

Acne medication may delay progress of multiple sclerosis

Alberta researchers investigate common medication as alternative MS treatment

A common acne medication that has been available for over 30 years has the potential to delay the progress of multiple sclerosis and, if proven effective, will offer an inexpensive option for the treatment of early MS.

Clinical researchers in Calgary and 13 other Canadian centres will be taking an in-depth look at an oral therapy known as minocycline after initial studies have shown promising results. A new \$4 million multi-

centre clinical trial involving 200 participants from across Canada is being funded through the MS Society's MS Scientific Research Foundation.

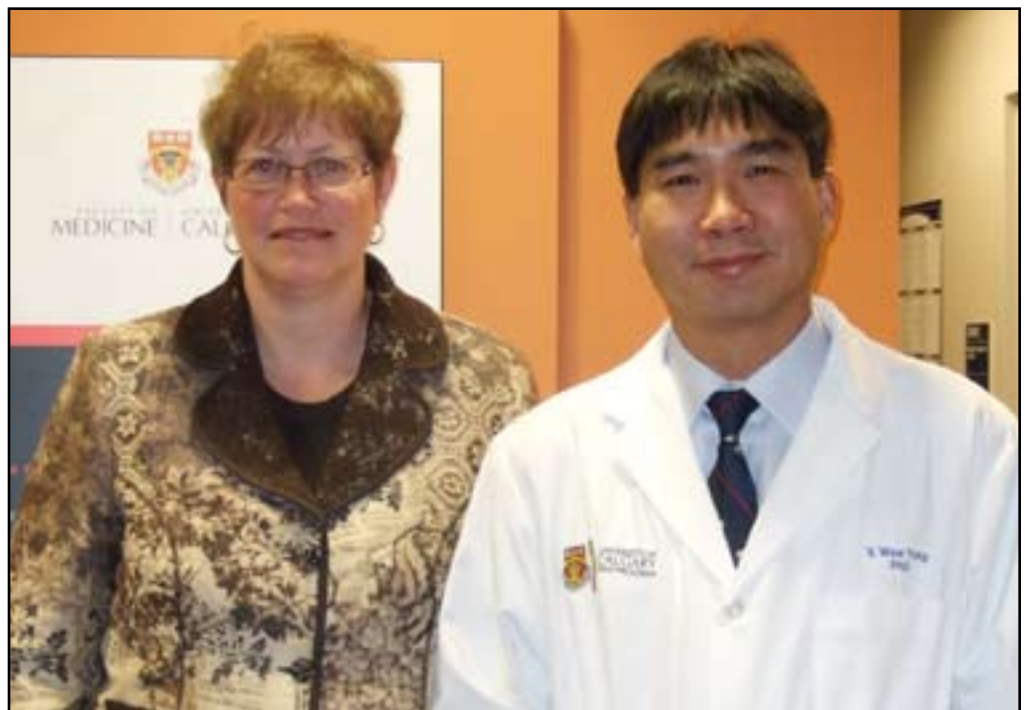
"The benefits of minocycline are straight forward: it's relatively cheap, has few side effects and can be taken in pill format," says Dr. LuAnne Metz, principal investigator for the study and a professor of clinical neurosciences at the University of Calgary. "The aim of our research

is to see if this common drug can reduce the occurrence of further disease activity in people who have experienced an initial attack of MS symptoms and who are at high risk of progressing to definite MS. Without treatment, two thirds of people facing this circumstance are expected to be diagnosed with MS within 6 months. We believe minocycline can reduce this number."

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Dr. Metz (left) and Dr. Yong.

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 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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One Person Does Make a Difference



I have this wonderful opportunity to thank so many people for helping us achieve the best year ever in Alberta and at a National level. Nationally, total net revenues increased by 10 percent. In Alberta, we raised an additional \$1.1 million over last year. It's very rewarding to see how much everyone's efforts really do make a difference. You will be pleased to learn that the MS Society

in Alberta contributed just over \$3 million of the total \$10 million national contribution to MS research. I am very proud of Alberta's significant contribution to research which has grown by \$700,000 over last year. Alberta's successful fundraising year has also led to increased client services, including public education, social action, and increased support to our Chapters.

There's such good momentum building here in Alberta and across the nation that I believe we can and will achieve tremendous progress in the years ahead. Lou Maroun, 2007 outgoing national Board Chair, said it best: donors, volunteers and all people affected by MS should demand answers to the cause and cure of MS...we should strive to double and triple our contributions to MS research so that this side of the mission can be accomplished.

So how do we do this? I believe the answer is right before our eyes. I witnessed a tremendous amount of support at our first MS Ambassadors Forum in November. I've never experienced such excitement in the air from so many committed people from across the province. Ambassadors will help influence government of the need for many more service improvements, and reinforce our request of the Alberta Government to invest in the Society's endMS National Campaign that shows so much promise.

The notion of recruiting more MS Ambassadors to help generate increased support really took root in Calgary over the past year. During the course of three separate luncheons attended by over 140 business leaders, we were able to raise not only significant awareness of MS, but also just over \$500,000 of new money to the endMS research campaign. As you will learn from the story of the Moore family (page 4), every person and family can make a difference through their individual gift of time, money or talents. Each one of us knows someone affected by MS who can help us achieve our mission – if we only ask. If you or someone you know would be a good MS Ambassador, please contact **Julie Kelndorfer at (780) 440-8756 or julie.kelndorfer@mssociety.ca**. Through the power of a dedicated group of people with a common purpose, we will reach our goal as we strive to make MS a provincial priority in Alberta similar to other disease groups.

Neil Pierce, President, Alberta Division

Minocycline

Continued from page 1

Previous clinical tests of minocycline have shown an 84 per cent reduction of MS lesion activity in MRI results.

