



# MS Connections

A newsletter connecting Albertans who want to end MS • [www.mssociety.ca/alberta](http://www.mssociety.ca/alberta)

Summer 2008

## Caring for those who need help the good, the bad and the...

*actually it's mostly good, but there are areas that need improvement*

**W**e certainly have come a long way in providing care, dignity and respect for individuals who need help meeting some of their basic needs. For young people in Alberta living with MS, there are some shining examples of how to do things right. There is still room for improvement, but things are getting better. Unfortunately, there are still instances where young people with MS and other neurological disorders live in facilities designed to take care of seniors.

As with most young people with MS, independence is an important ingredient for quality of life. Loss of independence is demoralizing and can rob an individual of the things that really matter. Dwight used to meet his son in the morning and walk him to school. Due to staff shortages, there is no one available to get him ready on time. Staffing problems are part of a

larger labour shortage throughout Alberta. They are not the facility's fault, they are not Dwight's fault, but Dwight has to pay a price of losing something important to him.

Yet "it's nice to be here," says Dwight. The leg spasms he suffered from while living at home made it impossible to be by himself.

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**"In two years there'll be a whole new batch of people in here. Unfortunately I'll be here till I'm 70."**

Dwight Hudson, a resident at West Highlands Good Samaritan in Lethbridge, put it this way: "In two years there'll be a whole new batch of people in here. Unfortunately I'll be here till I'm 70."

Dwight is 51 and was diagnosed with MS at 32. He has lived at West Highlands for nearly two and a half years. Dwight is very active. In fact, his room is filled with paintings, sketches and sculptures he's created. He also helps coach his son's baseball team and even umpires games.

### Minister introduces MS Society in the Legislature



**MS Ambassador Helen Chesterman pins a carnation on Health and Wellness Minister Ron Liepert. Minister Liepert introduced representatives of the MS Society into the Legislature on May 6. All MLAs were given a carnation and invited to wear it in support of Albertans living with MS.**

MS Connections is published quarterly by the MS Society of Canada, Alberta Division. It is intended to provide news and information for Albertans with MS, their families, caregivers, medical professionals and other stakeholders. The information and opinions contained in this newsletter are obtained from sources believed to be reliable, but their accuracy cannot be guaranteed. We value your comments, feedback and reprint requests—please email them to [info.Alberta@mssociety.ca](mailto:info.Alberta@mssociety.ca) or call us at the numbers listed below.

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## 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.

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# Important changes to Alberta's health system



Albertans were recently informed of pending changes to Alberta's health care system. Ron Liepert, Minister of Health and Wellness, announced the abolishment of the nine Regional Health Authorities (RHA) in favour of a single provincial health services Board. This change took effect on May 15, 2008. The establishment of this new health system governance model is intended to improve access to health services in Alberta and to make the province's health care system

more efficient and effective. The Minister's decision signals that the buck stops with him. This should contribute to a more accountable and responsive Alberta health care system. I am sure that readers of MS Connections will ask the question of how this might benefit Albertans living with MS.

I welcome these changes for the reasons to follow. The delivery of health services through nine separate health region boards contributed to inconsistent and inequitable service levels across the province. Using the self-managed home care program as an example, people with similar needs living in different health regions may have received different levels of support depending on the budget and priorities of each health region. The former RHA-based system did not allow portability of home care entitlement levels from one region to another in the case of someone who changes residence or transfers to a new region to attend school. Similarly, the level of long-term care accommodation and services varied greatly from one region to another.

As the president of the MS Society in Alberta, I welcome the opportunity to make our case before one department instead of trying to influence changes across nine distinct health systems. This will work to our advantage as we host a forum of MS stakeholders from across the province. The MS forum will create an inventory of current MS services, identify service gaps and develop new collaboration strategies. The new Minister of Health is interested in receiving a report from this forum. The report will identify better strategies for coordinating and delivering MS services in the community. In our view, the MS forum and subsequent report can make a strong case for creating a special MS population initiative across several government departments to improve MS services and research as part of a provincial MS strategy.

Now that Alberta Health and Wellness will be more involved in the delivery of health care and promoting healthy and safe communities, we have a better chance of receiving government endorsement for the creation of a provincial MS vision and strategy which has been done for other disease areas like Diabetes and Heart & Stroke. Efforts to streamline service delivery systems is warranted not only in the department of Health and Wellness and other government ministries, but also within organizations like the MS Society and between partnering organizations and professionals representing nursing, neurology and other allied health partners.

So, I remain optimistic that the changes announced by the Minister of Health, along with improvements that we can make as stakeholder organizations and professions, can lead to better health care. I'm also pleased that such a position is shared by the Alberta Medical Association.

Neil Pierce, President, Alberta Division

# Teaching patients about MS therapies

## A vital tool in achieving quality of life

Since February 2007 Lynn Whitman has been working with community neurologists in the Greater Edmonton and Northern Alberta regions. Her specific nursing role is to provide education and hands-on coaching to patients who have been prescribed MS Drug therapies by their neurologist. Deciding to go on an MS therapy is a critical decision that will impact future quality of life and further choices for how to best manage MS symptoms and challenges. From the time the prescription is filled out to the actual injection and anticipated benefit, patients have a lot of questions, a lot of hope, and some uncertainty as to how this will help them live better with MS.

Lynn comes to us with expertise in

## St. Paul's first MS Walk a huge success!



**Thumbs up to the St. Paul WALK which took place on May 10, 2008. It was the first MS Walk to take place in St. Paul and was a great success. 250 WALKers raised over \$55,000.**

comprehensive nursing care for persons with MS gleaned from her work at the Glenrose Hospital Spinal Cord Injury Unit. She is passionate about helping people with MS and loves teaching clients and their families. Currently she is stretched by the challenges of keeping up with referrals and trying to contribute to the MS community with the many learning, sharing and networking opportunities that arise. We look forward to working with

Lynn in the future at MS education events.

