

Member Profile

Gloria and Garth Teel

It is every parent's wish that his or her children be happy and live a long and healthy life. Sometimes, however, things don't go exactly the way we wish they would. In the case of Gloria and Garth Teel, MS made a lasting impact.

Eleven years ago, Gloria received a telephone call at work from her twenty-five year old daughter, Marina, who was living in Calgary at the time.

"They say I have MS," Marina told them.

Up until then, the Teels had no inkling that anything was awry. Marina was working at a hotel in Calgary. She loved her work and the city, had lots of friends and life was good. Although she'd been experiencing some vision problems, she hadn't mentioned anything to her parents. Gloria's first reaction was one of incredulity.

"We're a healthy family. We don't get things like that," she recalls saying when she heard the news.

It wasn't long before denial was no longer an option. Marina became quite ill

with classic MS symptoms. The Teels traveled to Calgary to be with their daughter and, while there, attended an informational seminar put on by the Alberta Division of the MS Society.



"It was shocking, but very informative," remembers Gloria. "I had known other families affected by MS, but really didn't understand much about the disease. I thought everyone ended up in a wheelchair."

When Marina became very ill during the first year after diagnosis, she returned to the family home in Winnipeg Beach. It was summer and the heat caused a great deal of discomfort, as it so often does for people living with multiple sclerosis. The Teels had air conditioning installed in their house.

"It was a relief to have her at home. I know it was difficult for her and we were a little overprotective but we felt bad to leave her in Alberta alone when we knew she wasn't well," Gloria admits.

Since that time, Marina has come a long way. After the first few years, she has not had many serious exacerbations. Now 36, she works as a pharmacy technician, is married, and is expecting a

child. Her employer is understanding and is flexible about Marina's work hours. Things seem to have fallen into place.

The Teels have been active in the local MS Society self-help group and find it helpful to talk to others with similar experiences.

Although the future remains uncertain, the Teels are philosophical about what it may hold. They are thankful that Marina has the inner strength to deal with the challenges of MS. They feel sadness, worrying that their daughter might not always be healthy and well, but they also feel fortunate that she has been able to continue to lead a fulfilling life.

"We're a lucky family," Gloria states. "I'm not one to worry too desperately. If something happens, we'll deal with it when it does."

As caregivers, the Teels have some wise words: *"The best thing you can do is get your signals from (the person with MS) as to how to treat them. And, take it one day at a time. If today is good, enjoy it."*

MS

A special session for individuals supporting and caring for people with MS, "**Enhancing Quality of Life for Caregivers**" will be presented at the November division conference, **Today, Tomorrow and Beyond: Learning, Coping, Sharing**, taking place Nov. 3-5. See page 3 for details.

Waiver: 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, however, represent therapeutic recommendation or prescription. For specific information and advice, consult your physician. Articles contained in this newsletter do not necessarily represent the position of the Multiple Sclerosis Society but are solely representative of the positions and opinion of the contributors.

Share your story with us:

Would you or someone you know like to share a personal story of living with MS? You could be our next Member Profile. Call **Gwenda Ramsay** at **988-0910** or toll free at **1-800-268-7582** if you are interested or would like more information.

Today, Tomorrow & Beyond: Learning, Coping, Sharing

Friday - Sunday, November 3- 5

**An educational conference on
living with MS**

Plan to attend this important event. Workshops, seminars and presentations are designed to meet the needs of people living with MS, caregivers and health care professionals. Friday and Saturday evenings offer opportunities to socialize.

Child care is available for children 5 years and under and interactive programs for young people 6 -11 and 12 -17 are also offered.

Highlights include:

Current Research & Treatment

- with *Dr. Maria Melanson, Neurologist, MS Clinic, Health Sciences Centre*

Panel on Invisible Symptoms

Developing a Support Network

- with *Dr. Ron Richert*

Enhancing Quality of Life for Caregivers

“Potholes & Roadblocks: Don’t Give Up!”

- Long Term Disability Insurance and CPP Benefits

Maintaining a Balanced Life through Humour & Play - with Barb Nolan

“Life is not a Dress Rehearsal - Get Real”

with *Moshe Stern, Associate Professor, University of Manitoba*

And lots more!

