple sclerosis (SPMS) who do not respond to interferon beta (IFNB). Researchers from Spain performed a two-year study of azathioprine (AZA) which is an oral immunosuppressive medication, combined with IFNB-1b in SPMS patients who had not responded well to IFNB-1b alone. Patients with SPMS were eligible for this non-controlled prospective study if they had two or more relapses requiring corticosteroid treatment or deteriorated by at least 0.5 points on the Expanded Disability Status Scale (EDSS) while on IFNB-1b in the year preceding the study. Patients were to continue treatment with IFNB-1b (8 MIU daily, subcutaneous) and received AZA (50 mg three times a day, oral).

Safety was assessed in terms of adverse reactions and laboratory measures graded according to the World Health Organization toxicity scale. Efficacy was explored by changes in relapse rate, EDSS, 9-hole peg test (9-HPT), neuropsychological scores, and magnetic resonance imaging (MRI) results. Neutralizing antibodies (NAB) were measured. Ten SPMS patients (6 females) with a median EDSS score of 4.5 were enrolled. One patient withdrew because of gastrointestinal complaints, one was withdrawn owing to poor compliance, and 8 patients completed therapy. The

only frequent side effect was lymphopenia, reported at least once in all patients. Annual relapse rate was reduced by approximately 50% in the second year. There was a significant trend for EDSS increase. Total lesion load measured by MRI decreased at 12 and 24 months; only one patient had active lesions. No changes were seen in the 9-HPT. There was a significant improvement in neuropsychological tests after 24 months ($p = 0.045$). One patient tested positive for NAB throughout the study, and transient NAB were detected in 4 patients. In conclusion, combination therapy with IFNB-1b and AZA was safe and generally well tolerated in patients with SPMS. Strict clinical and laboratory monitoring is recommended during this combination therapy. It is important to note that while this may suggest additional options for advancing SPMS, larger controlled trials would be necessary to confirm these results.

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MS Society Announces New Co-Chair

Manitoba Division is pleased to announce that Jennifer Moszynski was appointed as Co-Chair of the Government and Community Relations Committee last summer. Jennifer shares this important position with Co-Chair Ruby Laughren.

The GCRC is governed by a volunteer group of 13 members of the MS Society. Through government and community relations efforts, the goal of this committee is to ensure all people with multiple sclerosis in Manitoba have the opportunity to participate fully in all aspects of life.

Jennifer is currently Policy Advisor for the Associate Deputy Minister of Primary Care & Healthy Living, Donna Forbes. Jennifer completed a B.A in Philosophy (1998), going on to receive her Masters Degree in Political Studies (2003) in which she jointly studied Canadian Public Administration and Foreign Policy. Jennifer worked for the University of Manitoba and the University of Winnipeg as a research and teaching assistant from 1998 to 2003. Jennifer also sits on the Board of Directors for Manitoba Division.

Jennifer brings with her a tremendous breadth of knowledge and expertise to the committee. The MS Society

looks forward to working with Jennifer on issues that are of concern to people affected by multiple sclerosis.



DID YOU KNOW?

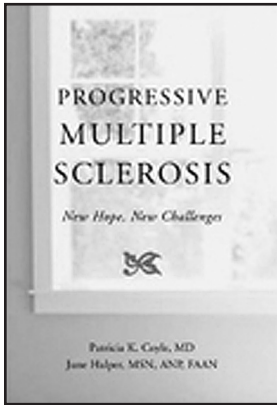
Our MS library has undergone several improvements making it even easier for you to find what you're looking for. It provides readers with ease of accessibility, clear signage, and best of all, reading space with comfortable chairs.

Books, audio and video are constantly reviewed, ensuring that only up-to-date and relevant information on MS is available. New books, DVDs and CDs about MS are regularly added to our library, giving you a multitude of subjects to read about.

Sign up for a free library card today and take advantage of the many and unique books, audio and video our MS library has to offer.

BOOK REVIEWS

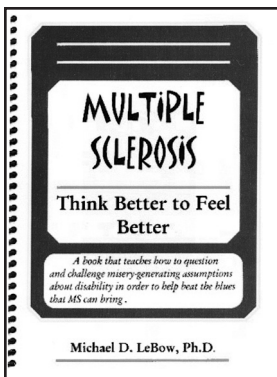
by Darell Hominuk



Living with Progressive Multiple Sclerosis: Overcoming the Challenges (2008)
By Dr. Patricia Coyle, MD and June Halper, MSN

This updated and expanded second edition uses clear

and understandable language to explore symptoms of progressive MS including treatments. The book covers the latest information on progressive MS such as diagnosis, disease modifying therapies, new drug treatments, management of difficult symptoms and coping strategies. Few pieces have been written on the subject, making this book an invaluable resource in health care.



