



CANADA

Multiple Sclerosis Society of Canada

175 Bloor St. E., Suite 700, North Tower, Toronto, Ontario M4W 3R8



Parenthood and MS

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Volume 33

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March 2006

“We want to be the organization that will end MS”

says new National Chair Lou Maroun

Lou Maroun, the new national chair of the MS Society of Canada, recalls his first introduction to the organization over 12 years ago:

“When I saw how committed the staff are – how driven to excel – I became interested in the MS Society. Then I learned that the same was true of our volunteers. That says a lot about an organization. The MS Society has a mission which it pursues aggressively – and successfully. Coming from the business world that is very satisfying to me,” he adds.

Mr. Maroun grew up in Sydney, Nova Scotia, where he had distant relatives with MS and knew others with the disease. But it wasn't until he took his son's place in the RONA MS Bike Tour – Atlantic in 1994 that Mr. Maroun got involved in the fight against MS. When he stopped to share some ideas with the tour

organizers, they immediately recruited him to be on the advisory committee.

Since then, Mr. Maroun has served on the Atlantic Division Board of Directors, including a term as division chair, before moving to Toronto to become President and CEO of Summit REIT, one of Canada's leading real estate investment trusts and Canada's largest industrial landlord. In Toronto, he joined the National Board of Directors and, prior to his election to national chair in November 2005, served as secretary-treasurer.

“Over the years that I've been involved with the MS Society, I've seen a steady growth in professionalism and commitment to our mission. We attract the best and the brightest to our cause,” Mr. Maroun says.

“The public's perception of us has also changed: Canadians see us as a valuable part of their communities *and* as the organization

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Lou Maroun



Doug Bergeron, third from left, with his mother, Elinor, wife Sandra, and Alistair Fraser, president and chief executive, MS Society of Canada, at the National MS Society Dinner of Champions in Santa Clara, Calif. A Canadian now living in California, Mr. Bergeron has committed \$1 million to the MS Society of Canada in support of research and services.

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that will ensure an end to MS.”

Mr. Maroun emphasizes the community focus. “We began as a grassroots organization – and those roots still run very deep and strong in communities across this country. This means that our approach is cooperative and consensual – we go to great efforts to get buy-in from everyone.”

It's no surprise that Mr. Maroun is enthusiastic about MS research. “I feel that we are tantalizingly close to a cure. I get excited about the research that Dr. Brenda Banwell is doing with children. It is very distressing to see young children sick with this disease, but it is a very real opportunity to identify how and why MS occurs.”

He also celebrates the other half of our mission, client services. “I still find the results from our client services survey fascinating. How simple to ask the people we help – our clients – how they want

us to help them! No one had done it before. Now we are basing our services on their needs.

“It's remarkable to see how people's responses are shaping our services today and into tomorrow.”

Looking forward, Mr. Maroun sees the future as a time of growth and re-commitment to 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.

On a more personal level, Mr. Maroun is looking forward to travelling across the country and meeting staff and volunteers with the MS Society. “I travel in the course of my professional work, and I'd like to use that opportunity to meet with our people so that I know their issues – and that they understand what we want to accomplish in our drive to end MS.”

Mr. Maroun emphasizes that the MS Society is on the right path, but cautions that it will not

be easy. “We are now competing against thousands of other non-profits, rather than hundreds. This means that there is an ever-growing demand on charitable dollars. But we have a compelling story to tell Canadians – and a compelling need. Our challenge now is to step up the pace and accelerate our search for the cure.

“We've built an incredible organization – our volunteers and staff are of the highest calibre: this is the time for us to rally all our strengths and drive hard towards the end of MS.”

Munich Reinsurance Company joins the fight against MS



**Münchener Rück
Munich Re Group**

A leader in life and health insurance, Munich Reinsurance Company has recently become a leader in providing hope to Canadians living with MS.

With a gift of \$20,000 to the MS Society of Canada, Munich Reinsurance Company has joined a group of donors who lead the world in their funding and commitment to MS research. This donor support enables the MS Society to invest in studies that uncover information on living better with MS today as well as studies that seek to end this disease.

The MS Society of Canada is honored to count Munich Reinsurance Company among this group and thanks them for their commitment to individuals and families that have been touched so deeply by multiple sclerosis.



Click on **www.MSProgram.ca** for support

www.MSProgram.ca gives you instant access to:

- Real-life stories of courage and hope
- Experts who can answer your questions and address your concerns
- MS-related news and research articles

Get up-to-date information and support whenever you need it.

Visit www.MSProgram.ca today.



Multiple Support Program
1-888-677-3243



CLIENT SERVICES UPDATE

New initiatives focus is client-centred

Dear Fellow Members and Friends:

For over half a century, dedicated volunteers and staff of the MS Society have given their best to fulfill that part of our mission that directs us to “be a leader in... enabling people affected by MS to enhance their quality of life.”

And for more than a quarter of a century, I've held senior volunteer roles in Canada and internationally with respect to services for people affected by MS. From that perspective, I would like to introduce a regular column to highlight progress in fulfilling this aspect of our mission.

In the past few years, we have made significant progress in ensuring the MS Society's programs and services are client-centred, consistently evaluated and continuously improved from coast to coast. How have we done that?

In 2004 we conducted a nationwide survey by which 10,500 Canadians affected by MS – most diagnosed with MS – told us what Society programs and services gave them the greatest benefit in terms of quality of life.

In November 2004, the National Board of Directors approved a nationwide Framework for Client Services, which gave us the means to build consistent, quality services using tools such as risk management, program evaluation and ethical decision-making.

