



# MS Connections

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

Winter 2008-2009

## MS Stakeholders meet to discuss new approach to MS care

### Rural Alberta a key discussion item during province-wide Forum

A group of about 80 people met recently to exchange ideas for developing a more collaborative approach to MS care in Alberta. The MS Stakeholders Forum took place in Edmonton on October 29 and 30, 2008 and saw people from around the province gather to discuss how medical and community organizations can work together more effectively for the benefit of Albertans affected by MS.

The MS Stakeholders Forum was inspired by the fact that there are several MS initiatives currently underway in Alberta i.e. the Jayman MS Alberta Project, the Regional MS Clinic, and case management strategies, to name a few. While these and other initiatives do excellent work, are there opportunities to learn from each other and become even better? This question was at the heart of the MS Stakeholders Forum.

Hosted by the MS Society of Canada, Alberta Division, the MS Stakeholders Forum included representatives from health care, government and community organizations. Individuals with MS were also present to voice their opinions. The event was truly unique in that it was the first time representatives, or 'stakeholders', from so many aspects of MS care gathered to discuss how we can work better together.

"It takes vision and initiative to move things forward," said Marlin Styner, Chair

of the Premier's Council on the Status of Persons with Disabilities, and one of the attendees. "The MS Stakeholders Forum was a unique opportunity for service providers, the medical community, people

**"It takes vision and initiative to move things forward. The MS Stakeholders Forum was a unique opportunity for service providers, the medical community, people living with MS, their caregivers and families to all contribute to that vision."**

*Marlin Styner*

living with MS, their caregivers and families to all contribute to that vision."

Dr. Raj Sherman, Parliamentary Assistant to the Minister of Alberta Health and Wellness, delivered opening remarks to the Forum attendees. In a recent letter to the MS Society, Dr. Sherman said "I look forward to continuing to work with you to build a comprehensive MS approach for



**Marlin Styner, Chair of the Premier's Council on the Status of Persons with Disabilities.**

Alberta." One of the key points to come out of the Forum was the need for a more comprehensive approach for supports and services for people with MS in rural Alberta. "We recognize the need to work together if we're going to do a better job of helping the over 11,000 Albertans living with MS," said Neil Pierce, President of the MS Society, Alberta Division. "There are a lot of people delivering excellent care throughout the province. We just need to work together to ensure no one falls between the cracks."

To read the report from the MS Stakeholders Forum, visit [www.mssociety.ca](http://www.mssociety.ca).

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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## 2008/2009

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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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# Sustaining the momentum



It seems like all we hear about today is the doom and gloom of the global economic crisis. As an optimist by nature, I want to use this column to speak about the good things that are happening in the world of MS right here in Alberta and across the country.

Looking ahead, one of the things I am most excited about is the tremendous opportunity we have to work together to provide even better service to all Albertans living with MS. To that end, the

MS Society, Alberta Division, hosted the first ever MS Stakeholders Forum on October 29 and 30. This was a very unique gathering of health care agencies, government ministries, and clients to begin a discussion around developing a new, consolidated approach to MS care in Alberta. Dr. Raj Sherman, Parliamentary Assistant to the Minister of Health and Wellness, shared his vision for the future of health care in Alberta. Dr. Sherman and the Minister have both said community agencies play an important role in complementing the health care system. It's our hope that in the coming years we can elevate the importance of MS care and services in the same way as Heart & Stroke and Cancer have done which has attracted significant investment and opportunity to better coordinate services and improve the health and quality of life outcomes for Albertans living with MS.

While we work hard at brokering closer working relationships between government, the health care system and community organizations, we are also obliged to look for opportunities to improve our own internal operations. Recognizing this, the Alberta Division Board of Directors, in consultation with our Chapter offices, just approved a three-year plan to expand Chapter boundaries to extend the reach of MS Society services to those who need them or who in turn can help us. This decision was made upon the recognition that the Society lacks a presence across half the Province.

As we navigate the rough economic waters over the coming months, the role of our MS Ambassadors will be so much more important in helping us reach out - to those who need our help and to those who can help us. Over the last year we have benefited greatly from the work of our MS Ambassadors. In September we had our 2nd Ambassador Forum, during which MS Ambassadors from around the province gathered to share past successes and establish future goals.

I would be remiss in not acknowledging the challenges an economic downturn poses as we try to sustain the incredible financial growth experienced in Alberta over the past number of years. To this end, our operating philosophy is to keep our foot on the accelerator to drive continued progress. This is premised on the belief that Albertans with a family member, friend or neighbour will continue to support their home charity and will once again lead the nation as the largest contributor to MS research and the highest per capita donor in the country. As we look ahead to the uncertainty of the coming months, we are aware that you will be carefully managing your charitable giving. I would just like to take a moment to remind you that our programs and services rely on your generosity.

Neil Pierce, President, Alberta Division

# Calgary-based Enerflex sponsors MS Walks in Alberta

## Partnership began with Calgary Enerflex employees

The MS Society of Canada, Alberta Division, is proud to announce a new partnership with Enerflex Systems Ltd. Beginning in 2009, the Calgary-based energy services company will sponsor all MS Walks in Alberta. The next time you participate in a MS Walk in your community, you will see signs and banners that proudly display "Enerflex MS Walk."

"This sponsorship allows Enerflex to give back to the community as well as increase staff camaraderie as they volunteer and participate in the Enerflex MS Walks across Alberta," said Blair Goertzen, Enerflex CEO.

Enerflex first became involved with the MS Society in 1997 when a Calgary employee was diagnosed with MS. Enerflex employees rallied to support their co-worker, putting a team in the Walk and raising \$6,000. Inspired by that passion, the company decided to become involved as an official sponsor



**Enerflex now sponsors all MS Walks throughout Alberta.**

of the Enerflex MS Walk in Calgary the following year.

This corporate support fueled the enthusiasm of employees and cultivated the relationship between Enerflex and the MS Society. As a result of that enthusiasm, Enerflex decided to expand their partnership to all of the Walks in Alberta for 2009.