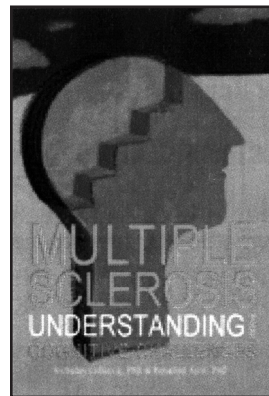
Multiple Sclerosis: Think Better to Feel Better (2005)
By Michael D. LeBow, Ph.D

This book offers a revealing perspective on five "misery generated disability assumptions" that a

person can undergo after diagnosed with MS and then guides her/him to think differently in order to feel happier, more upbeat, and more hopeful.

The author attempts to empower the reader by helping them to face the obstacle in front of them and overcome it. The reader becomes more compelled to re-examine themselves and the world around them. Written simply and with clarity, it convinces one to adopt a new perspective on experiencing life's simple things and its best rewards.

If knowledge is power, then this book is for anyone who wants to gain some new ideas on how to better cope with the ever-changing challenges that MS brings. Michael lives with MS and is a professor of clinical psychology at the University of Manitoba.



Multiple Sclerosis: Understanding the Cognitive Challenges (2006)
By Nicholas LaRocca, Ph.D & Rosalind Kalb, Ph.D

This comprehensive book is the first to discuss cognitive

dysfunction related to MS, including the changes that can occur, assessment and treatment, and strategies for dealing with the impact of daily life. Written for people living with MS, their families and caregivers, the book is both approachable and understandable. Little has been written on this important topic, making this book an invaluable reference.

MS Awareness Month

EVENTS

May 13 – Achieving Independence: Travel 101

This educational event will take place on Tuesday May 13th from 6:30 - 8:30 p.m. in the Program Room at 1465 Buffalo Place. This is an opportunity to hear presentations from specialists in travel planning, traveling with medications and travel insurance for people living with disability/chronic illness. There will also be displays of information and a chance to “ask the experts”!

To register for this free session or for more information, please call Ellen Karr at 988-0917 or email at ellen.karr@mssociety.ca

May 15 – Brain Awareness Days

The University of Manitoba is hosting a series of events as part of a world wide Society for Neuroscience “Brain Awareness Week.” At St. Boniface Research Centre along with presentations, poster sessions and science fairs, the MS Society has been invited to set up a booth highlighting the MS Society, programs and services, research and fundraising activities.

May 20 – Display at Health Sciences Centre

The MS Society has once again been invited to set up a booth at HSC promoting the MS Society of Canada, Manitoba Division activities.

FORGING NORTH – Supporting those with MS and their families throughout Manitoba and beyond

The mission of the MS Society continues to be a central to all programs and services at the MS Society. Ensuring that anyone who has MS and their families receive the support that they need is a priority. Recently Susan Hologroski, Information and Support Services Manager, has begun working with Health Care Professionals from the Burntwood RHA, Community Health Promoters and local Hospital and Clinic Staff to raise awareness of services available to those in communities such as Lynn Lake, Norway House, Thompson and Leaf Rapids. The project is in its infancy stage. The hope is to develop a Professional Registry for those working in the Health Care field to refer anyone requiring resources, education or support to the MS Society.



MS Society Hosts Health Care Professional & Members Conference

**Gender and MS
Saturday, November 15, 2008**

Manitoba Division is pleased to announce the third biennial conference developed for the health care professional involved in the care of people with MS, and for people affected by MS.

The Multiple Sclerosis Society of Canada, Manitoba Division is holding a unique conference delving into many important areas about MS, including treatments, effects on the family, and emotional aspects of the disease. Whether you are a health care professional or a person living with MS, you are sure to gain new insights into the challenges of life with MS and improved ways to cope with/treat individuals with MS.

Leading experts from across North America will be presenting on a variety of topics including:

- Research Updates and MS Clinic Updates
- Mind, Matter and Myelin: The Affective, Behavioral and Cognitive Issues of MS
- Sexual Health and MS
- Bladder and Bowel Problems
- Parenting with MS (Kids to Teens)
- Pregnancy, Menopause and MS

- Caregiving: Healing Ourselves While Healing Others

The MS Society is pursuing accreditation from the following organizations:

- Royal College of Physicians and Surgeons
- Manitoba College of Family Physicians
- Manitoba Pharmaceutical Association
- Canadian Ophthalmological Society
- Opticians of Manitoba
- Massage Therapy Association of Manitoba Inc.

The conference is still in the planning stages. More information will be presented in the next MS Connections newsletter. The above schedule is subject to change.

Please direct questions to Darell Hominuk at 988-0902 or toll free at 1-800-268-7582.



Children and Teens with MS Return to Summer Adventure Camp in Summer 08!

