



Jeannine Comeau, read about her on page 4

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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A Message from Dena



**Dena Simon, President
Atlantic Division**

Spring Forward!

It has been a very long winter and I'm sure I speak for many of us when I say I am so happy to see the warm and sunny days becoming more frequent.

During the month of April, we celebrate our wonderful volunteer network. From Corner Brook to the Annapolis Valley and from Charlottetown to Cambellton – our dedicated volunteers are the core of the MS Society and allow us to be a truly Atlantic Division. They give us a presence in many communities and help us serve clients in all four provinces. Our grassroots volunteers are the heart of what we do and we applaud you!

Our volunteers also lead us into one of our busiest times of the

year. May is MS Awareness month, marked with a flurry of activity in many Chapters. We raise awareness through flag ceremonies, carnation campaigns, library donations, other special events and our very important MS Walk on May 24th. For the first time, the MS Walk is being held on the same day throughout Atlantic Canada and I encourage you to show your support for our walkers in whatever way you can.

The warm weather reminds us that our NS and NB RONA MS Bike Tours are coming up in July with participants already registering and collecting donations. Participating in events like the bike tours is an easy way to bring friends and family together while supporting our important mission. We want you to know that the MS Society's work in enhancing quality of life and funding research to find a cure for MS will continue, even in this economic downturn.

As we propel forward with our events this spring and summer, I am happy to report that our local endMS campaign is also moving ahead. Excitement is building regarding new Regional Research and Training Centres, so stay tuned.

This newsletter is filled with stories that I hope will inform you on the activities of the MS Society; what we've done, what we are doing now and our exciting plans for the future.

Sincerely,

Dena Simon,
President, MS Society of Canada
Atlantic Division



Be part of something monumental. Funded largely by the MS Society, Canadian researchers have brought the cure for MS within reach. Let's take this last step together.

endMS.ca
It's time. Give now.

1-800-361-2985



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May is MS Awareness Month

MS ATLANTIC



The Multiple Sclerosis Society of Canada marks the month of May as MS Awareness Month. It is a time to raise our profile in as many ways as we can on behalf of people and families living with MS and on behalf of those who strive all year to achieve the mission of the Society.

To that end, the MS Carnation Campaign is in full swing and is one of the most high profile public activities that happen each May – just in time for Mother’s Day.

This year, mall sales have been expanded with new locations in both Saint John, NB and Halifax, NS which is at 15 sites, up from nine last year.

“The visibility of the carnation campaign raises awareness and valuable funds for the MS Society putting us front and centre in our local communities,” says Jessesar MacNeil, Manager, Development, Atlantic Division. “We’re looking forward to another successful year, thanks to the enthusiasm of our incredible volunteers.”

Carnations are for sale from May 7th to 9th and will be in retail locations all across Atlantic Canada. Please come out and buy some carnations for a special person in your life and support our cause.

If you are interested in volunteering to sell carnations, please contact your local chapter or call the Atlantic Division office at 902.468.8230 or 1.800.268.7582.



Do you know of a special volunteer we can profile in MS Atlantic?

Contact Monica Jordan at monica.jordan@mssociety.ca or phone 1-800-268-7582.



Lieutenant Governor Barbara Hagermen, Mickey Edwards, and Tom Killorn, Chapter Chair, PEI (left -right)

PEI Volunteer Recognized

Eighty-year old Mickey Edwards of Charlottetown, PEI was presented with the **2008 MS Volunteer of the Year Award** for her invaluable work with the MS Society of Canada.

Mickey has been volunteering with her local Chapter of the MS Society since 1973 and is an integral part of the Chapter’s activities. As a veteran of the MS Carnation Campaign, she has led the Kings & Queens Chapter to annual victory, winning the Carnation Cup with her successful management of their campaign.

Congratulations Mickey and thank you for all of your efforts!



To Mom With Love

It's not hard to imagine . . .