In addition to the sponsorship agreement, Enerflex staff continue to volunteer and participate in the Enerflex MS Walks out of personal support for the cause.

"This sponsorship is of tremendous

benefit to the MS Society in Alberta," said Alison Hagan, Director of Development with Alberta Division. "Not only does it help to keep our costs low, it also helps create awareness throughout the province about MS and Enerflex."



**Blair Goertzen, CEO, Enerflex. Sponsorship of the MS Walks in Alberta delivers increased "staff camaraderie."**

Last year, MS Walks in Alberta raised \$2.5 million. With Enerflex's support, we hope to raise \$2.6 million in 2009. For more information about MS Walks in Alberta, visit [www.mssociety.ca/alberta/scwalk.htm](http://www.mssociety.ca/alberta/scwalk.htm). For more information about Enerflex, visit [www.enerflex.com](http://www.enerflex.com).

## Golf tournament raises \$24,000 for Albertans with MS



The Federation of Rural Electrification Associations and Federation of Alberta Gas Co-ops Ltd. hosted their 2nd annual golf tournament in support of the MS Society, Alberta Division. \$24,000 was raised to support outreach services for people with MS in rural . Pictured from left are: Bert Paulssen, Chairman, Federation of Alberta Gas Co-ops Ltd.; Premier Ed Stelmach; Mrs. Marie Stelmach; Deb Wynia, President, MS Society, Drumheller Chapter; Joan Ozirny, Board Member, MS Society, Alberta Division; Merv Rockel, President, Alberta Federation of Rural Electrification Associations

# MS neurologists visit Wainwright

## Wainwright hosts MS Clinic, MS Information Session and MS Health Professionals Seminar

Some exciting news from Wainwright! On October 24, after two years of planning, Teresa Adams brought forth her dream of arranging an MS Health Clinic in Wainwright. Teresa is President of the Battle River Chapter of the MS Society and was overjoyed the event finally came together. Edmonton neurologist Dr. Makus traveled to Wainwright for the day and saw a total of 9 people (some of them extended care patients) who were not able to make the trip to Edmonton

**“Despite seeing some severely affected patients, I was struck by their courage.”**

*Dr. Makus*

to see a neurologist. Dr. Makus was very enthusiastic about the prospect of seeing patients in Wainwright more regularly. “The Wainwright clinic was, for me, a touching experience,” said Dr. Makus. “Despite seeing some severely affected MS patients, I was struck by their courage and the enthusiasm of the volunteer group in assisting these patients. I would be delighted to do the clinic on an annual basis.”

Over the lunch hour on the same day, the Battle River Chapter also hosted a Health Professionals Seminar during which Dr. Makus shared the latest in research, drugs, and medical updates. The seminar attracted a number of local people, including doctors, optometrists, pharmacists, sponsors, volunteers, and a representative from the Wainwright Health Centre. It was an exciting day for many as Dr. Makus helped people who

hadn't been able to see a neurologist in years, if ever. Wainwright looks forward to seeing Dr. Makus again.

On October 16 the Battle River Chapter also hosted a MS Information Session. Dr. Jodi Kashmere from Edmonton attended the dinner event and provided general information about MS, including the latest MS research and information on MS drug therapies.

These important events in the Battle River Chapter would not have been possible without the generous support of Biogen Idec, Husky Energy, and the Husky Energy Employee Fund.



**Teresa Adams (left) and Helen Chesterman of the Battle River Chapter hosted a MS Information Session in Wainwright on October 16. Dr. Jodi Kashmere, an Edmonton neurologist, talked about various MS issues including MS drug treatments, research, and symptom management.**



**Dr. Makus (seated centre) attended a one-day clinic in Wainwright on October 24. The clinic was part of a series of MS-related events including an Information Session and a Health Professionals Seminar. Also in the photo are: (back from left) Jeannine Christopherson and Doug Tokaryk, MS Society representatives, Val Tondou with Husky Energy; (front from left) Dr. Makus' daughter, Dr. Makus, and Darrin Woodman from Biogen Idec.**

# endMS.ca

## Campaign update

In the last issue of MS Connections we reported that the MS Society's first ever national campaign had kicked off in September. At that time we had reached the \$20 million mark en route to our total goal of \$60 million. We are very excited to report that our current total is \$32 million. In other words, we are more than half way there.

The endMS Campaign is designed to attract more young scientists to the field of MS research. The goal is simple: the best MS researchers + more MS research = an end to MS in the shortest possible time. To find out how you can help reach the goal of ending MS, visit [www.endMS.ca](http://www.endMS.ca). It's time, let's end MS!



The endMS Campaign will see new MS therapies developed sooner to help over 11,000 Albertans living with MS. To learn more about the endMS Campaign and track its progress, visit [endMS.ca](http://endMS.ca).

# CONNECTIONS 2009

## A conference to connect Albertans affected by MS

October 23 & 24, 2009      Mayfield Inn, Edmonton

### Speakers and topics include

Dr. Peter Reickman: neuroprotection and neuroregeneration  
Dr. Al Condeluci: Community connectedness & interconnectedness  
Dr. Michael Yeung: research update  
Dr. Jackie Bakker: fatigue  
Dr. Jennifer Rodgers: psychological aspects  
Dr. Penny Smyth: pregnancy and menopause  
Aprile Royal: "Green lights & red flags" - early diagnosis

Tell us what you would like to learn about at the conference by completing a short survey at:

[www.mssociety.ca/alberta](http://www.mssociety.ca/alberta)

### Who should attend?

- Anyone affected by MS
- Family & friends
- Health professionals
- Students and community resources



Alberta Division

# MS Ambassador Program celebrates 2nd year with provincial forum

**O**n September 19 & 20, 2008 we held our 2nd Annual MS Ambassador Forum at the Hilton Garden Inn in Edmonton. The Forum began on Friday evening with a celebration and welcome reception for our current and new MS Ambassadors from across the province. The theme for the Forum was "Expanding Your Sphere of Influence." MS Ambassadors chose from three different streams to assist with expanding their sphere of influence and helping the MS Society: media relations; public speaking; and MS Awareness Days.

