

Judith Cooper

Judith was a twenty-three year old university student living in Brandon when she went to an eye doctor to get her new contact lenses checked. It was a grey, dull day in February, something to which most Manitobans can relate. Her doctor saw something during the routine eye test that he didn't like. He referred her to an ophthalmologist for further investigation. The ophthalmologist examined her and told Judith that she had either a brain tumour or multiple sclerosis. He referred her to a neurologist. It began to dawn on Judith that the vision problems she had been having were not just related to the gloomy weather.

Judith was terrified. Her grandmother had only recently passed away due to a brain tumour – and she knew nothing about MS. A trip to the local library only fuelled her fears, especially when a dictionary definition read “can be fatal.” She also realized that the various symptoms she had already experienced (but attributed to stress) were very real and perhaps due to a chronic disease. “I had trouble putting in my contact lenses because I couldn't feel them on my fingertips,” she said. “I also had major back spasms that left me flat on my back.”

Member Profile



The Coopers: (L-R) Brianne, Judith) with Kenna “the wonder poodle,” Brent and Emma

Her mother, a registered nurse, flew in from Ontario to be with her. The trip to the neurologist led to a spinal tap, a brain scan, and ultimately to the MS diagnosis. From eye doctor to diagnosis all in one week! The neurologist prescribed ACTH, a form of steroid treatment, which meant twice daily trips to the hospital for the injections for three weeks.

Judith took some time away from school, but later that year, completed her Bachelor of Education with a Major in Primary Education and a Minor in Psychology. She worked as a

substitute teacher, then provided private care to special needs children for two years.

She met Brent in 1990 and within six weeks they were engaged. Finding out about her diagnosis posed no problem for Brent. Judith describes the day she told him: “When I saw that things were getting serious, I said there was something I had to tell him.” I said: “I have MS.” “Oh,” he said. I have diabetes.” That was that.

Judith had been involved with the Brandon and District Chapter of the MS Society, seeking information and volunteering. The chapter newsletter even ran a wedding announcement



Member Profile continued...

for the couple and, a year later, of their daughter's birth.

"I had Brienne against medical advice," Judith admitted. "But my pregnancy period was the best I ever felt. I never had the flare-up afterwards either." But, when her baby was 14 months old, new symptoms began to develop. Judith recalls a particular day when she had just put Brienne in her crib. "I blacked out. I was on the floor and I couldn't move. Then I started throwing up." Although she doesn't experience blackouts anymore, the vertigo is still a problem. "I feel nauseated and 'swimmy,' like things are twirling."

When asked if this affects her appetite, Judith explained that she doesn't feel hunger or thirst sensations. "I have to force myself to eat and remember to drink enough water."

The couple now lives in Dauphin, Manitoba with daughters Brienne, 14 and Emma, 10. Five years ago, Judith started to use a cane. "It took me awhile to get over the stigma," she said. "I kept thinking – I'm still young. I don't need this." Her perspective changed when her mother sent her a natural wood walking stick of her grandfather's. It didn't have the institutional look her other cane had.

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These days, Judith gets around the house with the cane or with the support of the walls in her home. For outings, she uses a power wheelchair, bought through lots of fundraising and with the help of service clubs. The chair has increased her activity level and allows her to get out on walks with the family. "Using the chair meant, that for the

first time, I could see Emma ride her bike," she said enthusiastically. "We go for family bike rides. I take the dog on my lap and off we go!"

Judith admits to finding it difficult being house-bound during the winter. "I don't go out unless someone takes me out," she said. While at home she does costuming for her daughters' highland dancing, sews for the family, quilts, crosstitches, knits and reads.

She is an active volunteer with the Parkland Chapter of the MS Society, helping out with fundraising events and writing articles for the chapter newsletter. She is the chapter representative on the Manitoba Division Communications Committee, participating by

teleconference once a month. "Judith's commitment and contributions to the committee have added new and valuable perspectives to our work," said Jeanette Edwards, chair of the

committee and division co-chair. "Her presence has reinforced the importance of chapter involvement in division activities."

Not only has the MS Society benefited from Judith's contributions, but she finds that volunteering helps her too. "It's nice and homey there. I feel like I'm helping a friend. I enjoy being part of it. I hope to make a difference. It gets me out - helps me focus on something else."

The family pitches in around the house. The girls have their chores and Brent does housework and more than half the meal preparation. "He's the unsung hero of our life," Judith said fondly. "He pulls it together, does everything and doesn't complain."