For more information on what MS treatment entails, call the Division office and ask for two new resources: a booklet entitled "The Treatment Question: Should I start an MS Medication" and an article by Dr. Paul O'Connor, Medical Advisor to the MS Society of Canada. To speak to someone about MS therapies, call your neurologist's office or the MS Society at **1-800-268-7582**.

Excerpt from

## The Treatment Question: Should I start an MS Medication?

Many clinical trials have shown that beta-interferons (Avonex, Betaseron, Rebif) and glatiramer acetate (Copaxone) are safe and effective in the treatment of MS. As a result, the MS Society of Canada, the Canadian MS Clinics Network and the National MS Society in the U.S. recommend treatment with one of these four medications as soon as possible after diagnosis.

Tysabri is also an option, but it's generally reserved for people who have tried another therapy unsuccessfully. Tysabri is a new drug and your doctor

can help you decide whether it's for you.

Treatment is recommended because of the growing body and scientific evidence that indicates that inflammation, demyelination and axonal loss begin very early in the MS disease process. This means that long before you had your first symptom, MS was causing damage to your central nervous system. For many people, MS is only diagnosed years later when the effects of the disease become more obvious. So once it's confirmed that you have MS, it's important to start treatment early to give your body a better chance of fighting the

MS disease process and preventing any further damage from occurring.

Treatment won't be the best option for everyone. Disease Modifying Drugs (DMDs) are most effective in people with relapsing-remitting MS. They are not effective for those with primary-progressive MS. Women who are pregnant or breastfeeding are generally advised to put off starting a DMD. Tell your doctor if you're planning to become pregnant because that will also affect whether or not you should start treatment.

To read more and receive a copy of this new resource call **1-800-268-7582**.

# Friendly Visiting program delivers smiles

In March of 2005 a vision for an enhanced Friendly Visiting program in Alberta was formed. With the support of the Alberta Government we are expanding this informal support program for persons with MS in long-term care through the development of a comprehensive, trained volunteer network. The program is a way of providing support, decreasing loneliness and isolation, increasing awareness of community resources and engaging in shared activities.

**“The main highlight for me has been the opportunity to...add purpose and enjoyment to both her day and mine.”**

Sisters Michelle and Gina started volunteering for the friendly visiting program one year ago. Michelle is a Registered Nurse and Gina is in her final year of her nursing degree. Gina decided to get involved after she heard Jeannine Christopherson, Outreach Coordinator for Edmonton Chapter, speak about the program. “I knew it was a right fit for me. I wanted to make a difference in the life of someone struggling with MS, and the Friendly Visiting Program is an amazing way to do that,” says Gina.

Since then both Michelle and Gina have been paired up with clients and have found it to be a very rewarding experience. “[As] a Registered Nurse, [I] have encountered patients living with MS in the hospital and community. Through



**Gina and Michelle volunteering for the Kids area at the St. Albert WALK are also Friendly Visiting Volunteers. As part of this program they are matched up with clients who have MS and are living in continuing care facilities. They visit these clients on a regular basis to provide support and engage them in shared activities.**

the Friendly Visiting Program, I am able to spend one-on-one time with a client on a regular basis, which is very rewarding. The best part is bringing a smile to the client's face when I visit," says Michelle.

"I think the main highlight for me has been the opportunity to get to know my client and the opportunity to add purpose and enjoyment to both her day and mine," says Gina. "I hope more individuals will join the cause to improve the day-to-day lives of people dealing with MS."

If you are interested in volunteering as a Friendly Visitor please contact:

#### **Edmonton**

Julie Kelndorfer  
Volunteer Manager - Alberta Division  
Julie.kelndorfer@mssociety.ca  
1-800-268-7582

#### **Calgary**

Marie Wong  
Manager, Volunteer Resources  
Calgary Chapter  
Marie.Wong@mscalgary.org  
1-800-268-7582

## The goals of the Friendly Visiting Program are:

- 1** To expand and complement existing outreach friendly visiting services to residents with MS who live in long-term care.
- 2** To provide opportunities for people with MS to interact with a member of the community outside of the family and health profession.
- 3** To promote a sense of dignity and self-worth.
- 4** To reduce social isolation that a resident may be experiencing.
- 5** To provide support & companionship to residents and offer appropriate activities.
- 6** To provide information about multiple sclerosis, the MS Society of Canada, and appropriate community resources.
- 7** To increase the MS Society's awareness of long-term care residents' needs and/or issues.

## Student gets fundraising help from friends



**Kaitlyn Lee (right), 15, organized a bake sale at her school to raise money for MS. Her mom was diagnosed with MS three years ago and Kaitlyn has been involved ever since. Her friend Chloe Sarafin (left) and a few others helped make the bake sale a huge success. Kaitlyn also participated in the Edmonton MS Walk. So far this year she has raised about \$1,000.**

## What's your legacy?

Making a difference that lasts a lifetime — and even longer

Each year many individuals decide to make a legacy gift to the MS Society, a donation that can help the Society in future years or immediately — it's your decision.

The majority of legacy gifts are in the form of bequests, which includes leaving a portion of your estate in your will to the MS Society. A bequest allows you to make a gift for the future without affecting your estate during your lifetime. However, there are other types of legacy gifts such as gifts of life insurance, annuities, property and trusts. Gifts of securities have become very popular recently since the Federal Government eliminated the capital gains tax on donations of stock and listed securities to a registered charity such as the MS Society. In addition to this tax benefit, a tax receipt is issued based on the full value of the stock at the time of the donation.

By making a legacy gift (also called a planned gift) to the MS Society, you become a member of the Evelyn Opal Society. This Society was created in honour of Evelyn Opal, the founding member of the MS Society of Canada. Members have established a legacy gift as their commitment to ending MS. We would be pleased to welcome you in realizing this vision.

We are aware that some individuals and families have quietly included the MS Society in their estate plans. If you are one of these donors, please let us know so we can show our appreciation.