The keynote speaker for the Celebration Luncheon on Saturday spoke on the five qualities of remarkable people and weaved in how MS Ambassadors fit into this sphere. A great couple of days of sharing, networking, learning, and celebrating!

For more information about the MS Ambassador Program and how you can be involved, contact **Julie Kelndorfer** at **(780) 440-8756** or **julie.kelndorfer@mssociety.ca**.



**MS Ambassadors from across the province attended the 2nd Annual MS Ambassador Forum in Edmonton on September 19 & 20, 2008.**

## **MS** AMBASSADOR PROGRAM

### ***A United Voice for the Cause and Cure***

## Mary MacGregor

Profile of an MS Ambassador



Mary MacGregor, a single mother of three, was diagnosed with MS seven years ago. When she first received the diagnosis, she struggled to cope with not only her MS but the challenges of raising her children. While watching her mom recover from several relapses, Mary's 12-year-old daughter decided to help by organizing her own birthday party and, instead of gifts, asking for donations to go towards the MS Society. Her daughter then continued to raise awareness through her school work.

With three children who were heavily involved with extra-curricular activities,

Mary had little extra time to volunteer but decided that she wanted to help, even if it was a little at a time. "I thought, 'if my daughter could do something, why couldn't I?'" So, after riding in the RONA MS Bike Tour for six years, she was approached about becoming an MS Ambassador. "As an Ambassador, I would be afforded the opportunity to increase my awareness of the disease, learn advocacy skills for all people with MS, and possibly connect with someone who would otherwise not know where to turn. All of these options were within my control as opposed to when life was so terribly out of control."

The MS Ambassador program has helped Mary, and after years of dealing with her MS she realizes that, "MS is not something to hide. I may be one of the many cases where it is actually something to celebrate. With research, drug therapy and the connections that I have made, I am so very grateful to be where I am now."



MS Society - Alberta Division has a Facebook page. Become a fan and stay up to date with upcoming events, functions, and news. This is a great tool to stay up to date with fellow fundraisers from across the province, chat and share ideas.

Go to **www.facebook.com** and sign up as a member. Once you have a Facebook account, search MS Society - Alberta Division and become a fan.

# Ask Jeannine



Welcome to a new regular column in MS Connections. Jeannine Christopherson, a MS nurse and Outreach Coordinator with the MS Society, Edmonton Chapter, will answer your questions about MS.

If you would like to ask Jeannine a question, email it to [info.alberta@mssociety.ca](mailto:info.alberta@mssociety.ca) or call the editor, Angie Wight, at 780-463-1190 or 1-800-268-7582.

## How do families best cope with a diagnosis of MS?

When a family member is diagnosed with MS, resulting issues involve the whole family. Many people are shocked and feel out of control when presented with the diagnosis. It is especially difficult for clients to deal with the unpredictability of the disease; health professionals cannot

tell them exactly what course the disease will take. Education is the first step in coping with the diagnosis. MS Clinic nurses provide education and make referrals to the MS Society which offers newly diagnosed packages that can be mailed out. Face-to-face education can also be provided and the web site ([www.mssociety.ca](http://www.mssociety.ca)) offers many educational pamphlets which will be very helpful for families. A concerned family member should feel free to ask questions; these can be directed to the Clinic nurse or to MS Society staff members who will always try to find an answer. No question is insignificant; if it causes worry seek



an answer. If questions are answered in a timely fashion it usually takes 6-12 months to adjust to the diagnosis of MS. If the individual is upset, angers easily and has difficulty sleeping or any of the three he or she may seek individual support services from the MS Society or counseling from the family doctor or a psychologist. Open communication within families will help all members deal with the diagnosis.

Jeannine Christopherson  
RN, BScN, MSCN  
Outreach Coordinator, MS Society of  
Canada, Edmonton Chapter

## New Executive Director in South Peace Chapter

The MS Society of Canada - Alberta Division is very pleased to announce that Rhett Demetrick has joined the MS Society as the Executive Director of the South Peace Chapter. Prior to accepting this position, Rhett was the owner/operator of Canada's second largest commercial photo studio and brings a wealth of business experience.

Rhett has previous ties with the MS Society: he served on the Board of Directors with the South Peace Chapter, and after his aunt, mother-in-law, and wife were diagnosed with MS became an active participant in the Calgary MS Walk.

If you live in the South Peace area you can contact **Rhett at (780) 532-3204** or [info.southpeace@mssociety.ca](mailto:info.southpeace@mssociety.ca).



The MS Society of Canada - Alberta Division is inviting you to "Be Green!" You can view our newsletter online at [www.mssociety.ca/alberta](http://www.mssociety.ca/alberta) — scroll down to "Publications." If you would like to opt out of paper delivery please email [angie.wight@mssociety.ca](mailto:angie.wight@mssociety.ca).

# My MS Story

## A personal account of one person's challenge living with MS



Geneva Macgillivray  
Nanton, AB

**M**y MS story begins in the late 1950s

when my own mother was diagnosed with MS. Back then, doctors offered my parents no positive information, advising only that no cure was available. Then, as is still the case today, there were a lot of unknowns when it came to analyzing the many different symptoms of MS.

With guidance, encouragement and incredible love from our parents, my four siblings and I grew up in a family that was impacted as MS robbed my mom of control over her own body. Despite observing mom for many years and later my two younger sisters when they became afflicted with MS, I was puzzled and sought medical advice for my own symptoms: incredible fatigue, weakness during my long daily morning walks, and sudden numbness of my writing hand.

I had always been very physically active and fit, but something had changed. The constant fatigue and incredible heaviness in my right leg, when I walked each and every day, was just not right. When diagnosed almost 10 years ago, I was dumbfounded. It never occurred to me that MS was lurking somewhere in my body. My symptoms were mild and I was otherwise strong and healthy. My neurologist expressed I might be a candidate for drug therapy. I chose

Rebif because it seemed the drug with the least side-effects. I began self-injections in February 2002.