When speaking with Judith, one can't help but be intrigued by the acceptance in her voice. Not resignation – acceptance. "I don't want to sound like Pollyanna," she says, "but I try my best to look on the *up* side. I'm not perfect – I get down and depressed. Sometimes I feel I don't contribute as much as a "normal" person, that I'm worth less - but I know I'm not. I've learned to celebrate the little things, otherwise it's really, *really* easy to think of yourself as less than you are."

"I've learned to celebrate the little things."



Research News

Clinical trial of Fampridine-SR underway. Study sites in Canada open for enrolment

Medical Update Memo

Summary

Investigators at research centres in the United States and Canada are enrolling participants in a 21-week clinical trial testing the safety and effectiveness of **Fampridine-SR** (an oral, sustained-release formula of 4-aminopyridine being developed by Acorda Therapeutics) compared with inactive placebo to improve walking ability in 240 people with MS.

Details

Fampridine-SR blocks tiny pores, or potassium channels, on the surface of nerve fibres, and thus may improve the conduction of nerve signals in nerve fibres whose myelin coating has been damaged by MS.

Dr. Andrew Goodman (University of Rochester, New York) and colleagues recently reported the results of a study of **Fampridine-SR** to treat MS symptoms (*American Committee for Treatment and Research in MS, 2004*). In a double-blinded, placebo-controlled dosing study, 206 people with MS received either **Fampridine-SR** – taken twice daily – or inactive placebo for 12 weeks. The results indicated a trend (an effect which does not quite reach statistical significance) toward improved walking speed in the **Fampridine-SR** groups, and a significant increase in leg strength. Side effects included dizziness, insomnia and nausea, with two people in the

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 represent therapeutic recommendation or prescription. For specific information and advice, 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.

highest dose group having seizures (one from an accidental overdose.) That dose is not being included in the current study. The current study was designed based on these and other study results.

Eligibility

People eligible for participation include individuals 18-70 years of age with clinically definite MS of any form. Participants must have adequate cognitive function to understand and sign the informed consent, and must be able to perform the required study procedures, which include tests of walking speed. Participants should be able to walk, although with some difficulty. Women of childbearing potential must have a negative pregnancy test.

Individuals on a disease-modifying therapy are permitted to participate but should discuss the details of their therapy with the study coordinator. The primary outcome measure for the study will be an improvement in walking ability, which will be measured using the "Timed 25 Foot Walk" test and the "MS Walking Scale - 12." Secondary outcomes will include measurements of leg strength and muscle spasticity (stiffness and involuntary muscle spasms). Safety is being evaluated based on reports of side effects, measurement of vital signs, blood tests, and electrocardiograms.

Contact

Below is a list of the Canadian sites participating in the study. All sites are not yet enrolling patients. For information about study enrolment at a site near you, please call 1-877-716-2518, toll-free, weekdays from 10:00 a.m. to 4:00 p.m. (Eastern Time).

Foothills Medical Centre, Calgary
Ottawa Hospital General Campus, Ottawa
QEII Health Sciences Centre, Halifax
University of British Columbia, Vancouver

(With information from the National MS Society [USA] National Research Dept. and National Communications & Government Relations)

Social Action



MS, Employment and Income Support What Are My Options?

PART 1

Whether you have recently been diagnosed with MS or if you have lived with MS for many years, you've probably

thought about how this condition could affect your ability to continue working and earning income. You may have wondered about what financial options are available if you decide to stop work. This two-part series will examine some of these questions. Part 1 deals with MS in the workplace.

Staying Employed

The first thing to emphasize is that just having a diagnosis of MS is *not* a reason to stop working. Many people with MS stay employed for many years after their diagnosis. However, unfortunately, unemployment does eventually become a reality for a lot of people. In other words, MS may or may not affect your ability to keep working, or the length of time you can stay employed. It's different for everyone, depending on a whole host of factors such as the type of work you do, your specific symptoms and disease progression, and how well your employer accommodates your needs.

Don't Do Anything Hasty

Regardless of your particular circumstances, the most important thing in deciding how to deal with your employment situation is not to do anything hasty – like quitting your job or switching to part-time work – without investigating the consequences. It's probably a good idea to review your current work situation. Think about the kind of work you do in relation to the type of MS symptoms you are experiencing, or have experienced.