For information regarding legacy gifts or other types of donations, please contact:

**George Jacob**  
**Director, Major Gifts & Planned Giving**  
**(403) 250-7090 or**  
**[george.jacob@mssociety.ca](mailto:george.jacob@mssociety.ca)**

# Family battles with Regional Health Authority for adequate Home Care funding

## MS Society advocates on family's behalf

**G**arry and Beth Chmara live on their family farm in Eaglesham, Alberta, about 130 km northeast of Grande Prairie. Beth has very advanced MS symptoms and Garry cares for her at home along with the assistance of two live-in caregivers.

When the Government of Alberta removed the maximum monthly home care allowance, the Chmaras were relieved. The previous monthly cap of \$3,000 meant the family had to spend \$2,000 from its own savings each month to provide for Beth's care. However, Garry and Beth soon realized that the financial

**“All of [Beth’s] nourishment is by tube feed and is food off the table, as we have managed to ‘super blend’ fresh foods for the tube feed.”**

relief they were looking forward to was being held up by bureaucratic red tape.

The Peace Country Regional Health Authority (RHA) knew the cap had been removed, but claimed it was awaiting additional funding from Alberta Health & Wellness to increase payouts for self-managed care. A few months later, the Peace Country RHA would institute its own monthly cap of \$3,500. This seemed to be in direct contrast to the original intent of Alberta Health and Wellness



**Garry and Beth Chmara with Beth's caregivers. A successful appeal to the Peace Country Regional Health Authority (now defunct) means more funding will be provided for Beth to receive the care she needs at home.**

when it removed the cap: that is, to establish a monthly allowance based on client need rather than an artificial ceiling. (Note: on May 15, 2008 the nine regional health authority boards were replaced by one provincial governance board called the Alberta Health Services Board.)

With the help of the MS Society, Alberta Division, Garry Chmara appealed to the Peace Country RHA. In Garry's own words, he describes the state of Beth's MS, the level of care she requires, and his struggle to have her care provided for.

### **What kind of care does Beth need?**

Beth needs 24-hour close monitoring in order to minimize the possibility of aspirating or choking on saliva. In addition, Beth needs assistance with almost all daily functions because of her extremely limited mobility of legs and arms. As she cannot speak, we must be constantly vigilant to Beth's needs, discomforts, etc., as well as trying to “intelligently” guess what she may be wanting to tell us. Beth is completely incontinent and we have worked out effective ways of managing this. All of her nourishment is by tube feed and is

food off the table, as we have managed to “super blend” fresh foods for the tube feed. Beth needs relatively few medications and these are administered more on an “as needed” basis. Good skin care maintenance is essential and is being provided by our live-in caregivers. Beth has never developed a bed sore.

**Is it possible to have Beth stay in a continuing care facility?**

Our family physician, whom we have known for over 30 years, advised us more than two years ago that if Beth were placed in a long-term care facility she would almost certainly expire within two years. The facility would be unable

myself or damage to equipment due to my exhausted state, but was fortunate to not experience any incidents.

I am the only person who can drive so that means that I am the only person to get the mail, food, etc. In addition, if any medical emergency arises, I immediately drop farm matters and tend to getting and accompanying Beth to a medical facility (one hour by road).

Our caregivers have excellent training and background. Two are nurses from the Philippines and have worked for a minimum of three years looking after severely disabled individuals before coming to Canada. They are entrusted with the primary responsibility of Beth’s day-to-day needs, skin care management, etc. Beth’s care and the planning of such is a team effort and the expertise of our caregivers is acknowledged and supported.

**What kind of care does Beth receive at home and is it enough?**

Beth receives 24-hour close monitoring, etc. The problem with the situation is that we were working with two live-in caregivers who oversaw Beth for about 100 hours per week, while I managed Beth for the remaining 70 hours per week. This situation was not just severely taxing on myself, as I also had to manage the farm and look after all household maintenance, but it also affected our finances as the health region funding was still approximately \$2,000 per month less than was required for two live-in caregivers. Further, there was always a possibility that I might fall asleep while watching Beth and not notice her being in harm’s way, or that my health would deteriorate to the point that I could not continue with my share of the appropriate care.

We were anticipating the arrival in April of a third live-in caregiver to alleviate most of the stress on myself. This would have meant a personal financial commitment of approximately \$4,500 per month over and above the \$3,000 from the health region. This would have resulted in us having to sell our farm in order to pay the bill. Our goal continues to be having Beth remain here in our home which fully accommodates

everything now and into the future.

**When Alberta Health and Wellness removed the \$3,000 monthly ceiling, did you apply to receive a larger monthly amount?**

The cap was removed by the province on May 16, 2007 in order to accommodate families such as ours. We had been corresponding with our regional health authority as well as Alberta Health and Wellness and the Premier’s office during the previous two years, pointing out the unfairness of the cap and our desire and need to keep Beth at home. (The cap was set at \$3,000 per month in 1991 and never adjusted for inflation.)

As Beth’s MS progressed over the

**“Our family physician...advised us more than two years ago that if Beth were placed in a long-term care facility she would almost certainly expire within two years.”**

to provide the careful continuous live monitoring needed to avoid choking or aspiration. It therefore became apparent to us that a continuing care facility was not an option.

**What was your role as caregiver and how did this affect your ability to run the farm?**

We have a small grain farm operation which we maintain with large machinery, so my time commitment is not as significant to farm management as with most farmers. Seeding and harvest can be extremely busy times, but with proper preplanning the situation has been manageable. I do not feel that our farm has been negatively affected by our situation, although it was significantly threatened by the shortfall of government funding for Beth’s care. Additionally, I was always at risk of causing harm to

**“We had been corresponding with our regional health authority as well as Alberta Health and Wellness and the Premier’s office during the previous two years, pointing out the unfairness of the cap and our desire...to keep Beth at home.”**

years, we realized the day would come when we would require more than the funding provided. We were relieved to learn of the cap’s removal and immediately contacted Peace Country Health about receiving funding to cover the full costs of our two live-in caregivers. The region, however, demurred, stating that it needed to develop new policies and guidelines for self-managed care. We were advised to wait.