By that May, I was back on the golf course with more strength than I'd had for almost 2 years. The drug seemed to be working. Then I had a nasty knee injury about four and a half years ago. A lengthy time spent waiting to see a specialist and subsequent surgery in May of 2005 have all caused my mobility to be far from what I'd like it to be. Yet I still get up each morning and go to work.

Each day challenges present themselves, the toughest of which is accepting the physically stiller life I now lead. Though my legs do not go all the places I'd like them to, I maintain a daily regimen of mild yoga, stretching and breathing exercises. When I feel the need to, I do use my cane, but even getting used to that takes some expertise I have found! I operate my own studio offering sessions on my Proellix Whole Body Vibration machine as well as own, write and produce a bi-monthly publication called the Nanton Review.

A goal of mine is to continue organizing the MS Carnation Campaign here in Nanton, where I live, so that we may see increased awareness about how families deal with MS.

If you would like to tell your MS Story, contact **Angie Wight** at [angie.wight@mssociety.ca](mailto:angie.wight@mssociety.ca) or **780-463-1190** or **1-800-268-7582**



### Enerflex MS Walks in Alberta

Register now! [www.mswalks.ca](http://www.mswalks.ca)

Walk fundraising goal:  
\$2.6 million in Alberta

#### Choose between these 11 Walks across Alberta:

- April 25: Lloydminster, Lethbridge
- April 26: St. Albert
- May 2: Grande Prairie
- May 3: Drumheller
- May 9: St. Paul
- May 24: Medicine Hat
- May 31: Edmonton, Red Deer
- June 7: Calgary, Brooks



### RONA MS Bike Tours in Alberta

Register now! [www.ms biketours.com](http://www.ms biketours.com)

Tour fundraising goal:  
\$3 million in Alberta

#### Choose between 4 Bike Tours across Alberta:

- June 13 & 14: 3 Tours
  - Leduc to Camrose
  - Airdrie to Olds
    - Red Deer
- Sept 12 & 13
- Mountain Bike Tour, Hinton



### MS Read-A-Thon

Register your school today!  
[www.msreadathon.com](http://www.msreadathon.com)

Encourage literacy while supporting a good cause!

# Walking the walk

(and biking the bike - huh?)

## MS Society employees walk, cycle and fundraise to end MS

Every year we ask you to ride, walk, or host a dinner party to raise money for Albertans living with MS. But we wouldn't ask you to do anything we wouldn't do ourselves. Our staff also ask their friends, family, and business associates (not to mention other staff) to support them as they participate in various MS events.

With a grand total of \$7,284 in the 2008 RONA MS Bike Tour - Mountain, Graham Metzger, Senior TeamMS



**Graham Metzger (front), Senior TeamMS Coordinator, raised over \$7,000 for MS during the 2008 RONA MS Bike Tour - Mountain.**



**Hilda Van Camp, Manager of Finance and Administration with Calgary Chapter, raised \$1,500 in the RONA MS Bike Tour - Airdrie to Olds.**

**“I watched the drive of people in their 70s and 80s ...and are totally dedicated, and I said, ‘why can’t I?’ ”**

Coordinator, is one of the top staff MS fundraisers in Alberta. “I ride because I believe in the Bike Tour and what it’s trying to accomplish,” said Graham. “I’m connected to this cause because of the inspiring people I’ve met who have MS. The money I raise means a lot to me, because it means a lot to other people.” Hilda Van Camp, Manager of Finance and Administration with Calgary Chapter, raised \$1,500 in the 2008 RONA MS Bike Tour - Airdrie to Olds. “I watched the drive of people in their 70s and 80s still raising funds and are totally dedicated, and I said, ‘why can’t I?’ My drive was the motivations and passions that drive others,” said Hilda.

### Top ten MS Society staff fundraisers in Alberta

Name	Position	\$ raised	Event
Graham Metzger	(Senior TeamMS Coordinator)	\$7,284	Bike Tour
Neil Pierce	(President, Alberta Division)	\$2,690	Walk
Mark Mahl	(Director, Leadership Giving)	\$2,060	Bike Tour
Garry Wheeler	(V.P. Alberta Division)	\$2,050	Bike Tour
Ryan Drury	(Manager, TeamMS)	\$2,010	Bike Tour
Hilda Van Camp	(Manager, Finance & Admin)	\$1,500	Bike Tour
Alison Hagan	(Director, Development)	\$1,445	Walk
Julie Kelndorfer*	(Director, Volunteer Resources)	\$660	Global Dinner Party
Ellen Geddes	(Events Coordinator)	\$620	Walk
Ann Stewart	(E.D. Lethbridge Chapter)	\$610	Walk

\* Julie’s son Joshua, 5, captained his own team - “Joshua’s Friends Team.” Joshua raised \$1,000 and his team total was \$2,345.

## Have something to buy or sell?

The MS Society of Canada - Alberta Division is very excited to announce our new Classifieds section! To buy or sell items, visit [www.mssociety.ca/alberta/classifieds.htm](http://www.mssociety.ca/alberta/classifieds.htm).



From left: Mark Mahl, Director of Leadership Giving, MS Society, Alberta Division; Pat Simmonds, Board Member, MS Society, Edmonton Chapter; Amanda Stadel, Investor Relations Manager, BioMS Medical Corp.; Garry Wheeler, Vice President, MS Society, Alberta Division; Dr. Chris Power, Professor, Department of Medicine (Neurology), University of Alberta.

# PAMS holds first Edmonton event

## Lloydminster event planned for January

The very successful PAMS (People Against MS) events in Calgary have made the trek north. Edmonton held its first event on November 14 at the downtown Sutton Place Hotel. Nearly 40 people enjoyed breakfast and listened to Dr. Chris Power review his work in MS research. To date, over \$800,000 has been raised through Alberta PAMS events. If you would like to attend the next PAMS event in Edmonton, Calgary or Lloydminster (January 30), contact **George Jacob in Calgary at (403) 250-7090, [george.jacob@mssociety.ca](mailto:george.jacob@mssociety.ca)** or **Mark Mahl in Edmonton at (780) 440-8764, [mark.mahl@mssociety.ca](mailto:mark.mahl@mssociety.ca)**.

