

Riverview Health Centre and MBTelehealth Expand MS Society Reach

On Saturday, October 25th the MS Society of Canada, Manitoba Division reached out across Manitoba to speak to people affected by primary progressive multiple sclerosis. This was made possible by the generous support offered by the Riverview Health Centre.

Specifically, President, Norm Kasian allowed the MS Society to use one of their largest MBTelehealth rooms to broadcast a cutting edge National Education Series on progressive MS to nine northern and remote sites.

Dr. Peter Rieckmann, a neurologist and Director of the MS Program at the University of British Columbia, and Wendy Morrison, nurse and Clinic Research Coordinator from the MS Clinic at the University of British Columbia Hospital were flown into

Winnipeg to speak as experts in the field of primary progressive multiple sclerosis, an area that historically has had limited focus. Dr. Rieckmann's very informative presentation covered current research on progressive forms of MS, why current disease modifying

drugs do not work in progressive forms of MS, and the management of progressive MS. The information provided by Wendy Morrison was very practical and included tips on managing living with progressive forms of this disease.



Through the use of MBTelehealth technology, approximately 170 individuals participated in this event including individuals from the Brandon, Dauphin, Winkler, Thompson, Swan River, Flin Flon, The Pas, and Russell regions. These individuals were able to view this live presentation in the

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comfort of their own communities as a result of this cutting edge technology. According to one of the rural site facilitators, many of the participants reported being very impressed with the technological capabilities, and as one member put it, "felt connected."

The MS Society will continue to reach out to more and more rural and remote areas using MBTelehealth, as it is a cost-effective tool that allows us to connect with individuals affected by MS throughout Manitoba. It also assists the MS Society to provide up-to-date programs and services to a larger number of individuals living with MS in this province than traditional methods of information sharing. MBTelehealth is another tool that fits within the overall philosophy of Client Services that states we will allocate resources to provide meaningful benefit to the greatest possible number of primary clients, rather than greatest possible benefit to a select few.

by Tracy Brown



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Progressive Multiple Sclerosis

by Dr. Andrew Gomori

Multiple Sclerosis affects between 55,000 and 75,000 Canadians and it is often diagnosed between the ages of 15 and 40 years. The disease is



Dr. Andrew Gomori

particularly common in countries that are further away from the equator but exceptions exist. There have been tremendous advances in the drug treatment of Multiple Sclerosis. These treatments are most effective

in the Relapsing-remitting form of MS (RRMS) and unfortunately they are not effective in the progressive forms of the disease, even though there is a lot of ongoing research to find therapy for the progressive forms.

The clinical course of MS has been divided into four types. These definitions describe the phenotype of the clinical presentation and subsequent course, as we do not yet have the ability to define the clinical course biologically based on either the MRI scan or any biomarkers. The two most common progressive forms of MS are going to be the focus of this article.

Secondary progressive MS (SPMS) is characterized by an initial

Relapsing-remitting disease course followed by progression with or without occasional relapses, minor remissions and plateaus. SPMS may be seen as a long-term outcome of RRMS, in that most SPMS patients initially begin with Relapsing-remitting disease where there is no progression between relapses. Once the baseline between relapses begins to progressively worsen, the patient has switched from RRMS to SPMS. Even a single remote initial exacerbation followed many years later by a gradual progressive course falls within this definition. SPMS patients tend to have greater disability than RRMS and the disability develops from both incomplete recovery from exacerbations as well as gradual progression.

Primary progressive MS (PPMS) is defined as disease progression from onset with occasional plateaus in a very variable course. The essential element in PPMS is a gradual, nearly continuously worsening baseline with minor fluctuations, but no distinct relapses. PPMS is the form of MS that is most distinct from the others and the form most difficult to diagnose, as the gradual worsening course doesn't follow the classical dissemination in time criteria. This form of MS tends to occur in an older age group than other forms, and unlike other forms, afflicts males and females in approximately equal numbers. In addition, PPMS usually presents as a myelopathy (spinal cord involvement) and often tends to have less cerebral

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MRI change than other forms.

Fatigue may be the single most disabling symptom of the progressive stage of MS. It is an overwhelming sense of tiredness, a lack of energy or feeling of exhaustion. Managing fatigue involves determining contributing factors that may not be neurological, review of sleep habits and review of current drugs. The patient may need to schedule rest periods, employ energy conserving techniques and use cooling techniques. Muscle weakness, spasticity and sensory symptoms are common in the progressive stage of MS. Other major symptoms include chronic pain affecting 40-50 percent of people with MS, cognitive dysfunction that may involve difficulty with multiple tasking, information processing, memory and abstract reasoning. Depression is also quite common and must be treated with professional help, counseling and often medications.