Client services staff and volunteers began major initiatives in 2005 related to risk management and program evaluation. They will expand in 2006. What does this mean? It is all about creating safer and better programs for our clients, volunteers and staff by putting into place appropriate strategies and practices – such as screening measures – to ensure we have the right people offering the right programs using the best methods. Once these initiatives are in place for all client services activities, the result will be far more effective, safe and meaningful programs and services.

In November 2005, the National Board approved a Strategy for Supporting Caregivers of People with MS, which will ensure the full integration of caregivers in the activities, decisions and priorities of the Society at all levels.

As a person who has lived with MS for nearly three decades, and with a loving wife and family who have embodied what it means to be caregivers, I know so well that the challenges of living with MS are many but we cannot be “all things for all people”. These initiatives will ensure every dollar spent on services at the MS Society is as carefully managed as our research dollars, which are so conscientiously adjudicated and allocated.

It's an exciting time in the journey of the MS Society of Canada. Our services and programs are moving to new levels of effectiveness and value. Volunteers and staff across the country are to be commended for the extraordinary efforts they put in every day to bring hope to the thousands of Canadians affected by MS.

Your colleague in the cause,

Reid Nicholson
Chair, National Client Services



MS Canada

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175 Bloor St. E., Suite 700

Toronto ON M4W 3R8

Tel: (416) 922-6065

Fax: (416) 922-7538

Toll free: 1-866-922-6065

Website: www.mssociety.ca

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.

Chair: Lou J. Maroun

President & Chief Executive:

Alistair M. Fraser

Editor: C.K. (Cindy) DesGrosseilliers

Editorial Advisor: Deanna Groetzinger

Translator: Les Traductions Transol Inc.

Layout/production: Corin Toporas

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Get the facts you need about MS from our National Education Series

Spring 2006 will see a reprisal of two popular education series as well as new online education opportunities. To register or find out more, please call the numbers below.

Living for Today: Managing MS Pain provides insights and tools to help manage this challenging symptom.

- ♦ Regina SK – April 8 – (306) 522-5600 or 1-800-268-7582
- ♦ Windsor ON – April 9 – (519) 977-0401
- ♦ Steinbach MB – June 10 – (204) 326-1434

Living Well with MS: Medical Research and Hope provides insight into how researchers are uncovering the nature of MS, developing new treatments and looking for ways to prevent this disease.

- ♦ North Bay ON – April 22 – 1-866-274-1483
- ♦ Penticton BC – May 6 – (250) 493-6564
- ♦ Grand Prairie AB – May 7 – (780) 532-3204
- ♦ Longueuil QC – May 27 – (450) 466-5209
- ♦ London ON – May 28 – (519) 672-5855

Please note: if you are unable to attend these sessions, web casts will be offered (in French and English) this spring.

Online Education: these online education conferences are offered to anyone with internet access:

- ♦ **Learning for Life: Managing MS-related bowel / bladder dysfunction.** English: May 16 / French: June 7
- ♦ **Learning for Life: Managing MS-related sexual dysfunction.** French: May 23 / English: June 13.

Learning for life: Ask the Expert

Do you have questions about MS and are unsure of where to go for answers? Do you have concerns about family issues, complementary medicine, or MS symptoms and their management? Whatever your area of interest, at Ask the Expert you have the opportunity of connecting with top health professionals and researchers in multiple sclerosis from across North America.

The MS Society of Canada, through an unrestricted education grant from Biogen Idec Canada, have created Ask the Expert as an online forum for people with MS and their families to submit questions to be answered by respected professionals in particular fields.

Visit www.mssociety.ca to learn more or, if you are interested in receiving information on this initiative (including the upcoming launch date), please send an e-mail to educationonline@mssociety.ca and you will be added to the distribution list.

Pregnancy registry to be launched

The myriad of questions about reproduction and MS, including information on pregnancy and fathering a child, may soon have answers thanks to a new project being launched by a University of British Columbia researcher.

Dr. A. Dessa Sadovnick is heading a project to collect data on reproduction and multiple sclerosis. This unique pregnancy database grew out of the Canadian Collaborative Project

on Genetic Susceptibility to MS, of which Dr. Sadovnick has been a leader since the early 1990s. The genetic study is funded by the MS Scientific Research Foundation, which is related to the MS Society of Canada.

Through the North American Pregnancy Project, Dr. Sadovnick and collaborators across Canada and the United States will collect a wide range of information about pregnancy and other

aspects of sexual functioning relating to both women and

men with multiple sclerosis. The result should be solid answers to questions for which now there is only partial information or best guesses.

Dr. Sadovnick plans to launch the project in April 2006.



2005 National Award Recipients

Each year, the Multiple Sclerosis Society of Canada honours the incredible achievements of people with MS, caregivers, volunteers and other supporters in the fight against multiple sclerosis. The following are our 2005 national award recipients.

André Lespérance

Laval QC

National President's Award

André Lespérance was diagnosed with multiple sclerosis over 15 years ago and since then has been devoted to our mission.



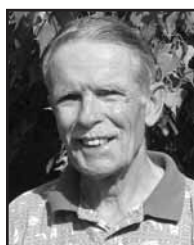
André has been involved with Quebec Division since 1994, when he became a board member and a perennial part of the RONA MS Bike Tours. Thanks to him, RONA became provincial sponsor in 2002 and national title sponsor in 2004. He also played an important role in the Opal Evening, Golf Marathon and Rock and Roll events. André has helped the MS Society to grow by providing support, guidance and inspiration to staff and volunteers alike.

Malcolm Gray

Ottawa ON

National Opal Award

The Opal Award recognizes how caregivers improve the lives of people with MS. Malcolm and Bev Gray were an extraordinary couple



who shared 45 wonderful years – 35 with MS.