If you *did not* receive your conference package in the mail, please call Jan at **943-9595** or **1-800-268-7582**

Social Action Report

Another Busy Year Underway for the Manitoba Division Social Action



Committee

Sandy Popham, Chair,
Social Action Committee

The committee begins its year with a number of new items to report. Firstly, we are thrilled that long-time committee member **Sandy Popham** has agreed to chair the committee. Although we've managed to carry on without a chairperson for the past year thanks to our committed and hard-working committee members, having someone take on this leadership position can only strengthen and consolidate the committee's work. Many thanks to Sandy for stepping forward. We're still looking for someone to fill the vice-chair position to back her up and share some of the workload.

The committee has identified an additional new priority – the provision of a comprehensive, specialty MS Clinic with guaranteed funding and adequate resources. This item was top of the agenda at our most recent meeting with Health Minister Chomiak on September 7th, and will continue to be

addressed by the committee. Although there are MS clinics in most other provinces, such a much-needed service for Manitobans with MS does not exist here.

Meanwhile, work continues on our other priority issues – drug cost reimbursement for Betaseron® (treatment of secondary progressive MS), and long-term disability insurance and CPP. The Insurance Working Group is busy preparing a workshop for presentation at the Today, Tomorrow and Beyond conference in November. Titled "*Potholes and Roadblocks – Don't Give Up!*", the workshop is intended to educate people about dealing with different problems they may encounter, warn them about specific pitfalls and advocate for change. Check it out at the conference on November 4th.

And watch for future issues of the Social Action Update. The committee has decided to produce this once or twice a year as a way of keeping people informed about its activities and



encouraging them to get involved. If you would like



more information and/or would like to become involved, call **Sharon Segal, Social Action Coordinator at 988-0904 or 1-800-268-7582.**

MS Bulletin Board

FOR SALE

Amigo Scooter - 15 years old but in good condition.

MS

\$1000 or best offer

Call 947-0476

Hello and Good-Bye

Changes at the MS Society



Anyone who has contacted or visited the Manitoba Division of

the MS Society has been touched by something in which Michelle Gibbens has had a hand. As Services Director since 1997, Michelle has headed up the Individual & Family Services Department, ensuring the breadth and quality of services and programs offered to people with MS and to their families. Her caring attitude, practical nature and great attention to detail, accompanied by superior organizational and management skills have made her not only an extremely effective manager, but also a valuable and respected colleague.

As sorry as everyone is to see her leave the division, we are nevertheless thrilled by the fact that she is staying with the MS Society in her new role as Manager of the National Caregivers Special Assistance Program. In this part-time position, Michelle will work with staff and volunteers in Manitoba, Saskatchewan and Alberta as well as at the National level to develop and deliver this program comprised of three components:

- To provide direct financial assistance to family caregivers
- To provide educational initiatives for caregivers
- To conduct research into caregivers' needs

The J.W. McConnell Family Foundation funds the three-year pilot project. Its goals include:

- To enable the MS Society to look at current offerings
- To put forward other potential options for services and programs
- To provide creative and constructive solutions for support
- To meet caregivers' needs based on feedback received
- To better connect with caregivers

Michelle is pleased at this opportunity to stay involved with the MS Society. It will enable her to spend time completing her Masters in Social Work, while fulfilling her personal and professional commitment to the mission of the Society.

We know that Michelle will continue to make substantial contributions to the MS Society and we wish her only the best in her new position.

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Shauna Sheldon, formerly Special Event Coordinator with the Parkland Chapter, has recently accepted the positions of Coordinator of both the Southern (Morden) and Central Plains (Portage la Prairie) Chapters. Her primary responsibilities will be in the area of Individual and Family Services and administration. Shauna has been with the Society for just over one year and in that time has

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proven herself to be energetic and innovative - a real asset to the organization.

“ I am looking forward to meeting chapter members,” she says. “ I hope they will stop in and introduce themselves, use the services and check out the literature we have available.”

In Morden, Shauna will be busy recruiting new board members, while in Portage la Prairie, she hopes to get Tai Chi and Adapted Aquatics programs up and running by January.

Drop in and visit Shauna during these hours:

Southern Chapter:

Tuesdays, 9 a.m. - 5 p.m.

Central Plains Chapter:

Mondays, Wednesdays and Thursdays,
9 a.m. - 5 p.m.