Bladder dysfunction such as urgency, hesitancy and incontinence are also common. These patients may benefit from pelvic floor exercises and specific medications. Bowel dysfunction such as constipation affects over 50 percent of patients with progressive MS and this can be treated with maintenance of appropriate fluids, plenty of fiber in the diet and trying to have consistent regular bowel regime and physical exercise. Sexual problems are common and must be treated with
4 appropriate measures, including

discussions with the patient and the partner, treating related problems, alternate techniques, lubrication and treatment of erectile dysfunction.

The prognosis of progressive MS is extremely difficult to determine. There is great variability between different patients. Many patients reach a plateau and do not get any worse. This is very typical of a patient who, for example may be wheelchair bound due to severe spinal cord involvement and paraplegia and in spite of this, they maintain upper extremity function, as well as cognitive function and they may remain in that state without any further progression for several decades. In general, motor and cerebellar involvement suggests a poorer prognosis than sensory symptoms. The amount of damage and activity seen on MRI scanning may also play a role in prognosis. In general, the more clinical or MRI activity, the worse the prognosis, at least over the short term.

The treatment of progressive forms of MS is a great dilemma. Whereas we have treatments for the Relapsing-remitting form of the disease, the disease modifying agents that are helpful in reducing the frequency of relapses and slowing down the progression of the disease are not helpful in the progressive forms, except for some of the early relapsing-remitting SPMS patients who have been shown to respond to Interferon beta 1b in a clinical trial. Although the response was modest at

best, even this medication is generally not helpful once the patient has reached a stage where there is significant difficulty with ambulation.

It is now well recognized that Multiple Sclerosis is an immune disease where there is considerable inflammation in the early course of the disease, which becomes less notable once the secondary progressive stage develops. On the other hand, axonal damage, which starts at the beginning of the illness is progressively increasing and eventually the axonal loss becomes the predominant pathologic change, in addition to loss of myelin and it is this complication that is likely responsible for failure to respond to the existing disease modifying agents that we have and work in the earlier stage when inflammation is significant.

There is tremendous amount of research trying to find effective therapies. It is likely that the eventual success will be halting the disease in its earlier relapsing-remitting stage and thereby preventing the evolution of the chronic progressive state. For example, a very recent report from Israel describes experimental treatment whereby they remove a patient's own mesenchymal stem cells (cells in our bone marrow that can turn in to heart tissue, bone cartilage and nerve cells) and grow them into large quantities in a laboratory and inject them back into the patient. A summary from the MS Society of Canada indicates this is an

experimental treatment that may alter the natural course of primary progressive multiple sclerosis and lead to some recovery of function in some patients. Early data from about 25 patients suggests that the mesenchymal stem cell treatment can repair existing damage to the nerve cells. According to the MS Society of Canada, the ease of isolation and culturing mesenchymal stem cells makes them attractive for investigation as a potential therapy. However, further work and results are required to further our understanding of the abilities of mesenchymal cells in relation to MS. Dr. Mark Freedman, an Ottawa researcher with expertise in bone marrow stem cell treatments is planning an international meeting on mesenchymal stem cell treatments and hopes to eventually begin a clinical trial in Canada. The MS Society of Canada will be watching these developments very carefully and will post new information on www.mssociety.ca when available.

Research in MS is progressing at a remarkable rate, with more potential therapy in the pipeline than any other time in history. The MS Society of Canada, and other MS societies worldwide are a driving force of MS research, supporting and stimulating world class research into ways to prevent, better treat and eventually cure this unpredictable disease of the brain and spinal cord.

Knowledge Betters Life with Primary Progressive MS

by Stephen Kennedy

Though she was medically diagnosed with primary progressive multiple sclerosis in January, 2005, Jo-Anne Findlay had suspected she had MS years before.

"I had already done a lot of reading ahead, so I had kind of self-diagnosed myself. So, when we got the diagnosis, I already knew. I had told my husband four months before that this is what it is. It was primary progressive because I never had a relapse or anything like that. My oldest son had done a project on MS nine years ago and I remember reading it going, 'You know, I think I might fall into one of these categories.'" A number of symptoms including fatigue and difficulty walking had clued her into the possibility of MS. Her son had also asked if Jo-Anne had MS when he noticed she had difficulty walking.

