

# What's Happening in Government & Community Relations

June 2007

## Committee Revitalization Efforts Prove Successful!

Since the Government and Community Relations Committee started to meet on a regular basis again, (January 2007), committee membership has expanded to 13, with six new members joining and seven members staying on to do the important work of this committee. Our membership includes people from urban and rural areas of the province, people of various ages; people with different types of MS represented; and an almost even split of female and male representatives. This balance means that several perspectives are represented.

Long time member Ruby Laughren, a primary caregiver and

new member Jennifer Moszynski have agreed to co-chair. This dynamic group has begun to tackle some important new issues



Jennifer, with daughter Ryan

and continues work on other important issues.

Ruby explains her motivation for co-chairing the committee. *"I decided to co-chair as I now have more available time and energy to put into the committee. The committee has been revitalized and our new members have*

*brought lots of enthusiasm and issues forward that we can hopefully work toward resolving."*

Jennifer has her own reasons for becoming involved: *"... I am finally at a place in my life where I feel the need to give back...It will be five years this July since my eye doctor first suggested that I had MS...So far my life remains fairly unaffected – at least physically. Emotionally, this experience has changed my life. I believe there is a cure and that we can get there together."*

The MS Society's Darell Hominuk will be adding the Government & Community Relations portfolio to his position.



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## Pharmacare Deductible Installment Payment Plan Works for Some

**S**ome MS Society members have applied and are registered on this new payment plan that alleviates the need to pay your deductible for Pharmacare before you can have your drugs covered. If you are eligible, you will be able to divide your deductible up into more affordable

monthly payments, while your medication is covered through Pharmacare.



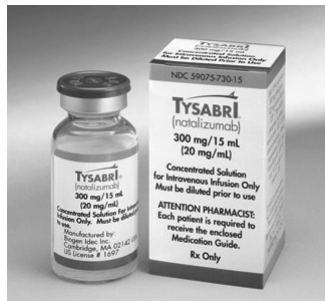
Sharon Hughes, a member of the G & CR Committee is on the new plan and says "Having a limited income, it was often tight to pay \$250-300/month for medication until my Pharmacare coverage started, so making 12

*pre-authorized monthly payments was attractive. Pharmacare staff and pharmacists were most helpful with completing the application. I'm receiving medications with no upfront cost, and Manitoba Hydro sends a monthly withdrawal statement. It couldn't have been easier."*

## TYSABRI® - To Cover or Not To Cover, That is the Question

**I**n September 2006, following rigorous review, Health Canada approved Tysabri® as safe and effective. This is the only drug approved in Canada for use with people who have relapsing-remitting MS and are resistant to first line treatment with beta interferons or glatiramer acetate. The M S Society of Canada agrees with Health Canada that given alone Tysabri® is a safe and effective treatment for people with relapsing-remitting MS.

The federal/provincial/territories Common Drug Review (CDR) reviews



drugs approved by Health Canada and recommends to the provinces if they should include new drugs in their formularies. The CDR announced in May 2007 that it does not recommend provinces cover the cost of Tysabri® in their drug programs, recommending more research be conducted before approval is given.

The MS Society of Canada

feels that the treatment of MS is a highly individual decision made between a doctor and patient and the widest possible number of choices need to be available to treat this disabling disease.

Tysabri® has been approved for reimbursement in the United States, France, Germany and Sweden.

We will be engaging in discussions with provincial health officials regarding the coverage of Tysabri through the Pharmacare Program and will update you on the progress of these discussions.

# Self/Family Managed Care Option

## – YOU Are In Charge

**M**anitoba Health has an option in the Home Care Program offering eligibility to people to take on their personal care as self managers. An assessment is required. Individuals would be responsible for coordinating, managing and directing non-professional services they need to remain living at home/ in their community.

The Independent Living Resource Centre (Wpg) offers support resources -f information packages and training sessions to help individuals learn how to manage this option successfully. As well, if a person needs assistance carrying out their responsibilities as an employer, they may pay a small administrative fee to the brokerage program for this service. An approved family member may also act as the employer on an individual's behalf.

Members in rural communities would like to receive services through the self/family managed care option of Home Care, but their Regional Health Authority may not offer this option. Here is an account from a member of the G & CR Committee who uses the Self

Managed Care Option:

**My MS** has progressed to the point where I am unable to use my hands or legs. I can't let that get me down! As resilient people, when faced with adversity, we adjust and deal with things accordingly.

Self-managed health care may be an option for *you*. Think about it - you can do it. I've been on this program for over seven years now and there have been some challenges. The biggest one is maintaining enough staff.

In the beginning, with the help of a private health care agency I had my staff, and very few problems. I had time to work on setting up my own accountants etc. I promised myself that within one year I would no longer need the assistance of the agency. As time got closer for me to be my own manager, I was nervous! My biggest concern was that I have the mental capabilities, but not the physical ones. I found individuals to help me with my

paperwork and "be" my hands!

It was advantageous to have a coordinator set up and look after all scheduling and staff, but I knew I had the ability to do it myself. There are times when not having enough staff is challenging. Believe me; it usually will work out in the end. Don't get discouraged!

My self-managed program began in 1999. I understood the program and knew what to expect. I had to hire staff, set up a schedule, find myself an accountant, train staff, open a bank account etc. I felt that I was thrown into a hole that I was going to have a hard time getting out of. As time progressed and I became a more confident, I knew I would find a way out.

The greatest advantage to this program is peace of mind. When you hire your own staff, YOU are in control of who will enter your home and work with you. The road along the way does have its bumps, but you will be satisfied with the end result! Be positive and keep your head up high.

Darwyn Wowk,  
*MacGregor, MB.*

## Expanding Housing Choices Province-wide

The seven-suite second phase of the Housing for Alternative Living housing project at 340 Princess Ave., is finished and the Selection Committee will begin to interview potential renters on the waiting list. Ellen Karr, the MS Society's Client Services Coordinator is a member of the selection committee.

This initiative is a great start toward addressing the unique housing and care needs of people living with MS in Winnipeg. Members also want to see similar initiatives outside the city.

The timing to recommend development of other housing options, particularly for younger people living with MS who have high care needs could be very good. Discussions with officials at both the WRHA and the Department of Health indicated that there is a real openness to

providing services in a more individualized and creative way, including examining how personal care home structures have been used to date and changes regarding delivery service models, such as supportive housing and specialized supports. This approach is happening throughout the province.

There has been a recent influx of money from the federal government for low cost, affordable housing initiatives. This makes it a good time to approach the government and recommend that a percentage of these funds be earmarked for the purpose of developing affordable, accessible and safe housing for people living with disabilities.

The Government and Community Relations Manager will be setting up meetings with the appropriate minister.

## Accessible Rural Transportation Needed for Medical Appointments

While a number of rural communities have found ways to offer accessible transportation for people with disabilities to travel within their communities, there are not many options available for travel from community to community. There are accessible buses available on the Greyhound/Grey Goose bus routes if you order 72 hours ahead of time, but for communities not on the bus route, your ability to travel in an accessible vehicle totally

depends on what private accessible vehicles may exist in your community.

This is not a new issue.



Some of our rural members have raised this issue because they are finding it difficult to travel into Winnipeg to attend their medical appoint-

ments at the MS Clinic.

We've raised these concerns with the WRHA and the Deputy Minister of Health.

The Seniors and Aging Secretariat is dealing with similar issues and has been suggested as a resource to contact and collaborate with to address this need.