Minocycline works by inhibiting the activities of an enzyme and immune cells that are keys to initiating MS attacks. It has been used in acne treatment for its anti-bacterial effects but studies have shown its anti-inflammatory properties could be important factors in slowing down MS. These insights were discovered through pioneering research funded by the MS Society of Canada and led by Dr. V. Wee Yong at the University of Calgary (UC). Drs. Metz and Yong lead the MS program at the Hotch-

kiss Brain Institute at UC where many of the early studies on minocycline took place.

In comparing minocycline to current therapies, the cost savings would be substantial. In generic form, minocycline is available for as low as \$800 per year. Current MS therapies can cost between \$18,000 and \$40,000 per year. Researchers note that minocycline would not necessarily replace current therapies, but might delay the timeframe in which they would be required.

Enrolment will begin in early 2008 and 14 MS clinics are involved including institutions in Calgary, Vancouver, Burnaby, Edmonton, Red Deer, Saskatoon, London, Toronto, Kingston, Ottawa, Montreal, Quebec City, Sherbrooke and Halifax. Investigators will compare 100 mg of oral minocycline twice daily to placebo over a period of two years.

What is minocycline?

Minocycline is used to treat bacterial infections including acne; pneumonia and other respiratory tract infections; and infections of skin, genital, and urinary systems. Minocycline is in a class of medications called tetracycline antibiotics. It works by preventing the growth and spread of bacteria. It comes in pill format. Recent studies have demonstrated its anti-inflammatory properties, a key factor for MS researchers to look closely at the drug.

Is minocycline a cure for MS?

No, but if the research hypotheses are confirmed, minocycline may prove to be an effective early treatment that delays the full onset of multiple sclerosis. Early studies have shown an 84% reduction in MS lesion activity on brain MRI, meaning this treatment has the potential to slow the disease down significantly.

Will minocycline be a replacement for current disease modifying therapies?

Researchers note that minocycline wouldn't necessarily replace current therapies, but would likely become another treatment option. Individual response is expected to vary. It may delay the timeframe in which other treatments would be required and it may prove to be useful in combination with other approved therapies.

Can I get it now?

Minocycline is generally available as a prescription medication for acne and other bacterial infections but until it is proven to be beneficial it is not recommended for treatment of MS.

How can I get involved?

For this particular study, enrollment does not begin until 2008. At this time, study sites will enroll people within 90 days of their first attack of MS like symptoms. People who currently have MS or suspected MS are not eligible.

MS

AMBASSADOR PROGRAM

A United Voice for the Cause and Cure

Ambassador Profile

Levi Barron
MS Ambassador

Occupation

15-year-old student in grade 10 at Bowness High School in Calgary.

How long have you been an MS Ambassador?

Since November 1, 2007.

Why did you decide to become involved?

I want to spread awareness that kids get MS and to be proactive with my disease.

What areas do you want to work in as an ambassador?

Government lobbying and public speaking - I'll do this by sharing how MS has affected my life as a teenager.



Alberta PAMS events raise \$500,000 for MS

Just about 50 people gathered in Calgary on November 8 to support a cause they all share. Emotions ran close to the surface as individuals shared their personal connection to multiple sclerosis and their personal commitment to helping end it.

This is a unique group of people, primarily from Calgary, who gather a few times a year under the auspices of something called PAMS. What is PAMS? The short answer – PAMS is People Against MS. The long answer, that which lies at the heart of the group and provides a common purpose – PAMS is an initiative of the MS Society to bring together individuals who are in a position to make a substantial difference in the fight to end MS.

What is truly remarkable about the PAMS program is its potential for growth. Relying on the personal connections of supporters, each



Al Schreiner,
President & C.O.O.
Stream-Flo
Industries Ltd.

PAMS event gets larger and larger, as individuals invite their friends and colleagues.

For the time being, PAMS events in Alberta are held every few months in Calgary, at the Calgary Petroleum Club. Informal luncheons,

sponsored by **Scotiabank**, enable individuals to learn of recent developments in MS research and announcements of major gifts to MS research, as well as meet people who are also touched by this horrible disease. **Dr. V. Wee Yong**, a MS researcher at the Hotchkiss Brain Institute in Calgary, shared some of the very promising MS research taking place here in Alberta at the



Keith Mychaluk,
Senior Geologist,
Birchcliff Energy Ltd.

Universities of Calgary and Alberta. Indeed, Alberta is home to some of the best MS researchers in the world.

Plans are in the works to host PAMS events in Edmonton and Red Deer and more information will be provided as soon as it is available. In the meantime, if you are interested in attending a PAMS luncheon, you can call **Neil Pierce**, President of the MS Society of Canada, Alberta Division, at **780-440-8752**.

Since PAMS started in Alberta, \$500,000 has been raised to support the endMS Research Network. At the November 8 luncheon, the Moore family made a significant



PAMS luncheon on November 8 in Calgary. From left: Dr. Garry Wheeler, Vice President, MS Society of Canada, Alberta Division; Debbie Moore; Kristie Moore; Ken Mayhew, Vice President, Fundraising, MS Society of Canada; Lorraine Evans-Cross, Executive Director, MS Society of Canada, Central Alberta Chapter; Fred Moore, President, Altus Energy Services Ltd.

contribution to the fight to end MS. **Fred Moore**, President of **Altus Energy Services Ltd.**, and his wife **Debbie** have a personal stake in ending this disease. Their daughter **Kristie** was diagnosed with MS in 1998. Also in attendance was **Keith Mychaluk**, Senior Geologist with **Birchcliff Energy Ltd.** and **Don Barkwell**. Don was featured in the last issue of *MS Connections* for his \$350,000 contribution to the endMS Research Network. Don was invited to participate in PAMS by his good friend **Al Schreiner**, President and C.O.O of **Stream-Flo Industries Ltd.**