Continued on next page

**Standing, from left: Sandy Beaudry, PAMS committee member; Jim Spiers; Mary MacGregor, PAMS committee member.**

**Front, from left: Wendy Spiers, Carol Becker.**



# The Brick MS Drive Fore a Cure

Last September the MS Society, Alberta Division held its first annual "The Brick MS Drive Fore a Cure" golf tournament. 156 golfers participated and over \$120,000 was raised, catapulting the MS Society into the upper echelons of charity golf tournaments in the Edmonton area.

## Top Teams

- 1) 10 G's - \$3,809
- 2) High Knicks and a Hot Chick - \$2,925
- 3) Fore Mom - \$2,620
- 4) C. Casino Gals - \$1,910
- 5) Lame Ducks - \$1,820

## Top Individuals

- 1) Henry Van Steenberg - \$5,000
- 2) Lyle Reid - \$5,000
- 3) Robert Pon - \$2,319
- 4) Gerry Beerda - \$1,685
- 5) Daryl Appleton - \$1,576



The '10 G's' team were the top fundraising team in the golf tournament. They are: Bill Gillespie, James Glass, Mike Donison and Robert Pon.

Continued from previous page

## What is PAMS?

PAMS is a high-profile volunteer-driven event to cultivate relationships with business and community leaders to support the mission of the MS Society. The goal is to increase awareness of MS research and our programs and services so that community leaders are informed and willing to engage in the fundraising activities of the MS Society.



Also attending the Edmonton PAMS event were, from left: Dawn Dietz and Micky Wasylcia with the Federation of Alberta Gas Co-ops Ltd.; Janeth Mitchell and Len Boyko with the Alberta Federation of Rural Electrification Associations.

## Volunteers needed for Friendly Visiting program

The Friendly Visiting Volunteer program provides informal support for persons with MS living in continuing care.

If you think you could be a Friendly Visitor or would like more information, contact:

**Edmonton & area** — Scott Robson at [scott.robson@mssociety.ca](mailto:scott.robson@mssociety.ca) or 780-463-1190

**Calgary & area** — Marie Wong at [marie.wong@mscalgary.org](mailto:marie.wong@mscalgary.org) or 403-250-7090





**A group of young adults with MS in the Capital Region have formed their own group for support, recreation and social opportunities.**

# Young adults with MS in Edmonton rely on each other for support

Affectionately known as “YADS” (short for young adults), this group’s motto is ‘We make MS look good!’

**I**n June of 2008, a group of 18 to 35-year-olds attended a focus group at the Edmonton Chapter to discuss how the Chapter could best support them with programs and services. The unanimous decision was to create a group that meets for support, education, recreation and social opportunities. The group meets twice per month, once in a formal support group setting and once as a recreational evening.

The group itself has grown to twenty members, plus spouses, family members and friends who also attend the group from time to time. The members are

very motivated and eager to make this group work and are heavily involved in promoting the program and determining the events that the group holds each month.

The young adults group has been used as a model for a similar group in

Lethbridge. Discussions are underway with the MS Society of Canada’s National Office to create a Young Adults Retreat in the Fall 2009, which would be led by the Edmonton group, but that would be open to young adults from across the country.

For more information about the young adults group in **Edmonton**, contact **Jillian Szkuldecki at 780-440-2730 or [jillian.szkuldecki@mssociety.ca](mailto:jillian.szkuldecki@mssociety.ca)**. For more information about the **Lethbridge** group, contact **Ann Stewart at 403-328-7002 or [ann.stewart@mssociety.ca](mailto:ann.stewart@mssociety.ca)**.

# Premier MS Wine Gala and Auction raises \$90,000

Fine wine, delightful dishes, fabulous entertainment and the fight against MS were all on the menu once again at The MS Premier Wine Gala and Auction. A partnership event with the MS Society, Alberta Division and the Hilton Garden Inn – West Edmonton, the gala was kicked into high gear this year raising an amazing \$90,000, more than doubling the amount raised last year.

Thanks in part to generous sponsorships from a number of businesses including First Truck Trailer and Bus Centre, BioMS, Sorell Financial and countless others, the night could not have been more perfect. The exciting live auction also included the generous donation (by David Fehr) of a fully restored 1957 Chevrolet Bel Air!

On October 25, one hundred guests were treated to a lovely cocktail reception, followed by a delicious five course meal paired with delectable

wines for each course. The evening was lead by Sommelier Irv Barros from Vines Riverbend Wine Merchants. His presentation gave everyone great insight on what wines to pair with different foods and gave everyone a hands-on

experience into the wonderful world of wine tasting.

Following the meal and live auction the guests were treated to an intimate and interactive performance with Juno and American award-winning performer Alfie Zappacosta.

"This event is great for a number of reasons, first and foremost we are offering our guests a unique and exclusive opportunity to learn about wine and enjoy first class entertainment up close and, more importantly, we are raising awareness about MS and getting community leaders engaged in helping us fulfill our mission to end MS", says Ryan Drury, event organizer.

If you are interested in getting involved in next year's event, either through sponsorship or purchasing a table, call the MS Society at **780-463-1190**. The event is tentatively booked for October 24, 2009.

**Thanks in part to generous sponsorships from... First Truck Trailer and Bus Centre, BioMS, Sorell Financial and countless others, the night could not have been more perfect.**



**From left: Pat Ozirny, President, First Truck and Trailer; Pat Laforge, President & CEO, Edmonton Oilers; Suzanne Deschamps, Board Chair, MS Society, Alberta Division; Bruno Muller, Board Member, Edmonton Oilers Community Foundation; Cal Nichols, former Board Chair, Edmonton Investors Group.**

# 2008 Annual Awards Winners

MS Society of Canada, Alberta Division  
Saturday, November 1, 2008  
Red Deer, Alberta

Every year Alberta Division recognizes individuals and organizations who have made an outstanding contribution to the MS Society throughout the year. We are proud to recognize and celebrate the achievements of this elite group.