"When I was diagnosed initially, I wasn't surprised and I was quite relieved because I didn't have two weeks or two months or a shorter life," she notes.

With a young family, Jo-anne's primary concern was being there for those that needed her and despite the restrictions MS has put on her, she has been able to fulfill her role as a mother and wife.

"My concern was that I didn't want to impact my family in any way," she recalls. She didn't initially contact the MS Society for fear there would be mailings or calls that would bring MS to her family. "In hindsight, I think it seemed ridiculous, but I didn't want the MS to enter our home; I wanted it to be removed from it."

When the symptoms became more pronounced, however, she began telling friends and family and sought out the MS Society. "Once I made that contact with the MS Society, it just opened up tons of doors for me," she remarks.



Jo-Anne is pictured here on the far left. Her younger son Colin (second from right) was this year's WALK Top Fundraiser raising over \$18,000 and his top fundraising team "Friends of Jo-Anne" raised over \$24,000.

"One of the best things I got was the Peer Support," Jo-Anne says. "I just had questions, so I didn't think I needed a lot of support, but the woman I was linked with, she told me so many things that I didn't even know I needed to know, like how to get a handicapped parking pass, how to navigate certain things with a walker. She provided great support

because she could understand what I was facing. She also gave me the freedom to say I feel bad about some of it, whereas I think within your own family or friends you certainly don't want to let them know that you feel badly. So I think a Peer Support is just invaluable to people."

Jo-Anne also took advantage of other programs and services provided by the MS Society.

"I went to the Newly Diagnosed services that Susan ran and that was very good too. When you look around the table, you see everybody is in completely different spots and affected by different things. Again, it put out what the resources are there, gave you a little more information. An individual with MS came and spoke, as well as the nurse from the Health Sciences Centre," she recalls.

"Attending the primary progressive seminars - I really like that," she says, "the group just for the primary progressives. I think with primary progressive sometimes you feel a little left out because you're really different than the relapsing-remitting and it's not that one's better or worse, it's just really different. With the primary progressive group that they have now, everybody is a great support for one another and you can listen to each other's story and although our stories are very different and our symptoms are very different, I think it's a place where people feel safe and they can go and say whatever."

The main physical challenge Jo-Anne has with her MS is walking and getting about. She uses a cane, walker and scooter to get around, depending on where she needs to go and what she needs to do. She hasn't found, though, that it has lessened her ability to live her life as chooses.

She attributes maintaining her lifestyle, primarily focusing on the time she spends with her family, on keeping herself and the people she cares about informed about MS. Her husband attended a seminar on primary progressive MS with her and found it a good way to have a better understanding of MS.

"I just think as much knowledge as I can have is really important. It may not change the way things happen, but I'll know that I'm trying to do everything I can do to live well."



HCP and Members Conference a Success

by Darell Hominuk

MS Today: Dealing With Difficult Topics drew 169 people at the Delta Winnipeg Hotel on November 15 and was a tremendous success! The flow of presentations was seamless and the content was of high calibre. We received numerous evaluations which revealed a high level of satisfaction with the speakers and the content of the talks.



The conference offered seven one-hour talks by leading experts from across North America. Dr Abe Snaiderman provided a talk on *The Affective, Behavioural and Cognitive Issues of MS* and stated that the conference was one of the best conferences that he had been invited to present. He went on to say that it was well organized and that the talks were relevant to people living with MS and to health care professionals treating patients with MS. The other speakers included: Dr Ruth Ann

Marrie who spoke on *MS Research Updates and MS Clinic Updates*; Dr Fred Foley on *Sexual Health and MS*; Kelli Berzuk, PT on *Bladder and Bowel Health*; Kathleen McCue, MA, LSW on *Parenting With MS*; Pat Kennedy, RN, CNP on *Pregnancy, Menopause and MS*; and Liz Wolff MMFT on *Caregiving*. In addition, our President, Wendy O'Malley provided a presentation on the MS Society's first capital campaign called *endMS*. The full day conference also included massage services, an exhibitors hall, a continental breakfast and a served hot lunch.

The HCP & Members Conference is unique in Manitoba as it incorporates an inter-professional education approach. That is, both health care professionals and persons living with MS have an opportunity to interact in a shared learning environment, thus enhancing their understanding of MS.