Scotiabank is an ardent supporter in the fight against MS. In addition to sponsoring the Calgary PAMS luncheons, **Rick Waugh**, Scotiabank President & CEO, serves as honorary chair of the MS Society of Canada's national fundraising campaign. This past May, Scotiabank employees also held a novel fundraiser, the Scotiabank Male Leg Wax-Off Challenge for MS, which featured 20 men who dared to "take it all off" for pledges to the cause. The event was organized by former Scotiabank employee, **Carling Middlestead**, who now works for the local MS Society, in honour of her sister

Danica, who has MS. The event raised almost \$21,000, including more than \$10,000 through the

Team Scotia Community Program, which matches funds raised by Scotiabank employees.



From left: Kristie, Fred, and Debbie Moore.



From left: Neil Pierce, President, MS Society of Canada, Alberta Division; Don Barkwell (title and company); Ken Mayhew, Vice President, Fundraising, MS Society of Canada; Dr. V. Wee Yong, MS Researcher, Hotchkiss Brain Institute, University of Calgary.



Scotiabank employees attended the November 8 luncheon.

ANNUAL AWARDS WINNERS

Celebrating our Success

SATURDAY, NOVEMBER 3, 2007

COAST EDMONTON PLAZA HOTEL • EDMONTON, ALBERTA

Each November, Alberta Division hosts its annual general meeting, and one of its annual highlights is the awards ceremony which recognizes those individuals and organizations for their generous support of our Society over the past year. The theme of this year's AGM was "celebrating our success," and we're pleased to introduce you to those who helped us make 2007 such a successful year.

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

National Awards

National Award of Merit - Alberta (Non-Member)

Wal-Mart Lloydminster

In addition to being the Lloydminster WALK's top corporate team for several years (raising more than \$10,000 annually), the store has also been a major player in the WALK's media campaign. On various occasions, Wal-Mart has offered up a highly visible location within the store to sign up WALKers and Teams and distribute Chapter information. They also selected the MS Society as its charity of choice for its annual Charity Barbecue, with funds raised going directly to the 2007 Super Cities WALK for MS.



Diana Joseph

arranging the Jayman MasterBUILT gift of \$1,000,000 to the Hotchkiss Brain Institute's MS program and the Alberta MS Project.

National Award of Merit - Alberta (Member)

Diana Joseph, Calgary

Diana is president of Wen-Di Interiors. She is a past member of the board of Alberta Division and was the co-chair of the 2003 Focus on Research fundraising campaign. For many years she organized the Designing for a Cure fundraising event to support MS research. Most recently she was instrumental in

National Award of Merit (Non-Member)

Dr. V. Wee Yong, Calgary



Dr. Yong

Dr. V. Wee Yong is a Professor in the Departments of Oncology & Clinical Neurosciences and co-director of the MS Program at the Hotchkiss Brain Institute at the

University of Calgary. His interests lie in the area of neuroimmunology and regeneration of the central nervous system. Dr. Yong heads a \$5 million multi-disciplinary study of the role that enzymes called matrix metalloproteinases (MMPs) have in multiple sclerosis. He is chair of the Medical Advisory Committee of the Multiple Sclerosis Society of Canada. He is also the liaison member of the MS Society of Canada with the US National MS Society's Senior Research Programs Advisory Committee.

Opal Award

Gail Shantz, Eckville

Gail's husband, Brent, was injured at work in 2000 when he lost



Gail Shantz

Alberta Division Awards

his balance and fell off some equipment. An MRI later revealed that Brent lost his balance due to primary progressive MS. Brent's initial symptoms have since become much worse. Gail sees to all of Brent's personal needs. With the assistance of a nanny, she is able to work out of the house to provide for the family. Along with Brent, Gail is also the primary caregiver for Brent's mother.

President's Award

Katie Gerke

After being diagnosed with primary progressive MS in 1989, Katie attended DeVry Institute of Technology and earned a Bachelor's Degree in Computer Information Systems. She graduated in 1996 and became a software analyst. Between 2001 and 2004, Katie had to adapt to living in a group home environment, after having lived



Katie Gerke

independently prior to that. Katie now lives in long-term care and runs a home decorating business from her room at the facility. She has recently started to paint with her mouth and hopes to become a successful artist. Katie is an accomplished public speaker and has spoken at several high profile functions. In 1996 Katie became a member of the Disabled Sailing Association of Alberta and began to sail competitively. She is an award winning disabled sailor.

Volunteer of the Year Award (Joanne Robinson Award)

Dianne Rogers, Calgary

Dianne Rogers has been a Peer Link volunteer for the MS Society, Calgary Chapter, for the past two years. She spends 2-3 hours per week helping people with MS and has tremendous compassion for the people she talks with. Many clients are socially isolated and this contact is priceless to them. Dianne has also been active in the area of public education - assisting Client Services staff on several occasions with a display table at a conference or workshop



Dianne Rogers

Development Volunteer of the Year Award (Pat Stewart Award)

Rudi Schimmel, Edmonton

Rudi has been actively involved in the RONA MS Bike Tour - MS 150 Leduc to Camrose committee for over 10 years. His dedication, knowledge, leadership and loyalty is second to none. Whenever something is needed Rudi is the guy



Rudi Schimmel

to come through with it. He is very dedicated to the cause and cure.

Professional Care Award

Sharon Peters, Calgary

Sharon is a respected member of the nursing team at the Calgary MS Clinic. She provides people affected by MS with knowledge that they will need to make well informed decisions about their care. Sharon has presented numerous educational programs for Calgary Chapter over the years. Her ability



Sharon Peters

to take the most complicated and technical information and translate it into an easy, everyday format for all to understand is truly a gift and is appreciated by all in attendance.