In 1970, when Bev was diagnosed, she and Malcolm decided that MS was “their” disease; although MS resided in Bev's body, they both lived with it everyday. Malcolm made Bev's life easier as she coped with progressive MS. He made their home more accessible and became a full-time caregiver upon retirement. Bev died in April 2005, but Malcolm continues to be an important part of the MS Society and the Ottawa Chapter.

Dr. T.J. (Jock) Murray

Halifax NS

Nancy R. Perkins Award

A leading researcher and clinician, Dr. Jock Murray is beloved by the people with multiple sclerosis he has treated. He has always given thoughtful attention and support to individuals and families, providing up-to-date information on MS and referrals to the MS Society of Canada.



Since the creation of the Dalhousie MS Research Unit in 1980, Jock's multi-disciplinary approach has included clinical care, education and research. As director, he has cared for over 2,700 people and inspired thousands more.

Dr. Jennifer Rodgers

Edmonton AB

National Award of Merit, Member

As a psychologist with the University of Alberta Hospital, Dr.

Jennifer Rodgers provides support to many individuals and families coping with multiple sclerosis. Her wise counsel has made a daily difference to many. Jennifer's goal has been “to help individuals and families discover the resources within themselves to maximize their quality of life.” Jennifer presents often at MS Society events.



Dr. Jean K. Mah

Calgary AB

National Award of Merit,

Non-Member

A pediatric neurologist, Dr. Jean Mah is involved in the nation-wide study of the development of multiple sclerosis in children which began in 2004. Before then, she recognized the needs of children with multiple sclerosis and worked with the MS Clinic in Calgary to develop programs. Her young patients and their families are extraordinarily well served by this compassionate physician.



MS Carnation Campaign celebrates 30 years in 2006

Since its humble beginnings in 1976, the MS Carnation Campaign has come to represent hope and resilience in the fight against multiple sclerosis. Now, in its 30th year, the MS Carnation Campaign raises over \$1.5 million per year to support the MS cause.

The MS Carnation Campaign takes place in May, MS Awareness Month. In the days before Mother's Day, volunteers across the country will sell carnations in local communities on behalf of the MS Society of Canada.

Since its inception, the program has raised close to \$45 million to fund MS research and services. In these 30 years, the face of multiple sclerosis has changed greatly: drug treatments are available to help control the disease; diagnosis is more efficient resulting in improved care; 24 MS clinics are open across the country and, most importantly, hope for finding a cure is at an all-time high.

Help celebrate the birthday of the Society's longest running fund-



raiser by volunteering or purchasing flowers during the MS Carnation Campaign. Please call 1-800-268-7582 to find out how you can get involved!

Super Cities WALK for MS is back – bigger and better than ever!

The MS Society's largest fundraiser, the Super Cities WALK for MS, is growing again! This year, the community fundraiser will take place in five new cities: St. Stephen, NB, Corner Brook, NF, New Tecumseh, ON, Kindersley, SK and Killarney, MB.

The expansion follows another record-breaking year for the Super Cities WALK for MS. In 2005, the program raised \$11 million, up from \$9.6 million in 2004.

Funds raised help support groundbreaking MS research and services in your local community. For example, monies raised through the Super Cities WALK for MS helped establish a \$4.3 million study of the development of MS in children. In Canada, 45-55 children are diagnosed with MS each year, some as young as three years old.

You can help in the fight against MS by registering now for the 2006 Super Cities WALK for MS in your community! For event registration and information, visit www.supercitieswalk.com or call 1-800-268-7582.

We've also upgraded our online registration system that will make participating in the WALK even more fun for you and ensure that funds raised go further in the fight against MS.

Online registration highlights include:

- ♦ Ability to sign up and gather donations online
- ♦ Set fundraising goals and watch your progress on a personalized graph
- ♦ Faster team registration for captains
- ♦ E-mail notification when someone gives a donation online or joins your team
- ♦ Team captains can now track total team revenue generated online

If you've never WALKed before, consider making this the year you get involved. If you love the WALK, consider inviting friends and families to join you in TeamMS! You'll be glad you did – and you'll be helping us in our quest to end MS.



Parenthood and MS:

Arriving at a decision that works for you

By Gemma Graham
Communications Intern

It's common for individuals in their twenties or thirties to consider if and when they will have children. It's a big decision! Add multiple sclerosis to the mix and many women – and men – can feel overwhelmed.

The choices have immediate implications, but also long-lasting ones as babies grow into children, then teenagers. What is the right thing to do? And how can you plan with a disease as unpredictable as MS?

Multiple sclerosis can be diagnosed at any time in life, from childhood to late adulthood, but for most people the first symptoms occur between the ages of 15 and 40 – the time when people are finishing school, starting careers and planning families.

The good news is that there is no right or wrong answer about parenthood and MS. Decisions about whether or not to have children will be as individual as you are. Factors such as fatigue, your current physical status, and the course of your disease will be a part of your deliberations.

Let's face it: going through pregnancy and delivery, and then raising a child, is mentally and physically exhausting whether or not MS is a factor. But often these issues seem trivial to women and men who want a child to hold and nurture for years to come. This feeling is no different for people with multiple sclerosis. After all, multiple sclerosis does not impact the parental instinct or the ability to be loving and caring.

"I had some reservations about becoming a parent... We [my husband and I] debated on what to do and decided to try for children. Facing a future without children just seemed implausible to me," says Judith Cooper, a mother of two, ages 10 and 14, who lives in Dauphin, Manitoba.

The physical limitations sometimes associated with MS mean that people who are considering starting a family must plan ahead. It is imperative to have the appropriate support (spousal, family, professional), routines and equipment in place to ensure MS does not either impede the parenting experience or be detrimental to the health and safety of both the parent with MS and the child.

"I was always frightened to hold my daughter in case I dropped her or fell, so I got a bassinet that had wheels on it so I could wheel her everywhere with me," says Andrea Butcher-Milne of Barrie, Ontario, whose daughter is now six. She was diagnosed with MS in 1997.