The decision to merge health care professionals with people living with MS into the same audience came as a result of feedback from members during the 2003 conference. Members expressed a need to hear more in-depth information about MS than simply the "basics". The merge was introduced in the 2006 conference and again for 2008. The blend proved successful attracting 114 members and 55 health care professionals to the conference.

All presentations were recorded for educational purposes and are available to borrow from our library.

In addition, written presentations are available on-line – please visit www.mssociety/manitoba.ca and print the session(s) of your interest.

The MS Society, Manitoba Division would like to thank our sponsors for their generous contributions. The Conference could not have been possible without the support from TevaNeuroscience, EMD Serono and AventPro.



Holidays 101



At no other time of year do we require such fine balancing of all our activities. On top of work - paid or volunteer - home responsibilities, child rearing, and sometimes elder care, we now add entertaining, gift

giving, house guests, and more. Engaging in meaningful activity can increase one's health and well-being. However, for people living with MS, trying to balance too many activities may lead to stress, fatigue and worsening of symptoms. Caregivers may also be overwhelmed by "holiday madness".

The following strategies may help you and your caregiver to keep stress to a minimum and help you and your family to enjoy the coming holiday season.

Keep expectations realistic

Decide what is most important to you:

- Urgent – must be done today
- Important – must be done in the next few days
- For later – must be done this week or month
- Perhaps never – let it slide

Why not send Happy New Year notes or an update letter instead of Season's Greetings cards? Friends and family will be glad to hear from you at any time of year.

If you anticipate this may be an emotional time for you and your family due to a recent death in the family, serious illness, or divorce, talk together about what would feel best for all of you, and adjust your celebrations accordingly. Don't add to the stress by ignoring your feelings.

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Don't overdo it

Bake, decorate and exchange gifts for fun and enjoyment, not with a sense of obligation. Eat and drink in moderation and encourage others to do the same; participate in a cookie exchange or visit a bake sale; watch your family decorate while enjoying some hot chocolate around the fire; set limits on gifts; eat smaller portions so you can try everything without overeating; and don't drink and drive. Take frequent rests or "time outs" as needed.

Feel free to say "no"

If you are invited to a party, consider dropping in for a couple of hours rather than spending the entire afternoon or evening. Take time for your own social, spiritual and physical needs. Use the holidays to relax, catch up with friends and family, and re-energize for the coming year.

Hate to cook?

Order your turkey and the rest of the meal from a local store, restaurant or hotel. All you'll have to do is have someone pick it up or have it delivered and serve! For a change, try a potluck with all guests bringing a dish.

A time for everyone

You don't have to do it all! Children can help tidy up, bake cookies, even wrap some presents. Don't worry if things aren't just the way you would have done them - enjoy the variation, it may be a new tradition in the making. Try gift bags. No wrapping is required and **10** they are environmentally friendly.

Don't forget your body

Maintain your regular exercise program. It can reduce stress and help burn those extra calories you've consumed.

Adapted from www.otworks.ca by Ellen Karr



Gift Ideas for a Loved One Who Needs a Helping Hand



All of the items listed are available through local drug stores, medical supply companies and hardware stores.

A motion detector night light.

Great for preventing falls when walking at night, especially when the person does not like to sleep with any type of light source.

Safehip hip protectors are new to the market and can reduce the risk of breaking a hip when falling. Made out of cotton and lycra with built-in padded shells, these "undergarments

or shorts" are very discreet to wear under one's clothes.

Cooling products are a great idea for people with MS who are heat sensitive. Many items such as vests, hats, neck kerchiefs and wristbands are available to beat the heat. Visit the MS Society website mssociety.ca for a list of suppliers.

Bed rails and poles. These devices can be used with almost any bed. They are very handy for people who have difficulty getting in or out of bed.

Bathing aids. Long handled bath sponges are great for bathing and showering, cost as little as \$15 and help with those hard to reach places such as one's back and feet. Properly installed grab rails on the shower wall will make it easier to get in and out of the bath safely and prevent falls.

Ice picks for canes. Great when it becomes icy and slippery outside. The ice picks attach simply to the cane and can be found at most drugstores where canes are sold.

Walker accessories. For a few dollars, you can purchase a cup holder that clips to the walker and allows the person to carry a drink while using their walker. Look for ones that secure tightly to the walker. A carry bag or pouch works well for other items, such as books, eye glasses, etc.

Stove reminder. This requires an electrician but may be worth it for

someone whose memory is failing. This gadget will automatically sound once the stove had been turned on, and will continue to sound every few minutes until the stove is finally shut off. A microwave with easy-to-read dials can also be safer, especially for re-heating foods.