In August 2007, the MS Society of Canada, in collaboration with Easter Seals Camp Merrywood and support from the Paediatric MS Clinic at the Hospital for Sick Children, offered the first-ever Canadian camp for children

and teens with multiple sclerosis (ages 7-19). The Summer Adventure Camp was generously funded by the RBC Foundation and an anonymous family foundation.

The camp was held at Camp Merrywood, a 30-acre site located on the banks of Big Rideau lake, near Perth, Ontario. Fully accessible, the camp offered participants a wide range of activities including sailing, swimming, kayaking, sports and games, crafts, drama, an overnight camping trip and more. The participants also met Aaron Solowoniuk, drummer from the punk rock band 'Billy Talent', and committed supporter of the MS Society of Canada through initiatives such as the MS Scholarship Fund.

Evaluations by both parents and camp participants were compiled after the 2007 camp. The results were overwhelmingly positive. Based on this input, one of the only changes for camp 2008 is that it will be held for a full week, rather than just three days.

This summer, children and teens with MS will again step away from their daily lives with MS for a week long **Summer Adventure Camp** from **August 9th-15th, 2008**. Stay tuned for information about how to apply in spring 2008 by checking the MS Society website www.mssociety.ca or by calling 1-866-922-6065.

ACHIEVING INDEPENDENCE: TRAVEL 101

Do you dream of faraway places, exotic destinations or even local Manitoba



resorts but wonder whether you can make this dream a reality? Has living with multiple sclerosis stopped you from wandering from home? We have answers to your travel questions!

The MS Society of Canada, Manitoba Division is hosting an educational event, Achieving Independence: Travel 101 for people living with MS and their travel companions. This is an opportunity to hear presentations from specialists in travel planning, travelling with medications and travel insurance for people living with disability or chronic illness. There will also be displays of information and a chance to "ask the experts!"

The panel of presenters includes:

- Randi Gage, grief recovery specialist with experience in travel planning
- Mira Thadani, pharmacist
- Vince Stycke, insurance representative

Tuesday, May 13, 6:30-8:30 p.m.
Program Room, 1465 Buffalo Place

To register for this free session or for more information, please call **Ellen Karr at 988-0917** or email at ellen.karr@mssociety.ca.

MANITOBA SELF-HELP GROUPS

The MS Society understands the importance of bringing members together to support each other in dealing with issues and problems with MS. Member facilitated Self-Help Groups run all throughout Manitoba. If you would like to join one of our Self-Help Groups please contact the following staff in your area.

Parkland Chapter/Norman RHA

Robin Searle – 622-2940

Westman Chapter

Cindy Stumme – 571-5671

South Central Chapter (Portage la Prairie and Morden) Interlake

Nadine Konyk – 471-0402

Current Groups:

- Portage la Prairie
- Steinbach
- Selkirk

Winnipeg

Ellen Karr – 988-0917

Current Groups:

- Male Caregivers
- Female Caregivers
- CHuMS
- MS Friends
- Kildonan
- On our Own
- Moving Forward

Peer Support

People diagnosed with MS often find themselves filled with uncertainty as they struggle with the physical and emotional changes in their lives. Peer support is an alternative to coping with these changes alone. It is people in similar circumstances listening to each other, exploring ideas and identifying alternatives. A volunteer, trained and supervised through the MS Society, would be selected to match your specific needs. Peer Support contact is mainly by phone and is available throughout Manitoba.

To find out more about this program or to request a peer support volunteer, please contact Ellen Karr at (204) 988-0917 or toll free at 1-800-268-7582 or email at ellen.karr@mssociety.ca .



MS Classifieds **FOR SALE**

4 wheeled Shoprider Sovereign scooter

- Primarily used indoors
- New battery and charger
- Asking \$1600

HillRom electric hospital bed with vertical bar

- Asking \$1400

**Please call 467-7417 /
467-8531 / 461-2056 cell
Re: Gladys B.**

MS Discussion Forum

The Multiple Sclerosis Society of Canada, Manitoba Division has a unique on-line discussion forum that offers people living with MS the opportunity to post messages, receive responses and reply to others. Reaching a worldwide audience, **MS Discuss** has posted hundreds of messages and displays 15 different forums:

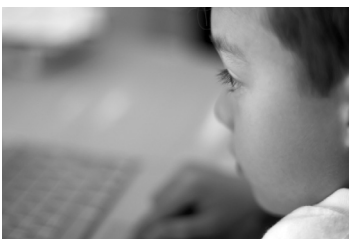
- *Questions and Answers about MS*
- *You've been Diagnosed with MS...*
- *Treatments, Therapies and Alternative Medicine*
- *Emotional Support*
- *For People with Primary-Progressive MS*
- *For People with Secondary-Progressive MS*
- *Financial Assistance*
- *For Kids with MS*
- *For Teens with MS*

- *20-Somethings*
- *For Caregivers*
- *Achieving Wellness*
- *For Women*
- *For Men*
- *Read any Good Books Lately?*

Visit www.msdiscuss.com and connect with other people who have common experiences and concerns. After all, no one knows more about what it's like to have MS than other people living with the disease.