Women and men with multiple sclerosis who are considering having a child should ensure all their questions and concerns are addressed by appropriate healthcare professionals including a neurologist, physician / midwife who will supervise the pregnancy and delivery, MS nurse, occupational therapist (to assist with adaptations to the home) and genetic counsellor.

There are numerous questions ranging from



continued on next page

becoming pregnant, managing the pregnancy and labour and then extending to parenting itself. While each individual and couple have unique situations in respect to MS and life circumstances, the following questions and answers can provide the basis for further discussion with your partner and/or physician.

Can MS be passed to my child?

There is a slightly increased risk that children of parents with MS might develop the disease compared to the general population. The risk varies depending upon factors such as the number of family members with MS and whether MS is on both the maternal and paternal sides of the couple.

However, in up to 80 percent of families, one parent is the only family member to have MS and thus the risk their child will develop MS over their entire lifetime is approximately three to five percent. While this risk is higher than the general population risk of 0.2 percent, it is still very low. Put another way, there is over a 95 percent chance that your child will not develop MS.

How will MS impact my pregnancy?

Many women with MS experience a remission of symptoms during pregnancy, especially during the last three months, although this can depend upon the clinical course of MS the woman is experiencing at the time of conception.

“Pregnancy was the best I ever felt,” says Judith Cooper. “I think my emotional state of being so happy contributed to me doing so well.”

However, there appears to be a higher risk of MS relapses within three to six months of delivering the child, but again this varies. “During pregnancy I didn't have any clearly defined attacks,” says Andrea Butcher-Milne. “Six months after my daughter was born my MS symptoms actually got worse so I went on one of the disease-modifying drugs and that really helped.”

The possibility of an MS relapse following the birth of the baby should be planned for so

that you have the appropriate assistance in place to help care for the baby while you recuperate from the relapse.

It makes sense to talk to a physician (probably an MS neurologist) who has expertise treating MS symptoms and relapses and who is knowledgeable about the safety of specific drugs and other exposures during pregnancy.

Overall, having good support from your healthcare team during this period is essential. That team will probably include your obstetrician, family doctor, midwife, neurologist and MS nurse.

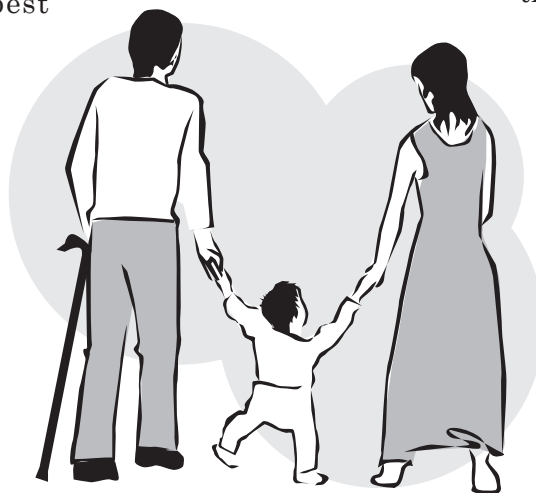
Is it okay to have an epidural during labour? What will labour be like?

There is no definitive answer to either of these questions. Labour is an individual experience. Fatigue should be taken into account, as labour can be very exhausting. Discuss fatigue with your physician and ask what options and support will be available to you if you become too tired during labour.

“My first delivery was natural; the only drugs I received were Demerol and another drug to numb the area for the episiotomy. I was in labour 23 hours and was treated as a high-risk patient due to my MS,” recalls Judith Cooper. “My second labour was C-section because I was stuck at 5cm [dilation] for almost 15 hours and was very tired.”

If you choose to have an epidural anesthetic to block the pain, again plan ahead and have a discussion with your doctor as to whether the procedure is right for you. Keep in mind that some anesthesiologists will not administer an epidural to a woman with MS because it means inserting a needle into the epidural space of the spine. Make sure the hospital where you plan to deliver has an anesthesiologist willing to administer

one, if that is your decision. You should also be aware that some women – totally unrelated to MS – encounter problems with the procedure such as low blood pressure, headaches, allergic reaction and/or relaxation of the muscles needed to push – meaning assistance is required to deliver.



Other methods to help with labour include using various breathing techniques of which the Lamaze method is probably the best known. An epidural relieves pain while Lamaze involves acknowledging the pain and using breathing methods to manage it. It also teaches effective pushing methods to help deliver the baby.

Based on your physical ability, you and your doctor or midwife should decide which is best for you. A woman should not be categorized as having a “high-risk” pregnancy solely on the basis of having MS. Keep as many options open as possible. The goal is to ensure the safest delivery for

Dads have MS too: What men need to consider

A lot of the issues that women experience can be applied to men, especially in the age of co-parenting. But there are a few differences.

Medications: According to Gwen Alcock, MS nurse and coordinator of the St. John's MS Clinic in Newfoundland and Labrador, “Most men make the decision to come off their therapies, particularly the disease-modifying therapies, when they are trying to conceive with their partner.” Talk to your physician about this decision and ways to manage MS while you are trying to conceive. A man also has the choice of freezing sperm before starting treatment.

Labour: MS fatigue may stop you from being with your partner through all the hours of labour, but you can still provide important emotional support. You and your partner could consider having a close family member and/or friend spend part of the labour with your partner while you take a break. Finding a balance and using the support and resources available are important skills to learn for both labour and the years to come.

Child care now and in the future: Finances, the physical status of the partner with MS, and the needs of the child may dictate who is responsible for primary child care. Discuss this openly and continue to do so as your MS and the child's needs may change over time. Also, don't be surprised if some stereotypes about male roles and parenthood arise – these can be emotionally ingrained rather than logical. Remember, a father does so much more than teach his child to ride a bike.