Community Resources

WORKink Manitoba: The Virtual Employment Resource Centre

WORKink is an Internet-based employment centre specializing in employment resources for persons with disabilities. Through partnerships with agencies and employers across the province, it provides many resources available through conventional employment agencies, and it is available all day, every day through any computer connected to the Internet. Here's what you will find:

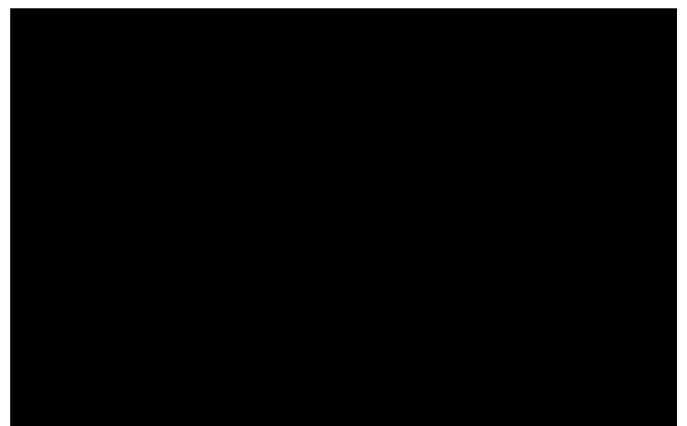
Current job postings and links to employers' web sites

Online employment counseling
Articles relating to employment, self employment, and disability
News releases
Electronic 'thank you' notes
Links to agencies, labour market information, job search tools and more
List of upcoming community events
Access to job accommodation information

Can't find it? E-mail your question and **WORKink** experts will find the answer.

WORKink Manitoba focuses on Manitoba's job market – written *for* Manitobans *by* Manitobans. All services are provided free of charge.

Visit WORKink Manitoba at
<http://mb.workink.com>



Members' Corner

Assiniboine Park Zoo Accepts Service Animals

by Geoff Fierce

Winnipeg's Assiniboine Park Zoo has proven that it is still one of the best and most innovative zoos in Canada, if not the rest of the world. In a country where there is no "Canadians with Disabilities Act", enforcing equal access everywhere, the zoo has shown that it is willing to be progressive - a leader in the community. It is the first large public zoo in Canada to allow guide dogs and their users to enter their premises. The Assiniboine Park Zoo embarked on a new era of cooperation with the disabled

community at large. Anyone wishing to take his or her service animal into the zoo should

contact Doug Ross, Zoo Director at 986-6925. He will arrange an orientation tour of the zoo. After having an orientation, they are welcome to the zoo during regular hours at standard fees.

Service animals include: Guide Dogs for the Blind/Visually Impaired, Hearing Dogs for the Deaf/Hearing Impaired and Assistance Dogs for the Physically Disabled. Animals must be registered as a service animal and have identification showing the owner and animal have been trained to work together by an accredited school or trainer.



Book Review

by June Vermeersch



The Kinder Side

Lyn Risidore

201 pages

This is a delightful book! A pleasure to read, while providing information, hope and inspiration for those with milder forms of multiple sclerosis. Risidore reminds the reader that:

"Undoubtedly, you tend to hear of the more severe cases and cannot help but picture yourself eventually ending up the same way" and that "two-thirds of people with MS are still ambulatory."

Risidore shares her own experience from a very personal perspective, as well as those of her children and spouse. Written in 1987, the book provides insight into a physician's viewpoint. Short stories from others with varying degrees and symptoms of multiple sclerosis are included.

Risidore does not undermine the serious impact MS has. Her writing brings a positive perspective to management techniques, and the psychological, physical and social aspects of multiple sclerosis.



Bone Marrow Transplantation Study

The Multiple Sclerosis Scientific Research Foundation is funding a multi-centre project to determine definitively whether transplanting bone marrow stem cells in people with MS can stop the disease. The Multiple Sclerosis Scientific Research Foundation is related to the MS Society of Canada, its main funding source. Dr. Mark Freedman (MS neurologist) and Dr. Harold Atkins (bone marrow transplant physician), both at the University of Ottawa are leading the study. It will involve 36 people with rapidly progressing multiple sclerosis who are likely to become severely disabled. Twenty-four of the participants will receive bone marrow transplantation, while 12 others with the same kind of MS, but not wishing to have the procedure will comprise the control group.

The study will be coordinated through the combined efforts of The Ottawa Hospital Blood and Marrow Transplant Program and the MS Research Clinic at The Ottawa Hospital. The study will also involve the MS Clinic at St. Michael's Hospital, Toronto, and the Bone Marrow Transplant Unit at the Princess Margaret Hospital, Toronto, as well as the MS Clinics at Notre-Dame Hospital and the Montreal Neurological Institute and the Bone Marrow Transplant Unit at the Royal Victoria Hospital, Montreal. Assessments

admission to the study will be carried out at the four clinics. Recruitment will begin in October 2000.