Maureen Allen Social Action Award

Cathy Armstrong, Calgary

Cathy is a social worker in the area of mental health and has been a member of the Calgary Chapter Government & Community Relations Committee for 13 years. She participated in the development of the award winning Journey to Wellness program and the development of the children's program, which offered a one day support program to children and teens whose parent had a diagnosis of MS. In addition to program development, Cathy has been very involved in assisting the MS Society to

address the systemic issues regularly faced by individuals with MS.

**Board Chair's Special Recognition Award
Community Police Radio Network (CPRN), Edmonton**

For the past 10 years, the Community Police Radio Network has provided very generous support to the RONA MS Bike Tour – MS 150. On the days of the event,



Graham Yeske

approximately 15 CPRN volunteers drive the route looking for cyclists who are unable to complete the tour. They also provide traffic control at checkpoints and work closely with our first aid volunteers to ensure that any accidents along the route are properly managed. They also provide financial support in the amount of \$1500 per year.

**Paul Scott Award
Holly Beutler, Edmonton**

Holly has served under four presidents within 9 years which in of itself is a feat of considerable



Holly Beutler

dimension. She has committed herself to integrity, diplomacy and inclusiveness ensuring that everyone who needed Alberta Division assistance received what they needed to the best of her ability. Holly has made the biggest difference to the Society because of her belief that she can make a difference.

**Special Service Award
Enerflex Systems Income Fund, Calgary**

In 2002, Enerflex became the Title Sponsor for the Calgary WALK. Since their involvement, the Enerflex Super Cities WALK



Enerflex CEO Blair Goertzen

for MS has grown from 2165 participants raising \$349,448 in 2002 to this year's all time high of 2300 participants raising over

\$800,000! In 2007, Enerflex signed on to sponsor the Calgary WALK for an additional five years, once again demonstrating their dedication and passion to our cause.

**Communications Award
Michelle Lang, Calgary**

Michelle's work over the past year has significantly increased awareness of the issues that impact individuals affected by MS. On December 17, 2006 her feature story, *Old Before Her Time*, was published. The story follows Tanya, who has MS and is in long term care, for six months and chronicles her challenges, successes and relationships. Michelle followed up this important piece with several articles addressing issues within the spectrum of continuing care.



Michelle Lang



2007 Top Fundraisers. From left: Earl Nolan, Gary Haug, Dan Sims, Cec Holmes, Ken Kerr, Chris Kieser (front), Julia Daniluck and John Mullen.

The Couple and MS

By Cate Archibald, PhD, RPsych,
Clinical Psychologist,
Optimus Program,
Foothills Medical Centre

The challenge of MS

MS can be unwieldy for couples to cope with and presents unique challenges and changes that require the adjustment of two people within the context of other challenges and changes experienced through life. An important factor affecting the strength or resilience of a relationship, with or without a chronic condition, is a strong sense of connection to each other.

Communication Barriers

Building and maintaining connection is not an easy task for anyone, but can be more difficult when a couple is living with a chronic condition like MS. Factors contributing to communication barriers can include: the health/symptoms of the person who has the diagnosis – whether he

or she is experiencing an exacerbation of symptoms such as pain, fatigue, sexual dysfunction, depression or cognitive impairment or other medical conditions; the health of the partner; and/or high stress from financial pressures, housing, children, other life demands and availability of social support. It may also be hard to talk to each other due to differences in the adjustment phase and coping styles, misconceptions about MS, “illness” beliefs, a tendency to protect each other, as well as discomfort with certain topics.

The phase of adjustment to MS experienced by each person can be quite important. If one or both is in the denial phase, it is difficult to move forward together. Denial may be psychologically based, but alternatively, it may be associated with MS-related changes in cognition that can affect some people.

Coping styles may also differ. One person may prefer to learn about MS only on an “as needed

basis” or as little as possible because “more information means more worry”, while the partner may cope best by finding out as much as possible about the disease, more of an “information is power” approach. Just because your partner may not read all the materials you provide or attend a support group does not

If one or both is in the denial phase, it is difficult to move forward together.

necessarily mean that he or she isn't also sad or anxious about what is happening – it is just a different coping style.

Beliefs about “illness” may have their roots in our family of origin and past experiences. Some people may have a negative view of “illness” and, coupled with misconceptions about MS, they may act with intolerance or criticism. Willingness to understand and provision of accurate information can significantly improve connection and future communication.

Often one or both of the couple may try to protect the other person by not talking about things that are likely to cause distress, and in some cases, this might mean that much is not shared or discussed. Some topics may also be uncomfortable to discuss, even before MS entered the picture, such as sex, or bowel and bladder issues.

These are some examples of communication barriers that can affect how connected a couple feels.



Some topics may be uncomfortable to discuss, even before MS entered the picture, such as sex, or bowel and bladder issues.

It is very important that a couple have a strong foundation through the trials and tribulations of life and MS, and a strong foundation requires communication, understanding, balance in the relationship, loving actions and sense of “shared journey.” Bridges, not barriers.

Building Connection

Building connection can start by acknowledging your different communication styles with the goal of finding common ground around communicating, because you can't figure out how you are going to incorporate MS into your lives without talking about it. One way to improve communication is to learn new skills that promote assertiveness, or an “I count, you count” approach, which is direct and respectful of each other. The **EDESC*** is an acronym for five communication steps that help to achieve assertive communication.