As it was costing us \$2,000 per month of our own money – in effect a subsidization of the health care system – and we were already working on obtaining a third live-in caregiver, we

continued to write and phone the local health authority and Alberta Health and Wellness. Over the next few months it became apparent that there appeared to be a disagreement between Alberta Health and Wellness and the regional health authorities.

The provincial budget had been set and passed in April, while the cap removal happened the next month. Home care allocations from Alberta Health and Wellness for the new budget were very generous; I believe about a 26 percent increase from the previous year. But it seemed that each health region stalled in providing more funds to self-managed care. They were waiting for the province to come up with the extra dollars.

Our situation stagnated regardless of our pleadings. We considered taking the health region to civil court (what used to be called small claims court), but learned that a public body must be tried in the Court of Queen's Bench, which for us meant delays and considerable expense.

#### **How did the MS Society advocate on your behalf?**

In mid-December it had been indicated to us in a letter from the CEO of Peace Country Health that the new policy would be provided early in the new year. Two months later we had still seen no action so I contacted Neil Pierce, President of the MS Society, Alberta Division, to see if he could motivate the health region. But he learned that the new policy had already been adopted the previous week. Finally in early February 2008, nine months after the removal of the cap, we discovered that Peace Country Health had instituted its own cap of \$3,500 per month, a paltry \$500 more that would certainly not help us much.

The region had also set up a formal appeal process for families such as ours and was intending to provide us with all of this information in March. Within a few hours of learning this, I had decided that our best course of action would be to compose a "letter to the editor" that outlined our plight, requested the provincial political parties to provide their reactions (we were in the middle of the Alberta 2008 election campaign),

and questioned if similar things were happening in self-managed care funding in other health regions in the province.

In addition to other media interest, the letter convinced Michelle Lang, a reporter with The Calgary Herald, to write an article about our plight. Her article revealed that other health regions had also set their own new ceilings, none more than about \$1,000 per month more than the previous cap. Prior to the provincial election date, the Alberta PC party answered my question in a position paper, essentially stating that the government agrees that increased funding for families such as ours is

**"...in February 2008, nine months after the removal of the cap, we discovered that Peace Country Health had instituted its own cap of \$3,500 per month, a paltry \$500 more...."**

paramount.

As part of its appeal process, Peace Country Health set up a special appeal panel which heard our presentation on March 11. At our invitation, Mr. Pierce was present at the appeal and addressed the panel members, all members of the Peace Country Health Board of Governors. Lorna Young, Executive Director of the MS Society's South Peace Chapter, was also present as an observer. In addition to short presentations from Beth and myself (I read Beth's statement to the panel), we presented a letter from our family physician attesting to our situation and his concurrence with our need to keep Beth at home.

#### **What did the appeal panel conclude?**

At the appeal we requested compensation of approximately \$20,000 to make up for what we had paid since the ceiling had been removed in May

2007. (Since August 2006, when we acquired a second live-in caregiver, we have paid approximately \$30,000 of our own funds to make up the shortfall.) This request was denied on the grounds that it had been our decision to employ two caregivers before the health region had made its decision on the need for our extra funding.

The panel agreed to provide us with \$6,000 per month effective March 1, 2008. They acknowledged that our costs for three live-in caregivers would be about \$7,500 per month based on the figures we had provided, but that care-at-home costs are a shared responsibility between the health region and the family. \$1,500 per month would be our "share" based on the charge of \$1,500 per month for individuals or their families in long-term care. So there has been an acknowledgment of full funding to be provided, less a \$1,500 per month share for the family. We consider the family share to be a miscalculation on the part of the appeal panel and we are pursuing it further with Alberta Health and Wellness.

#### **What will this decision mean for you and Beth?**

Until the \$1,500 per month is removed, we shall continue to have fewer funds available for the comforts of life, the provision and maintenance of special equipment for Beth, and so on. We are continuing to subsidize Beth's care at home. The average cost to the province today for a long-term care bed, when one factors in all considerations, is more than \$10,000 per month after the \$1,500 per month fee is taken into account.

Our farm is once again secure and our future here is also secure. It is our intention to continue to confer with our family physician over the state of Beth's health and the care that we can provide for her at home. We are grateful for the efforts of Neil Pierce and the Alberta Division of the MS Society for all their assistance. We are certain that we would not be where we are today without their help. We are also most grateful to Premier Stelmach for his efforts in having the cap removed from the provincial guidelines in 2007.

# 17-year-old raises \$9700 for MS over dinner

**O**n November 17, 2007, 17-year-old Neil Blue hosted an extremely successful third party fundraiser for the MS Society that raised \$9700. The fundraiser was organized by Neil and hosted by the Edmonton Demolay chapter of which he is a member

The Demolay is a youth group for young men aged 12-21. The group is dedicated to preparing themselves to lead successful, happy and productive lives. "It is a group of great young men

**"...my uncle had a cane to help him walk but now he can't walk, is in a home, and can't even speak, so I wanted to do something to help."**

who really want to make a difference in the community," says Neil.

In 2007 Neil was serving a term as Master Councilor of the Demolay and therefore had a part in deciding what charity their upcoming event would support. "I chose MS because I have an aunt and uncle who have been affected by the disease," says Neil. "I remember when I was young my uncle had a cane to help him walk but now he can't walk, is in a home, and can't even speak, so I wanted to do something to help."

The event he organized was a murder mystery dinner with a silent and live auction. The event took place at the Shrine Centre - a space which was donated to them by the Shriner's. Along

with fellow Demolays, Neil dressed up and acted out the murder mystery. "It was a lot of fun and everyone really enjoyed it, we asked females from the Edmonton Jobies group to play out the female roles," says Neil. Close to 175 people attended the event.

At the end of the evening combined proceeds from ticket sales and auction items came to \$6700. "My dad helped me out a lot in making sure we would raise money with the event but I didn't expect it to be as much as it was," says Neil.