Talk your expectations through with your partner and keep a perspective about all the different ways someone is a parent.

both mother and child.

Judith Cooper found it helpful to learn as much as possible in advance. “We took the pre-natal classes, saw the film on labour, did the stretches, the breathing and the coping techniques.”

Some women with MS – as well as women who do not have MS – have C-sections if problems develop during labour. It is smart to plan for this possibility since a C-section requires more recovery time – sometimes up to several weeks. Both Andrea and Judith had C-sections and were able to turn to family for assistance while they recovered.

Can medication for MS be used during pregnancy and breastfeeding?

There are no clear-cut answers to this questions since at present data is limited. Generally women are advised not to continue the disease-modifying therapies when planning to conceive, during pregnancy and while breastfeeding. (See the article on page 10 for the results of one recent study, *Beta interferon therapy use during pregnancy*.)

This is an issue for Danielle of Nova Scotia, who is considering becoming a mother. “My biggest concern about having children is that I would have to come off my medication,” says Danielle, who is 25 and was diagnosed in 1993. “I've been taking [one of the therapies] for seven years, and it works for me. If I have a child, I could be off my meds for almost two years.”

Again, planning ahead is key. Ideally, a woman who wants to become pregnant should stop the disease-modifying therapy (and other medications as indicated by her physician) before becoming pregnant. She should remain off the medications during the pregnancy and then resume them following delivery, if she is not planning to breastfeed the baby. Another good strategy is to have a discussion with your neurologist or MS nurse about ways to manage MS during pregnancy and breastfeeding.

Andrea Butcher-Milne followed this advice. “I wasn't on any medication before I got pregnant. I decided to wait until I had my child before I began to take medication for MS,” explains Andrea. “I didn't want to go on meds for a bit and them come off for several years and go back on.”

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What about fatigue and parenthood?

Fatigue is an all too familiar symptom for people with MS as well as for mothers taking care of a newborn. A baby's needs can't be placed on hold so methods and routines to manage fatigue need to be developed to ensure you can care for your baby. Consider extra help with household chores, sleeping when the baby sleeps, and enlisting help when the baby is fussy. Getting as much rest as possible is the key to keeping up with your baby's needs, and your own.

"You are definitely going to get fatigued so plan ahead once the baby is born," cautions Andrea. "Plan to take twice as much time to finish a household chore than before you had a baby to take care of. It may not take twice as long but give yourself that time frame in case it does."

It is wise not to wait and see if you can handle a baby and MS fatigue. Instead, you and your partner should have the resources and support in place before the baby is born. For example, you can organize family and friends to help out several times a week. Or you may be able to hire a housekeeper to take over household chores for a period of time.

While adjustments may have to be made, parenthood is a viable option for most women and men with MS. Adjusting for physical limitations, fatigue and other MS symptoms is part of the challenge of living with this disease. Children need love and support, and you can provide those things regardless of MS. Focus on what you can do – rather than on what you cannot do!

"Children take a lot of resources, a lot of money and a lot of patience – a lot of everything!" exclaims Judith. "But they give you a tonne in return."

"Absolutely go for it," Andrea adds.

Gemma Graham's mother has MS and this subject is very close to her heart. She adds, "As someone whose mother had MS while I was growing up, I can confidently say that my mother was no less capable of raising two children than any other woman."

This special insert was made possible through an unrestricted educational grant from



Beta interferon use during pregnancy linked to miscarriage, low birth rate

In September 2005, researchers at SickKids Hospital in Toronto reported that women being treated for multiple sclerosis (MS) with beta interferon therapy have an increased risk of miscarriage or low infant birth weight.

The research strongly suggests that women with MS who become pregnant while taking beta interferon should contact their physicians about discontinuing the drug until delivery. In addition, women who are considering becoming pregnant and are using beta interferon therapy should talk to their physicians about how long they should discontinue therapy before becoming pregnant.

The research team found that continued use of beta interferon therapy through pregnancy resulted in a 39 percent increase in miscarriages, a 30 percent increase in non-live births and a lower overall birth weight in live births compared to women who stopped therapy and to healthy controls.

"Most importantly, we recommend that women with MS who are pregnant or planning on becoming pregnant speak with their neurologists. Discontinuing beta interferon therapy during gestation should not necessarily increase the risk of relapse of MS, as pregnancy tends to reduce such risk," says Dr. Gideon Koren, the study's principal investigator. The researchers also recommend women with MS resume interferon therapy very soon after delivery if they do not intend to breastfeed.

For more information, see the medical update on the MS Society website (www.mssociety.ca – go to Research and then Research News).

Many thanks to Dr. A. Dessa Sadovnick, professor of Medical Genetics, University of British Columbia, for her expert advice during the development of this article.

See page 4 about the new pregnancy registry project.

Annual Report to Members

There has never been a more hopeful time in the fight against multiple sclerosis.

Life is difficult for all of us sometimes, but when you add a disease as harsh and unpredictable as MS often is, life becomes immeasurably complex.

Because of the dedication of our members, volunteers, donors, event participants, researchers and staff, we can offer people with multiple sclerosis and their families comfort and hope. Comfort through our information, education and support programs. Hope for improved treatments and a cure through our MS research program.

Your financial support and volunteer time means so much more than you can imagine: it is inspiration. It inspires fellow members, volunteers and staff to reach new heights. It inspires our researchers and gives them the freedom to envision an end to MS. Most importantly, it inspires people with multiple sclerosis and their families to dream... and to hope for a world without MS.