E = empathize with the other person by saying, “I understand that you ___”

D = describe the situation or behaviour in specific terms, “When you do ___” or “When ___ happens,”

E = express your feeling(s) about the situation, “I feel ___”

S = specify how you would like the situation/behaviour to change, making it directly applicable to your “D” statement, “What I would like instead would be ___” and you can invite collaboration by also saying “Would that work for you?”

C = consequences – expressing the positive consequences if this change was made, “If you did ___, it would mean a lot to me” or “If this changed, I think things would go more smoothly.”

Making sure that that you are observing the **HALT** rule (that neither one of you is very Hungry, Angry, Lonely and/or Tired when you are making time to talk about difficult topics), your EDESC communication might go like this...“I understand that you have been very busy at work and that finding time to talk is difficult. When you say that we'll talk and then we don't, I feel worried and alone. What I would like instead is that we agree on a time to meet to talk, and then talk at that time. If we could find a way to talk, by setting up a meeting, it would mean a lot to me. Would this work

The foundation of a relationship can be built by making regular “deposits” in the “couple account.”

for you?” This example highlights another way to build connection by making time to talk. The couple needs to create a “positive listening environment” so that each can trust that it is safe to share feelings. If emotions are intensifying, the HALT rule may also be used to take a breather, with the understanding that the discussion will resume when things are calmer. Calling a HALT helps avoid being aggressive. Also, try to focus on one item at a time, not a whole list.

Talking about uncomfortable things could be approached in a “starting with small steps” approach, or practicing with easier topics before tackling the tough stuff. A health care professional or couple therapist can facilitate if you need a jump-start.

Learning more about MS from Multiple Sclerosis Society literature, seminars, support groups, the MS Clinic and health care professionals is an effective way to deal with misconceptions and negative illness beliefs.

In a caring relationship, there is mutual concern for each other's experience, feelings and needs. Even though one partner has been diagnosed with MS, the other partner's well being should be of equal concern. It is important that all attention does not focus on the person who has the diagnosis, and also to avoid competition about who is affected the most. The experience is different for each person but you are on the same team.

The foundation of a relationship can be built by making regular “deposits” in the “couple account.” This can come about from effective communication, respect, mutual concern, but also finding activities you can do together, saying “thank you”, doing something nice for the other person that s/he would value, having a sense of humour/fun, and keeping romance alive with a telephone call or a love note in a lunch box. Making time for your sexual relationship, addressing any sexual changes that arise from MS (or other issues) and being open to creative adaptations are other ways to keep intimacy alive and build connection. When there are withdrawals and not enough deposits, the couple account can go in the red.

Finally, learning how to communicate more effectively, addressing MS and developing adaptive strategies can be challenging and may require support from a knowledgeable mental health professional. The sooner barriers and disconnection are addressed, the better.

* EDESC – DESC acronym comes from Bower, S.H. & Bower, G.H. (1991). *Asserting Yourself*. “E” has been added by Dr. Lynn Sloane.

Calling All Family Caregivers

If you are an MS family caregiver we want to hear from you!

The MS Society of Canada, Alberta Division, is committed to supporting family caregivers. We recognize the vital role that you play in supporting individuals who have MS and we want to acknowledge and celebrate your dedication and contributions.

We will be dedicating space in every issue of *MS Connections* for family caregivers. It is our hope that you will help us with this section. You are the experts so we would like to hear from you about your experiences. Perhaps you have some tips or friendly advice to pass along from

caregiver to caregiver that might help others who are in similar situations?

We would also like to hear individual stories. So often caregivers feel alone and isolated in their role, let's try and break down the walls of silence and create a space that offers insights into how others are coping.

This is your space so please send us your thoughts, experiences and advice.

Topics to consider:

- Inspirational quotes or poems that have helped you during a challenging time
- Recipes that are quick and easy

and cut down on meal preparation time

- Resources that have been helpful
- Stress relieving techniques
- Support groups, networks, websites and blogs
- Caregiver articles and studies
- Humour – we all could use a laugh!

If you would like to submit a piece related to caregiving and MS please send it to: Jacqueline Rawson, Communications Coordinator at jacqueline.rawson@mssociety.ca. If you do not have access to a computer you can contact Jacqueline at **1-800-268-7582 or 780-463-1190**.

MS ActiveNOW

The Edmonton Chapter continues to develop the MS ActiveNOW program, with plans to introduce the program throughout the province over the next year. MS ActiveNOW is a provincial health promotion strategy created by the MS Society to:

- increase awareness of the benefits of physical activity for persons with MS,
- assist fitness and lifestyle professionals to design proper exercise programs for persons with MS and,
- increase access to exercise and physical activity programs in the community for persons with MS

We have a new MS ActiveNOW brochure "Active Living Choices" which contains important information about the benefits of exercise and points to keep in mind

when starting your own exercise program, as well as the *MS and Exercise DVD*, which is both educational and motivational in nature. Call or email our office if you would like a copy: **1-800-268-7582; active@mssociety.ca**

You can also visit the MS ActiveNOW website for lots of information about MS and exercise, as well as a variety of resources and links to other websites and literature. Go to: www.mssociety.ca/edmonton/active.htm



Navigating Aids to Daily Living (AADL)

The MS Society has witnessed increased requests for help in completing applications and an increase in appeals for equipment from AADL, particularly for power wheelchairs. In addition, the MS Society has received more requests to provide equipment funding that is not covered by AADL or where the application has been denied. The MS Society will address these issues on two levels: (1) individual - through advocacy, education and support, and (2) systemic - influencing changes through Government & Community Relations.

Systemically

In collaboration with the Alberta Disabilities Forum (ADF), the MS Society has met with Alberta Seniors and Community Supports, including the Assistant Deputy Minister, and the Director of AADL to discuss our concerns.