Participants must be able to travel to and stay in one of the treatment centre areas (Toronto, Ottawa, or Montreal) for periods of time during the treatment procedure

and be able to return periodically for monitoring. Repeated trips to Montreal for specialized MRI scanning will also be required for non-Montreal residents. The study coordinators will

assist with arrangements.

Myelin Gene Regulation Research Project

A project on myelin gene regulation funded by the MS Scientific Research Foundation was also announced this summer. This research is looking for the "switches" that turn central nervous system repair off and on. Dr. Alan Peterson, McGill University, is the principal investigator of this project and his collaborators work in laboratories at the University of Toronto, McGill University, Laval University and Pennsylvania State University.

In MS, the central problem is the attack by immune system cells on the myelin covering that protects the nerve fibres in the central nervous system, allowing them to transmit signals from the brain at lightning speed. When myelin is damaged, the nerve sig-

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nals are slowed or stopped, causing many variable MS symptoms.

The five laboratories will be studying the myelin production control system from different angles, allowing advances in knowledge to be made quickly.

In previous research, Dr. Peterson has shown the process of myelin maintenance (myelination) is different from that involved in myelin repair (remyelination). He has also indicated that these processes may be different in different areas of the central nervous system and that there may be gender differences as well.

In this new project, the focus will be on one important component of myelin, called myelin basic protein (MBP) and to identify all the regulatory mechanisms that determine how the MBP gene works. In previous work, Dr. Peterson found the MBP gene has dozens of molecular “switches” and that they have many levels of interaction. Understanding which molecules are involved and how they interact could lead to treatments involving switching the correct portions of the gene on or off to maintain myelin or to repair it after it has been damaged by MS attacks.



Who is a Caregiver?

In response to our recent promotion of the *Today, Tomorrow & Beyond* weekend event, we have had some questions about the workshop entitled *Enhancing Quality of Life for Caregivers*. The most common questions we have been asked are “Who is a caregiver?” and “Am I a caregiver?”.

The word “caregiver” can be used to refer to a number of different people who might be involved in the lives of someone living with MS. For example, sometimes health care professionals are referred to as caregivers. More commonly and for the purposes of the upcoming workshop, the term is used to refer to “informal” caregivers. In other words, well partners or spouses as well as other family and friends of persons with MS who care about and provide a range of support to them. In these instances, the caregiving is based on a personal rather than a professional relationship. Sometimes caregiving means simply “caring about” a person and/or providing emotional support. Other times, caregivers or support people might provide assistance with daily tasks and activities, sometimes including assistance with physical care.

The word “caregiver” can be used to refer to a number of different people who might be involved in the lives of someone living with MS.

The Multiple Sclerosis Society of Canada is launching a three-year pilot program to better understand the needs of informal, family caregivers of individuals with MS and to determine which services would be most helpful in meeting those needs. The Manitoba, Saskatchewan and Atlantic Divisions will be participating in this pilot program, funded by the J.W. McConnell Family Foundation. Over the next several months, the program will be developed to provide direct financial support, while incorporating educational opportunities and research on family caregivers’ needs. The focus of the program will be on providing creative and constructive responses to family caregivers’ self-determined needs for support. The development of

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program will begin this fall and additional information will be provided as it becomes available.

The *Enhancing Quality of Life for Caregivers* workshop being offered at the Today, Tomorrow & Beyond conference on Saturday, November 4, 2000 will be the first opportunity for family caregivers of Manitobans with MS to provide input and learn more about the pilot program. Additionally, participants will have an opportunity to meet and talk with other family caregivers about their needs.

For more information about the *Enhancing Quality of Life for Caregivers* workshop or the Caregiver Special Assistance Program, please contact **Michelle Gibbens** through the Manitoba Division office at **1-800-268-7582 or (204) 943-9595.**



Introducing... Your New & Improved Special Assistance Fund

MS Society chapters in Manitoba have provided financial assistance to persons with MS through special assistance fund programs for many years. For the last three years, the Manitoba Division has administered a Special Assistance Fund program for Manitobans with MS who do not reside within an existing chapter area.