Recipe books with one-dish meals that can be prepared in a microwave. Look for those in large print and plain language.

Good-grip kitchen utensils are available in any department store. They can make peeling vegetables, slicing cheese or even squeezing lemons much easier due to their built-up, flexible handles.

A fanny pack or back pack allows both arms to be free when shopping.

Personal Response Services. Services can also be a welcome gift and offer peace of mind for the giver. Victoria Lifeline is a 24-hour personal emergency response system. A person can wear a bracelet, a pendant, or clip the device to their belt. Like a pager, if they fall or have an emergency, they just press the button. For information call 956-6777 or 1-888-722-5222.

Adapted from www.otworks.ca by Ellen Karr





Research News

Alemtuzumab Results Published: Reduced MS Relapses and Accumulation

MEDICAL UPDATE MEMO

November 3, 2008

Summary

Treatment with alemtuzumab (Genzyme Corporation) reduced the accumulation of disability and the frequency of relapses in people with early relapsing-remitting MS, compared to interferon beta-1a. Those taking alemtuzumab had a 74% reduction in the risk of MS relapse compared with those on interferon beta-1a (INFB-1a) and a 71% reduction in the risk for sustained accumulation of disability. Those on alemtuzumab, an immune-suppressing monoclonal antibody, experienced adverse events more frequently, including immune thrombocytopenic purpura (a serious bleeding disorder), thyroid adverse events, and infections. The results, originally reported at medical meetings, have now been published

12 (New England Journal of

Medicine 2008 359;17: 30-45), and two Phase 3 trials are currently recruiting participants with relapsing-remitting MS.

Details

Alemtuzumab is a humanized monoclonal antibody directed at CD52 (a protein on the surface of immune cells) that is currently approved by the U.S. Food and Drug Administration as a single agent for treatment of patients with B-cell chronic lymphocytic leukemia. Its ability to target immune cells has led investigators to test its potential as a treatment for relapsing-remitting MS.

Drs. D. Alastair Compston, Alasdair J. Coles (University of Cambridge, UK) and colleagues have now published results of phase 2 clinical trial that compared high and low doses of alemtuzumab (given by IV infusion over three to five days once a year) with interferon beta-1a (INFB-1a), a standard MS therapy, in 334 people with early relapsing-remitting MS who had never taken any other disease-modifying therapies. The primary outcomes were the time to sustained accumulation of disability and the rate of relapse.

Those in the alemtuzumab groups were slated to receive two to three cycles of the annual infusion. However, dosing was temporarily suspended due to the occurrence of immune thrombocytopenic purpura (ITP), a rare condition in which low blood platelet counts can lead to abnormal bleeding. After the first

cases of ITP occurred, one of which was fatal, Genzyme implemented a patient safety monitoring program which includes patient and physician education and regular contacts with patients. A total of six alemtuzumab-associated ITP cases were identified and, when necessary, promptly treated.

Most of those on alemtuzumab received their second infusion cycle (207 out of 223 total), but fewer went on to receive a third cycle (46 out of 223). The results reported in this publication follow the participants out to 36 months of the study.

Results

The results were nearly the same for the two doses of alemtuzumab, so the data for patients receiving this drug were pooled for the comparison with INFB-1a. After thirty-six months, those taking alemtuzumab experienced significant reductions in the risk of MS relapse compared with those taking INFB-1a (74% reduction, with an annualized relapse rate of 0.36 for INFB-1a versus 0.10 for alemtuzumab) as well as significant reductions in the risk for progression of disability compared with those taking INFB-1a (71% reduction). Among secondary outcomes that were measured, significantly more of those on alemtuzumab remained relapse-free at 36 months (52% for INFB-1a and 80% for alemtuzumab). In addition, the mean disability score (EDSS) for those on alemtuzumab improved slightly (by 0.39 point) while the mean score of those on INFB-1a declined slightly (by 0.38 point).

Among other side effects reported in the Phase 2 study, patients who received alemtuzumab were more likely to develop thyroid disease and mild to moderate infections (i.e., infections requiring no specific medical intervention or requiring only oral medication). Thyroid problems are reported to have been easily detected and treated. Patients who received INFB-1a experienced injection site reactions, fatigue, flu-like illness, headache and abnormal liver function tests.