**Note:** Presenting the winners with their award is Suzanne Deschamps, Alberta Division Board Chair.

## National Awards

### President's Award

#### Joan Ozirny, St. Albert

Joan's boundless energy and dedication have been an inspiration to clients, health professionals and staff throughout Alberta. Joan is often sought out for media interviews, MLA presentations, client advocacy scenarios and peer support. She is a highly organized volunteer and has played a key role in the success of the MS Society in Alberta.



Joan Ozirny

### National Award of Merit, Member Joan Ozirny, St. Albert

Joan has contributed many years as a member of the Edmonton Chapter and Alberta Division Boards. As an

advocate for client services, one of her most significant successes was working to include MS drugs on the Alberta Formulary in the early nineties. As well, Joan always dreamed of a comprehensive MS Clinic in Northern Alberta and has advocated this for many years. Hence she has been an avid supporter of recent MS Society efforts to achieve this goal.

### National Award of Merit, NON-Member Gordon Bertie, Edmonton

Gordon has participated in the MS Bike Tour for six years. Last summer Gordon turned 60 and dedicated himself to reaching the \$60,000 mark for his cumulative fundraising total. To reach that goal he would have to raise \$28,000 in one year, something he had never done before. By the end of the 2008 MS Bike Tour, Gordon had surpassed his goal and



Gordon Bertie

raised a grand total of \$34,000 - the highest any participant has raised in the Leduc to Camrose Tour.

### Opal Award

#### Annie Vanhell, Lethbridge

Annie's husband, Ralph, was diagnosed with MS in July, 1996. By the fall of 1996 he was using a cane and a year later he was in a wheelchair. In April of 2005, Ralph was placed in Designated Assisted Living as his medical needs could not be met at home. Annie visits Ralph every evening and incorporates as many activities and outings as she can without compromising his health or care. Ralph has day passes on the weekends and comes home every Saturday and Sunday. Annie takes Ralph to Lethbridge for all of his appointments, and a stop at Tim Hortons is part of the routine.



Annie Vanhell

## Alberta Division Awards

### Volunteer of the Year Award - Joanne Robinson Award

#### Chris Keiser, Sherwood Park

Chris helps individuals deal with the challenges of MS. In particular, he helps men adjust to and accept their diagnosis. He provides hope that they can overcome the diagnosis and provide for their families. Chris also promotes the MS Society and provides public education about MS. He is also a top fundraiser in the MS Walk.



**Chris Keiser**

### Development Volunteer Of The Year Award (Pat Stewart Award)

#### Cindy Bakala, Calgary

Cindy has volunteered with the MS Society, Calgary Chapter since 2001 and is an active member of the Calgary Chapter Board. She is also involved with MS public education, fundraising, and the RONA MS Bike Tour committee. Cindy has an unlimited amount of energy and her fellow committee members look to her for guidance and support. Cindy was also the site coordinator at the MS Walk



**Cindy Bakala**

for a number of years before she stepped down to become a participant and raise funds with a team she recruited.

### Special Service Award of the Year Andy's Oilfield Hauling Ltd., Blackfalds

Andy's Oilfield Hauling has been a cash sponsor of the MS Walk for over ten years and a very good friend to the Central Alberta Chapter. Three years ago the Central Alberta Chapter received a donation of a four-year lease on a vehicle. However, the "MS Awareness Van" needed some fuel. The Chapter approached Andy's Oilfield Hauling and they said "Sure, not a problem." This incredible partnership with Andy's Oilfield continues to help Central Alberta Chapter raise awareness.



**Sheldon Murray of Andy's Oilfield Hauling**

### Board Chair's Special Recognition Award First Truck and Trailer, Edmonton

First Truck and Trailer has been a major



**Pat Ozirny of First Truck and Trailer**

financial supporter of Edmonton Chapter programs and MS Society research over the last number of years. Their support has made it possible for Edmonton Chapter to provide a variety of programs and services to persons with MS in the Capital Region. Since 2005, First Truck has donated over \$18,000 to Edmonton Chapter. More recently, First Truck has made a generous donation to the MS Research Foundation - a \$25,000 donation over five years.

### Communications Award

#### Newcap Broadcasting, Lloydminster

NewCap Broadcasting has been a dedicated supporter of the MS Society for many years, offering over \$16,000 in advertising annually for the MS Walk in Lloydminster. NewCap also provides extensive coverage of the MS Carnation Campaign and has initiated multiple stories on other Chapter programs and initiatives, including Kids Kamp and the Safeway We Care Campaign. NewCap has played a crucial role in significantly raising the public profile of the MS Society in Lloydminster.



**Kurt Price of Newcap Broadcasting**

### Paul Scott Award Tara Maloney, Red Deer

Tara began with the Central Alberta Chapter over nine years ago as the receptionist. She was promoted to Executive Assistant because of her commitment, hard work and eagerness to take on a challenge. One of the challenges she took

Continued on next page...

on was overseeing the registration process for the MS Walk and RONA MS Bike Tour. Tara also coordinates the Carnation Campaign for all of Central Alberta. She has always been a cheerful, helpful, positive employee and is a pleasure to work with.



**Tara Maloney**

**Maureen Allen Social Action Award  
Helen Chesterman, Edgerton**

Helen has been a tireless champion of social change for many years. As Chair of the Alberta Division Government Relations Committee, Helen helped develop strategic relationships with key MLAs, leading to a friendly visiting program and improved care and accommodations for young people in long-term care. Helen is also a MS Ambassador and wears the "ambassador hat" in many of her personal and professional relationships.