However, Neil didn't stop there. He proceeded to contact the Alberta Masonic Youth Foundation and the Alberta Parents Club. Both of these



**17-year-old Neil Blue organized a third party fundraiser for the MS Society that raised \$9700.**

associations were so impressed with his efforts that together they contributed an additional \$3000.

"Sure, organizing the event was stressful and it required a lot of hard work but I really wanted to make a difference so I put my mind to it and pulled it off," says Neil. He also added that "if I can do it then other people can jump on the bandwagon as well."



**Ann Stewart, Executive Director of the MS Society, Lethbridge & District Chapter, receives a handful of cash from Lynette Harty of the University of Lethbridge. The university hosts a dinner every year to celebrate student success and every year the students choose a local charity to support. The dinner includes various games students and staff can pay to play. Proceeds this year were donated to the Lethbridge & District Chapter of the MS Society.**

Never underestimate that a small group of thoughtful, committed people can change the world, indeed it's the only thing that ever has. *Margaret Mead*



From left: **Dr. Samuel Ludwin (Professor of Pathology, Queen's University)**, **Yves Savoie (President and Chief Executive, MS Society of Canada)**, **Fred Moore (President, Altus Energy Services)**, and **Bert Wyman (Calgary lawyer)**.

*PAMS: People Against MS*

# Moving mountains

A group of committed Albertans is doing all it can to end MS

Last May a “small group of thoughtful, committed people” met over lunch in Calgary to share their stories and express their interest in a common cause. The fourth PAMS (People Against MS) luncheon saw about 40 people gather to reaffirm their desire to do what they can to end MS. While enjoying a light but delicious salmon lunch at the Calgary Petroleum Club, guests heard **Dr. Samuel Ludwin** discuss progress to date on the endMS campaign. **Yves Savoie**, President and Chief Executive of the MS Society of Canada, explained why this campaign

**Bert's contribution brings the total PAMS commitment to the endMS Campaign to about \$600,000.**

holds so much promise for all Canadians living with MS.

The highlight of the luncheon came as Calgary lawyer **Bert Wyman** explained his personal involvement with the Campaign. Bert's wife has MS and for that reason Bert has been a regular face at the Enerflex MS Walk in Calgary for the last 15 years. This will be the first year Bert has missed the walk in all that time.

Bert's commitment goes beyond participating in the Walk. He recently made a very generous contribution to the endMS Campaign. Bert's contribution brings the total PAMS

commitment to the endMS Campaign to about \$600,000, excluding the \$1.5 million contribution from the Alberta Government. This is a very impressive number considering PAMS is an event exclusive to Alberta. In fact, for the time being, the PAMS luncheons take place only in Calgary. However, plans are underway to introduce the luncheons in Edmonton, Red Deer and possibly Medicine Hat. The Calgary PAMS luncheon was made possible through the generous sponsorship of TEVA Neuroscience.

Funds raised from the PAMS events,

together with the Alberta Government's contribution, will be invested in Alberta-based research projects primarily out of the Universities of Alberta and Calgary. Alberta is home to some of the brightest MS researchers in the world.

For more information about PAMS or to attend the next luncheon in Calgary, please call **George Jacob** at **(403) 250-7090** or email **george.jacob@mssociety.ca**. A similar luncheon is scheduled for Edmonton in the fall. Please contact **Mark Mahl** regarding this event at **(780) 440-8764** or **mark.mahl@mssociety.ca**.



**Bert Wyman (left) with Neil Pierce, President, MS Society of Canada, Alberta Division. Bert's commitment to ending MS includes walking in 15 MS Walks and making a generous contribution to the endMS Campaign.**

## What's PAMS all about?

PAMS brings together individuals who share a common goal of ending multiple sclerosis. Community leaders with the means to make a substantial difference meet periodically to learn about new developments in MS research and other important MS issues. The PAMS network grows as supporters introduce their friends and colleagues to the MS Society and the PAMS concept. And with this growth, we are brought even closer to achieving our mission.



**Karen Mychaluk played a key role in getting the PAMS luncheons off the ground in Calgary and creating the success they enjoy today.**

## The Brick MS Drive Fore A Cure!

Join us for an unforgettable day of golf, exciting hole challenges, great food and a live and silent auction! All of this while raising money 'fore' a cure! Our goal is to raise \$100,000 and with your support we know we can do it!

**Thursday September 11, 2008**  
**Raven Crest Golf and Country Club**  
**Breakfast at 7:00am**  
**Golf at 8:30am**  
**Registration Fee: \$75.00**

All participants must raise a minimum of \$125 in pledges to participate.

For more information and to register visit [www.mssociety.ca/alberta/golf.htm](http://www.mssociety.ca/alberta/golf.htm) or call our office at (780) 463-1190.



# Caring for those in need

Continued from page 1



**Dwight Hudson lives at West Highlands Good Samaritan in Lethbridge. He's a baseball coach, umpire, painter, sculpture, father.**

There are five people with MS at West Highlands. While that does provide opportunities for social interaction, the individuals with MS live with, eat with, and participate in activities with the general population, most of whom are in their 70s, 80s and 90s.

There is a newer facility which has taken a different approach to caring for individuals with MS and other young people not suffering from dementia. Bethany Collegeseide in Red Deer is on the campus of Red Deer College and has separate units, indicated by colour, for people in similar circumstances. The red unit for young adults has 14 residents, 15 including the resident dog Rusty. About half of them have MS.

The young adult unit is striking in its social interaction, busyness, and overall vitality. Dawn Finkbiner is 57 and has witnessed the bad and the good in long-term care for young adults. After her husband died in 2005, Dawn went to a facility in Drumheller where she

spent one year. "Out of 112 people at the Drumheller facility, three were cognitive, everyone else had dementia of some sort. It was horrible," said Dawn. "I regularly had panic attacks. I saw no future, no hope in that place."