4 Depending on the nature of the work,

clearly some people's jobs will be impacted more than others by their MS symptoms. If your job has been consistently affected from the outset, you will need to begin thinking about adaptations and changes sooner than someone whose symptoms affect their job performance very little.

Make sure you are familiar with the benefits to which you are entitled in your current job. Although some do, most benefit plans do not provide short or long-term disability benefit for pre-existing conditions. That is one reason why it may be a good idea to stay in your job if you did not have MS before you started working there. If you switch to a new position you may find that you are not covered for disability benefits. People also often think about switching to part-time work to better deal with their MS symptoms. Again, this could negatively affect your benefits, so look into it.

Even if your job is causing you difficulties, quitting it prematurely or reducing your hours could be worse. Look into the possibility of arranging a more flexible work schedule, or investigate adaptations that can be made to accommodate your needs. You have much more control over your rights if you stay at work than if you leave voluntarily. However, if it eventually becomes clear after some time and investigation that nothing can be done to adapt your job to your condition then it is time to look at other options – retraining, finding another job that is more appropriate, working fewer hours or stopping work altogether.

Know Your Rights

So long as you can still do your job, you cannot be discriminated against because of the effects of MS. Provincial and federal human rights legislation prohibits discrimination in the workplace on the basis of physical or mental disability. This means that employers cannot refuse to hire you or fire you because you have a disability; nor can they do things like pay you less, change your hours of work or working

conditions, or give you fewer hours just because you have a disability.

In addition, employers have a duty to provide reasonable accommodation for the special needs of employees with disabilities, up to the point of “undue hardship”. This means that they must make every reasonable effort to accommodate your needs. It is up to the employer to prove that every reasonable effort at accommodation has been made and that accommodating you would cause “undue hardship” for the employer.

Human Rights legislation is paramount in Manitoba. If there is a conflict with other legislation or a collective agreement the Human Rights Code prevails. The Manitoba Human Rights Commission is responsible for implementing the code. It is generally best not to file a formal complaint until all other options have been explored, but the commission can always be approached for opinions and/or advice.

To Disclose or Not To Disclose

Another thing people often wonder about is whether or not to tell their employer and/or fellow workers that they have MS. There are advantages and disadvantages to making your diagnosis public. This is a personal decision only you can make. You are under no obligation to disclose your diagnosis if MS is not affecting your ability to do your job. On the other hand, if you require adaptations or workplace accommodation, you will have to reveal the reason to your employer. Also, if you have to fill in a form for your group insurance plan and you are specifically asked if you have a chronic disease, you have to reveal your diagnosis. However, many group plans do not ask for specific medical information.

Look for the broken **MS** to ensure that materials you receive are from the Multiple Sclerosis Society of Canada.

That being said, depending on your particular circumstances, you may find it beneficial to let others know what you are dealing with. In general, the more people know, the more understanding and supportive they will be. People often have misconceptions and misinformation, so it can be helpful to educate both your employer and fellow workers about MS. The more your employer knows, the better you are likely to be accommodated. It will be easier for your colleagues to assist you and to appreciate why you need “special treatment.” In particular, you may find it helpful to explain to others about MS fatigue and other invisible symptoms, as well as the variability and unpredictability of the disease, all of which can easily be misunderstood.

Workplace Accommodation

Accommodation basically involves adjusting your work environment to give you the equal opportunity as everyone else to do your job. There are numerous adaptations that can be made. These can range from something as simple as having a larger computer screen or a fan at your workstation, to being able to take regular rest breaks, installing ramps or constructing an accessible washroom in your workplace. Other options could be working from home, switching to flex time or job sharing. These are just some examples. The specific adaptations that will work for you depend on your particular symptoms and needs. Work with your employer to figure out what is best for you.

In the end, only *you* know what you need, how long you can continue to work and how to cope with your MS on the job. Take the time you need to assess or reassess your situation, and to make whatever decisions and changes you need. Know your rights, explore other options as necessary and seek out the support and assistance of others.

Part 2, examining income support options, will appear in the next issue of *MS Connections*.

Hello and Goodbye

Change in Rural Client Services Coordinator Position



Nadine Konyk

We were sorry to say goodbye to Russ Wolfe who has moved to Ottawa to pursue further studies, but we are delighted to welcome Nadine Konyk into the position.

Nadine is familiar with the MS Society, as she worked here for several months in 2004 in a temporary position with the Winnipeg Chapter.