Comment

"This phase II trial has shown good early results", comments Dr. Paul O'Connor, clinical advisor to the Multiple Sclerosis Society of Canada, "however, the potential side effects that have been associated with the drug are significant. Therefore, the MS Society is cautiously optimistic that these findings may point to a potential new therapeutic strategy for MS. More clinical trials are needed to assess long-term safety and efficacy before being used as a treatment for MS."

This adds to the growing body of evidence that shows earlier treatment in MS is a better strategy than waiting until the disease progresses.

With information from the National MS Society (USA)



Government Relations Update

by Darell Hominuk

More Support for Caregivers in Manitoba

The Manitoba Government recently announced that Manitobans who are the primary caregivers for family members or other loved ones are now eligible for a \$1,020 tax credit. The pursuit of a tax credit for caregivers in Manitoba was a top priority for Manitoba Division and we congratulate the Department of Healthy Living and the Department of Finance for the adoption of this progressive change.



Manitoba's new fully refundable Primary Caregiver Tax Credit becomes effective January 1, 2009 following a

three-month qualifying period. It will provide up to \$1,020 a year to individuals who are primary caregivers for spouses, relatives, neighbours or friends who are Manitoba Home Care clients (equivalent to Care at level 2, 3 or 4 with level 4 requiring maximum care). This might include individuals with a disability, people with life-threatening illnesses or those needing care or supervision for more than three months.

To be eligible, the primary caregiver must not receive money for their help and must be identified by the client. A caregiver may not earn the credit for more than three people in a given month.

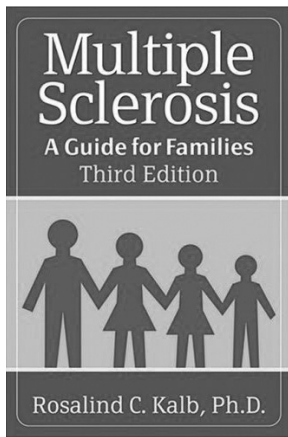
For information on claiming this tax credit through the income tax system, contact the **Manitoba Tax Assistance Office** at **204-948-2115** or **800-782-0771** (toll-free) or by e-mail at **TAO@gov.mb.ca**.

We Need Your Input

The Government and Community Relations Committee of the MS Society needs your help in identifying the priority issues that are affecting Manitobans living with MS. Whether it is housing, transportation, accessibility or any other issue, you can help by contacting us with your suggestions. Please e-mail **Darell Hominuk** at **darell.hominuk@mssociety.ca** with your suggestions by January 31, 2009.

Book Review

by Ellen Karr



Multiple Sclerosis: A Guide for Families

**By Rosalind Kalb,
Ph.D.**

We now have in the MS Society library the third edition of this comprehensive guide compiled by one of our favourite MS specialists. A diagnosis of MS affects the entire family and can upset the balance of everyday life. This practical book addresses many issues from diagnosis to parenting to caregiving.

Have you ever asked yourself tough questions such as:

- How can we manage our financial situation?
- How can I enlist the help of my children without causing them undue stress?
- How will my marital relationship be affected?
- How do we talk about wills, health care directives and other legal concerns?
- Where can we go for help?

Various authors have written chapters covering a wide range of topics such as these and many more. The third

edition includes new readings and updated references to provide you with the most current information.

Whatever your family system is like, you will find useful information in this book to help achieve, restore and maintain a healthy balance and harmony.

More Books!

The Manitoba Division MS Library has also acquired several new books which will be reviewed in upcoming MS Connections:

Life on Wheels: The A to Z Guide to Living Fully with Mobility Issues
by Gary Karp

Mental Sharpening Stones: Manage the Cognitive Challenges of Multiple Sclerosis
by Jeffrey N. Gingold

Multiple Sclerosis: The Questions You Have, The Answers You Need
by Rosalind C. Kalb, PhD

Women, Work and Autoimmune Disease: Keep Working Girlfriend!
by Rosalind Joffe and Joan Friedlander



Is There Anybody There?

"I feel so alone."
"My friends have disappeared."
"My family doesn't understand."
"I have no one to talk to."
"Do other people feel like this?"
"I feel so trapped."



These are comments that Client Services staff often hear from people who call us. It is not uncommon for people who are living with MS to feel isolated, trapped within the confines of their homes, their bodies, their personal world that is so strongly influenced by the effects of their disease.

The MS Society offers a number of programs and services to help people connect with others for support, understanding and social contact. However, there are some who are unable to make use of these resources. One such group that has become apparent to us is mothers with young children who are either stay-at-home mums or working mums. These women do not

have the time or flexibility in their lives to attend programs such as self-help groups or social/recreation programs.