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Upcoming MS Chat Rooms

All times listed are in Central Time

March 2008

www.msforkids.com

Thur., Mar. 20 7 p.m. to 8 p.m.

www.msforteens.com

Thur., Mar. 20 8 p.m. to 9 p.m.

www.msforparents.com

Tue., Mar. 18 8 p.m. to 9 p.m.

April 2008

www.msforkids.com

Thur., Apr. 17 7 p.m. to 8 p.m.

www.msforteens.com

Thur., Apr. 17 8 p.m. to 9 p.m.

www.msforparents.com

Wed. Apr. 15 8 p.m. to 9 p.m.

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MS Getaway Weekend 2008

All Aboard! The MS Society is pleased to announce the 4th Annual "Cruise Ship"

MS Getaway Weekend from Friday, June 20 to Sunday June 22, 2008 to be held at the "tried and true" Lakeview Resort in beautiful Gimli, Manitoba. Designed for people living with MS, their children, and caregivers, the weekend retreat will consist of indoor and outdoor activities, personal services, games, entertainment, food, awards/prizes, and opportunities for information sharing. The weekend is all about relaxation, having fun and meeting new people.

We all know how expensive it can be paying for hotels and motels on a vacation or weekend trip, not to mention the cost of meals and snacks at restaurants. The MS Society endeavours to provide a quality weekend to its members, while trying to keep the registration fees as affordable as possible. Every year, the MS Society substantially reduces member fees by subsidizing Getaway Weekend. For 2008, rising costs of accommodations, meals, services and activities has

necessitated the increase of registration fees. However, the event remains affordable! For example, the food, hotel, and registration fee for a family of four is only \$350, and entitles the group to a standard hotel room for two nights, food and participation in all planned activities, personal services and entertainment for Friday, Saturday, and Sunday. That's a savings of over 50%! This is one weekend trip that won't cost an arm and a leg!

A lot of the favourite activities are returning this year including aquatics, gentle Yoga, Tai Chi, bingo, mini golf, Bocce ball and golf. New activities this year include croquet, "Cruise" Games and arts & crafts. Get ready to relax and feel pampered with the many and various personal services including massage, reflexology, manicures, pedicures, mini facials and make-up applications. These are just a few of the many new and fun activities currently being planned for Getaway Weekend 2008.

Ensure that you fully complete the registration package and send it to us with your payment as quickly as possible. Due to increased demand, registration is limited and on a first-come first-serve basis. Registrations and fees can be mailed, faxed or dropped off at our office. Phone orders will not be accepted and rooms cannot be reserved in advance. The maximum number of people for a standard family size

room cannot exceed four. Reservations can only be made by the MS Society – no other reservations will be honoured. We reserve the right to change rooms for people who have special needs. Registration packages will be mailed to all current members of the MS Society during the first week of April. If you have not renewed your MS Society membership, please do so promptly to ensure that a registration package is mailed to you. You also receive a 20% discount on registration as a member.

Please contact Darell Hominuk at 988-0902 or 1-800-268-7582 for more information.



Disclaimer: The Manitoba Division of the MS Society is proud to be a source of information about multiple sclerosis. The content in *MS Connections* does not represent therapeutic recommendation or prescription. For specific information and advice, please consult your physician. Articles in this newsletter do not necessarily represent the position of the Multiple Sclerosis Society but are solely representative of the positions and opinions of the contributors.

CONTRIBUTORS

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

Tracy Brown, Darell Hominuk, Susan Hologroski, Ellen Karr, Stephen Kennedy, Norm Velnes

NEW Primary Progressive (PPMS) Support Group

Supporting each other, learning about nutrition and energy conservation are just some of the topics that will be discussed at the PPMS support group. "Getting together with others who are living with PPMS, and talking about problems and issues is what I am looking forward to," says one of the members of the newly formed group.

If you have Primary Progressive MS and you would like more information about this support group, contact Susan Hologroski at 988-0901 or susan.hologroski@mssociety.ca.

Group meetings are held in the Program Room at the MS Society #100-1465 Buffalo Place, the last Thursday of the month from 1-3 pm.





WALK in 2008 on Sunday, April 27
in Brandon, Lac du Bonnet, Portage la
Prairie, Morden, Russell, Steinbach,
Swan River and Winnipeg.

WALK in 2008 on Sunday, May 4 in
Flin Flon and The Pas.

WALK in 2008 on Saturday, May 10
in Dauphin.

Registration is on now!
supercitieswalk.com



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