It's a dark 5am cold January morning. You turn off the deafening alarm and pry your eyes open against your will. You get up, make breakfast and attempt to cajole an unwilling participant to get dressed, eat and simply 'wake up'! Next, you rush out the door, lifting a heavy, smelly and awkward bag into the trunk of your car, while reminding your passenger to 'hurry up and buckle up.' Arriving at your destination with minutes to spare, you wrestle cumbersome equipment over a small and wriggling body. For the finale, you expose your previously warm hands to the cold frigid air in order to lace up special boots with sharp steel blades. You then smile and witness the excitement on their face as you send your child careening across a slippery surface with a long stick in hand heading for that little black puck.

It's the very ordinary plight of many moms and Chad Comeau says his mom Jeannine did all that and more.

" I love my mom, she's always been there for me . . . She taught me important things about life when I was a kid and now, I admire her even more . . . "

"My mother was the consummate hockey mom, taking my brother and me to practices and giving up her weekends for tournaments," says Chad. "And it didn't end with hockey. Of course, I played every sport I could and she was there. She supported me in anything I wanted to do."



Chad Comeau with his mom Jeannine

Chad says that it's the normal every day things that make his mother deserve to be celebrated.

"I love my Mom – she's always been there for me. Whether she was sitting through bad reports about me on parent teacher night or trying to impress on me the importance of hard work and being kind to others," says Chad. "She taught me important things about life when I was a kid and now, I admire her even more for the way she stays positive in her own life despite her challenges."

Jeannine Comeau, originally from Sudbury, ON, was diagnosed with primary progressive MS in 1997 at the age of 47. She moved to Weymouth, Nova Scotia with her husband eight years ago, after taking an RV trip back to see his family. That trip convinced them to stay.

Chad joined his parents, moving from Sudbury, in December 2002. A few months later, tragedy struck when his father died unexpectedly of a heart attack.

. . . continued on page 11

Did you know . . .

Some people with MS require the use of a medical alarm. This is a personal response service that lets you summon help in an emergency, even if you can't speak. The average cost of this type of service is between \$40 to \$50 dollars per month.

Dr. T. J. (Jock) Murray \$100,000 Scholarship

Last fall, the Atlantic Division held a celebratory dinner in honour of renowned MS neurologist, Dr. T. J. (Jock) Murray on the occasion of his retirement from clinical care.

Division President, Dena Simon, announced a \$100,000 scholarship in Dr. Murray's name that will support the endMS Research and Training Network.

"When you make a donation to this scholarship, you are investing in the movement to end MS," says Dena. "You are ensuring that the next generation of researchers have the necessary funds to continue the important work that Dr. Murray began."

The scholarship will be available for undergraduate, MD, PhD and post-doctoral students dedicated to MS research.

"We've reached more than 75 per cent of our goal for this scholarship," says Joanna Hamilton, Manager Leadership Giving. "Now, we're looking for community support to help us close the distance. Every gift makes a difference and every dollar brings us closer to a cure for MS."

If you would like to make a lasting contribution, please go to www.endMSatlantic.ca or contact Joanna Hamilton joanna.hamilton@mssociety.ca 902.468.8230.



Dr. T.J. (Jock) Murray

endMS.ca
It's time. Give now.

2009 MS Research Teleconference

with Dr. Peter Rieckmann, MS Society of Canada Research Chair, University of British Columbia

The Multiple Sclerosis Society of Canada is proud to announce the seventh annual MS Research Teleconference on Wednesday, May 20th, from 7 to 9 pm, Atlantic Time (7:30 - 9:30 pm. Newfoundland & Labrador).

This year's guest speaker will be Dr. Peter Rieckmann, MS Society of Canada Research Chair at the University of British Columbia (UBC) in Vancouver.

Dr. Rieckmann's major research interests are disease modifying factors and development of new therapeutic strategies to enhance tissue repair in multiple sclerosis. His clinical goals include enhancing awareness and education about MS, developing new, sensitive clinical scales as well as effective and properly resourced services for MS outpatient care leading to more customized treatments for patients.

This is an opportunity to gain insights on the latest MS research and have general questions answered by one of Canada's leading neurologists.