We asked ourselves, "What can we do to help these moms connect?" and came up with the idea of a Mums' Network. Mothers who agree to share their contact information are placed on a list which is circulated to the network members. They now have a number of people in a similar life situation that they can talk to when they need someone. Connections can be made via telephone or email. This gives the opportunity to members throughout the province to be in touch with one another. It is up to the members how they choose to connect with one another. The only requirement is that all participants keep private and confidential the identity of network members and the content of any discussions that they have.

If you are interested in becoming a member of the Mum's Network, please contact **Ellen Karr** at **988-0917, 800-268-7582** or by e-mail at **ellen.karr@mssociety.ca**.

Living in an age of technology, the MS Society is using new ways to reach out and connect with people throughout the province of Manitoba and beyond. These include:

- MS Discuss is an online message board that connects people from all over the world who have common experiences and concerns. You can

post and reply to messages from others in 14 forums on a wide variety of topics at www.msdiscuss.com.

- Three MS information websites offer message boards for children and teens who have a parent with MS and for parents who have MS. These can be accessed at:

www.msforkids.com

www.msforteens.com

www.msforparents.com

- MBTelehealth is a system that broadcasts education sessions from an originating site, through cameras and a wide screen TV set-up, to any receiving site. Members see and hear the presenter and the presentation live and can ask questions and take part in the discussion.

The MS Society has “beamed” presentations and education/support sessions out to the many Manitoba communities including Steinbach, Morden, Portage la Prairie, Brandon, Dauphin and Thompson.



Fatigued? Learn How to Manage Your Energy

An energy management course designed for adults in the community with fatigue secondary to MS is being offered by Cara Brown, Occupational Therapist. Please note that you must be a patient of the HSC MS Clinic to

participate.

To benefit from the course, your fatigue must be severe enough to have a negative or inhibitory impact on your daily life and function. The program aims to decrease fatigue by teaching ways of managing energy. The importance of rest and the proper use of technology, equipment, and your body will be taught. Designing a schedule in order to balance your lifestyle will also be covered. The sessions will use lectures, discussions and activity stations to teach this information. Home practice activities will be provided each week to customize learning to your specific situation.

The program will involve one 2-hour session every Monday for six weeks, from January 19, to March 2, 2009. No class on February 16, 2009.

Participants are expected to attend all sessions, participate in class discussion and activities and complete home practice activities. If you are interested in participating, please call the MS Clinic at 787-3805. Ask for an appointment with Cara Brown to discuss the fatigue group. In that appointment, we will determine if this is the right course for you, you will learn more about the course as well have an opportunity to meet the facilitator in advance of the group session.

Space is limited. A waiting list will be developed for a future course if there is adequate interest.

Rupert's Land Caregiver Services Presents Caregiving with Confidence: Roles, Relationships and Resources

**January 21st and 22nd, 2009
Canad Inn Fort Garry, Winnipeg**

If you are a caregiver, keep these dates open and plan to attend this conference presented by Rupert's Land Caregiver Services (please note change of date and location). The general public is invited to attend the keynote presentation on Wednesday evening at 7:00 p.m. given by Karen Toole, "Dignity: Exploring the Strengths and the Struggles".

Plenary and breakout sessions on Thursday will cover many topics including self-care for caregivers, dealing with financial burden, impact on family, navigating the system, dealing with dementia and more. The closing presentation will be on "Share the Care," the inspirational evolution of a shared caregiving model by Sheila Warnock, author of the book of the same title.

The MS Society has participated in the planning of this conference. If you have any questions or would like to register, please contact **Ellen Karr** at **988-0917** or **800-268-7582** or Rupert's Land Caregiver Services at **452-9491**.

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

New MS Discussion Website

National Multiple Sclerosis Society has created a new website for people in their 20's and 30's and living with MS. The www.realtalkrealanswers.com website "Real Talk. Real Answers. Living with MS in Your 20s and 30s" isn't a support group, it's a new and unique online program that provides young adults with MS with an opportunity for candid, real, frank discussion and an opportunity to get answers to their questions about living with MS.



Changes to the Therapeutic Counseling Program

The Therapeutic Counseling Program has been changed from a subsidized program to a referral program.

For more information about this program please contact **Susan Hologroski** at **988-0901** or e-mail susan.hologroski@mssociety.ca.