The purpose of Special Assistance Fund programs is to provide financial assistance to persons affected by MS who are experiencing financial barriers to purchas-

ing services, aids or equipment that will enable them to enhance their quality of life.

The Manitoba Division, Individual & Family Services Committee is pleased to announce the approval of a new Special Assistance Fund Policy by the Board of Directors. It has been implemented effective September 1, 2000.

The new policy increases the maximum allowable amount of funding to \$300 from \$200 per fiscal year (September 1 – August 31) per household. Additionally, the range of services, aids and equipment eligible for funding has been expanded.

Important Special Assistance Fund Information:

MS The MS Society does not duplicate or replace funding available from other sources.

MS Applicants and staff administering Special Assistance Fund programs must ensure that all other funding sources have been explored.

MS Special Assistance funds are designed to meet a one-time or short-term need and not to provide ongoing financial assistance.

The new policy increases the maximum allowable amount of funding to \$300 from \$200 per fiscal year...

MS Applications will be processed on a first-come, first-served basis until the annual budget amount has been depleted. Once the annual budget amount has been depleted, no new applications will be processed until the new fiscal year.

For information or to request a Special Assistance Fund application form, contact your local chapter or the Manitoba Division office.

In Sickness and Health

by Carolyn Turnbull

Wheelchairs:

Black (Cdn. Wheelchair MFG)

Good condition \$430

Brown (Everest & Jennings)

lighter and smaller \$380

Call 489-4022 or (204) 746-8808

I recently received some health counsel from a caring relative. He regularly deals with a nutrition enterprise and these people alerted him to certain "wisdoms" about multiple sclerosis. He thoughtfully mailed me a copy, hoping that this would help somehow.

This researcher claims that MS is brought on by an infection of fluke parasites which attempt to reproduce in the brain. They are drawn to that site when the host happens to hold toxins such as benzene and toluene in their body systems. According to said author, the only way to kill the worms is to "zap" them with currents of electricity. Re-infection can occur if one consumes meat (except fish or seafood) or through contact with pets or infected family members. We are advised to get rid of the pets and warned not to kiss loved ones on the mouth! We are further advised to eliminate body pollutants by having fillings removed (or teeth extracted outright). Some carbonated beverages are purported to contain the aforementioned toxins, so we must cease drinking them completely. Milk is not nec-

essarily a health alternative. It would seem that pasteurization alone will not guarantee elimination of these very tenacious parasites. If we choose to drink milk, it must be boiled first.

This is tabloid medicine at its very worst. It hooks into all the hygiene horrors and hysterical myths about incurable disease. As one with MS who has read this article, I personally feel tainted with the impression that we are all somehow responsible for our fate, that we are unclean, that we practise poor nutrition and that we deserve to suffer medieval "cures".

Positive support systems and a good attitude can help one cope with the vagaries of MS immensely. I personally can't imagine anything more unsettling to

one's state of mind than getting rid of one's pets, drastically changing one's diet, having painful trips to the dentist, and living with the constant stressful worry of infecting loved ones. As well, we are advised to implement these changes within a fairly speedy time frame. The author even goes so far as to suggest that MS (an auto-immune disease affecting myelin in the brain and spinal cord) and amyotrophic lateral sclerosis (in which nerve cells affecting the muscles die off) are the same disease. To me, this suggestion alone indicates an extremely poor grasp of the intricacies of MS and ALS.

If one is to be paranoid about parasitic

worms, it should be noted that flukes do

not commonly bother bovines, however, many fluke species do have a swimming larval phase which can invade water bugs, snails, crabs, and fish. When higher vertebrates (i.e. man) consume such tainted prey, these parasites get passed along very efficiently. Thus, if we buy into the absurd theory that flukes cause MS symptoms, it would seem somewhat irresponsible to have fish and seafood endorsed as complete red meat substitutes. It is also illogical to think that once inside a human host, these same flukes would be attracted to your brain to breed. They need to be expelled from the body to continue their life cycle. It makes much more reproductive sense for them to remain within the gastric system, which, in fact, is where they are commonly found.

The book's author disputes the existence of an 'MS gene', and cites several vague case studies in support of the "fluke" theory. This discredits fine researchers such as Dr. Dessa Sadovnick and George Ebers who have done legitimate groundbreaking studies linking genetics and multiple sclerosis.