How to register:

1. Online at www.mssociety.ca/teleconf_research
2. Call Claudette Villena 1-866-922-6065 extension 2217 or email: claudette.villena@mssociety.ca



Dr. Peter Rieckmann

Deadline for registration is May 18, 2009.

MS WALK

EVERY STEP MATTERS.





Atlantic Canada
Sunday May 24, 2009
 1.800.268.7582
www.mswalks.ca

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MS Walk Spokesfamily



At the centre of the 12 member, Team Crazy Legs, you'll find its heart, Pam Gonnason, of Fredericton, NB. Pam was diagnosed with primary progressive MS four years ago at the age of 50. Her husband Trevor, daughters Heather and Megan, Pam's three siblings and their families round out the rest of the team. With the exception of one friend – they are all family.

“We found one of the unexpected benefits of participating in the MS Walk, as a team, is that it helps keep the family connected,” says Pam. “Sometimes it’s hard to find the time to get together because half of us live in different parts of the province, but being part of this team and fundraising together gives us the opportunity to catch up with each other.”

But even more than this, Pam found another compelling reason to join the MS Walk.

“I’d never fundraised before and I found that with MS, we had so little control in our life. Doing something like raising money has given me some degree of control over this disease,” says Pam. “I have to believe that there will be a cure for MS and I want my family and friends to be a part of it. When my team crosses the finish line, we know that we have done something to help those living with the effects of this disease.”



MS Walk Sunday May 24th

MS Walk Site	Location	Check-in Time	Walk Time
Antigonish	Royal Canadian Legion	9:00 am	10:00 am
Charlottetown	HMCS Queen Charlotte	2:00 pm	3:00 pm
Corner Brook	Pepsi Centre	1:00 pm	2:00 pm
Fredericton	Fredericton Armoury	9:00 am	10:00 am
Halifax	Dalhousie Memorial Arena	11:30 am	1:00 pm
Miramichi	Beaverbrook Kin Centre	1:00 pm	2:00 pm
Moncton	Moncton Press Club	9:00 am	10:00 am
New Glasgow	Trenton Park	1:00 pm	2:00 pm
Saint John	Centre Samuel de Champlain	10:00 am	11:30 am
St. John's Mount Pearl	Reid Community Centre	8:30 am	10:00 am
St. Stephen	St. Stephen High School	9:00 am	10:00 am
Sydney	The Armouries	1:00 pm	2:00 pm
Truro	Bible Hill Central Elementary School	1:00 pm	2:00 pm

20 Years of Bike Tours for MS in Nova Scotia

In 1990, the first participants of the Nova Scotia Bike Tour, MS 150, cycled from Mount Uniacke to Wolfville and raised \$50,000. Twenty years later, the Nova Scotia RONA MS Bike Tour has grown to become the largest single fundraising event hosted by the Atlantic Division. We've crossed many different paths, ridden thousands of kilometres and raised more than 3.5 million dollars. Much has changed in twenty years, but our goal remains the same. Together, we will end MS.



RONA MS Bike Tour Spokesperson for Nova Scotia

It must have been fate.

As the President of the Nova Scotia Pharmacy Association and a community-minded person, Doug Ross was just finishing his term as a board member with a health charity when he was approached to join the board of the Atlantic Division of the MS Society.

Doug's affiliation was much sought after because of his area of expertise and his reputation as an active participant in the organizations he was engaged in; little did he know, in a few short months, he'd have such a compelling reason to continue.

Five months after Doug joined the Atlantic Division Board, his wife Irma was diagnosed with relapsing remitting MS.

That was 16 years ago. Since that time, he has become a dedicated



Doug Ross, NS Bike Tour Spokesperson

volunteer and integral part of the MS Society, sitting on many committees, participating in the MS Walks and of course, the RONA MS Bike Tours.

He says there are a lot of reasons why he's remained committed to helping those with MS.

"It's not just that my wife has MS. It is because of the people we've met, the commitment of the staff and volunteers, and the transparency of the organization," says Doug. "I believe that before we go to the *big sleep*, we are going to end MS. And we're going to have a Canadian tattoo on the cure."