Thank you again for all of your support,

Alistair M. Fraser

David L. Knight



Alistair M. Fraser
President
and Chief
Executive



David L. Knight
National
Chair

Statement of Revenue & Expenditure

For the year ended August 31, 2005 (in thousands of dollars)

REVENUE

	2005	2004
	\$	\$
Donations and special fundraising projects – net of related expenses	22,204	22,790
Allocations from United Way	1,000	1,000
Grants	2,263	1,802
Amortization of deferred capital contributions from the Multiple Sclerosis Scientific Research Foundation	–	118
Investment income	1,018	712
Memberships	96	100
Total	26,581	26,522

EXPENDITURE

	2005	2004
Program services		
Research	6,604	7,035
MS clinics	904	904
Client services	9,285	8,785
Chapter development	1,406	1,332
Public education	2,210	2,068
Government relations	956	870
Implementation costs and amortization of computer software and computer equipment	–	181
Total Program services	21,365	21,175
Support services		
Administration	3,253	3,293
Fundraising	1,413	1,384
Total Support services	4,666	4,677
Total Expenditure	26,031	25,852

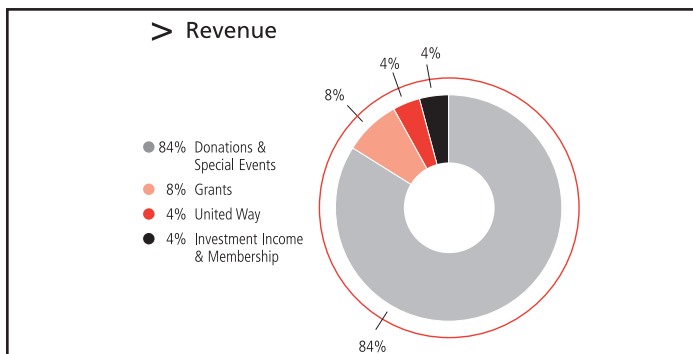
Excess of revenue over expenditure for the year

550 670

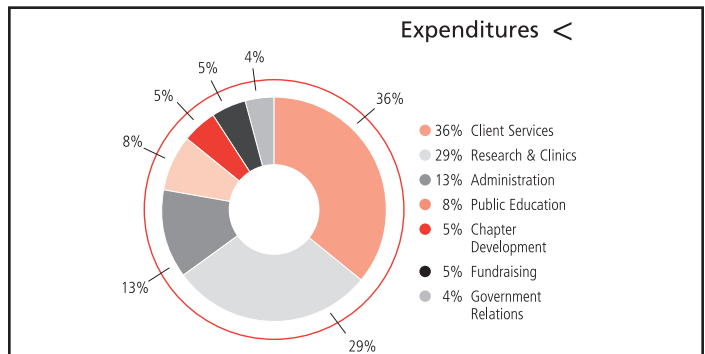
Our Mission:

To be a leader in finding a cure for multiple sclerosis and enabling those affected by MS to enhance their quality of life.

revenue



expenditures



To receive a copy of the full annual report, please call 1-866-922-6065.

Changes to medical, disability credits can save on taxes

New medical and disability expenses and credits introduced in 2005 – some just days before the federal election was called in November – should help reduce tax bills for some people with MS. Below are highlights of these changes and other tips that may benefit people who have MS. (A more detailed version of this article is available at www.mssociety.ca: click on Multiple Sclerosis, then Tips for Living with MS.)

Canada Revenue Agency (CRA) also has valuable resources or persons with disabilities including a publication called *Information Concerning People with Disabilities*. This publication and other resources are available at www.cra.gc.ca/disability or by calling CRA at 1-800-959-2221 (forms and publications) or 1-800-959-8281 (general enquiries).

Allowable medical expenses: There are more than 60 different medical expenses, devices and equipment that can be claimed as medical expenses for those who qualify. Medical expense deductions of particular interest to people with MS are prescription medications, medical devices and half the cost of an air conditioner if prescribed (maximum \$1,000). For more details, see the longer tax article at www.mssociety.ca or the CRA publication *Information Concerning People with Disabilities*.

Medical expense supplement: Individuals with high medical expenses and a low family income may be eligible for a refundable medical expense supplement. For more information, see line 452 in the General Income *MS Canada*, March 2006, p. 12

Tax and Benefit Guide from CRA.

Disability support deduction: Under proposed legislation, the attendant care deduction has been replaced by new disability support deduction and other deductions added. Essentially, the changes increase the list of eligible expenses that can be deducted by people with physical or mental impairments for products or services related to working or going to school. Please note, you cannot claim these expenses if you or someone else will be claiming them as a medical expense. See Form T929 for more information.



Caregiver tax credit: If you live with or provide in-home care for a parent, grandparent or “infirm” dependent relative, you should be eligible for a caregiver tax credit. The dependent relative must be an “infirm” adult or born in 1940 or earlier. Spouses are not eligible for this tax credit.

Disability tax credit: Under proposed legislation, eligibility requirements to qualify for the disability tax credit (DTC) have been expanded. People who have multiple impairments that have a cumulative effect of being severe and prolonged should be able to qualify for the DTC. In addition, eligibility requirements for impairments that are intermittent (such as MS symptoms) have been clarified.

For more information, see the

DTC Application Form T2201. If you qualify, the amount of taxes you or a supporting person must pay will be reduced by a non-refundable tax credit.

Gasoline tax refund: People who are medically certified as having a permanent disability because of a mobility impairment and cannot safely use public transportation can apply for a refund on part of the federal excise tax on gasoline. See information Form XE8, *Federal Excise Gasoline Tax Refund Program* at www.cra.gc.ca/disability or call 1-866-330-3304.

GST exemptions and rebate: If you buy a vehicle that has been modified for a person with certain disabilities or have those modifications made, you should be able to claim the portion of the GST related to the modifications. See Form GST518.