Beginning September 29, Nadine assumed the responsibilities of Rural Client Services Coordinator. She will be making weekly visits to the South East Chapter in Steinbach, the Morden office of the South Central Chapter, and acting as a resource for all communities within an hour and a half drive from Winnipeg.

Nadine earned her Bachelor of Human Ecology (Major in Family Studies; Minor in Gerontology) from the University of Manitoba. Previously employed as a Client Services Coordinator at the Alzheimer Society of Manitoba, Nadine brings practical experience and expertise to her position.

“ I like working with families and individuals,” she says. “My goal is to provide support and information and to bring more education and awareness about MS to the public.”

Nadine especially likes to work in the areas of stress management, referring people to resources within their own communities, and helping families to find and use their own strengths when dealing with issues.

Nadine is bilingual and is open to augmenting current programs to include French services if there is a need and an interest.

On the personal side of things, Nadine is embarking on an exercise program through the Winnipeg Parks and Recreation Program, loves nature and enjoys hiking.

She can be reached at (204) 471-0402.

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Separating Fact from Fiction Diet and MS ? ? ?

We have received many inquiries about what has become known as the “*Best Bet Diet*,” developed by Ashton Embry. Embry is a Canadian geological research scientist who, after learning that his oldest son was diagnosed with MS in 1995, set out to determine the most likely causes of MS and “best-bet” treatments. In 2004, CBC Radio interviewed him and he shared his findings about dietary strategies and MS. Embry postulates that the best treatment for MS is to remove particular foods from one’s diet such as dairy, gluten grains, and legumes while increasing the intake of polyunsaturated fats and supplements such as fish oil and Vitamin D.

His recommendations for using diet to slow down or halt the progression of MS have captured the attention of many people living with MS. Notably, his son has had no MS symptoms since starting the diet almost 10 years ago.

Unfortunately, there is no scientific research that proves the remedial results of Embry’s work, and, with so many websites claiming to display his work, it becomes difficult to distinguish reliable information from unreliable or invalid information. While the Multiple Sclerosis Society of Canada, Manitoba Division does not endorse this or any other diet, we wish to help individuals make informed

decisions with the most accurate and up-to-date information available. A reliable website worth visiting is the charity-based, volunteer-driven Multiple Sclerosis Resource Centre in the United Kingdom.

Unfortunately, there is no scientific research that proves the remedial results of Embry's work...

They provide downloadable and printable versions of Embry's first two booklets called *Escape the Storm: Fight Multiple Sclerosis with Science-Based Dietary Strategies* and *Escape the Storm: Lower the Risk of Multiple Sclerosis with Science-Based Nutritional Strategies*. To learn more about this diet, visit

www.msrc.co.uk/index.cfm?fuseaction=show&pageid=47

The Multiple Sclerosis Society of Canada, Manitoba Division does not provide therapeutic recommendation or prescription. The information supplied is for information purposes only, to help clients make informed decisions. For specific information and advice, please consult your physician.



Getaway Weekend - Fun and Successful

Treasure Island, the Getaway Weekend in Gimli, Manitoba on June 17 to 19, was an ideal way to introduce a social and recreational weekend for people living with multiple sclerosis. Over 160 people attended this weekend retreat. Friday night began with a wonderful dinner followed by a campfire and marshmallow roast near the beach. Several fun activities were offered on Saturday, ranging from miniature golf to meditation to a scavenger hunt. There was something for everyone!

Personal Services and Much More

A full 'personal services' schedule was provided, including massage, pedicures, reflexology and manicures, allowing members to feel pampered in a quiet and relaxed environment.

After dinner, there were two comedy shows and a social. Winners of activities and raffles received prizes. Sunday opened with a hearty breakfast, later giving some free time for attendees to venture outdoors and enjoy the sites the town of Gimli had to offer before heading home.



The weather was beautiful, and the Lakeview Hotel was ideal, with plenty of

room for all activities. Attendees could easily find quiet and interesting places inside and outside to sit and relax between activities of their choice, whether it be on the sun deck of the hotel, near the beach, the balcony of their hotel room, or throughout town. The food was excellent and everyone left feeling well-fed.

Additional services such as childcare and return transportation from Winnipeg to Gimli further complemented the services schedule making the weekend a great value. The registration fee for a single person was just \$100 and entitled each person to a standard hotel room for two nights, food and participation in all planned activities and services for Friday, Saturday, and Sunday.