"... we're going to have a Canadian tattoo on the cure."

What's New with DMTs

THE LENDING LIBRARY

Did you know that the MS Society has a great resource library available to you?

Theresa Denham, self-help group coordinator, from Enfield, NS recently borrowed a DVD entitled "Voices of MS" and here's what she thought . . .

"I thought it was very well done. Listening to the different stories of people with MS was very interesting and actually, it made you feel like you were in a self-help group - just watching."

It's easy to borrow from the lending library. Just check out the library resource list on our website and let us know what books, DVDs or VHS tapes you'd like to borrow. We'll mail your selections to you with a pre-paid envelope for an easy return.
Call 1.800.268.7582.

It is always of interest to know what is new in the treatment of multiple sclerosis. Recently we asked the four pharmaceutical companies with disease modifying therapies (DMTs) to participate in an update for MS Atlantic readers. Here's what's new!

Biogen Idec, the makers of Tysabri and Avonex recently announced a significant expansion of the infusion network in the Atlantic Provinces. Tysabri is available through the TYSABRI Care Program (TCP). Biogen Idec has increased the number of TCP infusion clinics from four to thirteen in the following areas: Bridgewater, Halifax, Kentville and Yarmouth (NS); Corner Brook and St. John's (NL); Charlottetown and Summerside (PE); and Edmundston, Fredericton, Miramichi, Riverview and Saint John (NB).

In addition to providing Tysabri infusions, these centers are also available for people enrolled in the MS Alliance Program to receive their weekly Avonex injections by a registered nurse.

The results of EMD Serono's CLARITY Trial – a phase III clinical trial designed to investigate the efficacy and safety of a new oral

disease modifying drug – are being presented at the American Academy of Neurology in April.

Recently, EMD Serono made improvements to injection tolerability with a new Rebif formulation. Another improvement is the upcoming availability of an Electronic Injection Device. This new device will allow for personalization of Rebif injections with a variety of comfort settings. The Multiple Support Program (MSP) was recently expanded to provide communication with people in over 170 languages over the phone.

Bayer Healthcare has recently changed the name of its support program from MS Pathways to BETAPLUS which provides all the information and support of the previous program. They have also announced the ExcelaCare PLUS Program which will provide next-day home delivery of Betaseron and other medications. Bayer Healthcare is also introducing a new electronic device, The PocketPlus Injection Diary, to help people manage their treatments.

MS

DR. MARK FREEDMAN in Cape Breton

Dr. Mark Freedman will discuss his recent ground-breaking research in stem cell transplants in MS. There is no charge for admission. Everyone Welcome!

May 15, 2009

NOON

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MS Multiple Sclerosis Society of Canada Société canadienne de la sclérose en plaques SP

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Inscrivez-vous au www.velotoursp.com

Vitamin D & MS Link

It's fact, not speculation anymore! Researchers at the University of Oxford and the University of British Columbia have discovered a direct link between Vitamin D deficiency and the genes that trigger multiple sclerosis.

It's been a long time supposition that a link exists between MS and Vitamin D, but now, MS Society of Canada funded researchers have found evidence suggesting that vitamin D deficiency during pregnancy and the early years may increase the risk of that child developing MS later in life.

The researchers found that proteins, activated by vitamin D in the body, bind to a particular DNA sequence lying next to the MS susceptibility gene (DRB1*1501), in effect switching the gene on.

"We have known for a long time that genes and environment determine MS risk," says Canadian



researcher Professor George Ebers, University of Oxford. "Here we show that the main environmental risk candidate – vitamin D – and the main gene region (associated with MS) are directly linked and interact."

Referred to as 'epigenetic effects,' these environmental factors are seen as increasingly important by scientists. Previous research by Professor Ebers' group complements this new finding that the environment interacts directly with the background genetics of MS.

"This research represents an important development in our understanding of the cause of MS," says Dr. Paul O'Connor, national scientific and medical advisor for the MS Society of Canada.