Our issues included: the number of catheters an individual can have on a monthly basis; the process for applying for power wheelchairs and appealing denials; and the restrictions with the Residential Access Modification Program (RAMP). The meetings have also provided an opportunity for the disability community to communicate the gaps in equipment offered by AADL, including air flow mattresses and environmental controls.

Advocacy

The MS Society encourages individuals who are applying for funding to contact the Alberta Division or your local Chapter so we

can provide you with assistance in completing the application and the Client Impact Statement.

A critical part of requesting funding for a power wheelchair includes a Client Impact Statement, which essentially describes, in the client's own words, how he or she will benefit from a power wheelchair. Too often statements are submitted

wheelchair that I currently find difficult or impossible?

- Will using a power wheelchair improve my quality of life? How? Describe how it will do this.

AADL Program Overview

The AADL program helps Albertans living with long-term disability, chronic illness or terminal illness



The MS Society has met with Alberta Seniors and Community Supports regarding a number of issues, including clarification on the process for applying for power wheelchairs.

that lack vital information about the individual and their circumstances. A statement should include responses to the following questions:

- Why do I need a power wheelchair?
- What are your limitations (physical, social, transportation, etc.)?
- What activities will I be able to participate in with a power

to maintain their independence at home, in lodges or group homes by providing financial assistance to buy medical equipment and supplies. An assessment by a health care professional determines the equipment and supplies that an Albertan can receive through this program.

Albertans pay 25 per cent of the benefit cost to a maximum of \$500

per individual or family per year. Low-income Albertans and those receiving income assistance do not pay the up to \$500 cost-share portion.

For more information visit: www.seniors.gov.ab.ca/aadl. Edmonton and area: 427-0731. Toll-free in Alberta: 310-0000, then 780-427-073

Residential Access Modification Program (RAMP) Overview

A RAMP grant for up to \$5,000 is available to modify the personal principal Alberta residences for eligible wheelchair users. Grants are for permanent modifications that facilitate access into a home, or movement within a home, by the wheelchair user.

Only one wheelchair user per household may apply for assistance. If the principal residence is a rental unit, the landlord is required to approve the modification by completing the Landlord Letter of Acknowledgement (Permanent) form. Applicants are encouraged to apply prior to the start of the project but applications with completed projects are eligible if the application is received by the program within 365 days from the completion date.

New

The Alberta Government recently approved a change to the RAMP program. Individuals who use a power wheelchair can apply for funding without having to meet the income criteria if they are building a ramp or making home modifications to accommodate the power chair. This change will enable more Albertans to remain at home.

For more details about eligibility and other information visit

www.seniors.gov.ab.ca/housing/family_special/supportive_housing/existing_programs/
e-mail: RAMP@gov.ab.ca

Call toll free: 310 0000 then dial (780) 644 8085.

MS AMBASSADOR PROGRAM

A United Voice for the Cause and Cure

In early 2007, the MS Ambassadors Program was created to help the MS Society reach out and be more visible. The program is strategically focused and offers individuals the opportunity to become involved in the work of the MS Society in a very distinct and substantial way.

Ambassadors fulfill a key volunteer role within the MS Society. They accept responsibility to help achieve strategic goals. As champions, they agree to be a visible face and voice of the organization throughout Alberta.

We want to introduce our MS Ambassadors to you. In doing so we will be featuring profiles of our Ambassadors in the newsletter and on our website. To learn more about the program please feel free to visit: www.mssociety.ca/alberta/ambassador.htm

Kevin O'Neil MS Ambassador

Occupation...

Senior Environmental Scientist with Stantec Consulting, based in Edmonton. Over a 30 year career in the field of environmental management.

Why are you an MS Ambassador?

I believe in giving back to the community at large. I have, in the past, been actively involved in my children's school and sports programs, community groups and professional associations.

MS has touched our family - my sister contracted this disease several years ago. I believe that through



the professional leadership of the MS Society, coupled with the enthusiasm of MS Ambassadors and the thousands of volunteer fundraisers in Alberta and elsewhere, we will provide the economic incentives necessary for medical researchers and practitioners to unlock the mystery of MS and find the ultimate cure.

Areas of work as an Ambassador...

Communications, government relations, fund development.

Other areas of involvement in the MS Society...

My wife and I are also active volunteers with both the Super Cities WALK in Edmonton and the RONA MS Bike Tour - MS 150. I have been the Team Captain of Cyndie's Cyclists for the past several years. Last year I personally raised over \$7,000 and my team raised over \$26,000.

TELUS and its employees/retirees make generous contribution

The MS Society of Canada, Alberta Division, was the beneficiary of a very generous contribution from the TELUS Dollars for Dollars program. The TELUS Dollars for Dollars program is a team member charitable giving program that invites TELUS employees and retirees to contribute to a registered Canadian charitable organization of their choice. TELUS matches those contributions dollar for dollar. In 2006, TELUS employees and retirees raised \$14,043.38 for the MS Society, Alberta Division, and TELUS matched that amount. In August 2007, we were very happy to receive a cheque from Telus for \$28,086.76. Thank you TELUS, and thank you to those TELUS team members and retirees who chose to give to the MS Society.



Dr. Bob Westbury (center), Chair, TELUS Edmonton Community Board, presents a cheque for \$28,086.76 to Neil Pierce, President, MS Society of Canada, Alberta Division, and Alison Hagan, Director, Fund Development, MS Society of Canada, Alberta Division.

Local realtor becomes MS Ambassador

Brenda Dubilowski was diagnosed with multiple sclerosis six years ago. Since then, she has developed a strong passion to find a cure and help those affected by MS. The challenge was figuring out exactly how to go about it. Brenda has figured out a way to help. As an Edmonton realtor, she is able to help individuals with MS find homes that can accommodate their unique needs. She has also taken on the challenge of advocating for barrier-free design to be incorporated into future building codes.