The positive feedback received by attendees was overwhelming. The Getaway Weekend was a first of its kind in Canada and was truly successful. The need for this kind of social and recreational retreat for people living with MS could not be any more apparent. With such overwhelmingly positive responses, we will be planning a second Getaway Weekend on June 23 to 25, 2006. Watch for more information in upcoming issues of *MS*

Connections or visit

www.mssociety.ca/manitoba



MS CONNECTIONS October 05

Upcoming Presentations you won't want to miss

"Where Are My Keys?"

Cognitive Issues for People Living with MS

Sat., November 5: 10 am -1 pm
MS Society Program Room,
141 Bannatyne Ave., Winnipeg

This session will help you understand the cognitive issues experienced by many people living with MS and will provide you with some coping strategies. Presenters:

Dr. Moira Somers, PhD

Dr. Somers practises in the areas of rehabilitation psychology and neuropsychology

Kristel Smith, occupational therapist,
MS Clinic

A person living with MS



This free session is sponsored by Serono Canada Inc. Refreshments.

To register or for more information please call **Ellen Karr at 988-0917 or 1-800-268-7582.**

Time to Prepare - Emergency-Preparedness

Know what to do! Will you and your family think clearly and logically in the event of a natural or "man-made" disaster? Come and meet with **Randy Hull**, Emergency-Preparedness Coordinator for the City of Winnipeg. Find out what plans are already in place and what you can do to be safe.

Wednesday, November 23: 6:30-8:30 pm
MS Society Program Room, 141 Bannatyne Avenue, Winnipeg

To register or for more information, please call **Ellen at 988-0917 or 1-800-268-7582**

Upcoming Chat Rooms

Our three special websites offer invaluable information and tips on dealing with family life with MS. There are three: one for children (ages 6-12) who have a parent with MS, a second for teens (13-17) with a parent with MS, and the third for parents who themselves have multiple sclerosis.

There are also three monitored chat rooms. You must register on the site to participate in these chat rooms. It's easy and completely confidential. Click on "Register" to create your login and password. Then go to "Chat Room" on the appropriate day and time, enter your login and password and you're all set to chat!

Be sure to mark the following dates on your calendar and plan to participate in these chat rooms. It's a great opportunity to connect with other people dealing with many of the same issues you are.

www.msforkids.com

Saturday, October 29

9:30 AM to 11:30 AM, Central Time

Topic: MS can be scary



www.msforparents.com

Tuesday, October 27

6:30 PM to 8:30 PM, Central Time

Topic: Being a parent with MS can be hard

www.msforteens.com

Wednesday, October 26

6:30 PM to 8:30 PM, Central Time

Topic: MS has changed my life



For further information about the above websites or chat room, call **Darell Hominuk at (204) 988-0902 or at 1-800-268-7582.**

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LIBRARY CORNER



The following selections are available at the Manitoba Division Library.

- Book Review -

***Multiple Sclerosis: A Self-Care Guide to Wellness (2005)* Edited by Nancy J. Holland, EDD, RN, MSCN and June Halper, MSCN, ANP, FAAN**

This updated and expanded second edition uses clear and understandable language to cover a wide range of topics related to multiple sclerosis, including a focus on staying well while living with MS.

Well written and informative, this guide covers important topics such as disease management, community living, life planning, health, lifestyle, and emotional issues, while providing practical advice on self-care that maximizes independence and promotes well-being and productivity.

If knowledge is power, then this book is for anyone who wants the facts on MS. Readers will gain new ideas on how to better cope with the ever-changing challenges that MS brings.

- DVD Review -

***"But You Still Look So Well"... Living with Multiple Sclerosis (2005)* By Audrey Geyer and Kevin Lindenmuth**

A follow-up to *"But You look So Well"* (2001,) this poignant and in-depth 85 minute documentary explores the lives of three individuals with MS and their families, and ways they have learned to cope and live with MS over time. Their personal and working lives are captured, portraying the emotional, social and physical challenges of MS.

The documentary also includes professional expertise by Dr. Robert Lisak, MD, a Michigan neurologist, known for his work with MS. **MS**

RESEARCH STUDY OPPORTUNITY

DO YOU LIVE WITH MS-RELATED PAIN?



Are you interested in participating in a research study that will assess the effectiveness of psychological interventions for pain management for MS-related pain?