Understanding the cause can help us grow closer to a cure to end MS.

NOTE: The study does not provide guidelines on vitamin D dosage. Decisions on treatment and/or supplementation should be made in consultation with a trained physician.



RONA MS Bike Tour Spokesperson for New Brunswick

For the past three years, Jack MacDuff, has been leading the Slow Spokes, of Moncton, through the team cheer competition at the New Brunswick RONA MS Bike Tour. At 59, Jack's been living with primary progressive MS for the past 17 years, but doesn't seem to have let his zest for life be slowed down by it, despite all that his team's name implies.

Jack is the president of his own company, a husband and father of three accomplished children, former skip of a Canadian Men's Championship Curling Team, and by all accounts, the life of the party. Jack started the Ticket to a Cure Lottery, a popular fundraising tool for bike tour participants in New Brunswick and Nova Scotia and says it's important to stay involved in the fundraising for multiple sclerosis.

"Although any answers the medical profession will discover may not affect me personally, I'm looking down the road. My hope is that researchers will find the cure to prevent MS from affecting future generations," says Jack. "And if there is anything we can do to improve 'the lot' of many by raising awareness and helping people – it's a good reason to participate."



Jack MacDuff, NB Spokesperson RONA MS Bike Tour

Charlie Broderick wins National Caregiver Award

His often used motto is, “the cup is half full.”

Charlie Broderick, retired principal and educator from Riverview, New Brunswick, is the primary caregiver for his wife Helen. He has cared for her since she was diagnosed with MS in 1979, but the intensity of her care increased when Helen’s mobility depended on the use of a wheelchair in 1986. Despite many limitations, Charlie and Helen enjoy a fulfilling life that includes two or three weekly outings and occasional family functions in PEI.

Throughout the time that he has cared for Helen, Charlie has remained actively involved with the MS Society. He was initially a volunteer at the local Chapter filling roles as chair and treasurer, and has since contributed at all levels of the MS Society.

Last year, he was the special guest speaker at the New Brunswick banquet for the RONA MS Bike Tour and he currently contributes to the Caregiver Advisory Group within our national client services department.

This past December at the Moncton, Chapter Christmas party, Charlie was presented with the National OPAL Caregiver Award for the outstanding and immeasurable support he provides to his wife and for his work at the MS Society on caregiver issues.

“I accept this award not only for the role I play in supporting my wife throughout the course of her illness,” says Charlie. “But also on behalf of all the other individuals who have been on this same journey and who are working as dedicated caregivers on a daily basis.”



Charlie receiving the award from Cecilia Dennis, Atlantic Division Board Member

IN MEMORIAM

This past December, the MS Society lost two valuable members and supporters. Our memories of their desire and commitment to help others while facing their own personal challenges comfort us and allow us to celebrate their lives.

Do not follow where the path may lead. Go, instead, where there is no path and leave a trail.

- Source Unknown

TRINA WHEELER
Corner Brook, NL
1975 - 2008

Trina Wheeler was a soft-spoken advocate for MS, despite her vision impairment and mobility issues. She fought for the rights of the disabled and advocated for change to the Newfoundland drug plan to cover MS drug costs. She was also the personal contact for people newly diagnosed with the disease. Trina’s dream was to help find a cure for MS and “we are still going to make that dream come true.”

KAY RENOLDS
Charlottetown, PE
1924 - 2008

Diagnosed with MS at the age of 25, Kay was never derailed from her calling to help others. She cared for her husband and two daughters and became active in the MS community, hosting the first-ever island-wide meeting of people with MS in her own home in 1954. Many of the services available on PEI for people with disabilities are a result of Kay’s work. “I haven’t done anything alone. It takes a group, a body of people. I’m just one of the cogs in the wheel.”

Local Author Releases 2nd Book About MS

Jamie Keith, 42, of Cape Breton, NS recently released, *My Multiple Sclerosis Adventure*, the 2nd version of his autobiographical book of poetry.

Keith's book of poems chronicles the progression of his disease and gives readers a glimpse into the life and daily struggles associated with progressive MS.