Home Buyers Plan: HBP allows first-time homebuyers to withdraw up to \$20,000 from their RRSPs on a tax-free basis to buy or build a home. In addition, you can use up to \$20,000 from an RRSP to buy or construct a house that is accessible for yourself (if disabled) or a relative who meets the criteria for being disabled under the program. See publication RC4135.

RRSPs: CPP disability benefits can be included when calculating base income for the RRSP contribution limit. To calculate your RRSP deduction limit for 2005, see Guide T4040, *RRSPs and Other Registered Plans for Retirement*.

Estate Planning: Estate plan-

continued on next page

RESEARCH IN BRIEF

ning is an important part of any financial plan. Regardless of your stage in life, it is a good idea to have a will. This ensures the smooth distribution of your possessions to the beneficiaries of your choice. Planning that involves a gift to charity (such as the MS Society) is also a good way to reduce estate taxes.

Tax relief for donations: Charitable giving is a great way to reduce overall taxes (it's also a great way to support the MS Society). Be sure to claim your 2005 donations (with receipts) and any unclaimed donations in the past five years on your tax form.

Tips and more information: Ensure you have all the information you need: keep a file with all tax information and receipts; keep track of your investments; prepare your own schedules of employment expenses, donations and medical receipts to reduce external preparation costs.

The Society's MS Bequest Help Desk is a good place for estate planning information (1-866-679-4557 or online at www.msbequesthelpdesk.ca).

CRA offers a free volunteer program to help people with low incomes and simple tax situations. For details, call 1-800-959-8281.

The tax information provided here may not consider all possible complications and should be considered as general advice only. Contact your own tax or financial advisor for individual advice. If you would like assistance finding a financial advisor call the MS Bequest Help Desk.

Thank you to Eileen Reppenhagen, CGA, for assistance in updating this article. See her website www.taxdetective.ca for more tax info and articles.

Disability progression same for men and women

Challenging the oft-held perception that multiple sclerosis is worse in men than women, a new study shows that disability caused by MS is not impacted by gender. The study, funded by the MS Society of Canada, involved more than 2,800 BC residents and was published in the January 24, 2006 issue of *Neurology*.

“Using an internationally endorsed scale that measures disability, the research team determined that men and women with MS require a cane to walk at around the same age,” said Dr. Helen Tremlett, lead investigator and assistant professor at the Department of Medicine, University of British Columbia.

Researchers used the Expanded Disability Status Scale (EDSS), which uses a scale from zero to 10. In the study, the average age to EDSS 6 – use of a cane required – was 60 for women and 59 for men. While women are more than twice as likely to develop MS as men, earlier studies suggested that men who did get MS became more disabled.

“Natural history studies like this are vital,” said Dr. William J. McIlroy, national medical advisor for the MS Society. “Information gleaned from such studies can help guide prognosis and facilitate decisions regarding initiation of drug therapies.”

Researchers noted that disease progression in this study was based strictly on a disability scale and did not measure other MS symptoms such as numbness, tingling and pain.

The study also challenged the perception that disability due to MS was worse when diagnosed later in life. The researchers concluded that on average, those who were diagnosed in their 20s required a cane age 55. This same level of disability was reached at age 71 for those diagnosed at age 50 and up.

Study reports variation of MS rates across Canada

Researchers at the University of Calgary reported significant regional differences among prevalence rates of MS across Canada. They found higher rates in the Prairies and Atlantic Canada.

Prevalence rates ranged from a low of 180 people with MS per 100,000 population in Quebec to a high of 350 per 100,000 in Atlantic Canada based on data from the Canadian Community Health Survey, a population-based general health survey. The study appeared in the October 2005 issue of the journal *Multiple Sclerosis*.

Canada is known as having a prevalence rate of MS that is among the highest in the world. Previous studies of MS prevalence in Canada have ranged from 55 to 240 per 100,000. They have generally been confined to specific geographic areas and were not easily comparable because of differences in methodology.

The researchers used data from the Statistics Canada 2001 Canadian Community Health Survey (CCHS) to compare MS prevalence across

continued on next page

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regions at a single time point, taking demographics into account.

According to the study, the overall weighted estimate of MS prevalence in Canada was 240 per 100,000. Prevalence was also reported by region: BC – 240 per 100,000; Prairies – 340 per 100,000; Ontario – 230 per 100,000; Quebec – 180 per 100,000; Atlantic – 350 per 100,000. Because of the small numbers involved, prevalence was not broken out by province within the Prairie and Atlantic regions.

Study researcher Dr. Luanne Metz said, “The study results support the existence of an environmental factor or factors independent of latitude. Looking at differences in the environment between these regions may help us uncover additional factors that influence MS risk. In Canada, this can be done as we are well organized, supported by the MS Society of Canada and the population and sociodemographic influences between regions varies relatively little but can be accounted for.”

For more information on these two studies, visit www.mssociety.ca and click on Research then Research News

Ottawa researchers learn how myelin is damaged

Researchers at the Ottawa Health Research Institute have developed a way to determine how the vital myelin covering of nerves in the central nervous system is damaged.

Dr. Peter Stys and his colleagues invented a state-of-the-art laser scanning microscope which enabled them to scrutinize living myelin from a rat model. They

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found the surface of myelin has tiny open pores that provide a gateway for calcium to enter. Too much calcium can injure the myelin.

They also found a way to block the calcium increase and the damage to myelin by using a compound known to block a receptor for glutamate. This specialized

receptor has been found previously in other parts of the brain, but this is the first time it has been detected in myelin.

“This exciting research opens the door for potential ways to protect the myelin sheath and to develop new treatments for MS,” said Dr. McIlroy.