A project is being done at the University of Manitoba (U of M) that will study what pain management interventions are helpful to individuals with multiple sclerosis. The primary researchers are **Jennifer Garinger PhD Candidate, Department of Psychology, U of M** and **Dr. Michael Thomas, Department of Psychology, U of M.**

By taking part in this study, you will have an opportunity to learn some strategies that may help you better cope with your pain. You will also have a chance, in a group setting, to share your experiences relating to pain. Your involvement will help us to better understand what strategies are most effective for individuals with MS-related pain.

The study is taking place this fall/winter at the University of Manitoba and involves:

- Several individual interview sessions
- 10 weekly sessions with a small group of up to 10 individuals, all with MS
- Your commitment to attend meetings and practice strategies

Individuals taking part in this research will receive an honorarium of \$25.

If you are interested in participating in this research project or would like additional information about the research, please contact **Ms. Jennifer Garinger** (Primary Investigator) **as soon as possible, at (204) 237-2694 or by e-mail atjgaringer@sbgh.mb.ca**

MS CONNECTIONS October 2005

SELF-HELP GROUPS AND ONE-ON-ONE PEER SUPPORT

The MS Society offers a variety of support programs to meet the varying needs of individuals living with MS. Some people enjoy being part of a group for the social interaction, information and the diverse and experiential support it offers, while others prefer to connect with an individual person. We now also offer *One-on-One Peer Support* throughout the province. For more information, or to start a group in your area, please call the contact person nearest you or call Darell Hominuk at 1-800-268-7582.

Beausejour

Contact: Bob Dickey (204) 268-2178

Brandon

Contact: Karen Black
(204) 571-5671

Carberry

Contact: Donna Pingert
(204) 834-2557

Carman

Southern Manitoba Caregiver Group
Contact: Diane Nesbitt
(204) 723-2221

Deloraine

Borderhills Senior Apts.
1:00 p.m., Last Thursday of the month.
Contacts: Sandra Moore
(204) 658-3552 or
Brenda Hicks (204) 858-2331

Flin Flon

Contact: Debbie Bailey (204) 687-3256

Gimli

Contact: Kathy Wiebe (204) 642-5760

Lac du Bonnet

Contact: Phil and Jeanne Lussier
(204) 345-6071

Morden/Winkler

Contact: Nadine Konyk(204)474-0402

Pine Falls, Pinawa

Contact: Bob Dickey (204) 268-2178

Pipestone

Meets 1st or 2nd Sunday of each month,
alternating between Pipestone and Moosomin.
Contacts: Donna Low (306) 646-2286 or
Lorraine Fidelak (306) 646-4328

Portage la Prairie

Contact: Susan Hologroski
(204) 470-6855

Russell

Contact: Rachel Chipelski (204) 773-2199

Selkirk

Contact: Dan Payne (204) 757-4773

Steinbach

Contact: Nadine Konyk (204) 471-0402

The Pas

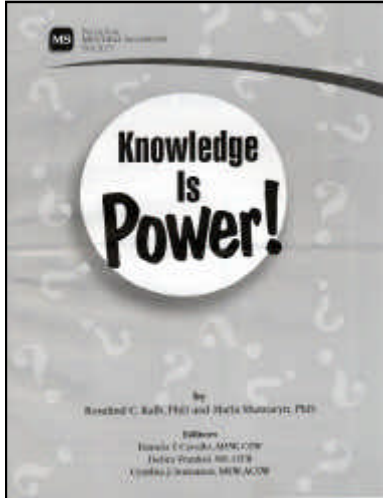
Contact: Robin Searle (204) 622-2940

Thompson

Contact: Debbie Thorne (204) 677-5265

Winnipeg

Male Caregivers Group, Female Caregivers
Group, CHuMS, MS Friends, Faces of MS
(ages 18-26), Parents with MS, Singles with MS
(*On our Own.*)
Contact: Ellen Karr (204) 988-0917



“Great program. It helped me realize that I am still the same person. The program is informative and enlightening”.

To register for the free mail-out subscription, call our toll free number at 1-800-268-7582 or Darell at (204) 988-0902. You may also send an e-mail to info.manitoba@mssociety.ca



The Knowledge is Power (KIP) program is a free mail-out educational and support series for individuals 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, 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

Members' Comments:

“KIP is very informative. I looked forward to receiving it in the mail. Wish it wouldn't stop. I found KIP a coping mechanism. I knew people out there cared.”