I taught one year in a fly-in Cree reserve. There was no central heating or plumbing and gas-sniffing was a rampant problem. Many of the unfortunate youth suffered lead poisoning from inhaling toxic fumes, yet none developed multiple sclerosis. Incidents of MS have been documented in Ireland, but the gypsies who reside there do not get it. There seems to be

some link between genetic groups and the incidence of MS. At the same time, there exists globally two MS-prone bands which swathe northern and southern hemispheres. A variety of MS-affected people dwell within these latitudes and these people include meat-eaters, vegetarians, people who practise varying levels of hygiene, people who have mercury fillings and even people with perfect teeth.

To live with MS, it is important not to be victimized by it. Charlatans are drawn to disadvantaged, discouraged and insecure people like sharks to a feeding frenzy. We who have MS must contend every day with challenges. We do not need to distract ourselves with artificial worries. Consult your physician. Ask questions, Educate those around you.

Who is susceptible to this drivel? Concerned friends and family can be suckered just as easily, or perhaps even more easily than affected persons. In today's society, it is unlikely that claims to cure are bona fide when they are

MS

Pharmacare Coverage for Zanaflex®

unendorsed by the greater medical community. Would reputable organizations really fund this type of "research"? Does it involve unrealistic sums of money? Ultimately, who benefits? At approximately thirty bucks a crack just to buy the book, we know who the real "parasites" are.

Reprinted with permission from "Abilities",
Spring 1997, Issue 30.

There seems to be a link between genetic groups and the incidence of MS.

In August 2000, Manitoba Health included Zanaflex® (Tizanidine hydrochloride), a new oral treatment for muscle spasticity, on the provincial formulary for Pharmacare coverage. Spasticity is a common symptom of MS and many Manitobans with MS have been waiting for the announcement of this coverage. Comparative analysis of Zanaflex® with other antispasticity medications indicates equivalent efficacy in controlling spasticity, with less weakness.

Self - Help Groups

The MS Society is pleased to offer a variety of support programs designed to accommodate the different needs of individuals living with MS. We recognize that some people enjoy being part of a group experience, for the social interaction, information and for the diverse and experiential support it offers. Others are more comfortable relating one-on-one and so this option is also now available throughout the province. Choose from the following support offerings:

Ashern

Lakeshore General Hospital. Group meets as members wish.

**Contact: Lyn Carbonneau
768-2852**

Beausejour

Beausejour United Church
730 James Avenue. Group meets as members wish.

**Contact: Gerri Pearson
1-800-268-7582**

Brandon**

Royal Oak Inn, 3130
Victoria Avenue or MS
Society office, Unit 8 - 920
6th Street -7:00 p.m., 2nd
Tuesday of month

**Contact: Leah Beaupre
571-5672** ** This location
also has a group for care-
givers and one for those with
mild or invisible symptoms.

Carberry

Carberry Public Health Unit
220 - 1st Street. Group
meets as members wish.

**Contact: Gerri Pearson
1-800-268-7582**

Dauphin

**Contact: Robin Searle
622-2940**

Deloraine

Borderhills Senior Apts.
2:00 p.m., 4th Wednesday
of month

**Contact: Sandra Moore
658-3552**

Gimli

**Contact: Kathy Wiebe
642-5760** for times/dates

Morden/Winkler

Morden MS Society office
101-400 Stephen Street
7:00 p.m., 3rd Wednesday
of month

**Contact: Edith Dyck
325-5754**

Neepawa

Neepawa & Area Drop-In
310 Davidson. Group
meets as members wish.

**Contact: Connie Zagula
476-3901**

Portage la Prairie

**Contact: Shauna Sheldon
239-1308** for times/dates

Roblin

**Contact: Gerri Pearson
1-800-268-7582 or Robin
Searle 622-2940**

Russell

New Civic Centre
7:00 p.m., 3rd Wednesday
of month

**Contact: Rachel Chipelski
773-2199**

Selkirk

Daerwood School
211 Main Street, 7:30 p.m.,
4th Tuesday of month

**Contact: Leslee Turmel
757-2148**

Steinbach

Personal Care Home, next
to hospital, 7:30 p.m., 4th
Monday of month

**Contact: Barb Friesen
326-7515**

Thompson

**Contact: Gerri Pearson
1-800-268-7582**

Winnipeg

A number of groups (both
daytime and evening)
exists for people with MS,
as well as for their family
members and friends. Also
offered are groups for Well
Male Partners and Well
Female Partners. Contact
**Gerri Pearson at
988-0902.**