Clinical trial underway for new antibody

Investigators around the world – including study sites in Canada – are enrolling 270 participants in a clinical trial evaluating the safety and effectiveness of daclizumab compared with inactive placebo.

Daclizumab is a laboratory-created monoclonal antibody that blocks the activity of a key immune activator in multiple sclerosis. A small study involving 19 people with relapsing-remitting or secondary-progressive MS conducted by Dr. John Rose and colleagues at the University of Utah found the therapy resulted in stability (nine participants) or improvement (10).

To be eligible, participants must be 18-55 years old, have definite MS, be taking one of the beta interferon therapies and have experienced a relapse or MRI-detected disease activity within nine months prior to screening.

For more information call the study enrolment centre at 1-800-772-0482 or visit the study website: www.choicestudy.com

MS Society ready to work with new government

The MS Society of Canada will work with the new minority Conservative government to ensure that issues that are important to people with MS and their families are top of mind.

“The election was an important opportunity to let all the candidates know about issues that are priorities for the 50,000 Canadians with MS and their families,” said Susan A. Murray, chair of the MS Society's National Government Relations Committee.

During the recent election campaign, the MS Society asked the main parties to answer seven

key questions related to income security, disability supports, access to home care and expensive prescription drugs, caregiver issues and health research.

All parties responded, and their answers are available at www.mssociety.ca, click on Advocacy, then Government Relations & Social Action / Elections 2006.

In the coming months, the MS Society will work with the new government along with other concerned organizations and coalitions to keep these priority issues in the forefront.

A Legacy for Future Generations

By Christopher Whitney, Manager,
Major Gifts/Planned Giving, BC Division

Imagine a future without MS. Jan Petrar knows one day this will be a reality, and she's doing something about it in the here and now.

Jan recently made a commitment in her will to support the MS Society of Canada's internationally respected research program. "Research gave me my life back. It also gave my daughter and son their mother back." That's why Jan is passionate about raising awareness of the MS Society's work and finding a cure for multiple sclerosis.

She knows what it's like to suffer through neurological pain, to deal with depression and fatigue. And she knows the impact this disease has on families and communities.

"When I was diagnosed with MS, there were very few treatment options available, and little hope. The development of disease modifying therapies ultimately changed the course of this disease for me, my family, and so many others."

Originally from Regina, Jan moved to Kamloops, BC in 1990 to further develop her thriving travel agency. As a business owner, she quickly learned the value of strong financial management and planning.

Today, Jan shares that knowledge and 25 years of business expertise as an instructor at a local college, teaching travel and tourism to the next generation. She also brings her experience to the MS Society as a volunteer, dedicating countless hours to raising awareness of and funds for the fight against multiple sclerosis.

"It's important that my children know the value of giving back, of making a difference in the community. For me, this has meant being involved as a board member with the Kamloops Chapter and BC Division of the



Jan Petrar, right, with her son and daughter at his recent graduation from University.

MS Society. But, I also wanted to create a legacy for future generations to show my kids there are many ways of contributing to something you believe in."

Jan's choice to leave a bequest to MS research was influenced by the way the Society uses its funds. "MS Society donors get far more back than they put in. Only the best and most relevant research projects are funded."

If you are interested in creating your own future legacy for multiple sclerosis, please contact the MS Bequest Help Desk at 1-866-679-4557 or visit www.msbequesthelpdesk.ca.



Multiple
Sclerosis
Society of
Canada

**A future free
from MS
is yours to give.**

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 I am interested in including the MS Society in my will.
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Yes, please contact me

Name: _____

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I give the MS Society of Canada permission to contact me by e-mail.

Clip this form, place it in an envelope and mail it to:

MS Bequest Help Desk

175 Bloor St. E., Suite 700, North Tower, Toronto, ON M4W 3R8

or fax to 416-922-7538

Estate Planning Information from a Trusted Source

**MS Bequest
Help Desk**

The MS Society of Canada has the information and knowledge to help you create your estate plan.

Call Mike den Haan at the MS Bequest Help Desk:

TOLL-FREE 1-866-679-4557

www.msbequesthelpdesk.ca

The MS Society collects the personal information requested on this form for the purpose of communicating to you information about the MS Society and its fund raising activities. If you have any questions about your personal information, please contact the National Vice-President, Communications at 1-866-922-6065. A copy of our privacy policy may be obtained at any MS Society office or at www.mssociety.ca.

Comedian Russell Peters shows support for MS Society

A full-page colour ad supporting the Multiple Sclerosis Society of Canada was in the December 5-12, 2005 edition of national news magazine *Maclean's*. The ad appeared thanks to the generosity of comedian Russell Peters. He was part of a group of Canadian celebrities who worked with *Maclean's* to help commemorate its 100th anniversary. In return,

Maclean's donated a full-page colour ad to the charity of Russell's choice – the Multiple Sclerosis Society of Canada.

The ad was in the form of a letter to potential MS supporters. It begins: “My family has been touched by MS and everyday, three more families will find out someone they love has been diagnosed with this chronic disease.”

Keep an eye out for Russell Peters in an upcoming sitcom being produced by Warner Bros. The Toronto-based comedian has been nominated for four Geminis and plays to sold out shows around the world.

CMSA ceases operations

At the November 19, 2005 meeting of the MS Society of Canada National Board of Directors, it was announced that the Canadian MS Association (CMSA) would cease operations in Canada as of December 31, 2005. The CMSA had operated in different parts of Canada for a number of years and was a source of some confusion among donors and supporters.

The CMSA's cessation of operations makes the Multiple Sclerosis Society of Canada the only national, bilingual organization raising funds for MS research and services in the country.



Comedian Russell Peters with Sarah Cowan, Manager, Communications and Government Relations, Atlantic Division at the event *In Conversation with Maclean's* held on November 7, 2005 in Halifax.

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