VLAP - Volunteer Legal Advocacy Program Working Group

This program provides members access to volunteers with legal and advocacy experience for legal advice. It also offers resource information, advice and assistance with CPP disability applications and so forth. We are looking at developing a working group in order to conduct a needs assessment for members and determine the viability of bringing this program to Manitoba.

Are you interested in becoming a part of this working group? If so please contact **Susan Hologroski** at **988-0901** or e-mail susan.hologroski@mssociety.ca.



Progressive MS Programs

Once again we are offering these two highly successful education programs on primary and secondary-progressive MS. They are designed to provide current and accurate information about the two progressive forms of MS. Some of the topics include symptoms, management, wellness, transition and resources.

Primary-Progressive MS Program
Mondays, February 23, March 2, 9 and 16, 1 to 3 pm.

Location: TBA

Secondary-Progressive MS Program
Mondays, March 23, 30, April 6 and 20, 1 to 3 pm.

Location: TBA

To register please contact **Ellen Karr** at **988-0917/800-268-7582** or by e-mail at **ellen.karr@mssociety.ca**.



Attention to All Caregivers in Manitoba!

Are you caregiving for a spouse, partner, or adult child who is living with MS? Would you like to meet other caregivers with similar experiences but can't find time to make it to a support group meeting? A new program called the MS Caregivers' Tele-network will provide family caregivers of people living with Multiple Sclerosis with an opportunity to share their experiences of caregiving, acquire information and knowledge, and increase feelings of well-being in a supportive and confidential environment. Now, you can call from the comfort of your own home and be connected to other caregivers throughout the province by phone. Meetings would be held once a month and facilitated by Nadine Konyk, Rural Client Services Coordinator with the Manitoba Division of the MS Society of Canada.

We are currently determining interest among caregivers for this program. If you are interested or would like more information, please contact **Nadine** at **471-0402** or toll free at **(800) 268-7582**.



Funding Program

Caregivers Special Assistance

Fund is a funding program designed to offer caregivers of those with MS, an opportunity for respite and rejuvenation through activities or services that offer a balance in their lives and replenish their resources. Types of activities or services that have been funded in the past include, a break away, facility memberships and relaxation massage. Caregivers can apply once in our fiscal year (September 1 - August 31) for up to \$300.00.

To receive an application package please contact **Susan Hologroski** at **988-0901** or e-mail at **susan.hologroski@mssociety.ca**



MS Society Division Office is Scent-free

Many organizations, including municipal and federal offices have instituted scent-free policies in their work environments and the MS Society, Manitoba Division has followed suit.

Thank you for keeping this in mind as you prepare to come to the office.



CONTRIBUTORS

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

Tracy Brown, Jo-Anne Findlay, Dr. Andrew Gomori, Susan Hologroski, Darell Hominuk, Ellen Karr, Stephen Kennedy, Nadine Konyk

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.

MS Discussion Forums

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.



Upcoming MS Chat Rooms

Effective December 1, 2008

Due to a lack of consumer participation in the on-line MS Chat Rooms for **msforkids.com**, **msforteens.com** and **msforparents.com**, the chat rooms will be discontinued indefinitely for reflection and re-evaluation. The websites will continue to provide information about MS and post new messages on the Message Boards.

If there are any questions or concerns, please contact **Darell Hominuk** of Manitoba Division at **204-988-0902**.

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:

- Wendy O'Malley.. President
(204) 988-0916
- Tracy Brown..... VP of Client Services & Operations
(204) 988-0907
- Darell Hominuk..... Resource Coordinator & Program Planner/
Government Relations
Manager
(204) 988-0902
- Nadine Konyk..... Rural Client Services
Coordinator, South Central
Chapter, Morden/Portage
South East Chapter,
Steinbach
(204) 471-0402
- Susan Hologroski... Manager of Information &
Support Programming
(204) 988-0901
- 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

KNOWLEDGE
is **POWER**

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 **(800) 268-7582**.

MS

We will never walk on the moon.



Be part of something monumental. Funded largely by the MS Society, Canadian researchers have brought the cure for MS within reach. Let's take this last step together.

endMS.ca
It's time. Give now.



Be a walker. Be an end to MS.

Join over 70,000 walkers across Canada in the movement to end multiple sclerosis. Step up and make your mark in 2009.

register for 2009
www.mswalks.ca

MS WALK
EVERY STEP MATTERS.



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Return undeliverable Canadian addresses to:
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Winnipeg, Manitoba R3T 1L8
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