“Very beneficial. It puts things into perspective.”

MS Bulletin Board

LIBERTY STAIR LIFT
Doesn't fit our new home

YOURS AT NO CHARGE!
Call **Arnie Cavett** at **889-8990** for more information

FREE TO A GOOD HOME
Orthokinetics Bravo! Scooter

3-wheeled electric scooter
Lightweight/light duty.
Not effective in snow!

Needs new battery and new wheel
(approximately \$200)

Contact **Ron** for more information at **338-0490** or ardecy@netscape.net

For sale: Cricket Electric Lift
Ideal for smaller bedroom.
Asking \$1,000.

Phone **Cecil** at **669-2085**.

INSPIRATION

Thinking about What's Important

by John Hudson

I thought it was just a documentary like any other, when I tuned into a History Channel program that chronicled the polio epidemic of the early 1950s, and the desperate search for a vaccine by Dr. Jonas Salk.

Poliomyelitis, or “infantile paralysis”, as it came to be known, swept across the prairies during 1952-53 like a summer dust storm. It waged a brutal assault on the muscles of people who contracted it, causing paralysis, breathing difficulty and death.

Strangely, polio found its home in middle-class or wealthier communities, where populations lived in more sanitary conditions than their destitute counterparts. It was determined that people who lived in less clean conditions actually had more robust immune systems, and thus had greater resistance to the virus.

Winnipeg was hit particularly hard during the epidemic. As I watched the program, lots of grainy, black-and-white newsreels showed many of the victims, confined to iron lungs or disfigured from the effects of the disease. Tragically, most who contracted polio were young children, whose immune systems were not yet fully developed.

Survivors of the epidemic gave riveting accounts of those moments in history, recalling the fear that gripped the city and how parents kept their kids largely indoors during the summer, which became known as “polio season.” The Royal Canadian Air Force was called into action to fly iron lungs into

Winnipeg during the summer of 1953, a

year that saw 2,317 people contract the disease.

Among them was a woman who gave a very personal account of how polio struck her down that year. She was just in her early twenties when she came down with a severe fever that progressed to muscle weakness, then finally to paralysis. At that time, she was also expecting her first child.



“I can remember feeling the extreme weakness, and then I noticed that I was having to put more and more effort into breathing,” she said. “Eventually, I became totally paralyzed, and spent the next six months in an iron lung.”

She recalled the frustration and fear at being unable to breathe on her own, and then unable to speak. “I was in this iron lung, unable to speak or to move, and I could feel myself going into labour. I wanted to cry out for help, but of course I couldn’t. Fortunately, someone clued into what was happening before things went any further.”

Yvonne Hudson got the help she needed in time for her to give birth in the iron lung to a healthy baby boy, named Robert, who also happens to be my cousin.

Just a few weeks ago, I went to visit my Aunt Yvonne on a sunny Saturday afternoon. We talked mostly about family, and how each of us had spent our summer. Periodically, she had to take a “sip” of breath through a respirator attached to her wheelchair, a result of the post-polio syndrome.

She looked fabulous for her 75 years, and this, I believe, was a reflection about how she feels on the inside. In spite of all the challenges she has been given, she never allowed defeat to creep in, even for a moment.

I can still recall how she enjoyed writing a newsletter for polio survivors, and was shocked at the “assistive technology” she used in order

She looked fabulous for her 75 years, and this, I believe, was a reflection about how she feels on the inside.

to type. It was a pencil, or similar object, clenched between her teeth. “I was

never a fast typist,” she used to say with a grin, “but I’m usually accurate.”

Whenever I asked my aunt if she ever felt depressed or angry about the terrible toll the polio had exacted upon her, she always gave me the same answer. “Who or what could I possibly get angry at?” she would ask. “And besides, I have a husband who loves me a lot, and that’s all I really need.”

It was true. My Uncle Bill has been much more than just a provider, for as long as I can remember. He can finish just about any sentence his wife begins, and knows her needs at any given moment. Most importantly, there is so much love and devotion in that house that you can feel it when you step through the door.

For me, it’s a lesson worth learning, that there is nothing more important than the love and support of a family and spouse to strengthen our sense of self.

The things that can’t be seen are the most important possessions of all.



Affordable Housing

There is something new offered by the **Residential Rehabilitation**

Assistance Program (RRAP). The Secondary /Garden Suite assists in the creation of affordable housing for low-income seniors and adults with a disability by providing financial assistance to convert/develop existing residential properties that can accommodate a secondary self-contained unit.