**Helen Chesterman**

**Professional Care Award  
Lil Demchuk, Elkpoint**

Before retiring, Lil worked in the Elk Point hospital for many years providing care and support. After her retirement she applied the same level of quality care and support to people with MS in her community. Lil was instrumental in starting a

support group in the region and focused especially on newly diagnosed and caregivers. She is a MS Ambassador par excellence, giving of her time freely and generously to educate, support, visit and connect around MS challenges.

**(Note: photo unavailable)**

# The Top 30

2008 was an outstanding year for MS fundraising in Alberta. Thirty unique individuals raised \$10,000 or more in either the MS Walk or RONA MS Bike Tour - an amazing feat indeed. Here they are pictured at right displaying their awards. (Note: A few award winners are missing from the photo as they were unable to attend the awards ceremony.)

**Event**

- MS Walk Edmonton
- RONA MS Bike Tour - Leduc to Camrose
- RONA MS Bike Tour - Hinton
- MS Walk Edmonton
- RONA MS Bike Tour - Hinton
- RONA MS Bike Tour - Leduc to Camrose
- MS Walk Calgary
- RONA MS Bike Tour - Airdrie to Olds
- RONA MS Bike Tour - Airdrie to Olds
- MS Walk Edmonton
- MS Walk Medicine Hat
- RONA MS Bike Tour - Leduc to Camrose
- MS Walk Calgary
- MS Walk Lloydminster
- RONA MS Bike Tour - Leduc to Camrose
- RONA MS Bike Tour - Airdrie to Olds
- RONA MS Bike Tour - Leduc to Camrose
- RONA MS Bike Tour - Red Deer
- RONA MS Bike Tour - Leduc to Camrose
- RONA MS Bike Tour - Airdrie to Olds
- MS Walk Calgary
- MS Walk Edmonton
- RONA MS Bike Tour - Airdrie to Olds
- RONA MS Bike Tour - Airdrie to Olds
- RONA MS Bike Tour - Airdrie to Olds
- RONA MS Bike Tour - Airdrie to Olds
- RONA MS Bike Tour - Hinton
- RONA MS Bike Tour - Leduc to Camrose
- MS Walk Calgary
- RONA MS Bike Tour - Hinton

**Name**

- Julia Daniluck
- Gordon Bertie
- Dr. John Mullen
- Chris Kieser
- Greg Van Tighem
- Darcy Trigg
- Ken Engler
- Bryan Simister
- Perry Parker
- Simmy Saran
- Craig Walker
- Rod Neumann
- Keith Mychaluk
- Gail Taylor
- Frances Harrison
- Jan Hancock
- Doug Hansen
- Dan Sims
- Ken Kerr
- Verne Barr
- Dana Torossi
- Donna Romanuik
- Bob Merrick
- Laura-Lee Dyck
- Jim Campbell
- Albert Hulzebos
- Danny Lynn
- Timothy Mahoney
- Annette Matisz
- Suzanne Deschamps

**Total**

- \$40,546
- \$33,620
- \$33,587
- \$25,220
- \$22,229
- \$16,675
- \$15,234
- \$15,091
- \$15,046
- \$14,275
- \$13,695
- \$13,305
- \$12,642
- \$12,614
- \$12,429
- \$12,304
- \$12,271
- \$12,150
- \$11,846
- \$11,371
- \$11,100
- \$11,006
- \$11,000
- \$10,405
- \$10,250
- \$10,050
- \$10,000
- \$10,000
- \$10,000
- \$10,000



# 10

# Tips for managing your MS from a pharmacist's perspective

The pharmacological management of MS symptoms can be a challenging task for the clinician and patient. Specifically, some patients may often feel overwhelmed by all the information provided to them involving the proper use of their medications. Your pharmacist is an expert on how to get the most benefit from your medication and is able to help you decide on a treatment plan that best meets your needs. Here are 10 tips from a pharmacist's perspective that will help you receive the best quality care.

**Education.** Take the time to understand the exact roles of the various members of the inter-professional team of MS clinic specialists so that you can have an active role in your MS care. Understanding the services provided by each of the team specialists will prepare you to make informed decisions about the medical treatment you are receiving. For example, discuss your medications with your pharmacist to select a drug treatment best suited to your individual needs.

**Take charge of your health.** Your healthcare provider will provide you with education. However, you also have the personal capacity to know the best treatment plan for you and your lifestyle. Work with your healthcare provider to address any concerns you may have so as to ensure your personal needs are being met. This will lead to optimal adherence to the healthcare plan and a better overall outcome.

**Prioritize your top 3 concerns.** Managing your symptoms can be a challenging task. It is important to

let your healthcare provider know of your most urgent concerns. Perhaps it is a medication that is ineffective at managing your pain or perhaps you are experiencing unbearable side effects from one of your medications. The pharmacist can address those key issues and help alleviate your symptoms to a more tolerable level by suggesting an alternative treatment strategy together with your doctor.

**Keep a list of your medications handy for your healthcare provider and for yourself.** This includes all prescription medication, over-the-counter drugs, vitamins and herbal products. This will help you and your healthcare provider discuss any issues and determine which medications are working for you and which ones are not. It will also allow the pharmacist to adjust any medications if necessary. In addition, if a new drug needs to be introduced, a list of your current medication regime will allow the pharmacist to determine if there are any possible drug interactions that require attention. As a result, to improve ease of access and knowledge of your entire medication history, it is imperative to use one pharmacy for all your drug-related needs whenever possible.

**Keep a daily diary.** How well is a particular drug working for you? One way to determine this is by keeping a daily diary of all your symptoms. Keeping a diary will allow you to monitor for any signs of improvement or onset of side effects as a result of a medication. For instance, if you are experiencing neuropathic pain symptoms, you can keep track of whether a treatment is

working for you by recording in your daily diary the severity of pain from a scale of 0 (no pain) to 10 (worst pain imaginable) every day before you start treatment and while on treatment. Depending on the results of your daily diary, your pharmacist or healthcare provider can address any concerns and work on developing a treatment plan that will work for you.