While at Drumheller, she learned about Collegeseide from a mental health worker. She's been at Collegeseide for two years. "I love it. I feel blessed to be here," she said.

The staff at Collegeseide do a lot of things right - the little things that most people take for granted but are important to people who are unable to care for themselves. "We have 'food focus' meetings once a month. When I first got here the food was very mushy. The food has improved 500%. I'm not so old that I want soft vegetables. I still like my vegetables crunchy," said Dawn.

Dawn asked the Collegeseide administration if the residents in the young adult unit could have a dog. She was told that if she got 100% consensus

among the residents, she could do it. She got 100% and the young adult unit now enjoys the company of a beautiful chocolate lab.

Dawn is her own best advocate. She works hard at improving quality of life in the facility and for her self. She is currently enrolled in the "Disability and Community Studies" program at Red Deer College. "I'm not studying for a job. I just want to keep my brain active." As its name suggests, the college is right across the street from Collegeseide, making it very accessible.

Although she is very happy at Collegeseide, Dawn's dream is to have a separate building just for young people with a disability. In fact, she's going to send a letter to the television program "Extreme Makeover" to see if they would take on a project like this. "The people who live here have so much life left. Unfortunately they live in a place that has so much death."

Lois Aarhus is another Collegeseide resident. Now 50, Lois was diagnosed with MS at age 21. At the time she was an outstanding fastball catcher. As she lost her ability to play, the two words that crossed her mind were "Why me?"

In her late 30s Lois began to rely on a wheelchair to get around. Although she didn't want to move to a facility, she had no choice. Her family wasn't able to provide the care she needed. She fell often and was frequently left helpless at home until someone came to her aid.

The first facility she moved to was in Lacombe. "Most of the residents there had alzheimer's or dementia. The staff would push my chair to the window so I could look outside and I would eat my meals there."

When Lois went to Collegeseide, the staff were eager to learn more about MS, another example of things done right. It's testimony of an enlightened facility when the staff want to learn how to take better care of their residents. As a result, Lois and a MS Society staff member

conducted a MS orientation for the Collegeseide staff.

Although she likes Collegeseide, Lois feels like it's not her home. "I have lost my independence and I have 34 roommates. I would rather be at home with home care, but I don't want to fall again."

Lois wants to be a writer. Together with the MS Society, she is trying to get a voice recognition program for her computer.

Bea Good has lived at Collegeseide for about 18 months. Prior to moving to a facility, she fell a lot at home. Her

brother moved from Grimshaw to help take care of her. Home care did visit Bea regularly, twice a day for 15 minutes each time. However, this was not enough to meet her needs. "I asked for another 15 minutes each day to help me get into bed, but I didn't get it. I showered only once each week because it was just too difficult. I didn't have any help with that either."

It was not Bea's first choice to move from home to Collegeseide. "I was told I would receive the same amount of physiotherapy that I received at home," she said. "However, there is no



**Lois Aarhus was diagnosed with MS at age 21. Although Collegeseide is far better than the first facility she lived in, she'd rather be at home.**



**Dawn Finkbiner is grateful she lives at Collegeseide. However, she is writing the "Extreme Makeover" people to see if they're interested in building a separate building for young people with a disability.**

physiotherapist (PT) at the facility, only a PT assistant. When I was at home I had a 2-hour session once per week with the PT. It was a complete workout. Now I get a 15-minute session Monday and Wednesday." That is another labour shortage issue. Collegeseide is trying to hire a PT but has been unable to find one.

Bea would prefer to live at home if she could afford it. "If that's not possible, I wish there were more staff here."

No single continuing care facility is going to satisfy the needs of every resident. Just like anyone else, young people with MS or another disability have different personalities. Some people adapt well to a community style of living, others do not. Perhaps the best we can strive for is a system that recognizes an individual's right to choose his or her care setting. When long-term care for young people is designed right, when it recognizes the unique needs of young adults, it can go a long way to reducing social isolation and greatly improving overall quality of life.

# *Streak* for



## MS WALK Kickoff

**O**n April 17th over 100 people came out to Kingsway Garden Mall in Edmonton to "Streak for MS." Everyone had their own personal streaking style - some were flamboyant while others a little more modest. But when the day was done all these people left Kingsway Mall making a statement that everyone in Edmonton could see because they had streaked their hair RED for MS!

We'd like to thank Altimo Hair Group in Kingsway Mall for making this possible as they donated their time and product for this event.



**Above: Will from Altimo Hair Group streaks Julie Kelndorfer's (Volunteer Manager Alberta Division) hair red for MS.**



**Left: Janet Goodall and Ryan Drury (Dev. Senior Coordinator) were flamboyant with their streaking style - getting matching red mohawks.**

**Below: A participant makes his mark against MS by streaking his moustache red and then smiles for the camera.**



# TELUS supports employees cycling in 19th Annual RONA MS Bike Tour – Leduc to Camrose

Joe McVea has been cycling in the RONA MS Bike Tour for 18 years. In recent years he has become one of the top fundraisers in the Tour, raising more than \$7,000 in 2007.

Last year Joe asked the company he works for, TELUS, to support him and the five other TELUS employees participating in the event by providing matching funds. TELUS quickly stepped up to the plate and gave \$5000 toward the TELUS participants.

**Telus quickly stepped up to the plate and gave \$5000 toward the TELUS participants in the MS Bike Tour.**

This year TELUS has greatly increased its involvement in the Tour. Now officially known as "Team TELUS," there are over 18 members on this team. TELUS has also decided to become a corporate sponsor of the event and will now be sponsoring a checkpoint at the Tour.

"TELUS's support of the RONA MS Bike Tour is greatly appreciated," said Neil Pierce, President of the MS Society, Alberta Division. "We are thrilled with this partnership and hope TELUS enjoys their experience at this year's Tour."

The RONA MS Bike Tour would not be possible without the generous contributions of our corporate partners such as TELUS. Monies contributed by our sponsors greatly reduce the costs associated with putting on the event and allow us to allocate more money to MS research and services.