Amazingly, Keith wrote the book with the aid of voice recognition software on his computer and he says he hopes his book serves as an inspiration for people to stay positive despite their challenges.

Diagnosed with MS in 1992 at the age of 25, Keith has been living in the Cove Guest Home since 2001. Both his mother, Margaret, and sister, Cheryl, also have progressive MS. His father, Thorton Keith, is the Secretary of the Cape Breton Chapter of the MS Society.

The cost of the book is \$10.00 plus postage and delivery. \$5.00 from each book is being donated to the Atlantic Division of the MS Society.

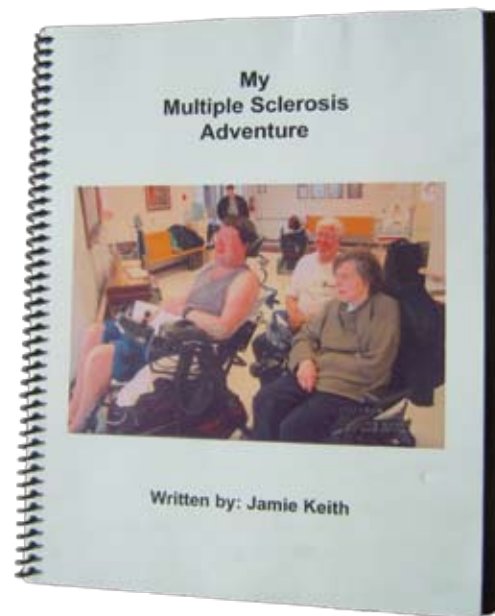
If you would like to buy a copy of the book, please contact Thorton Keith by email: tkeith@ns.sympatico.ca



HOPE COMES BACK by Jamie Keith

I discovered those steroids did help me
Rehab exercises, they were the key
Could only do workouts in the morning

Weakness was my afternoon last warning
It was sad not to reach any major goal
Was impassable with loss of control
Curse my MS fatigue at this juncton
It caused too much physical dysfunction



... continued from page 4

Since then, Chad, 28, has stepped up as primary caregiver for his mom. He built a new house completely outfitted to accommodate Jeannine's needs and lives there with her and his wife, Lisa.

Jeannine needs full-time care now and her MS is at times very difficult, but Chad says his mother is brave and there are still lots of fun times in his house. Mother and son love to watch hockey and weekend NASCAR races together.

"I think one of the things my mom loves most about watching NASCAR is getting to tease me in front of

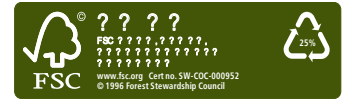
my friends," laughs Chad. "But, I think her greatest joy is watching hockey. Her dream would be to meet Sidney Crosby."

This is a tribute to a great mom, but also to a wonderful son. Perhaps that is an obvious part of the equation, a devoted son becomes that way after a lifetime of loving care by an amazing mother.

As they sit and watch the Stanley Cup playoffs this year, Chad and Jeannine will undoubtedly share priceless moments with each other that are an inspiration to any family.



Top Fundraiser Continues to Think Outside of the Box



Mark Stewart, Atlantic Canada's 2008 Top Fundraiser for the MS Walk, is challenging himself in a different way for 2009.

Putting a new twist on his fundraising efforts, Mark has pledged to walk 450 kms, the equivalent distance from Woodstock, NB where he lives, to Charlottetown, PE where he participates in the MS Walk.

Not surprisingly, Mark has already completed 75 per cent of his goal and in the process, lost 20 lbs. Way to go Mark!



Mark Stewart, Top MS Walk Fundraiser

Membership and Donation Form




Name: _____

Address: _____

City: _____ Province: _____

Postal Code: _____ Tel: _____

Email: _____

Spouse: _____

Person with MS Yes No

Individual memberships are \$10
 Membership for a person with MS is complimentary

Membership Renewal Yes No

Donation/ Fee Enclosed \$ _____

Credit Card Visa Mastercard Cheque

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