The objective of barrier-free

design is to design and build homes, and in fact all buildings, in such a way that people with mobility



Brenda Dubilowski

challenges have no barriers to accessibility. In order to achieve this, Brenda has teamed up with the MS Society and has become an MS Ambassador. As an Ambassador, she will address this issue with homebuilders and anyone else who can play a role in implementing these changes. She has also made a commitment to donate a portion of her commissions to MS research.

For more information on Brenda and her mission, visit www.BrendaSells.net or contact her directly at: 780-641-1321, brenda.dubilowski@remax.net.

Veteran Board Director takes on new role as Chair

Suzanne Deschamps joined the Alberta Division board in 1995 and remained a director until 2001. After a two-year hiatus, she rejoined the board in 2003, became secretary in 2004 and vice chair in 2005.

After her diagnosis in 1992, Suzanne believed that she needed

term as Board Chair is the Mission Statement of the MS Society of Canada: To be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life."

Suzanne is also eager to improve services and programs to those living with MS as well as the thousands of other Albertans affected by the disease. She also wants to continue the development of the Alberta Division strategic plan – Reaching Out and Partnering

for Success.

"Working with the MS Society staff and other board directors, I feel confident we can meet these goals, especially knowing that I am part of an organization that helps people cope with MS.

If you would like to learn more about becoming an Alberta Division board member, visit the website to learn more about the organization and then send us an email.

www.mssociety.ca/alberta
info.alberta@mssociety.ca



Suzanne Deschamps

to become involved with the MS Society. "I knew that with my involvement I would be able to support the mission of the MS Society and assist others suffering with MS," said Suzanne.

Suzanne's experience and talent as a board director make her the ideal person to assume the role of board chair. She officially took on that role on November 3, 2007, at the Alberta Division annual general meeting in Edmonton.

"I am especially proud to be involved in the MS Society as the new board chair for 2007-2008," said Suzanne. "One of the areas I would like to focus on in my

MS Support Groups in Alberta

Battle River /Wainwright call and ask for Teresa 780-755-2226.

Boyle Area call 780-689-4300 and ask for Deloris.

Camrose call 780-672-2993 and ask for Maureen.

Cold Lake/ Lakeland call 780-639-4145 and ask for Suzanne.

Drumheller call 403-820-7863 and ask for Karen.

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 867-445-4372 and ask for Shawn

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.

International Paralympic Committee recognizes Edmonton researcher



Dr. Garry Wheeler
Vice President
MS Society of Canada
Alberta Division &
Edmonton Chapter

The 2007 Paralympic Awards honour individuals who make a direct contribution to the Paralympic Games and the Paralympic Movement.

The Paralympic Scientific Award 2007 recognized **Dr. Garry Wheeler** for research in the field of sport for persons with a disability.

Dr. Wheeler has been instrumental in health promotion and sports activities for persons with a disability at home and abroad.

He continues to champion the benefits of active living through his work at the MS Society. Through a new provincial health initiative, the MS Society and Dr. Wheeler will help Albertans with MS improve wellness and achieve greater quality of life. This health initiative is called MS ActiveNOW.



"MS is Alberta's disease, so we're truly fortunate to have one of the best wellness experts in the world. Over 11,000 Albertans live with MS. By helping them achieve greater wellness and quality of life, we're helping all Albertans."

Neil Pierce, President
MS Society of Canada, Alberta Division

Left: MS Ambassador Chris Keiser enjoys a workout at Millennium Place in Sherwood Park, Alberta.

New Outreach Coordinator position aims to improve rural service delivery

"I had to make a decision within 48 hours," says Hessen Zoeller of leaving her position as Bike Tours Manager to spend a year teaching English in Japan. "It was a very difficult decision, and a bit of a whirlwind since I was scheduled to leave for Japan three weeks after the decision was made. The circumstances definitely took me out of my element."

Hessen is the new Alberta Division Client Services Outreach Coordinator since returning from Japan. Her involvement with the MS Society spans almost 10 years, reaching back to the late 1990s. "I first started working at the Society as a summer student in Client Services. My first assignment was to develop the Alberta Division Loan Library. In fact, if you look through the old newsletter archives, you will see a younger version of me on the front cover,



Hessen Zoeller in a traditional Japanese robe.

For more information about MS ActiveNOW, visit

www.mssociety.ca/edmonton/active.htm



MS ActiveNOW
Activating Your Life

flipping through a magazine with Adeline Blumer."

Since then, Hessen has worn very different hats at the organization, including acting as the Resource Coordinator in Client Services and Bike Tours Manager in Fund Development. "Yeah... looking back, I guess I am one of the lucky few to witness first-hand the power of the work we do in Services and Fund Development." Her past experience has shown her the importance of connecting regional teams that will impact the ultimate goal of fulfilling the mission.

Hessen will be looking to enhance delivery of Client Services in rural areas and assisting Alberta MS chapters to strengthen community partnerships. "Providing support to communities not already supported by a staffed chapter is a challenge requiring innovative resources and networking. By having a position dedicated to reaching out to those who work directly with people with MS, and supporting grass roots enthusiasm, we will be able to better support some of the smaller communities in our province." More specifically, the new role will involve working more directly with MS Ambassadors, volunteer chapters and community and health agency partnerships via MS Awareness Day Campaigns.

And when asked whether or not she mastered the Japanese language, Hessen had this to say: "Well, you couldn't live in Japan without knowing the basics and I definitely know enough to travel around the country and get by. Anything beyond that was...well...let's just say that I think I've improved my charades skills."

Hessen can be reached at Hessen.zoeller@mssociety.ca or (780) 440-8774.