**Be critical about the information you hear in the media and even from your friends and family.** Although your social circle cares about you very much, it is important to be very selective about the information you receive. There is no such thing as a miracle cure and medication that will work for one person may not work for you. Everyone is unique. Your MS team is able to do a thorough assessment of your symptoms and can refer you to reputable sources of information based on evidence-based medicine to help you learn more about your health.

**Adherence.** One of the most challenging issues patients have with disease modifying therapies is their undesirable side effects. All disease modifying drugs (DMDs) require to be injected, which can be unpleasant for most people. Moreover, some of the DMDs are associated with uncomfortable flu-like symptoms, which can negatively impact a person's overall wellbeing and daily functioning. This can be discouraging as these medications often make you feel worse. However, adherence is important, as these treatments have been shown to be effective at reducing the number of relapses to occur. Talk

to your healthcare provider about any issues you are having regarding your medication that are persuading you to skip doses. Your healthcare provider can suggest ways of managing these concerns.

**Non-drug alternatives.** A non-pharmacological approach can be very effective in managing some symptoms, especially when done in conjunction with medication treatment. For instance, a patient taking amantadine every morning to help with fatigue symptoms may still experience extreme fatigue in the afternoon. However, instead of increasing the dose of the medication, taking a nap mid-day may prove to be just as beneficial. Taking this approach can help the patient feel rejuvenated without increasing the dosage of your current medication. Explore all non-drug alternatives with your healthcare provider.

**Communication.** If you are ever unsure about your treatment plan or do not fully understand how the medication you are receiving will work for you, don't be afraid to ask questions. Questions such as "When will I expect to see some results?" or "Are there any food, drink or activities I should avoid while taking this medication?" are examples of important questions to ask. In addition, ensure your healthcare provider is aware of any allergies or adverse reaction you have had to a medication. You should always inform your healthcare provider of any other medical conditions that you may have in addition to your MS so that the most appropriate drug can be used to treat your symptoms without aggravating other medical conditions that you may have. This will help you avoid getting something that could potentially harm you.

**Stay positive.** Maintaining a positive attitude will help your overall physical and mental wellbeing. Keeping note of the things you are still able to achieve everyday is important for everyone. Set realistic goals and stay as active as possible.

# Respite Care Pilot Project

Living with MS produces a significant strain on the physical and emotional resources of individuals living with MS and their caregivers. Adequate access to respite care and services contributes to overall quality of life.

The MS Society - Alberta Division worked with Alberta Disabilities Forum (ADF) to develop a proposal for a provincial respite care pilot project. The proposal was submitted to Alberta Health and Wellness early in 2008 and was approved with a significant grant.

The project is being administered on behalf of ADF by the Alberta Coalition of Citizens with Disabilities. The MS Society is represented on the project's advisory committee.

Between July 21 and October

21, 2008, ADF and Alberta Seniors and Community Supports held 23 community consultations with caregivers and those who use their services (individuals, families) in fifteen centres around the province. The purpose was to identify the need for respite and other supports or information. These results are being used to develop a pilot project in which caregivers will apply for funding for respite in a number of categories.

Applications for one-time funding of up to \$600 were distributed to clients through MS Division and Chapter offices.

We are hoping the results of this pilot project will provide the basis for a much broader and province-wide approach to caregiver respite.

## MS Support Groups in Alberta

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

**Brooks** — call the Southeastern Chapter office at 403-529-6797. Ask for Shivonne.

**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.

**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.

# Dead Sea provides inspiration for giving

## With tax incentives, you can 'give' *and* 'receive'

"Do you know why the Dead Sea is dead?" asks Greg. "Umm, because it's full of salt?" I ask, about as sure of myself as I am that the Oilers and Flames will have the two best records in hockey this year.

"That's true," says Greg, "but all that salt doesn't have anyplace to go. Water flows into the Dead Sea but nothing flows out. It takes but doesn't give, that's why it's dead."

Greg Bowen is a financial advisor with Bowen Financial Inc. He has been a financial advisor for over 30 years and models his philosophy for living and giving after the example of the Dead Sea.



**"This is not just for wealthy individuals. It's for ordinary people like you and me." - Greg Bowen**

"Although I have no direct connection to MS, I believe it's important to give back in order to support my community."

Greg's involvement with the MS Society began about a dozen years ago with the RONA MS Bike Tour. "I had an assistant who rode with friends in the Red Deer tour, but I couldn't join them because it was their ladies only weekend. So I rode in the Alberta Lung Association's Bike for Breath. They discontinued that tour but I still had sponsors who had set money aside to sponsor me. So I rode with a friend in the MS Bike Tour in Red Deer and I've been riding in it ever since." As a matter of fact, Greg was the top fundraiser his first year in the tour in 2005 and the following year as well.

Recently Greg made the decision to help people with MS in another way.

**My premiums on the policy are...100% tax deductible. The MS Society benefits and I get a break at tax time. Everyone wins.**

By purchasing a \$50,000 life insurance policy and transferring ownership to the Central Alberta Chapter of the MS Society, the Society benefits and, come tax time, so does Greg. "This kind of giving generally appeals to people who already make an ongoing contribution to a charity," he says.

"This is not just for wealthy individuals," says Greg. "It's for ordinary people like you and me. My premiums on the policy are about \$98 a month and are 100% tax deductible. The MS Society benefits and I get a break at tax time. Everyone wins."

If you would like to learn how you can help Albertans with MS while receiving tax advantages, contact the MS Society's Leadership Giving representatives.

**Calgary/Southern Alberta**  
**George Jacob • (403) 250-7090**  
[george.jacob@mssociety.ca](mailto:george.jacob@mssociety.ca)

**Edmonton/Northern Alberta**  
**Mark Mahl • (780) 440-8764**  
[mark.mahl@mssociety.ca](mailto:mark.mahl@mssociety.ca)



**Greg Bowen began his connection with the MS Society riding in the RONA MS Bike Tour in Red Deer. He's been involved ever since.**

## 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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