Last year 1,500 cyclists raised a record-breaking \$1.25 million. Our goal for 2008 is to have 1,700 cyclists raise \$1.4 million.



## MOXIE'S IDOL



**On May 4 the Moxie's Marauders held a unique fundraiser for their team. The 2nd annual Moxie's Idol contest challenged employees to sing their hearts out to be crowned the new "Moxie's Idol." All proceeds from ticket sales went toward the team's fundraising efforts for the MS Walk in Edmonton. Over \$1500 was raised. "It was a really fun event and it's great to see teams extending themselves in such unique ways to raise money and awareness for MS," says Ryan Drury, Dev. Senior Coordinator.**





## AMBASSADOR PROGRAM



Mark Walsh

Profile of an MS Ambassador

### Why I decided to become a MS Ambassador?

From the first time I got involved with the MS Society through my wife's sister's illness and the RONA MS Bike Tours, I have made myself available to serve in whatever capacity I am capable of. I've attended TeamMS corporate breakfasts, top fundraiser

# A United Voice for the Cause and Cure

events, wrote an article for the bike tour newsletter, recruited teammates for the bike tours, and spread the word in my business and personal life of the possibilities of finding a cure for MS.

Each year I try to raise more than the previous year in fundraising as I know the value of where these funds go. As we move towards a real solution I feel a sense of contribution in helping the wellness of those suffering with MS.

Becoming a MS Ambassador is more of an extension of what I'm already doing and it seemed to be the right fit for me to increase my level of involvement in the cause.

### What areas do I want to work in as a MS Ambassador?

I have contributed in the past speaking to groups about MS and why I am involved. This is an area I am comfortable with. I have an easy way with people, can laugh at myself and my blunders and have a genuine concern for others who are suffering. I also speak from first hand experience about the realities of MS because I had a very dear friend die six

years ago of MS. My sister-in-law also suffers with MS.

### What do I hope to accomplish by becoming a MS Ambassador?

I hope to spread awareness of the disease to others who don't know much about it. I hope to encourage others to get involved in whatever way they can - serving, riding in the tours, fundraising and more of what I have done previously.

My sister-in-law has had a particularly difficult year and her struggle affects the whole family and others. I would be privileged to be a part of easing her struggle by assisting in finding a cure for this hideous disease.

I live a very busy life like most others; however, at the end of the day, when all the consuming details of life become silent with the passing daylight, can I say that I have done meaningful action to ease the suffering of my fellow human beings? This is a question I hope to continually say yes to through my life.

## MS Support Groups in Alberta

**Battle River /Wainwright** — call Teresa at 780-755-2226.

**Boyle Area** — call Deloris at 780-689-4300.

**Cold Lake/Lakeland** — call Suzanne at 780-639-4145.

**Drumheller** — call Karen at 403-820-7863.

**Elk Point** — call 780-724-2430 for further information.

**Fairview** — call 780-835-4868 for further information.

**Fort McMurray** — call 780-743-8239 for further information.

**Hinton** — call 780-865-8247 for further information.

**Pincher Creek /Crowsnest** — call 403-627-2106 for further information.

**Tofield** — MS Support Group last Wednesday of the month. 7 pm to 8:30 pm. Tofield Health Unit.

**Vegreville** — call 780-632-2848 for further information.

**Yellowknife** — call Shawn at 867-445-4372.

**South Peace/ Grande Prairie** — call the chapter at 780-532-3204.

**Edmonton** — call the chapter office at 780-471-3034.

**Calgary** — call the chapter office at (403) 250-7090.

**Lethbridge** — call the chapter office at (403) 328-7002.

**Red Deer** — call the chapter office at (403) 346-0290.

**Medicine Hat** — call the chapter office at (403) 529-6797.

**Lloydminster** — call the chapter office at (780) 871-0513.

# Extending MS support to Alberta communities

## MS Awareness Days roll out throughout the province

While MS Awareness Month traditionally happens in May, this year the MS Society got off to an early start! With information and resources in hand, Hessen Zoeller, Outreach Coordinator for the Alberta Division office, worked with local volunteers to kick-off MS Awareness Days in St. Paul, Elk Point, Wainwright and Drayton Valley.

Each MS Awareness Day has had its own unique flavour. The largest MS Awareness Day to date took place in Elk Point, boasting close to 50 participants

**“I’m trying to bring awareness in the smaller communities in Alberta and I am trying to tell the people in Elk Point that MS lives here,” says Lil Demchuk.**

and predominantly reaching the health professional community.

Reaching health professionals is a key benefit of this program, making it possible to connect the MS Society with frontline health care providers who can in turn provide MS Society information and resources to people affected by MS.

In Wainwright, the MS Awareness Day was combined with the annual Battle River fundraising dinner, where people affected by MS gathered to eat, drink and support a great cause. In true potluck fashion, several members of the



**The MS Awareness Day in Elk Point was one of the largest with close to 50 participants. Among those were: Top left to right – Sandra Lorenson, Hessen Zoeller, Lil Demchuk, Suzanne Deschamps. Bottom left to right – Carolyn Semiuk and Loreth Pinds.**

community brought their most delicious dishes to share, and attendees made donations in lieu of payment for dinner in an old-fashioned community hall. Both the MS Awareness Day and Battle River dinner beautifully illustrates the power of people coming together to fight MS.

MS Awareness Days in St. Paul and Drayton Valley had somewhat smaller turnouts, but their impact in helping people should not be understated. Hessen explains, “I find we often have that truly meaningful experience where we reach someone who really needs to connect with us. The examples differ from location to location, but the idea that we have really helped or supported someone makes rural outreach so very worthwhile.”

Volunteers have supported MS Awareness Days in a big way, making for a great start for an inaugural year. “I am forever impressed with the way community volunteers step up to the plate. We are so very lucky to have so many amazing MS Ambassadors work with us on this initiative.”