September 3, 2007

The MS Society of Canada
Alberta Division
#150, 9405 - 50th Street
Edmonton, Alberta
T6B 2T4

To the MS Society,

My name is Justice Poitras - Onespot and I turned 7 years old on July 27th. MS has affected my family. On August 9, 2006 my grandmother, Therese Whitney, passed away. She was only 54 years old and had suffered from MS for 26 years. I miss her very much.

In honor of my grandmother, I asked all of my friends to bring a donation to the MS society instead of presents for my birthday this year. I collected \$510.00 from all of my friends and my mama and daddy added \$240.00. It makes me very proud have raised \$750.00 to help find a cure for MS.

I have attached a list of names and addresses for tax receipt purposes.

Thank you for all the wonderful work you do for this terrible disease.

Sincerely,

Justice

Justice Poitras - Onespot



Above: A letter written by Justice to the MS Society.

Left: All of the girls who were at Justice's birthday and contributed to her cause.

Golf tournaments raise research and program dollars for MS



The MS Society hosted two golf fundraisers in Alberta and benefited from a third party golf event. All were very successful and raised vital dollars for research and programs for Albertans living with MS.

100 Stroke Challenge for MS

The MS Society, Alberta Division, in partnership with Legal Freight Services Ltd., hosted the first annual 100 Stroke Challenge for MS on September 13, 2007. Over 100 golfers made their way through the early morning fog at Raven Crest Golf and Country Club to take the challenge. Plenty of prizes were up for grabs, as well as hole giveaways and great food. When the day was done, the



Neil Pierce (centre) Alberta Division President, and his golf teammates which included Premier Ed Stelmach and his wife.

tournament raised an incredible \$80,000!

One of the teams that contributed to the tournament's success was team "FORE Mom", captained by Darrel Walker. The team name holds a lot of significance for Darrel. "My mother was diagnosed with MS

in 1957, was hospitalized for approximately 7 years, and passed away due to complications of MS in 1967 when I was 14 years of age," he said. Several years later, Darrel's wife started having symptoms and was diagnosed with MS in 1983.

Joining Darrel on team "FORE Mom" were his two sons and his wife. His sons golfed for their mom, and Darrel for his, in hopes that one day a cure will be found. Together the team raised

\$1,275. Darrel's contributions to the MS Society extend beyond the 100 Stroke Challenge; from 1991-2005 he participated in the RONA MS Bike Tour – MS 150, raising over \$45,000 during that time!

Thank you team FORE Mom and all the other participants for helping make this event such a great success!

100 Holes of Golf

Red Deer hosted their annual tournament "100 Holes of Golf" on September 10, 2007. At Spirit Creek Golf and Country Club, 42 dedicated golfers played 100 holes. Five and a half rounds later, the golfers forgot their exhaustion when they realized they raised \$63,000 for MS!

This year Red Deer tried something unique at one of the holes. When golfers reached the 'MS Hole', they were given items to simulate MS symptoms before they teed off – winter mitts to remove the feeling of holding the golf club, and glasses





Merv Rockel, President, AFREA, and Bert Paulssen, Chairman, Federation of Alberta Gas Co-ops Ltd., presenting the cheque to Joan Ozirny who accepted on the MS Society's behalf with Premier Ed Stelmach and his wife Marie.

to blur their vision. This hole also had a "Closest to the Pin" contest and a prize was awarded for that achievement – no small feat considering the handicap of using the symptoms items.

Central Chapter would like to thank all their participants and sponsors for making this such a successful event.

Federation Centre Golf Tournament

Alberta Division was the fortunate beneficiary of a third-party golf tournament hosted by the Alberta Federation of Rural Electrification Associations (AFREA) and the Federation of Alberta Gas Co-ops Ltd. On September 17, 2007 these associations held the 1st Annual Federation Centre Charity Golf Classic at Broadmoor Golf Course in Sherwood Park. Neil Pierce, Alberta Division president, had the privilege of golfing with Premier Ed Stelmach and his wife Marie. The tournament raised \$21,000 for the MS Society, which will be used to support outreach programs in rural communities in Alberta.

Interested in participating in a
caregiver support
 teleconference?

Contact Aileen Steele for more information:
aileen.steele@mssociety.ca
 780-463-1190.

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 information on MS?**

[[**MS**info]]

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Register Now!

Help us break the record-setting year for WALK and Bike.



Register **ON-LINE** right now!

www.mssociety.ca

Or phone us at **1-800-268-7582.**

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.

Publications Mail Agreement 40064145
Return undeliverable items to:
MS Society of Canada Alberta Division
#150, 9405 - 50 St, Edmonton T6B 2T4

2007 Final Fundraising Results

The Super Cities WALK for MS

Over \$2.1 million raised in Alberta...a new record!

Brooks	\$17,017
Calgary *	\$806,450
(*Enerflex Super Cities WALK for MS – largest in Canada!)	
Drumheller	\$49,335
Edmonton	\$604,528
Fort McMurray	\$51,179
Grande Prairie	\$33,251
Lethbridge	\$130,349
Lloydminster	\$118,692
Medicine Hat	\$70,066
Red Deer	\$124,396
St. Albert.....	\$91,829

RONA MS Bike Tours

Over \$2.3 million raised in Alberta...a new record!

Calgary	\$806,450
Edmonton (MS 150) Largest in Canada....	\$1,262,049
Red Deer	\$86,064
Mountain Bike Tour (2007)	\$304,277
Read-A-Thon	\$384,169
Carnation Campaign.....	\$79,045
North Peace Trail Ride	\$38,000
South Peace Trail Ride	\$45,000
100 Strokes (Edmonton)	\$80,000
100 Holes of Golf Red Deer	\$63,000