Eligible clients are homeowners, private entrepreneurs, and First Nations people owning residential properties that could create an affordable self-contained rental accommodation. Clients must enter into an Operating Agreement which establishes the rent that can be charged during the term of the Agreement. A ceiling is placed on the income of households who will occupy the new unit.

The assistance is in the form of a fully forgivable loan (does not require repayment,) which does not have to be repaid provided the owner adheres to the conditions of the program. The maximum loan available varies:

Zone 1: Southern areas of Canada - \$24,000/unit

Zone 2: Northern areas of Canada - \$28,000/unit

Zone 3: Far northern areas - \$36,000/unit

Additional assistance is also available under RRAP for Persons with Disabilities to undertake accessibility modifications for low-income persons with disabilities. It is worth noting that work carried out before the RRAP loan is approved is not eligible.

For more information on this program, visit the website:

www.cmhc-schl.gc.ca/en/prfias/rerepr/index.cfm



MS CONNECTIONS October 2005

SPECIAL EVENT NEWS

The 2005 event season has officially ended and we are delighted to report some impressive results. Here is what happened over the summer:

Elite Communications Cruisin' Manitoba for MS - June 26 \$76,000 Raised

It was a wonderful day to drive through the Manitoba countryside. The early morning rain cleared, making way for warmth and sunshine as 108 cars drove from Winnipeg to Beausejour where they received a hero's welcome by Mayor Harvey Giesbrecht and many town residents. A hearty Ukrainian brunch including kielbasa sausage, perogies and rye bread satisfied our drivers and their guests. Congenial Power 97 radio personality Hal Anderson entertained the crowd with hilarious party games and of course there was a show 'n' shine right out on Main Street.



Everyone then headed out to Pinawa for another show 'n' shine, musical entertainment by the Wickets, a great silent auction, more of Hal's inimitable games and a hay ride tour of Pinawa. The evening offered a scrumptious beef on a bun dinner cooked by Linda Krampetz and her helpers in Pinawa. The Awards Ceremony featured a moving presentation from Top Fundraiser Joseph Delannoy, who has MS.



He talked about how it has changed his life and expressed his appreciation for all the participants' efforts.

The event raised \$76,000. Thanks and congratulations to everyone who took part and especially to our Top Fundraiser Joseph Delannoy who raised \$4,078 and the Top Fundraising Team, Gimli Car Club who brought in \$6,798.



RONA MS Bike Tour Biking to the Viking - August 27 and 28 \$507,000 Raised

This year's tour attracted 761 cyclists who brought in a record amount of pledge money. Although it rained in the afternoon on Saturday, the weather cleared up in the evening in time for the Hoedown social on the beach at the Lakeview Hotel in Gimli. No problem making it through the tons of food served at the dinner – and it was delicious. Thank you to Danny's Whole Hog BBQ for providing and cooking the baron of beef.



The evening was topped off by a performance from the popular Men in Kilts.

Our top fundraiser was Bernard Lofchick who collected \$15, 128 in pledges and the Top Team was the Greatful Tread who amassed an impressive \$40,776.

Thank you to the 500 volunteers who helped make this such a successful and fun event.

**RONA MS Bike Tour - Riding Mountain Challenge
\$200,000 Raised**

For the very first time, there was no rain for the cyclists. What a great weekend! 317 folks rode the route from Dauphin to Wasagaming and back.



The Rookie of the year was Brad Dick of Team RONA from Portage, bringing in \$7,500. The Top Fundraiser was Jack Morris of Winnipeg who collected \$10,540. Team Kinertia was the top team, with \$19,200.

This was the first year we held the Bike Tour Idol contest and it was a great hit. Seven

talented acts entertained the group after a full day of cycling.

Hit a Ball for MS

A rainy spring barely affected the success of Hit a Ball for MS, the MS Society's popular golf fundraiser.



Photos on the Special Event pages by Kevin Grant Photography and Trevor Wideman.

OUR MISSION

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

CONTRIBUTORS

Thank you to the following people for their contributions to this issue:
Tracy Brown, Judy Hermiston, Darell Hominuk, John Hudson, Jayna Ives, Ellen Karr, Laurie Kozak, Gwenda Nemerofsky, Kevin Olfert and Sharon Segal.

MS Connections

October 2005

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Publication Mail Agreement #40050236

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