More MS Awareness Days will be taking place in the fall. If you are interested in having a MS Awareness Day in your community or have questions about upcoming events, please contact **Hessen Zoeller** at: **1-800-268-7582**.

We’d like to thank Fed Gas and Pharmasave which are generous sponsors of MS Awareness Days throughout the province – without their support none of this would be possible.

# Biogen Idec supports MS education events in Alberta

For nearly a decade the MS Society in Alberta has enjoyed a rewarding partnership with pharmaceutical company Biogen Idec. As a result of this partnership we are able to provide important MS education sessions to Albertans living with and affected by MS. To date the Alberta Division of the MS Society has received over \$70,000 in funding as well as other supports such as client resources. Some of our most widely used information resources are funded by unrestricted education grants from Biogen Idec.

Biogen Idec has sponsored several education events for health professionals throughout Alberta, helping our clients to access more services more easily. Last year the company travelled the province to inform the MS Society about new developments in MS research and MS therapies, specifically Avonex and Tysabri.

Recently, Biogen Idec committed an additional \$21,000 to the MS Society, Alberta Division, which will be used to support MS information events across Alberta. That money also includes a partial sponsorship of the MS Connections newsletter.



**Representatives of the MS Society, Alberta Division, accept a cheque for \$21,000 from Darrin Woodman of Biogen Idec (second from right). This sponsorship will support MS education events across Alberta and the MS Connections newsletter.**

## Biogen's progress in developing MS therapies

Founded in 1978, Biogen Idec is a global leader in the discovery, development, manufacturing, and commercialization of innovative therapies. Over the next five years, the company expects to spend approximately \$5 billion on research and development, much of which will be dedicated to MS. In MS, Biogen Idec is targeting multiple scientific pathways and diverse delivery approaches that offer choice and convenience for patients. The company is investigating T-cell and B-cell directed therapies, oral medications and is very excited about early-stage research programs tackling the next advancement for people living

with MS - nerve regeneration and remyelination.

In Canada, BIIB Canada currently markets two major therapies: TYSABRI® (natalizumab), the most recently approved treatment for relapsing forms of MS, and AVONEX® (Interferon beta-1a), the No. 1 prescribed therapy for relapsing forms of MS worldwide. BIIB Canada is committed to bring MS therapies to individuals suffering from MS. In Canada, it has partnered with the MS Society in offering unrestricted education grants for the MS Community.

Biogen Idec Canada continues to provide patient services in a threefold way:

1) MS Alliance TM improves patient

access to injection assistance.

This support program is designed for patients receiving AVONEX® MS Alliance can be reached 24 hours a day and 7 days a week at 1.888.456.2263

2) TCP Tysabri Care Program improves patient access and infusion clinics for TYSABRI® (natalizumab) The Tysabri Care Program is accessed at 1.888.827.2827

3) [lostandfoundnetwork.ca](http://lostandfoundnetwork.ca) The Lost & Found Network is an online community - a place where you can find other people who have been touched by MS, find advice, and find friends who understand.

# Vitamin D and MS

By Jodi Burton, MD, FRCPC  
Neurologist, MS Clinic of St. Michael's Hospital, Toronto  
Excerpted from Compass magazine, Vol. 8, No.3, 2007

Researchers strongly suspect a link between low vitamin D levels and risk of developing MS. Researchers began studying the relationship of vitamin D and MS because it has been known for decades that people who live in places with less ultraviolet (UV) exposure year-round (that is, farther from the equator) tend to have higher rates of MS. UV exposure (primarily from sunlight) is required for the production of vitamin D in the skin. Other research shows that low levels of vitamin D may be a contributing factor to other autoimmune diseases (including rheumatoid arthritis and inflammatory bowel disease) and cancer.

More research is needed to know for sure whether having high vitamin D levels can actually prevent MS or affect the course of the disease once it starts. We also do not yet know what dose of vitamin D3 may be effective in patients with MS or at risk of developing it - this is a very active area of research and it will take time to accumulate all the answers.

## Functions of vitamin D

It is widely known that vitamin D plays an important role in bone health, and that

deficiency can cause rickets in children and contribute to low bone density in adults. Vitamin D3 (vitamin D created by exposure to sunlight is called vitamin D3) also interacts with the immune system. Many immune cells have vitamin D3 receptors. Vitamin D3 can lower T-cell production and reduce certain

inflammatory substances and processes. The answer of why and how vitamin D relates to MS and other diseases is likely to be related to its effects on the immune system.

## How much is enough?

In countries near the equator, people who spend their days outside with most of their skin exposed get about 10,000 International Units (IU) of vitamin D3 in one day. The current recommended daily intake of vitamin D3 of about 400

IU is based on the amount in a teaspoon of cod liver oil, traditionally used to prevent rickets in children. In a country like Canada, especially in winter, some experts believe it takes at least 1000 IU per day, obtained from UV light or diet, to maintain a [healthy blood level.] The Canadian Cancer Society has recently recommended that adults consider taking 1000 IU per day of vitamin D during the fall and winter, and year-round if they are older, have dark skin, or don't expose much skin to sunlight in spring and summer.

The upper limit of safe vitamin D3 intake and the effects in the body of higher levels are currently under very intense study. At St. Michael's Hospital in Toronto, we are conducting research to examine the safety of giving much higher than currently recommended doses to MS patients. If shown to be safe, we will perform further studies to determine if these higher doses have any impact on relapses, disability and MRI lesions.

Because of current research linking low levels of vitamin D and development of MS, and given the current evidence in cancer prevention trials, many Canadian MS specialists now advise both patients and their close relatives to take supplements of at least 1000 IU vitamin D3 per day, up to 4000 IU per day, an intake we believe to be safe in otherwise healthy people with no history of heart disease, kidney disease or disorders related to calcium.

**This is a very active area of research and it will take time to accumulate all the answers.**

## STAY INFORMED!

The MS Society is committed to reaching out to all Albertans with MS. If you know someone who would like to receive a complimentary copy of MS Connections, please call us at

**1-800-268-7582.**

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